



# ARTHRITIS COMMUNITY RESEARCH & EVALUATION UNIT (ACREU)

## Client-Centred Rehabilitation

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## ***Executive Summary***

### ***Objectives***

- ◆ To further develop the concept of client-centred care in the Draft Policy Framework and Service Delivery Model as it applies to rehabilitation.
- ◆ To identify client-centred parameters for rehabilitation programs.
- ◆ To identify criteria for evaluating the extent to which various rehabilitation programs are client-centred.

### ***Methodology***

- ◆ Review of the literature
- ◆ Focus groups with adult clients with chronic disabling conditions

### ***Results***

We did not find a universal definition for client-centred care, rather, a variety of terms such as client-centred practice, patient focused care and patient centred care is used. Two main categories of literature were identified: individual client /practitioner level literature and system level literature. At the individual client/practitioner level the majority of the work was profession specific such as occupational therapy, medicine and nursing. Occupational therapy literature on client-centred practice was the most extensive and relevant to client-centred rehabilitation. However, it tended not to include broader system level issues. Other than the occupational therapy literature that focuses on individual therapist and client, little work has been done specifically in rehabilitation. As well, the profession-specific literatures define client-centred care

from the professional's perspective, not the client's.

At the system level, much of the work to date is acute care, hospital focused that emphasizes patient focused care that refers to the redesign of patient care so that personnel and resources are organized around the patient instead of departments. The notable exception is the work of the Picker Institute that has identified components of patient centred care at both the individual and system levels from the client's perspective. However, their work tends to be acute care focused.

In order to address the limitations in the literature with respect to identifying components of client-centred rehabilitation from the client's perspective we conducted focus groups with adults with chronic disabling conditions such as arthritis, total joint replacement, acquired brain injury, respiratory conditions, spinal cord injury, and multiple sclerosis. These client groups were chosen based on the target groups from the Rehabilitation Reform Pilot Projects.

The main themes that emerged from the focus groups were: individualization; participation in goal setting and decision-making, lack of preparation for life in the real world, the need for emotional support, and systems issues. The major theme underlying both the individual and system level issues was the issue of transition from rehabilitation programs to the community. Participants felt ill-prepared for community living and, once discharged, felt isolated and had difficulty finding out about and accessing community services. Furthermore, all participants talked about the need for ongoing access to rehabilitation and services once they have returned to the

community. All reported difficulties navigating the system.

From the literature and the focus group analyses the following client and system level components of client-centred rehabilitation were identified:

*Client Level Components of Client-Centred Rehabilitation*

- ◆ Client participation in decision making and goal setting
- ◆ Client-centred education
- ◆ Evaluation of outcomes from the client's perspective
- ◆ Effective communication
- ◆ Family involvement
- ◆ Emotional support
- ◆ Flexibility

Coordination/ Continuity

- ◆ Physical Comfort

*System Level Components of Client-Centred Rehabilitation*

- ◆ Client involvement in service planning
- ◆ Evaluation of the system from client's perspective
- ◆ System-response to client feedback
- ◆ Accessibility
- ◆ Coordination and continuity
- ◆ Interdisciplinary approach where multiple professions involved
- ◆ System and organizational support

There is no single, well-established tool for measuring client-centred rehabilitation, however, there are a number of tools that have been developed that are potentially useful. These include the Canadian Occupational Performance Measure, Goal Attainment Scaling, Picker Surveys, WASCANA Client-centred Questionnaire, and the Consumer Assessment of Health Plans Survey.

## ***Conclusions***

Client-centred rehabilitation encompasses much more than goal setting and decision-making between individual clients and health care professionals. It refers to a philosophy or approach to the delivery of rehabilitation services that reflects the needs of individuals and groups of clients. At the level of the individual client, client-centred rehabilitation refers to clients being actively involved in managing their health care and their rehabilitation process in partnership with service providers. At the service level client-centred rehabilitation refers to an approach to care that strives to incorporate the clients' perspectives into the provision of services. Attention must be paid to both levels in order to ensure a client-centred approach. With respect to measuring or evaluating client-centred rehabilitation, a multi-method approach that incorporates client surveys such as the WASCANA, as well as qualitative and quantitative data that tap into the system level components, is required.

## Chapter 1: Background

### ***1.1 Arthritis Community Research & Evaluation Unit***

The Arthritis Community Research and Evaluation Unit (ACREU) was funded in July 1991 under the Ontario Ministry of Health's Health System-Linked Research Unit Grant Program. ACREU was established to carry out health services research with the goal of reducing the impact of arthritis on individuals, their families, and on the population.

### ***1.2 Partnership with the Rehabilitation Program Policy Unit***

This research project was conducted in partnership with the Rehabilitation Program Policy Unit of the Mental Health and Rehabilitation Reform Branch, Ministry of Health and Long-Term Care. As a Health Systems Linked Research Unit, ACREU worked with Ministry staff to finalize the research question and to contribute to the client-centred rehabilitation policy framework. Research results will be incorporated into broader initiatives aimed at reforming Ontario's rehabilitation system.

### ***1.3 Objectives***

The overall objective of this work was to identify ways of operationalizing and evaluating client-centred care as it applies to adults with chronic disabling conditions in publicly funded rehabilitation programs. This work will support the Ministry's Rehabilitation Reform Pilot Project Initiative to test effective delivery of rehabilitation services and to test a service

delivery model developed by the Provincial Rehabilitation Reference Group (2000). One of the main purposes of this framework is to improve services to clients by creating a client-centred, coordinated, integrated continuum of rehabilitation services.

The specific objectives of our project were:

- ◆ To further develop the concept of client-centred care in the Draft Policy Framework and Service Delivery Model as it applies to rehabilitation.
- ◆ To identify client-centred parameters for rehabilitation programs.
- ◆ To identify criteria for evaluating the extent to which various rehabilitation programs are client-centred.

The methodology consisted of:

- ◆ Review of the literature
- ◆ Focus groups with adult clients with chronic disabling conditions

## Chapter 2: Literature Review

### 2.1 Literature Search Strategy

Relevant literature was identified from searches of computerized databases using both the British and US spellings of the term patient-centred(ness). Searches were restricted to English language journals published within the last 30 years (1970-2000 inclusive). Criteria for inclusion in the database were papers that provided a review, theoretical/ conceptual frameworks or models, research, or commentary relating to client-centredness.

Databases and web sites used to obtain information on client-centredness included:

Pubmed

[<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=PubMed>]

Includes: Premedline

Medline

HealthSTAR

Publisher- supplied citations

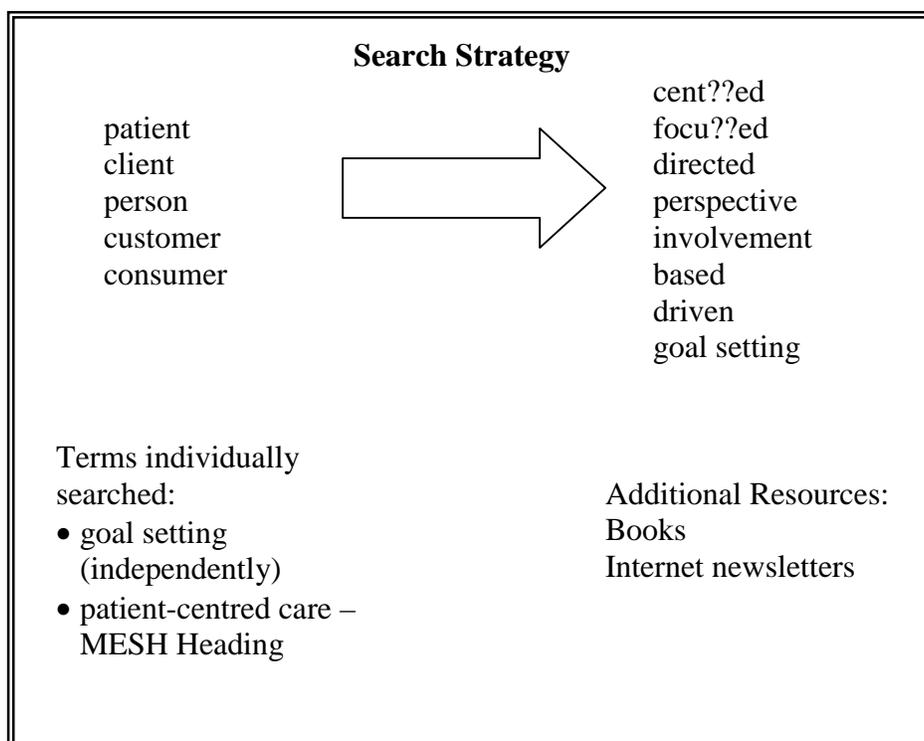
CINAHL

Wilson Business Abstracts

EMBASE

Social Work Abstracts

Picker Institute ([www.picker.org](http://www.picker.org))



Articles considered relevant from the search pattern were reviewed by the Client-Centred Rehabilitation Group in ACREU and entered into a reference manager database.

The database focused on the following areas:

General Practice  
 Rehabilitation (OT, PT, SLP, Audiologists)  
 Healthcare / care  
 Hospital/Long term care  
 Clinic  
 Specialist  
 Social Work  
 Nursing

The articles reviewed could be broadly categorized as professional level and systems level. The professional level articles give attention to interactions between the health professional and the client. The systems level articles focus on the context in which care is provided.

## ***2.2 Defining Client-Centred Rehabilitation***

One of our first challenges was to find a consistent, overarching definition of client-centred rehabilitation. A client-centred approach is identified in the paper “Managing the Seams: Making the Rehabilitation System Work for People” (Provincial Rehabilitation Reference Group, 2000) as one that facilitates responsive, individually appropriate, functionally-based goal setting involving the active and informed participation of the client. Beginning with this definition, we searched the literature for definitions and conceptual models that would help us further define the components of client-centred rehabilitation. In particular, we were looking for definitions and models that would apply to

the rehabilitation of adult clients with chronic physical disability. We took a broad systems approach that examined client-centredness at a variety of levels such as individual client/practitioner encounters, programs and organizations.

We quickly found that the terminology used in the literature is inconsistent and includes a variety of terms such as client-centred practice, patient-centred care, and patient focused care. We identified two main categories of literature: individual client/practitioner level literature and system level literature. Within these literatures, the three terms above are used with different meanings.

Much of the work on the individual client / practitioner relationship tends to be profession-specific. Different professional literatures reveal varying definitions and approaches to client-centred care. These professional definitions tend to focus on individual client/practitioner interactions from each profession’s perspective. Some professions are much further along in their thinking in this area than others. Occupational therapists in particular have been talking about client-centred practice for almost 20 years and are much further down the road than some other groups.

In the Canadian Occupational Therapy literature client-centred practice refers to “collaborative approaches aimed at enabling occupation with clients who may be individuals, groups, agencies, governments, corporations or others. Occupational therapists demonstrate respect for clients, involve clients in decision making, advocate with and for clients in meeting clients=needs, and otherwise recognize clients=experience and knowledge@ (p.49, Townsend et al., 1997). This definition seemed closest to what we were trying to

define as client-centred rehabilitation, however, it focuses on the level of the individual profession and does not include broader system level issues.

In medicine, the terminology used is that of a patient-centred approach referring to approach where “the physician tries to enter the patient’s world, to see the illness through the patient’s eyes”(McWhinney, 1989, in Mead and Bower, 2000). The way that the term “patient-centred approach” is used in the medical literature focuses on issues of communication, one component of client-centred rehabilitation.

At the system level, the majority of the hospital literature used the term, patient focused care, referring to the redesign of patient care so that personnel and resources are organised around the patient instead of departments (Kimble, 1997). The Nursing literature, being so closely linked at times to the hospital literature, employed more than one definition of client-centred care. Recently, there has been considerable response in the nursing literature to the restructuring of hospitals, and this literature defines "patient-centred" or "patient focused care" in the manner we have referred to as "patient focused care;" it is concerned with the changing structure and management and how this will effect the profession of nursing (Seago, 1999; Kimble, 1997; Gallagher 1997, Johnson and Cooper, 1997; Pence, 1997; Myers, 1998; Burchell and Jenner, 1996) However, there was also a substantial body of literature in nursing that explores client or patient-centred care as a philosophy of care that encompasses the physical, emotional, social and spiritual needs of the patient, and ideally includes mutual collaboration between the patient and the professional (Millers and Koop 1984).

Finally, at the system level, the Picker Institute uses the term patient-centred care to describe an approach that consciously adopts the patient’s perspective (Gerteis and Roberts, 1993). Unlike the medical literature, the literature from the Picker Institute defines patient-centred care more broadly than communication and incorporates a number of individual level and system level issues. The Picker approach was also very promising although the focus of most of its work to date has been on acute hospital-based care. They do not specifically define patient-centred care but do identify components essential to patient-centred care from the perspective of the patient (see section 2.4.2). It is important to note that the Picker Institute is the only one to approach defining patient centred care from the patient’s perspective. All of the other bodies of literature address patient-centred and client-centred care from the professional or organization’s perspective.

In the following literature review, we provide an overview of these five major bodies of literature that we divided into two broad categories: 1) professional/client level literature (OT, Medicine and Nursing) and 2) system level literature (Hospital and Picker Institute). We reviewed each category of literature with respect to how client-centred care is defined, research that has been conducted, and barriers to implementing client-centred care <sup>1</sup>. Although some of this literature was less

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<sup>1</sup> We also looked at physiotherapy, social work, and speech language pathology literature but did not find articles that specifically addressed or defined client-centred or patient-centred care. These terms were used in these literatures but the meaning of the term was not specifically addressed.

applicable to our conceptualization of client-centred rehabilitation, particularly that on patient focused care, we have included it because it is important to clarify the terminology and understand the different usages of these terms.

## ***2.3 Professional / Client Level Literature***

### **2.3.1 Occupational Therapy Literature: Client-Centred Practice**

In Canada, client-centred practice is considered a core concept of occupational therapy.

Client-centred practice refers to collaborative approaches aimed at enabling occupation with clients who may be individuals, groups, agencies, governments, corporations or others. Occupational therapists demonstrate respect for clients, involve clients in decision making, advocate with and for clients in meeting clients' needs, and otherwise recognize clients' experience and knowledge. (p.49, Townsend et al., 1997)

Guidelines for occupational therapy client-centred practice were initially developed in response to national and international trends in health service delivery. Canada was the first to develop national, generic guidelines that defined client-centred practice and related process and outcome issues for quality assurance in occupational therapy (Townsend, Brintnell and Staisey, 1990). Work on the Canadian guidelines was initiated in 1979 when the Department of National Health and Welfare and the Canadian Association of Occupational Therapists (CAOT) convened a National

Task Force. Groundwork had been previously completed during the 1960's and 1970's in Canada and the United States (Townsend et al., 1990).

To date client-centred practice has focused on the individual client-therapist level. Some discussion of client-centredness at the department level has been introduced, with less attention afforded to organizational or system level implementation or impact of client-centred practice. Implementation of client-centred care at the organization level has been difficult with issues such as lack of interdisciplinary care serving as a barrier to organization level implementation of client-centred care (Gage, 1994).

#### **2.3.1.1 Themes and Components of Client-Centred Practice**

The goal of client-centred practice is to create a caring, dignified and empowering environment in which clients truly direct the course of their care and call upon their inner resources to speed the healing process (p. 128, Matheis-Kraft, Loinger and York, 1990). In order for this to occur a shift in power from the therapist to the client must be realized with client empowerment as key (Gage and Polatajko, 1995).

What constitutes a client? In the Canadian occupational therapy context clients are defined as: individuals who may have occupational problems arising from medical conditions, transitional difficulties, or environmental barriers, or clients may be organizations that influence the occupational performance of particular groups or populations (p. 50, Townsend et al., 1997).

Six core concepts of client-centred practice have been identified (Law et al., 1990; Law, Baptiste and Mills, 1995):

1) *autonomy / choice*: each client is a unique individual who should be afforded information provided in a format understandable to them and upon which they may base their choice;

2) *partnership and responsibility*: there is a shift in power from the traditional medical paradigm such that both therapist and client work collaboratively, sharing responsibility in the provision of information, establishment of goals, selection of treatment and evaluation of outcomes;

3) *enablement*: there is a shift in paradigm from the traditional medical model of remediation to one of prevention, remediation, development or maintenance of occupational performance established collaboratively;

4) *contextual congruence*: consideration of the context in which a client lives (clients= roles, interests, environments and culture) are central to client-centred occupational therapy practice;

5) *accessibility and flexibility*: services are provided in a timely, accessible manner which are constructed to meet the clients needs;

6) *respect for diversity*: demonstrates respect for client values, and therapist does not impose his/her values

- ◆ base practice on clients= values, meaning, and choice as much as possible
- ◆ listen to clients= visions
- ◆ facilitate processes for clients envisioning what might be possible
- ◆ support clients to examine risks and consequences
- ◆ support clients to succeed, but also to risk and fail
- ◆ respect clients= own styles of coping or bringing about change
- ◆ guide clients to identify needs from their own perspective
- ◆ facilitate clients to choose outcomes that they define as meaningful even if the occupational therapist does not agree
- ◆ encourage and actively facilitate clients to participate in decision-making partnerships in therapy, program planning, and policy formation
- ◆ provide information that will answer clients= questions in making choices
- ◆ offer services that do not overwhelm clients with bureaucracy
- ◆ foster open, clear communication
- ◆ invite clients to use their strengths and natural community supports

(p. 51, CAOT, 1997)

### **2.3.1.2 Barriers to Client-Centred Practice in Occupational Therapy**

Barriers to the implementation of a client-centred practice in the occupational therapy literature may be summarized as being related to the client, the therapist, and/or the organization (Law et al., 1995; Wilkins, Pollock, Rochon and Law, in press). Sumsion and Smyth (2000) conducted a study using a postal questionnaire among 60 occupational therapists in the United Kingdom in which therapists rated (5-point

The Canadian Association of Occupational Therapists identified twelve guiding principles in client-centred practice:

likert-type scale) 16 barriers to client-centred practice identified from the literature with respect to how much each barrier prevented client-centred practice. In addition, therapists indicated how much each of 18 methods selected from the literature would assist in resolving these barriers. The three highest ranked barriers were: 1) the therapist and client have different goals; 2) the therapist's values and beliefs prevent them from accepting the client's goals; 3) the therapist is uncomfortable letting the client choose his/her own goals. The three highest ranked methods for resolving therapist barriers were: 1) case examples showing how to practice in a client-centred fashion; 2) management and peer support for use of client-centred practice; 3) involvement of all staff in client-centred practice training. Barriers as ranked in this study were primarily related to incongruence between therapist and client goals and values, with a smaller emphasis upon environmental and cultural barriers. Barrier resolution focused primarily upon educational strategies.

### **2.3.2 Medical Literature: Patient-Centred Care**

There was an extensive literature that discusses patient-centred care in the general practice setting. This literature tended to focus on issues around physician-patient communication. Research on patient-centred care has been conducted since the late sixties. Provided below is a discussion of the components within patient-centred care that have received attention within the general practice literature.

#### **2.3.2.1 Definition of Patient-Centred Care**

There is much disagreement as to what patient-centred care really means (Mead and

Bower, 2000). Epstein (1997) described many different models of patient-physician relationships, two of which embody patient-centred care: 1) the patient-centred model which focuses on both physicians and patients sharing power and understanding the medical condition and 2) the deliberative model which stresses the physician involving the patient in discussions and providing treatment options. Chewing and Sleath (1996) argue that the patient-centred model consists of the patient and provider collaborating in identifying treatment goals, choosing from regimen options, monitoring symptoms and evaluating and revising regimens. Weston and Brown (1995) provided a detailed model of patient-centred care which consists of six aspects: exploring the disease as well as the experience, seeing the patient as a person and being aware of his/her history and current situation, negotiation of goals, problems, priorities and roles of doctor and patient, and striving for health prevention and promotion.

#### **2.3.2.2 Patient-Doctor Collaboration**

Much of this literature has stressed that doctors need to listen to their patients and see them as individuals (Speechley, 1992; Krupat, Hiam, Fleming and Freeman, 1999; Rothstein, 1999). A study by Carroll, Sullivan and Colledge (1998) found that patients perceive physicians listening to them as the most crucial aspect of general practice.

Doctors also need to encourage the sharing of information, power and control with their patients (Krupat, Hiam, Fleming and Freeman, 1999). General practitioners not only have an obligation to provide information at the beginning of treatment, but throughout the therapy/treatment when the number of patient's questions is numerous (Speechley, 1992). Laine and

Davidoff (1996) argued that when practitioners share information with their patients, patients have the ability to make sound decisions about their medical care.

Before doctors involve their patients in their treatment, patients need to express the desire to collaborate. The literature has shown that patients place importance on being involved in decision-making with their physicians (Vertinsky, Thompson and Uyeno, 1974; Wensing, Jung, Mainz, Olesen and Grol, 1998). A number of factors influence whether or not patients would like to participate in their care. For example, studies have shown that individuals with higher incomes and higher levels of education play a more active role in provider-client decision-making (Chewing and Sleuth, 1996). In addition to socio-economic status, patients with enough expertise about the decision they are about to make are more comfortable participating in medical decision-making (Chewing and Sleuth, 1996). Guadagnoli and Ward (1998) found that patients would also like to participate in decision-making if there was more than one treatment option.

### **2.3.2.3 Implementation of Patient-Centred Care in Medicine**

The literature contained few studies on the implementation of patient-centred care in general practice. One exception was a study by Brown, Weston, and Stewart (1989) who found that framing the interaction between the patient and physician in the form of an interview promoted care by allowing for the definition of problems, goals, and relationship. The patient interview required that the physician actively listen to the patient, let the patient work at her/his own pace and be sensitive/considerate of what the patient would like to discuss. Another study discussed the development of shared-

decision making program which entails a patient viewing an interview that outlines their treatment options, and the benefits and disadvantages of each (Kasper, Mulley, and Wennberg, 1992).

While there were few implementation studies, there were numerous studies dealing with outcomes of patient-centred care that offer insight into how patient-centred care could be achieved in general practice. General practitioners could also derive ideas about implementation from the work of Kinmonth, Woodcock, Griffin, Spiegel and Campbell (1998) who had nurses and general practitioners attend training sessions to become familiar with national guidelines, patient-centred counseling and the practice of skills. Finally, implementation of patient-centred care could be achieved by using the Greenfield, Kaplan, Ware, Yano and Frank (1988) research intervention used with diabetes patients. Prior to their consultation with their physician, diabetic patients went through their medical chart with a clinical assistant (Greenfield et al. 1988).

### **2.3.2.4 Patient-Centred Care Analysis**

#### **Quantitative Analysis**

There have been a number of observation-based, quantitative methods used in general practice to measure the extent to which care is patient-centred (Stewart, 1995). Quantitative methods of measurement include coding of statements between patients and their physicians (Greenfield et al., 1988; Kaplan, Greenfield and Ware, 1989), rating scales (Langewitz, Phillipp, Kiss, and Wossmer; Ockene et al., 1988; Verhaak, 1988), scales measuring attitudes and values (Cockburn, Killer, Campbell, and Sanson-Fisher, 1987; deMonchy, Richardson, Brown, and Harden, 1988; Grol, de Maeseneer, Whitfield, and Mokkink,

1990), checklists of physician=s and patient=s behavior (Bryne and Long, 1976), and interviewing of patients after their consultation with physicians (Henbest, 1985). Mead and Bower (2000) offer an extensive review of the studies evaluating the reliability and validity of various measures of patient-centred care (please refer to Mead and Bower for more details). In an empirical study, Mead and Bower (2000) compared the reliability and validity of three observation-based measures of patient-centred care. Their study evaluated Henbest and Stewart=s (1989) scoring of physicians responses to patient=s requests/offers, the Roter method of coding verbal statements of doctors and their patients which was derived from the Roter Interaction Analysis System (Roter, 1993), and the rating scale (Mead and Bower, 2000).

In terms of reliability, interrater reliability was highest for the Roter-based method (.71) and lowest for the rating scale (.34). In terms of validity, the three measures did not correlate highly with one another indicating that they did not measure the same construct. Also, the rater scale and the Roter-based method correlated highly with psychosocial aspects of physician consultation; the Henbest and Stewart (1989) method did not (Mead and Bower, 2000).

### ***Qualitative Analysis***

Just as there is a tradition of quantitative analysis of patient-centred care in general practice, there is also a qualitative analytic approach. While this approach to evaluating patient-centred care advocates understanding the experience and context of the patient, the field research focuses more on the role of the physician. Future research needs to focus equal attention to both the

patient and the physician to reflect reality (McWilliam, 1995).

### **2.3.2.5 Patient-Centred Care Outcomes in Medicine**

There were number of articles in the general practice literature focused on the outcomes of patient-centred care (Anderson, DeVellis and DeVellis, 1987; Brody, Miller, Lerman, Smith, and Caputo, 1989; Greenfield et al 1988; Kaplan et al., 1989; Kinmonth, et al., 1998). The majority of such studies have focused on patients suffering from chronic illnesses such as diabetes, ulcers, breast cancer and high blood pressure (Greenfield et al., 1988; Kaplan et al. 1989; Kinmonth, et al., 1998) Outcomes of patient-centred care can be divided into subjective and physical health outcomes. Common subjective outcomes of patient-centred care include higher levels of patient-practitioner communication, greater patient satisfaction, comfort and control (Anderson et al., 1987; Brody et al., 1989; Kinmonth et al., 1998). Common physical health outcomes of using a patient-centred approach include improvement in blood sugar levels, blood pressure and overall health status (Brody et al., 1989; Greenfield et al., 1988; Kaplan et al., 1989).

### **2.3.2.6 Barriers To Patient-Centred Care in General Practice**

There was not much focus on the barriers to patient-centred care in the general practice literature. One barrier that was discussed was the challenge of communication (Brown et al., 1989; Harrison, 1982; Brown et al., 1995). Common problems of communication included misdiagnosis, and patients and physicians disagreeing as to what is the patient=s main problem (Brown et al., 1989; Brown et al., 1995). A second barrier to patient-centred care is its tendency

to be a non-hierarchical system. Harrison (1982) discussed how medical and non-medical members of a community clinic in Vancouver have an equal say in decision-making and review each other's work. Certain doctors might find such a system threatening (Harrison, 1982). Another barrier to achieving patient-centred care is the task of physicians and patients sharing expertise and power (Chewing, and Sleath, 1996). Finally, another challenge to patient-centred care is the paradoxical relationship between patient empowerment and physician control. For example, Skelton's (1997) study of whether or not physicians control or empower their patients suffering from lower back pain found that patients willingly left themselves in the control of the physician in order to meet their goals for health prevention. Another study by Deber, Kraetschmer and Irvine (1996) showed the contradictory situation of patients not willing to hand over total control to physicians in decision making, yet not wanting to fully participate in problem-solving.

### **2.3.3 Nursing Literature: Patient Focused/Centred Care**

The nursing literature employed more than one definition of patient focused or patient-centred care. Recently, there has been considerable response in the nursing literature to the restructuring of hospitals with its emphasis on "patient focused care" which is concerned with the changing structure and management of institutions and how this will effect the profession of nursing (Seago, 1999; Kimble, 1997; Gallagher 1997, Johnston and Cooper, 1997; Pence, 1997; Myers, 1998; Burchell and Jenner, 1996). However, there was also a substantial body of literature in nursing that explores patient-centred care as a philosophy of care that encompasses the

physical, emotional, social and spiritual needs of the patient, and ideally includes mutual collaboration between the patient and the professional (Millers and Koop 1984). In contrast to the definitions of "patient focused care" that emphasized the restructuring of nursing services, Campbell (1998) defined "patient focused care" as care that seeks to empower the healthcare consumer through the transfer of information and the facilitation of choice.

It is a general opinion in the nursing literature that nursing has always been more or less patient-centred (Brown, 1999; Campbell, 1998). Campbell (1998) noted that in the nineteenth century, Florence Nightingale considered nursing to be an act of caring not only for the symptoms of illness, but also of the person who was ill. Brown (1999) also identified the first use of the term "patient-centred communication" in the nursing literature to be as early as 1962, by nurse researcher B.P. Mathews, in reference to communication that encourages clients to discuss their lives outside of their condition.

In the intervening years a number of themes have emerged in the nursing literature. Holistic care is a persistent theme in patient-centred nursing, incorporating as it does the knowledge and recognition of the patient as whole person and the importance of providing emotional support, as well as physical comfort (Kirkpatrick, Ford and Castelloe, 1997; Millers and Koop, 1984). The gerontological nursing literature stressed in particular importance of protecting the patient's individuality, dignity and choice (Kenny, 1990; Lustbader 1996; Gillick, Berkman and Cullen, 1999; Kirkpatrick et al., 1997; Luckhurst and Ray, 1999). An excellent article by Brown (1999) addressed the recent literature in nursing and medicine on "patient-centred

communication," giving insight into the elements of patient-centred communication (PCC), methods of achieving this communication and research.

There has also been a fair development in the literature on patient participation and mutual goal setting (King 1981; Kenny, 1990; Alexy, 1985; Moughton, 1982; Hefferin, 1979; Biley, 1989), though the reported results of mutual goal setting have been mixed (Biley, 1989; Alexy, 1985; Hefferin, 1979). In the area of professional collaboration, Jones (1997) has developed a conceptual definition of multi disciplinary collaboration, and a measure of that collaboration.

### **2.3.3.1 Barriers To Patient Focused/Centred Care in Nursing**

The barriers to patient focussed care identified by the nursing literature are generally system based. There have been barriers suggested at the level of the provider (Millers and Koop, 1984), and Brown (1999) identifies several factors that affect the enactment of patient-centred communication, including provider-based, patient-based and system-based factors. But system-based barriers are the most likely to be mentioned in the nursing literature; they include a lack of support staff for nurses and a lack of autonomy in care (Millers and Koop 1984, Eubanks 1990).

The indicators for client-centred care in the nursing literature tended to be limited to a specific aspect of care, such as those identified by Brown (1999) in the area of communication. These included "allowing patients to give accounts in their own language and chronology," a "conversational style of interviewing," and "asking about context of patient's lives" (Brown, 1999, p.88). Carroll (1999) also identified several

sub-concepts, among them the health care process, communication, and attitude that may be used as indicators in multidisciplinary collaboration.

## ***2.4 Service/ System Level Literature***

### **2.4.1 Hospital Literature: Patient Focused Care**

The majority of the hospital literature referred to patient-focused care; the redesign of patient care so that personnel and resources are organised around the patient instead of departments (Kimble, 1997). Patient-focused care (PFC) was started in 1988 by Booz-Allen and Hamilton Consulting, an American management consulting firm interested in reducing costs while improving health care in hospitals (Burchell and Jenner, 1996); however, their ideas on decentralization date back to at least 1980. (Elliot, 1980, Hackman and Oldham, 1980)

The principles of PFC, among them the simplification of processes and documentation, the decentralisation of routine services and the cross-training of staff (Lathrop, Seufert, MacDonald and Martin, 1991; Johnston and Cooper, 1997; Pence, 1997; Myers 1998), show that it is primarily an organizational philosophy, rather than one intending to change the philosophy of the care. The effect is intended to be an improvement of care through such things as a greater continuity of care and less travel around the hospital (Lathrop et al. 1991; Johnston and Cooper, 1997; Myers, 1998). Myers (1998) included a sixth principle in her summary of the system, "enhanced patient autonomy and decision making," but does not explain how PFC can enhance patient decision making

beyond other than allowing them to "choose, somewhat, where they get their health care needs fulfilled." (Myers, 1998, p.181) At the system level, there seems to be a more active involvement of patients, as some hospitals have begun to borrow management techniques from business; Chaplin described the use of Quality Function Deployment to capture the voice of the customer (Chaplin et al., 1999, p.300)

Recently, some hospitals have adopted a broader definition of client-centred care. The Planetree model expands on the PFC layout changes to establish environments that are conducive to healing and account for patient's emotional needs for comfort, through the use of art and nature; Planetree also stresses emotional support, patient education, and patient and family involvement in care (Lumsdon, 1996; Weisman and Hagland, 1994; Damgaard, 1999; Planetree website). In addition to their changes to the usual hospital layout and procedures (Lumsdon, 1993; Weisman and Hagland, 1994), Planetree centres have implemented open-charting systems, in which patients are allowed to review and include their own comments (Damgaard, 1999). The Planetree model also calls for medical resource centres with audio and videotapes and easily comprehended reading material on treatments, both traditional and complementary (Damgaard, 1999). However, as noted by Robin Orr, ex-director of Planetree, although access to information is intended to be the hallmark of Planetree, there are few hospitals embracing this part of the model (Lumsdon, 1993). Instead many hospitals are restructuring their organisation along the principles established by Booz-Allen, while sometimes also incorporating ideas on room and hall design, and general consideration for patients from Planetree (Mancini, 1995; Guinn, 1993).

## 2.4.2 Picker Institute: Patient-Centred Care

The Picker Institute is an international leader in the field of healthcare quality assessment and improvement strategies. The Picker/Commonwealth Program for Patient-Centred Care was established in 1987. It is a non-profit affiliate of Care Group in Boston, Massachusetts. The Picker Institute's mission is to improve the quality of health care "through the eyes of the patient". They use a research-based approach to understand issues that are most crucial to patients. In addition, they assist healthcare providers and organizations in developing patient-centred approaches to providing care.

The term patient-centred care is used to describe an approach that consciously adopts the patient's perspective (Gerteis and Roberts, 1993). Picker grouped patient concerns and care into eight dimensions of patient-centred care.

- ◆ Respecting a patient's values, preferences and expressed needs
- ◆ Access to care
- ◆ Emotional support
- ◆ Information and education
- ◆ Coordination of care
- ◆ Physical comfort
- ◆ Involvement of family and friends
- ◆ Continuity and transition

These dimensions of patient-centred care were developed through: an extensive review of the literature; numerous structured focus groups with patients, their families, health professionals, and lay persons; pilot interviews with patients and families; and, intensive critiques by patients and health care professionals. Patient-centred care distinguishes itself from satisfaction surveys by focusing on clinically important elements of care.

A national survey of acute care hospitals was conducted using the instrument they had developed based on what the patients themselves really cared about. Field visits to organizations were also conducted to understand the culture of organizations that did well in the surveys or poorly. A number of findings from the early work of Picker were published in the book “Through the Eye’s of the Patient” (Gerteis and Roberts, 1993).

The focus of Picker in the last ten years has been to assist organizations in obtaining information from patients about their needs and concerns. The community has not been easy to convince that issues from the patient perspective need to be addressed. Clinicians and administrators went through a phase of denial and resistance to patient-centredness (Delbanco, 1995). Patients do have valid concerns and it is important to incorporate these as in future healthcare designs. Many factors are influencing the push toward client centred care including: a rise in patient expectations, changing culture, availability of information (Internet), and the feminist movement.

The Picker Institute continues their fieldwork to examine how far organizations are in their work with patient-centred initiatives. They have found that organizations call it different things, and implement different strategies but an effort is consciously being made to improve the patient experience.

Picker also provides patient-centred resources for improving the healthcare experience for patients through The New Visions: Ideas Worth Sharing Bulletin. This bulletin was initiated to provide opportunities for communication amongst various groups with respect to patient-centred work. The bulletin is distributed

via email and hard copy. Bulletins can be viewed on their web page ([www.picker.org](http://www.picker.org)).

## ***2.5 Measuring Client-centred Rehabilitation: Client-centred Tools***

There is no single, well established tool for measuring client-centred rehabilitation, however, there are a number of tools that have been developed that are potentially useful. In this section we review various measures that can be used to measure client-centred care in rehabilitation. Appendices A-D contain more detailed information about each measure. Although all of the organizations were very generous in sharing their research tools with us, for copyright reasons we are unable to reproduce the actual tools in this report.

### **2.5.1 Canadian Occupational Performance Measure**

Acting upon recommendations in the third guidelines document *Toward Outcome Measures in Occupational Therapy* (DNHW and CAOT, 1987), the National Health Research and Development Program (NHRDP) and the Canadian Occupational Therapy Foundation (COTF) funded a research team which developed the Canadian Occupational Performance Measure (COPM). The purpose of the COPM is to enable occupational therapy clients to participate in a meaningful way in determining the course of occupational therapy intervention (p. 192, Law et al., 1994). The COPM is an individual, standardized measure administered to a client or to a proxy respondent such as family, caregiver or teacher in a semi-structured interview. The COPM may be employed with clients throughout their life span (from cradle to grave) and is

applicable to a client's physical or mental health, across all ability levels. Within the context of the interview the client is asked to identify problems or issues s/he is experiencing with these activities, his/her current level of and satisfaction with the performance of these activities, and the importance assigned to each of these activities. The COPM measures the change in the client's perception of occupational performance over time in the areas of self-care, productivity and leisure. The median administration time of the COPM is 30 minutes (Law et al., 1990). Appendix A contains further details of the COPM.

### **2.5.2 Goal Attainment Scaling**

Goal Attainment Scaling (GAS), which Kiresuk and Sherman developed in 1968, refers to a process of evaluating therapeutic outcomes with patients (Appendix B). GAS consists of seven steps: 1) the goal setter/team identifies client's desires needs and present situation; 2) goal setter/team and client reach a consensus on which goals are attainable; 3) goals are designated a weight according to their importance; 4) outcomes are established for each goal; 5) a scale ranging from -2 to + 2 is assigned to each goal; -2 refers to the most unfavorable outcome, while +2 is assigned to the most favorable outcome; 6) an independent team or person will evaluate the outcomes; and, 7) the success of the program is evaluated by determining the score for each goal (Kiresuk and Sherman, 1968; Clark and Caudrey, 1983). GAS has been used with patients in the following areas: brain injury (Zweber and Malec, 1990; Joyce, Rockwood and Mate-Kole, 1994), gerontology (Rockwood, Stolee and Fox, 1993; Stolee, Stadnyk Myers and Rockwood, 1999), mental health (Willer and Miller, 1976) and pediatrics (Mitchell and Cusick, 1998).

GAS possesses both advantages and disadvantages. One reason why GAS is useful as a tool for the evaluation of therapeutic outcomes is that it monitors a patient's progress and change in therapy (Ottenbacher and Cusick, 1990; Joyce et al., 1994; Forbes, 1998; Stolee et al., 1999; Rockwood et al., 1993). Second, GAS allows for interdisciplinary team members and the client to negotiate goals (Gordon, Powell, and Rockwood, 1999; Forbes, 1998; Mitchell and Cusick, 1998). Third, GAS is flexible in that it is not a tool that is limited to one particular outcome/treatment measure (Ottenbacher and Cusick, 1990). A final advantage to GAS is how it allows patients to obtain insight into their condition/treatment (Mitchell and Cusick, 1998; Zwebber and Malec, 1990). Even though GAS has numerous favorable aspects, it has some problem areas. For example, comparison of GAS is difficult because of the subjectivity of the goals set by clinicians (Forbes, 1998). Another problematic area with GAS is the possibility of clinicians setting goals that are easily attainable (Rockwood, 1995; Turnball, 1998). Finally, the problem of assigning weights to goals is another disadvantage to using to GAS (Clark and Caudrey, 1983).

Various studies have provided support for both the validity and reliability of GAS.

The validity of GAS has been supported by studies showing significant correlations between GAS scores and other evaluation outcome measures (Malec, Smigielski and Depompolo, 1991; Stolee, et al., 1999) and significant correlations between scores of patients before and after GAS application (Malec et al., 1991). The reliability of GAS has been demonstrated by a study that showed an inter-rater reliability of GAS of brain injury patients between admission (.92) and discharge (.94) (Joyce et al., 1994).

Although GAS usually involves developing goals and outcome levels specific to the individual client, there have been some attempts to develop a standardized menu of pre-set goal attainment scales for common functional activities such as transfers and ambulation (Yip et al., 1998)

### **2.5.3 Picker Surveys**

The Picker Institute has developed a range of questionnaires for a variety of clinical settings (Appendix C). The questionnaires measure patient satisfaction and experiences with care in a variety of inpatient and ambulatory settings. All Picker surveys use a combination of reports and ratings to assess patients' experiences within important dimensions of care, their overall satisfaction with services, and the relative importance of each of the dimensions in relation to satisfaction. The face validity of the questionnaires is addressed throughout the development process by incorporating patients' and therapists' perspectives. The discriminant validity of the instruments is tested by the observed differences in problem rates between institutions.

### **2.5.4 Wascana Client-Centred Care Questionnaire**

Based on work from the Picker Institute, the Wascana group identified six dimensions to client care: respect and dignity; information, communication and education; physical comfort; emotional support and acknowledgement; involvement of family and friends; and integration of care. The WASCANA Client-Centred Care Survey was developed as a self-report measurement tool to evaluate the multidimensional concept of client-centred care (Asmundson and Jones, 1996). The questionnaire items were generated through discussions and feedback from health care patients and

providers in a rehabilitation setting. The WASCANA has been used primarily as part of an ongoing program evaluation protocol in a clinical setting. The questionnaire asks patients to respond to 40 questions scored from 1 (strongly agree) to 5 (strongly disagree) and takes approximately 30 minutes to complete. Questions relate to six domains: personal comfort, involvement in care, community integration, respect, information received, and emotional support. Reliability for each of the scales (4 reported) ranged from 0.76 –0.88. The subscale inter-correlations ranged from 0.37-0.72, all lower than the reliability estimates for the subscale, indicating that each subscale provides discriminant distinctiveness. Test-retest reliability has not been reported. A score of 2 or greater may represent a target for service quality management initiatives.

The WASCANA was used as part of two practice review projects conducted by the College of Physiotherapists of Ontario (Asmundson et al., 1998; Lineker and Wilkins, 2000). Clients with rheumatoid arthritis (RA) (Asmundson et al., 1998) and lower extremity musculoskeletal conditions [MSK] (Lineker and Wilkins, 2000) received physiotherapy (PT) and then were sent the WASCANA survey at discharge or at the end of the project. Using the WASCANA, clients in these two projects identified that physiotherapists (PTs) could improve care by helping the client more fully integrate into the community, providing them with more information about their disease and by involving them more in the care they receive. In the RA study (Asmundson et al., 1998), clients with longer disease duration were more likely to identify that the care they received was not client-centred. This suggests that targeting interventions to address the particular needs of those clients with long standing disease

may improve the client-centredness of rehabilitation interventions. In the MSK study (Lineker and Wilkins, 2000), clients who did not complete the PT intervention also completed the WASCANA and results suggested that they wanted to be more involved in the care they received. These results suggest that for identifying quality management initiatives, it is important to seek feedback from clients who do not complete the rehabilitation intervention.

### **2.5.5 CAHPS™ - Consumer Assessment of Health Plans Study**

The conceptual basis of the Consumer Assessment of Health Plans Study (CAHPS) was to produce a rating of health care plans based on information only consumers could provide, to assist in consumer choice of health plans in the United States. The developers sought to create surveys that are suitable for and allow valid comparisons across wide range of potential consumers and with all types of health care delivery systems. The adult core consists of Yes/No and Never/Sometimes/Usually/Always reports on aspects of health care and four global ratings on a 1-10 scale of various health professionals. Supplemental subscales can be added on communication, interpreter, dental care, mental health, chronic conditions, pregnancy care, prescription medicine, transportation, and well child care. Details with respect to the reliability and validity of the global ratings scale are included in Appendix D.

## ***2.6 Summary of the Literature Review***

There is no commonly used definition of client-centred care. Instead, a variety of terms such as client-centred practice, patient focused care and patient-centred care are

used, many times with different meanings. What most of the professional conceptualizations of client-centred care have in common is the notion of identifying each client's goals/wishes/needs and tailoring interventions accordingly. Other common themes are respect for client's decisions/wishes even if the professional does not agree and the need for effective communication and education. Other than the OT literature that focuses on individual therapist and client, little work has been done specifically in rehabilitation. As well, these literatures approach client-centred care from the professional's perspective, not the client's.

It is interesting that all the professions approach client-centred care from their own individual perspectives and not from a system level. One of tenets of client-centred care is the need for an interdisciplinary approach, which assumes a shared understanding of norms and values, yet the various professional groups do not even think about client-centred care the same way or usually only view it from the perspective of their individual profession. Although most professional literatures identify system level issues as barriers to implementing client-centred care, few approach the issue from a systems perspective.

With respect to barriers, many talk of health care professionals' reluctance to adopt a client-centred approach. This does not generally stem from a lack of interest or disagreement with the principles of client-centredness, although some papers discussed professionals' discomfort with shifting power and responsibility from professional to client, and the fact that the whole system is not client-centred resulting in little system support for client-centred care.

Much of the work to date at the system level is acute care, hospital focused. Issues for rehabilitation differ from acute care because rehabilitation clients usually have chronic illnesses that they are learning to manage and live with over the long term. It is therefore especially important that power is shifted to clients so that they can assume responsibility for managing their condition.

From the literature we identified the following important components that would seem applicable to a client-centred approach in rehabilitation:

1. client participation in decision-making and goal setting.
2. client-centred education: appropriate client education tailored to client's needs and wants for information
3. evaluation of outcomes from client's perspective, not just impairment level outcomes, but also at level of activity and participation.
4. system-response to client feedback
5. system coordination (could be primary worker, interdisciplinary teamwork etc.)
6. continuity: discharge planning and linkage to next phase of rehabilitation
7. follow-up
8. family involvement
9. effective communication
10. respect
11. choice
12. access
13. emotional support
14. physical comfort
15. system-wide support for client-centred care

The next step in the project was to understand the important components of client-centred rehabilitation from the client's

perspective. To this end, we conducted focus groups with adult clients with chronic physical disability.

## Chapter 3: Focus Groups

The purpose of this part of the project was to identify the important components of client-centred rehabilitation from the perspective of adult clients with chronic physically disabling conditions.

### *3.1 Focus Group Methodology*

We used a focus group methodology to examine client-centred care in the publicly funded rehabilitation system. The client groups studied included patients with chronically disabling conditions such as: arthritis, total joint replacement (Hip/knee), acquired brain injury (ABI), respiratory conditions (COPD), spinal cord injury (SCI), and multiple sclerosis (MS). These client groups were chosen based on the target groups from the rehabilitation reform pilot projects process. Since we were interested in the entire rehabilitation process we sampled for participants who had completed at least one course of rehabilitation. Clients receiving Stroke or Cardiac Rehabilitation were not included as there are other initiatives underway within the Ministry that are specifically addressing their needs. Prior to use, the University Health Network Ethics Committee approved all materials and procedures for the study. Informed consent was obtained from all participants.

#### **Inclusion Criteria:**

Focus group participants had to meet the following criteria:

- ◆ have a chronic condition for which they have received rehabilitation services in the publicly funded system.
- ◆ be able to participate in a 1 to 2 hour focus group session.

- ◆ be English speaking
- ◆ be able to get to the focus group session.

#### **Exclusion Criteria:**

The following criteria excluded individuals from participation in the focus groups:

- ◆ profound cognitive impairment
- ◆ aphasia

#### **3.1.1 Sampling for Focus Groups**

Separate focus groups were held with adults with chronic disabling conditions who had received rehabilitation services. Potential participants were identified through rehabilitation programs (e.g. Acquired Brain Injury Program; West Park Hospital) and disease-specific associations (e.g. The Arthritis Society; Canadian Paraplegia Association). They were contacted over the phone by program or association staff using a standardized script that described the research and were asked whether they are willing to be contacted by the researchers. If they agreed to be contacted, their names were forwarded to our study coordinator who contacted potential participants directly to provide them with more information about the study. Alternatively, program or association staff distributed information letters to potential participants about the study. Individuals who were interested in participating in the study were given a telephone number to contact our project coordinator directly. The project coordinator then provided them with further information about the study and confirmed their interest in participating. The referring program or association was not notified as to who actually participated in the focus groups.

### 3.1.2 Setting

The SCI, ABI, MS, Hip/knee and Arthritis focus groups occurred at Princess Margaret Hospital. The focus group for the respiratory clients occurred at West Park Hospital, and the focus group consisting of Patient Partners with arthritis occurred in London, Ontario. Patient Partners are individuals with positive findings of rheumatoid arthritis or osteoarthritis who have been trained to facilitate the musculoskeletal examination. Written consent was obtained from all participants.

### 3.1.3 Procedure

The focus groups were conducted following guidelines set out by Krueger (1994). Prior to the focus group, participants received a letter of confirmation, an information sheet, and a consent form. Participants were instructed to bring the signed consent form to the focus group. At the beginning of the focus group, the focus group leader emphasized the confidential nature of the discussion and reiterated that participation in the group would not affect the services participants received at any organization.

The focus groups were held at a time and location that was convenient for participants. A doctoral student, with a background in Physical Therapy and client-centred care, conducted the focus groups. She was trained and supervised by the PI. A second research assistant attended the focus groups to keep a speaker log and take notes. Each participant was assigned a number and a running record was kept of the first phrase of each speaker. The purpose of the speaker log is to aid with the analysis, i.e., to clarify if a particular view has been expressed by a number of persons rather than by one person many times. For confidentiality purposes,

only the first names of participants were used in the focus group discussions.

Questions were open ended and non-directive initially to encourage participants to identify issues of importance to them. As the discussion progressed, the questions became more specific to issues of client-centredness. Appendix E contains the types of questions (and probes to stimulate further discussion if necessary) that were used.

Focus groups were audio-taped and transcribed. To ensure confidentiality, when tapes were transcribed names were omitted and individuals were referred to by their assigned speaker number. The data were entered into Ethnograph, a program to help manage qualitative data.

### 3.1.4 Client Focus Groups Questions

Focus group discussions were opened with the following brief introduction. Examples of the focus group questions are listed.

#### Introduction

Thank you for agreeing to participate in these focus groups. As you know, we are trying to get a better understanding of clients' perspectives on their experiences in rehabilitation. There are no right or wrong answers. We are interested in your experiences and opinions. Let me reconfirm that the discussions that we will have today are confidential and should not be repeated outside of the group.

#### Focus Group Questions

- 1) To begin, can you tell me about your experiences in rehabilitation?  
What was helpful?

What made the experience more difficult?

- 2) Client-centred care means that the services are organized around the needs of the client, and not the health professionals. Would you say that that describes your experiences in rehabilitation? Why/why not? (Probe into areas of screening, goal setting, referral, and community linkages)
- 3) To what extent did you feel that you were included in the decisions being made about your rehabilitation? Did you feel that your individual concerns were addressed? What did the professionals do that made you feel that way?
- 4) How would you change the rehabilitation services you received to make them more client-centred? What would you keep the same?

### 3.1.5 Analysis

Data were analyzed using a Constant Comparative Approach (Strauss and Corbin, 1990). A coding scheme was developed using an iterative, inductive approach. The PI did initial open-coding of the focus groups and developed a preliminary coding scheme. Two research associates then each coded a focus group using this coding scheme. The PI and the two research associates then met to compare and contrast codes to finalize the coding scheme. Once a satisfactory level of agreement was reached, two researchers coded each focus group. They subsequently met to review the coding to ensure consistency in the definitions and interpretations of codes. The coding scheme was also reviewed by a research associate with a strong background in client-centred care who was not affiliated with the project. Once coded, the data were entered into Ethnograph, a qualitative data software package. The data were then examined for common themes within and between participant groups.

**Table 1: Demographics for Focus Group Participants**

AVERAGE LENGTH OF DISEASE	15 YEARS
Average Length of Disease for each condition (in years)	
Spinal Cord Injury	16
Acquired Brain Injury	9
Multiple Sclerosis	20
COPD	7
Arthritis	18

GENDER DISTRIBUTION FOR ALL CONDITIONS	MALE	FEMALE
	12 (43%)	16 (57%)
Gender Distribution For Each Condition	Male	Female
Spinal Cord Injury	3	0
Acquired Brain Injury	1	3
Multiple Sclerosis	1	1
COPD	4	1
Arthritis	3	11

AVERAGE AGE OF PARTICIPANTS IN YEARS (S.D.)	56 (13.5)
Average Age of Participants For Each Condition	
Spinal Cord Injury	42
Acquired Brain Injury	47
Multiple Sclerosis	47
COPD	65
Arthritis	58

### 3.2 Focus Group Results

Table 1 summarizes the demographics of the focus group participants. The main themes that emerged from the focus groups were: individualization; participation in goal setting and decision-making, lack of preparation for life in the real world, the need for emotional support, and systems issues.

#### *Individualization vs routinized group work*

When participants were talking specifically about client-centred care they were usually talking about their rehabilitation programs being individualized and tailored to their particular needs.

“but she (therapist) was very much into what was wrong with me and how she could tailor her help to make me better. So I felt she was very client-centred” ARTH #1

“Well, I think they were very client-centred. They were specific to me and specific to the need at the particular time” HIP/KNEE

This theme of individualization applied not only to each person’s individual goals and needs but also to a consideration of the person’s condition.

“As wonderful place as it is, I think that they have a very set way of doing things whereas they have physiotherapy, they have occupational therapy, they have pool therapy, they’ve got everything set up and it’s kind of for everybody. It’s very open. It’s not specifically for this type of problem.” ARTH #2

In contrast, when they were talking about programs not being client-centred, they were often referring to routinized group work.

“...everybody is doing the same thing, which is what they were doing before....so obviously it’s not client-centred there. It’s management centred. It’s easier for them if everybody does the same thing then they don’t have to worry, oh you’re on that machine, you’re doing this. Maybe the number of repetitions change. But that’s obviously not client-centred”. MS #1

“It’s not really patient based, it is sort of organization based. They’ve got the facility and they’re trying to fit you into their program.” ARTH #1

Clients felt that lack of individualization to their specific condition was often related to lack of expertise on the part of staff, particularly for conditions such as ABI, Arthritis and MS. There was little or no questioning of the expertise of staff in SCI.

The problem with us is that (ABI) is an unknown entity and it makes it so much more difficulty to obtain the correct treatment. How to get it. Where to get it. When to get it. How much to get – the whole thing. The physicians ought to know. ABI #1

So I didn’t have a good experience with him because I don’t think he was knowledgeable about rheumatoid arthritis. HIPKNEE

You see the problem is there aren’t enough professionals who have MS

expertise. Rehab specialists don't know that much. MS #1

***Participation in decision-making and goal setting***

When clients talked about positive experiences with rehabilitation they usually referred to situations in which they were actively involved in collaborative decision-making with staff.

“So I had a great experience. The next meeting they forewarned me and then reminded me that it was going to be a goal-oriented session and that if there were any services that I deemed necessary for myself, please feel free to provide that information” ABI #1

Much of this individualization referred to goal-setting specific to the client's needs and wants.

“What was excellent about it was that she catered not to the general rule but she was specific about my situation. All of us are different and brain injury is not going to be the same for the next person.” ABI #1

Clients were less satisfied when they encountered situations where they felt they were being labeled or their outcome pre-judged on the basis of their diagnosis alone with no consideration of their individual needs.

“But the physiotherapy wasn't [client-centred] for a long while....she basically said that somebody with my injury had a low probability of walking so that's what she assumed was going to happen [to

me], without trying to build me up so that I could walk. SCI #1

“...they had certain guidelines that your knee should bend to a maximum of 100. That was for everybody. That's the ideal. But hey, if my knee will bend to 75 and I can walk, I'm happy. Now take a look at the individual person and what their needs are.” ARTH #3

Routinized programs or group work were not usually perceived to be associated with individualized goal setting.

“But once you're in therapy, they don't say, 'How about you sit down and we'll talk about what you can and cannot do, what you would like to do'. They say, 'This is your program. This is what you do.’ MS #1

Participation in goal setting was positive if the client fit into the mold that the program provided.

“When I came...they asked me to choose three objectives. I said, I want to be able to shower, they said, we can fix that...I want to be able to walk upstairs, they said we can fix that...and I want to be able to work in the garden, they said we can fix that.” COPD #1

Participants reported more difficulties when their goals did not match those of the program.

“...it's a combination of not seeing the vision or maybe we're not communicating. Although wanting to walk or wanting to get back to where you were the day before your

accident...if they listened, they would hear those visions. And they would break down into steps...toward the goal would be great, but they tend to put you down in saying, 'That's beyond your capacity.' Well, who says? Let me try." SCI #2

"Too many survivors have been told you can't do this, you can't do that. You can only put square pegs in square holes and you can't climb to the top of the mountain. Well, you really can. So much of rehabilitation is missing from what, it's not what the clients want to do at all." ABI #1

These comments highlight the importance of allowing the client to retain hope about their future.

Client-centred care does not happen automatically. Some respondents (particularly in ABI and SCI groups) talked about having to struggle or fight to get client-centred care.

"To get really client-centred I had to fight for it." SCI #1

All participants talked about the importance of being self-directed and taking an active role in their rehabilitation in order for it to be successful. Members of the focus groups touched on the combined issue of receiving education and being self-directed. Specifically, clients discussed the connection between education and being self-directed in two different ways, one being how education can lead an individual to be more self-directed. The second way is how self-directed individuals seek their education resources. Overall, regardless of how education and self-direct are related to

one another, the combination of the two result in individuals being better equipped to cope with their chronic condition.

"I think the more you learn about your disease, the more you can participate in the treatment that's being offered to you" HIPKNEE

### ***Preparedness for participating in goal setting and decision making***

Although respondents wanted to be involved in decision-making and goal setting, they recognized their lack of preparedness to participate, particularly in the early stages of their rehabilitation. This lack of preparedness related to being too ill or incapacitated, uninformed about their condition, or unable to accept the long-term implications of their condition to be able to participate appropriately in goal setting and decision-making.

"I don't recall being well enough, comfortable enough with my own disease at many of the different times when I had surgery to actually question the therapy that I was getting or to make any recommendations about it. I really didn't feel that...knowledgeable about it." HIPKNEE

"I was too much like a child to make my own decisions. My family made a lot of decisions for me." ABI #2

"Mine is 100% once I smartened up, once I got past the denial stage where all I wanted to do is a magic silver bullet – out the door back to my important job and my busy social life very important lady I was. Once I got past that stage then everything was totally collaborative. 100%...."

## ARTH #2

***Preparation for life in the real world***

Most participants felt that their rehabilitation had addressed the physical issues of their condition and basic care needs well. However, many felt their rehabilitation had not prepared them for life in the real world. In particular they identified a number of practical community living skills and issues that they had not felt prepared to address as well as a number of emotional challenges.

This ill-preparedness was shaped by the age of the participant and the trajectory of their condition. Younger clients who experienced a sudden onset of disability, particularly those in the ABI and SCI groups, emphasized issues of reintegration into the community.

“[rehab hospital] is terribly linked to the community. They prepare you to live in the hospital and then discharge you into a place that you’ve never been.” SCI #2

In contrast, older clients with chronic progressive conditions talked about issues of ill-preparedness with respect to being adequately prepared to assume all of their previous activities. They usually had well-established work and family roles and the issues for them revolved around adjusting to changes or losses.

“and that’s the only trouble with rehab and I think that most women will tell you this...if I just did what they did in rehab I would be fine...they don’t wash walls, or do washing, or do the carpets or all the things you do at home” COPD #2

These older clients were often struggling with the loss of their work roles, often having retired due to illness.

“I mean I lost my career just like that. Bang! One day you’re traveling and enjoying life and the next thing you know bang! You’ve got no career, no nothing. So it was an uphill climb to pick up from there. But I think I managed it quite successfully.” ARTH #5

In contrast, younger clients were usually struggling with finding a career. Due to their age at onset of their condition, they usually didn’t have established work and family roles and so needed to develop them.

“They said it wasn’t practical for me to go back to work because I didn’t have any practical job skills, anything that I had to do manually like that took six times longer than the average person. It was just like a stab in the heart. I couldn’t believe it”. SCI #3

***Practical skills for community living***

Despite these age-related differences between some of the conditions, all participants talked about not feeling that they had been taught the types of skills that they would need to live in the community. Many of these skills went beyond physical functional tasks to include learning to manage interpersonal relationships and deal with the emotional challenges associated with having a chronic condition.

“The teaching practical skills....nobody ever takes you to the Eaton Centre on a Tuesday and says “We’re going to let you go alone for 3 hours, if you need help of some

sort we'll be here" SCI #2

Clients in the COPD focus group discussed at length the issue of changing their lifestyle for the sake of their chronic condition. However they felt that their rehabilitation did not provide them with the necessary tools/skills to deal with such a dramatic change in their life. One member of the COPD group expressed this sentiment:

They didn't, they didn't talk about that, all they did was say I am going to introduce you to this word called change of lifestyle. COPD 3#

Clients in the SCI group talked at length about the need to learn how to ask for help and manipulate others in order to survive in the community.

"And there are skills that you have to just learn...yesterday I went to a sports bar...it's got two stairs to get in. I just have to have the assertiveness to see two big guys and say 'Can you throw me up these two stairs'" SCI #2

### ***Emotional challenges***

In addition to the practical issues that clients have with respect to living with their chronic condition, participants described a range of emotional challenges that they had to contend with and for which they did not feel prepared. Participants conveyed a sense of loss of roles that permeated different aspects of their lives. Regardless of where the clients experienced loss, such loss affected their perceptions of their self-identity.

"Sometimes I could cry and I know that I've jumped in my vehicle and I've driven and where you going? No place. I just want to get out of

the house. Why? Because I wanted to leave what I used to do so well and so proudly in everything and I needed a few minutes to cry and the best place to do it is on the 401" COPD #4

Acceptance of their condition and limitations is a challenge that most participants faced. This was particularly evident for the younger members of the SCI and ABI groups.

"What do you want to be when you grow up? And I was 18 and that is really a tough thing to hit an 18 year old new injury, "What do you want to be?" I want to be 19 and I want to walk." SCI #2

However, it was also true for the older clients. A client with arthritis shares how long it took her to accept her chronic condition and the impact it had on her lifestyle:

"It took me 10 years to try and cope with everyday of having to get up at 6 o'clock and nowhere to go." ARTH #2

### ***Emotional support***

The need for emotional support to help meet these emotional challenges was a common theme throughout all the focus groups. Clients discussed receiving support from a number of sources, such as family, peers, staff and community organizations.

All clients mentioned the importance of the emotional and practical support they received from their families during their rehabilitation both in the hospital and the community. In most cases, they spoke positively of situations where their families

had been involved in goal setting and decision-making.

“Because they have a consultation, there is a long waiting list, but they have a consultation with you, and your family members and then they have goal-setting. Then they even upgrade that. Then at the end of your time with them, then they review the time with them, then they review the goals and see what was accomplished and hopefully everything has been.” ABI #2

Another member of the ABI focus group shared the same sentiment:

“I have been a client and still am a client of (rehab2) and I have been a client of M’s for a couple years. K as well. They have been fantastic as team, as a family support.”

Although participants acknowledged and valued the support they received from their families, many struggled with becoming dependent on their family members for assistance, particularly with day-to-day activities. For example, one person mentions how he had lost his ability to drive and how he had to rely on his wife to drive him around the community:

“I’m not driving these days. If I need to go anywhere she needs to drive me. It’s like she is sitting downstairs for 2 hours this morning I hate to impose that on her. So yeah...I’m kind of mad and why did this happen...” ARTH #4

Clients encountered difficulty in seeking assistance from their family members. For example, one participant described

struggling to obtain help from her daughter who was busy with her own life:

“Now my daughter she’s at home but she’s working and so it was a dog and pony show to get everything kinda organized you know by the stand so I could reach it. No one ever...you know I think the upside...the other side of it was that I just...I knew I could ask for it but I couldn’t be bothered. There was too much to cope with...with getting through the day and getting myself organized to bother hassling...If I have to hassle to get this for two hours twice a week its not worth it.” PTPART #1

The process of clients receiving assistance from family members was also complicated by the idea of being a burden to their family. The majority of COPD clients remarked on how they did not like being a burden on their family members. One client stated his difficulty with being dependent on his son for help with household activities:

“Yeah, but if you had a son with his own business; and listen I need you. How are you going to leave everything? It’s very tough.” COPD #2

In some situations, the support extended to family actually supplementing the care they received in an institutional setting, particularly acute care.

“Going into hospitals today if you have family member or somebody come in and you know help out or you just don’t get the help. The scary thing, the frightening thing for me to go for a stay in the hospital. Nobody looks forward to it but if you didn’t

have family members or loved ones who cared you would be in a world of trouble laying in the bed... not to get the right food or whatever like that.” SCI #2

Just as clients mentioned they relied on their family for support, clients also mentioned the importance of their family members receiving support. One client discussed the importance of their family members receiving assistance and guidance in dealing with their loved one’s chronic condition:

“...Family members wanting information. Family members wanting support. In many cases family members are very heavily stressed looking after a relative who got brain injury and looking is there any relief? Is there any respite care?” ABI #1

Peers were another important source of emotional support that was strongly echoed in all of the groups. Peers with similar conditions are important sources of motivation, mentoring, practical advice and guidance on coping with ones conditions.

“When I was doing physio as I had said before we worked in groups in five and six and we were all generally doing the same thing and I don’t know how this would extend to the year 2000 but being in a group of people doing the same thing adds a lot of camaraderie and I don’t know if you bought the aerobics tape or gone to the aerobics class but its a lot easier to quit when its just you, the t.v. and the tape than it is in the class when the people are still doing their exercises. To get people as a group doing activity that makes it harder for you stop quit, I think is very

important.” SCI #2

“It’s one of the best thing for me. First of all, yes the exercise but it was actually getting out, having a place to go with people who had the same things going on with them as I did. I have learnt... I just wanted so much from people I’ve come into contact with... Right now I’m learning. You’re not the only one going through it. You’re great. To do it by myself I would never do it. Go in there with somebody....” ARTH #3

While both the above quotes come from individuals with different chronic conditions, the common element between the two is how peers in rehabilitation not only provide motivation to participate, but to continue the rehabilitation process.

Many clients talked about the emotional support they received from their peers.

“And then you in a group or strangers and yes when you see the rotation it gets comfortable, but when you’re at the first level it very scary and who better than a listener to make you feel at home and they ask you, and a new face, and wow, got a friend here. And then afternoon, oh you want to talk to me, oh right let’s talk.” COPD #2

Mentoring took the form of certain individuals providing support in daily living and community re-integration. Participants were overwhelmingly positive as to the importance of peer support in rehabilitation, and felt that these relationships should be encouraged and facilitated throughout the rehabilitation process.

“... But in terms of profession, having a friend who was a lawyer as part of my physio group who was sort of a peer supporter, a mentor was terribly important and he sort of ...to a large extent... one of the things that a client should be urged to do is find people who are going to graduate before they do with similar abilities and interest and hook onto that person, you know...what kind of clothes you don't buy, what type of food you can eat by yourself when you're out.” SCI #2

“ I didn't think we didn't talk about a few things in these twelve weeks and one the things that I think we should have done much much more of is share our experiences.” COPD #1

All of the participants talked about receiving peer support during inpatient admissions. However, the continuation of this peer support in the community varied by the person's condition. Some clients, particularly those with Arthritis and ABI, reported receiving support from community organizations specializing in their conditions. Specifically, clients talked about how programs offered by community organizations helped them cope with their condition. For example, the Arthritis Self Management Program (ASMP) was identified by all of the participants with arthritis as a client-centred, self-directed program that provided them with considerable support in the community.

“The Arthritis Self-management Program. If you call The Arthritis Society and ask them about it. I think it's a full week course. It's not a gripe session. You actually learn a lot of the disease, how to get through

it and what else is out there for you. They give you an idea how to manage our pain, how to manage the emotions that you go through. Because they all know about it. It's a lot of like this – talking back and forth and learning about this.” ARTH #4

Staff can also be important sources of emotional support for clients. Such emotional support took the form of staff members offering advice, encouragement and direction. Clients talked about the importance of clinicians being positive, professional and goal-oriented.

Clients referred to receiving help from their general practitioners, specialists or therapists. One client described the encouragement that he received from a physiotherapist:

“One time, and it was the only one time, that (CARS) The Arthritis Society sent a physio to my home. I found her advice that she was giving me to be very positive and uplifting, that there was hope down the road and she talked a little bit about medications and guided me as towards the things that I should ask about. That was uplifting as well.” HIP KNEE

Difficulties arose when the clients felt that they were not being treated with respect or dignity. An individual in the Spinal Cord Injury group expressed how the institutional setting made it difficult for individuals to hold onto their dignity:

“Just about any sense of personal dignity or being undressed or having a bowel movement in a crowded washroom with three or four other

people. The whole world knowing how full your leg bag was or whatever. The institutional experience that I've experienced just says don't even bother trying to hang on to some dignity.... You just quit trying to keep it going anymore and accept that in this place I'm somewhere less than a full adult." SCI #2

Although staff could be important sources of support and motivation for clients, clients in all the focus groups discussed the issue of depression and how staff did not deal with their patients/clients being depressed. This was identified as a common situation for clients where they did not receive adequate emotional support from staff.

"Very common with people with arthritis and it's something a lot of the doctors don't address. It's actually just here. In the States, more so. They're very quick to notice the depression in arthritis people. Where here, they don't even know you're depressed most of the time" ARTH #1

Many participants attributed the staff's lack of acknowledgement of depression to a lack of knowledge and training in dealing with clients' emotional states.

"Depression is a major part of this syndrome and none of us have gone through it without some cycle of depression and its not often talked about. It's what they....getting in a bad mood or down. I've had my down days and whatever you know you really notice that I was depressed and again it was later that you recognized what was happening to me that I went out and got some of

my own help. It helped in that issue. It's not something that the staff were prepared... they knew it... but it wasn't something that they intervened with." SCI #3

A few clients raised the issue of staffing as part of the challenge of providing client-centred care. They stressed the importance of the staff having enough time to work with the individual client and not feeling rushed because there was a time limit in their interaction. Concerns about staff working too long of hours and being short staffed were also discussed. Increased staff turnaround was also a concern for inpatient clients because it takes a while to adjust to new staff.

"They haven't the time...at least they think they haven't." PTPART #3

"You're just hoping that you'll get a good nurse or somebody for at least 2 or 3 days and you feel comfortable and you feel a lot more at ease. If you get somebody new and then you have to know them and have to go through whole motions of what you need, this and that, what do you like and all that other stuff" SCI #3

### *System Level Issues*

#### *Access*

Issues of access into a rehabilitation program were not so great with these groups because our inclusion criteria stipulated that participants had to have completed a course of rehabilitation. Our sample therefore does not include people who may need rehabilitation but have not received it. However, issues of continuing access and

readmission were important to our focus group participants.

The greatest barrier to access was difficulty in identifying services that are available. Not knowing where to find help was a concern for many of the participants. Physicians were not necessarily knowledgeable about community resources. Participants described having to find services and resources on their own or with the help of their families. Information about these resources was lacking for both the health professionals and clients.

“I had absolutely no contact with The Arthritis Society. I didn’t know they existed” PTPART #2

“But there is nothing to help you. There probably is but I don’t know about or I didn’t know about it.” ARTH #4

“I guess one of the things that everyday I discover another resource or something like that that’s out there but its not obvious ... You feel pretty alone and its not that the programs aren’t there, they’re just not communicated to you in any consistent way.” SCI #1

Referral issues were raised by all groups and had several common themes. Pushing or fighting for a service while at the same time dealing with a condition was a common problem that was very difficult for many of the participants.

“So I’m not fighting just the emotional trauma of having to deal with the brain injury itself; I am also having to deal with the medical system that is not servicing us appropriately” ABI #1

“I knew I could ask for it but I couldn’t be bothered. There was too much to cope with...to bother hassling...If I have to hassle to get this for two hours twice a week its not worth it.” PTPART #1

Lack of knowledge and information on the part of health professionals of the roles of other health care providers and available services was a barrier to appropriate referrals. All groups talked about the lack of knowledge of health professionals, particularly general practitioners, about the system.

“Once you get at home, you get your own routine from your own family doctor, they don’t tell you a whole lot. One time if something goes wrong, suppose you got a cold or pneumonia or you broke this, you broke that...you know, fix that but that’s about it. But, if you want to know about some new program or something like that they have no idea. You know a lot of times they’ll say, “Well, if you do have some information, bring it back because I’d like to hear about it.” SCI #3

“They [doctors] don’t know what is out there. They don’t know how to refer. They don’t know where to refer them” PTPART #1

All groups mentioned that waiting period for access to services was too long and that during the waiting time they often lost even more function.

“they say there is going to be a waiting period and thank God it was shorter than they thought. It was still

6 months, but it was worth the wait. But in that 6 months, I had nothing to help me.” ABI #1

### ***Fitting the mold “meeting eligibility criteria”***

Although finding services was the first challenge for participants, the next hurdle they sometimes encountered was meeting eligibility criteria. Most groups raised issues regarding eligibility for services. Sometimes these eligibility criteria were exclusionary by age. Age requirements for entrance into programs may limit access for clients.

“So what happens if you are not a senior? So you just stand outside the door and look in?” PTPART #1

Clients felt the need to make themselves “fit” into the eligibility criteria for services. This was particularly true for community services and supports. In some instances, clients accepted services that were not needed in order to receive those that were needed.

“You have to make yourself fit the eligibility criteria that they have come up with” SCI #2

“But I had to do it [course] to get the funding for my home modification” SCI #3

“the process of getting done over like that leads to manipulating the process the next time” SCI #2

### ***Availability and location of services***

Availability and location of services was another system level theme. It was generally felt that there were not enough programs

that addressed their needs and the hours of operation were limited.

“I can understand the situation where only twelve weeks because of the number of people trying to get in the program.” COPD #4

“we maybe go to swimming aquatic program which there are not enough of” PTPART #4

Flexibility in where the service is provided seemed important to many participants whether it be close to home or in a center of choice.

“You know we’re very lucky to be able to be so close” COPD #1

“I’m very fortunate I live within two blocks of Variety Village” COPD #2

Participants talked about the need for programs to be flexible in terms of length of time they are offered. Similar issues were brought up with regards to homecare. The amount of time per day and the total length of service were too limited according to the participants.

“But boy if you could extend that to even sixteen weeks or even more then that would be super cause you’re always afraid when it comes to the end of that twelve weeks.” COPD #4

### ***Transitions between services***

Transition between services was weak to non-existent according to most groups. This was particularly true for the transition from rehabilitation facility to the community. Many participants, particularly in the ABI and SCI groups felt that this transition was

abrupt and left them feeling isolated and alone.

“But that transition period is not really a transition. You are just sort of dropped like a rock and then you’re out there to fend for yourself and that’s really hard” ABI #3

“then you’re out the door and you’re on your own” SCI #3

Many felt that the responsibility of the service seemed to end once the client was out the door. The client’s needs post discharge were often ignored.

“...post discharge needs which don’t seem to be the mandate of the institution” SCI #2

“I was never asked once...if I even needed home care. No one even ever asked...if I needed any help.” PTPART #1

“the negative aspect of it was there was no thought about the day when I was released about what I needed to have when I went home” HIPKNEE

This lack of preparation for discharge contributed to feelings of fear of leaving hospital.

“before I left I was scared I was scared to leave. I was telling everyone- Don’t kick me out! Don’t kick me out!” COPD #3

“Right before discharge I was deathly afraid to leave because everything was set up for me [in rehab hospital]” SCI #3

### *Ongoing contact after discharge*

A common theme was the need for an ongoing resource or contact while in the community. Many clients talked about the importance of feeling that they had someone to call to provide advice or support or further rehabilitation once they were in the community. For some, this support came from community organizations such as disease specific organizations. Others were affiliated with rehabilitation programs that provided this ongoing linkage.

“I said yeah I have been waiting nearly three months. He says you shouldn’t have done that, you’re a patient here. When you need us, you phone. Well I said I didn’t know that” COPD #1

In order to make the transition between services better a number of suggestions were made by the participants. The transition should:

- ◆ be appropriate to the post discharge needs of the client
- ◆ coordinated by a social worker, customer service representative, or case worker
- ◆ preplanned
- ◆ discussed by all team members

### *Help navigating the system*

Many participants mentioned the need for help and direction in navigating the system. Clients would like someone to help with transitions but often they are left to do this on their own.

“I would like to see still that the transition process between care, between hospitals or what ever it would be great if I had a case worker

to assist me to advocate for me...to resource for me on my behalf” ABI #1

“There is a system out there and there are skills you need to develop in navigating it.” SCI #2

“...but for people with serious illnesses and you’re being pushed to the urologist, and joint specialist and rheumatologists and all those kinds of things, you sometimes need a tour guide in the middle so if there was somebody that could answer those questions, and get you over the first few months, well then you had a chance to develop some asking skills, it would help orient it” SCI #1

### ***Summary***

The major theme underlying both the individual and system level issues was the issue of transition from rehabilitation programs to the community. Participants felt ill-prepared for community living and, once discharged, felt isolated and had difficulty finding out about and accessing community services. Further, all participants talked about the need for ongoing access to rehabilitation and services once in the community. All reported difficulties navigating the system. Those who had linkages such as through the ASMP or rehabilitation programs that maintained relationships with clients once they were discharged were much more positive and satisfied.

## Chapter 4: Components of Client-centred Rehabilitation

The objective of this work was to develop the definition of client-centred care as it applies to rehabilitation, identify client-centred parameters for rehabilitation programs and identify criteria for evaluating the extent to which various rehabilitation programs are client-centred. Our findings indicate that client-centred rehabilitation encompasses much more than goal setting and decision-making between individual clients and health care professionals. It refers to a philosophy or approach to the delivery of rehabilitation services that reflects the needs of individuals and groups of clients.

At the level of the individual client, client-centred rehabilitation refers to clients being actively involved in managing their health care and their rehabilitation process in partnership with service providers. At the service level client-centred rehabilitation refers to an approach to care that strives to incorporate the clients' perspectives into the provision of services. Attention must be paid to both levels in order to ensure a client-centred approach.

From the literature review and focus group data, we identified the following components that should be considered at each stage of the rehabilitation process:

### ***4.1 Individual Client Level***

*Client participation in decision-making and goal setting:* The rehabilitation program should be individualized to meet each client's individual needs and condition. The client defines the need, defines important goals and outcomes, and sets the priorities in collaboration with health professionals.

*Client-centred education:* Education and information are crucial to informed client participation in decision-making and goal setting. Information should be appropriate, timely and according to the client's wishes (Allshouse, 1993; Ellers, 1993). The client is at the center of the educational process and defines educational needs. Client-centred education encourages: autonomy; client participation; planning with client; empowerment; and, independence (Skelton, 1997). Education needs to include the skills needed for effective community living.

*Evaluation of outcomes from the client's perspective:* Evaluation of outcomes incorporates expectations of the client and considers the importance of performance areas to the client. Interventions need to be evaluated using outcomes that tap multiple dimensions (e.g. ICIDH-2). e.g. move beyond traditional measures of impairment and disability to include participation in mobility, personal maintenance, social relationships, home life, education, work, economic life. Further, the clients should evaluate their own progress towards the achievement of these goals.

*Effective communication:* Effective communication includes the transmission of information, thoughts, and feelings, so that they are satisfactorily received and understood (Daley, 1993). Client-centred communication allows clients to give their accounts in their own language and chronology, elicits clients' thoughts, perspectives, expectations, values, and goals, in the context of their lives, expresses concern for the client's well-being, provides clients with information for self-care and participation in health care decisions, and

promotes collaborative development of health care plans (Brown, 1999).

*Family involvement:* Family involvement is critical to client-centred care. Families are important sources of practical and emotional support. The family is defined broadly to include anyone the client recognizes as a significant relative, friend, or companion regardless of biological or legal relationships. Families need information about the client's condition and treatment, emotional support and ongoing help with caregiving.

*Emotional support:* Clients should feel their emotional needs and concerns are being addressed, that their wishes and decisions are being respected and that they are treated with dignity. Effective emotional support conveys a sense of genuine caring and concern for the client's needs and does not take away a client's hope. It includes expressing a positive affect, acknowledging the client's feelings, and providing useful information. Emotional support from a variety of sources such as peers, family and community organizations needs to be facilitated.

*Flexibility:* Services need to be flexible in terms of how, where, when and what type of service is provided.

*Coordination/continuity:* Client has key contact on team (primary conduit of information) and knows the roles and responsibilities of each team member at each stage of the rehab process. This is particularly important for transitions within the system.

*Physical comfort:* includes appropriate pain management, comfortable physical environment.

## 4.2 Service/ System Level

*System support for client-centred care:* There is a need for system support throughout the program/organization to facilitate client-centred care at the individual level. Some of the barriers to the implementation of client-centred care relate to the lack of support of the overall system for the therapists who are attempting to practice in a client-centred manner (Fearing and Clark, 2000; Sumsion, 1999) . The extent to which a particular program is client-centred is a function of the organization's culture, mission, and system design and operation (Gerteis and Roberts, 1993). These should reflect an overall support and philosophy of client-centred care.

*Interdisciplinary approach:*

An interdisciplinary team approach is needed in order to ensure integration and coordination of service when multiple professionals are involved with an individual client. An interdisciplinary team approach means that team members work collaboratively and interdependently. Team members should be aware of each other's roles and refer appropriately. In the absence of a team, there must be other mechanisms in place to support a holistic approach.

*Coordination/ continuity:* The provision of an effective continuum of service requires high levels of collaboration not just among professionals on a single health care team but also among multiple professionals on several teams and often across organizational boundaries (Ryan, Cott and Robertson, 1997). Effective "inter-teamwork" is necessary to minimize duplication and avoid gaps and fragmentation in service delivery. It is important that providers throughout the

continuum are aware of the roles of other providers and the availability of other services in the services.

*Accessibility:* As specified in the overall framework, issues of access include the need for multiple, clear, identifiable access points into the rehabilitation system. The ability to reinitiate contact with rehabilitation programs as necessary is important. Linked to accessibility is the need for better information for clients with respect to the existence of services.

*Client involvement in service planning:* Client perspectives need to be incorporated into the planning and provision of services. This involvement should be meaningful.

*Evaluation of system from client's perspective:* Needs to go beyond global ratings of satisfaction to include explicit feedback about concrete aspects of the client's experience. Resources must be available to collect and analyze these data.

*System-response to client feedback:* Systems should be in place to respond to client feedback.

The following tables identify the types of indicators or evidence that one might use to determine the extent to which a particular rehabilitation program is client-centred.

**Table 2: Client Level Indicators of Client –Centred Care**

	<b>CONCEPT DEFINITION</b>	<b>INDICATORS</b>
<i>Client participation in decision-making &amp; goal setting</i>	The client defines the need, defines important goals and outcomes, sets the priorities in partnership with health professionals. Programs are individualized to the particular clients' needs and condition.	<ul style="list-style-type: none"> <li>• goals are set at levels of ICIDH-2.</li> <li>• choice available re: treatment options.</li> <li>• use of tools such as goal attainment scaling and COPM</li> <li>• single items from Picker or CAHPS (q33,q34)</li> </ul>
<i>Client-centred education</i>	<p>Education and information are crucial to informed client participation in decision-making and goal setting. Information should be appropriate, timely and according to the client's wishes. Client is at the center of the educational process and defines educational needs. Client-centred education encourages:</p> <ul style="list-style-type: none"> <li>• Autonomy</li> <li>• Client participation</li> <li>• Planning with client</li> <li>• Empowerment</li> <li>• Active client</li> <li>• Independence</li> </ul>	<ul style="list-style-type: none"> <li>• client receives feedback after evaluation.</li> <li>• no “dead time” – educational material provided at first contact</li> <li>• check for understanding of educational material</li> <li>• receives written instructions/home program.</li> <li>• understands the risks and benefits and all evidence-based options for treatment are explored.</li> <li>• includes prevention strategies.</li> <li>• WASCANA</li> </ul>
<i>Evaluation of outcomes from client's perspective</i>	Evaluation of outcomes incorporates expectations of the client and considers the importance of performance areas to the client. Interventions need to be evaluated using outcomes that tap multiple dimensions. e.g. move beyond traditional measures of impairment and disability to include participation in mobility, personal maintenance, social relationships, home life, education, work, economic life. Further, the clients should evaluate their own progress towards the achievement of these goals	<ul style="list-style-type: none"> <li>• outcomes measured at all levels of ICIDH-2.</li> <li>• clients evaluate goal achievement e.g. goal attainment scaling (GAS) and Canadian Occupational Performance Measure (COPM)[participation level goals]</li> <li>• items added to WASCANA</li> </ul>

<p><b><i>Family involvement</i></b></p>	<p>Family involvement is critical to client-centred care. The family is defined broadly to include anyone the client recognizes as a significant relative, friend, or companion regardless of biological or legal relationships. Families need emotional support, ongoing help with caregiving and information about the client's condition and treatment. It is up to the client to define extent to which family is involved (social context is considered).</p>	<ul style="list-style-type: none"> <li>• WASCANA</li> <li>• describe ways that families are incorporated into the process</li> </ul>
<p><b><i>Emotional support</i></b></p>	<p>Clients should feel their emotional needs and concerns are being addressed, that their wishes and decisions are being respected and that they are treated with dignity. Effective emotional support conveys a sense of genuine caring and concern for the client's needs. It includes expressing a positive affect, acknowledging the client's feelings, and providing useful information.</p>	<ul style="list-style-type: none"> <li>• WASCANA</li> <li>• items from Picker</li> <li>• give examples of strategies to address emotional support (e.g. support groups, buddy systems, follow-up phone calls)</li> </ul>
<p><b><i>Flexibility</i></b></p>	<p>Services need to be flexible in terms of how, where, when and what type of service is provided</p>	<ul style="list-style-type: none"> <li>• receives timely assessment and treatment (waiting lists).</li> <li>• choice available of where treatment offered, time of day</li> <li>• language is appropriate in terms of culture and reading level.</li> <li>• services are culturally sensitive</li> </ul>

<p><b><i>Coordination/ Continuity</i></b></p>	<p>Client has key contact on team (primary conduit of information) and knows the roles and responsibilities of each team member at each stage of the rehabilitation process.</p>	<ul style="list-style-type: none"> <li>• Can identify which person is responsible for coordinating service.</li> <li>• Client given a choice of community resources and supports including those with others with same condition.</li> <li>• Client is given description of service offered and who pays for it, options for service are presented if available</li> <li>• WASCANA</li> <li>• evidence that the client can initiate contact - reactivate</li> </ul>
<p><b><i>Physical comfort</i></b></p>	<p>Includes appropriate pain management, comfortable physical environment. Needs to be developed further through focus groups.</p> <p>The Picker Institute has identified eight dimensions covering aspects of the physical environment that are most important to the client's experience.</p> <ul style="list-style-type: none"> <li>- Facilitates a connection to staff and caregivers</li> <li>- Conducive to a sense of well being</li> <li>- Convenient and accessible</li> <li>- Promotes confidentiality and privacy</li> <li>- Caring of the family</li> <li>- Considerate of impairments</li> <li>- Facilitates connection to outside world</li> <li>- Safe and secure (Fowler et al, 1999)</li> </ul>	<ul style="list-style-type: none"> <li>• WASCANA</li> </ul>

**Table 3: System Level Indicators of Client-Centred Care**

	<b>CONCEPT DEFINITION</b>	<b>INDICATORS</b>
<i>Client involvement in service planning</i>	Client perspectives need to be incorporated into the planning and provision of services. This involvement should be meaningful.	<ul style="list-style-type: none"> <li>• clients as members of planning groups</li> </ul>
<i>Evaluation of system from client's perspective</i>	Needs to go beyond global ratings of satisfaction to include explicit feedback about concrete aspects of the client's experience.	<ul style="list-style-type: none"> <li>• focus groups</li> <li>• questionnaires (WASCANA, Picker)</li> <li>• telephone surveys</li> <li>• checklist of methods</li> </ul>
<i>System-response to client feedback</i>	Systems should be in place to respond to client feedback.	<ul style="list-style-type: none"> <li>• quality improvement measures present that incorporate client feedback.</li> <li>• what mechanisms are in place</li> </ul>
<i>Accessibility</i>	At the system level, issues of access include the need for one or more , clear, identifiable access points into the rehabilitation system.	<ul style="list-style-type: none"> <li>• direct access to service</li> <li>• self-referral</li> <li>• choice of health provider</li> <li>• facilitators identifiable within the system</li> </ul>
<i>Coordination /continuity</i>	The provision of an effective continuum of service requires high levels of collaboration not just among professionals on a single health care team but among multiple professionals on several teams and often across organizational boundaries. This “inter-teamwork” is necessary to minimize duplication and avoid gaps and fragmentation in service delivery.	<ul style="list-style-type: none"> <li>• inter-team communication, goal setting, decision-making.</li> <li>• channels of communication</li> <li>• patterns of referral and decision-making</li> <li>• allocation of resources</li> <li>• boundary crossing functions of team members</li> </ul>

<p><b><i>Interdisciplinary approach where multiple professions involved</i></b></p>	<p>An interdisciplinary team approach is needed in order to ensure integration and coordination of service when multiple professionals are involved with an individual client. An interdisciplinary team approach means that team members work collaboratively and interdependently. In the absence of a team, there must be other mechanisms in place to support a holistic approach.</p>	<ul style="list-style-type: none"> <li>• measure of team function.</li> <li>• formal structure: meetings, charting, decision-making &amp; goal setting, authority structure.</li> </ul>
<p><b><i>System support for client-centred care</i></b></p>	<p>There is a need for system support throughout the program/organization to facilitate client-centred care at the individual level. Some of the barriers to the implementation of client-centred care relate to the lack of support of the overall system for the therapists who are attempting to practice in a client-centred manner. The extent to which a particular program is client-centred is a function of the organization's culture, mission, and system design and operation (Gerteis and Roberts, 1993). These should reflect an overall support and philosophy of client-centred care.</p>	<ul style="list-style-type: none"> <li>• Client-centred care is included in mission statement.</li> <li>• Staff orientation includes expectations for client-centred practice.</li> <li>• Job descriptions explicitly list client-centred care as major responsibility.</li> <li>• Administration &amp; supervisor support use of client-centred approaches.</li> <li>• Sufficient time for assessment and collaborative goal setting.</li> <li>• Use of client-centred approach evaluated in performance reviews.</li> <li>• There is ongoing staff development in client-centred care.</li> <li>• Modified environmental scan (Restall, Stern, and Ripat, 1997) – point person to complete</li> <li>• WASCANA staff version</li> </ul>

In summary, there is no single measure of the extent to which a particular rehabilitation program is client-centred. Instead, a multifaceted approach is required that incorporates a number of indicators at the level of the client/ professional and the system. Many of the client level indicators from the client's perspective are tapped by the WASCANA, however this measure in and of itself does not capture the extent to which a particular program is client-centred. In addition, evidence as to the presence of other components of client-centred care is needed.

### ***4.3 Implications for the Rehabilitation Reference Group Framework***

Our findings provide support for many of the directions put forward in "Managing the Seams: Making the Rehabilitation System Work for People" (Provincial Rehabilitation Reference Group, MOHLTC, 2000).

1) "Rehabilitation services must aim to meet the needs of individuals at the three levels of client need (impairment, activity limitation and participation)." [p. 22, Provincial Rehabilitation Reference Group, MOHLTC, 2000]. Our findings suggest that rehabilitation services mainly address two levels of client need (impairment and activity limitation) but that the participation level of client need is not being addressed adequately. Steps must be taken to ensure that rehabilitation services better prepare clients for community living. This will require:

- ◆ education of rehabilitation professionals with respect to participation level interventions

- ◆ training of physicians and allied health care providers with respect to the meaning and practice of client-centred care – both at the undergraduate level and for practicing clinicians
- ◆ linkages between various components of the system (e.g. hospital based rehab services and community based service providers).
- ◆ research to identify best practices with respect to participation level interventions.
- ◆ increased public awareness of community programming to meet ongoing client needs for community involvement

2) "For many years, services partners such as the Canadian Paraplegic Association, The Arthritis Society, and the Heart and Stroke Foundation have played pivotal roles within the rehabilitation system (providing peer support and counseling, volunteer led programs, information and service coordination) but their roles have not been recognized as being integral to the larger system" (p. 22, Provincial Rehabilitation Reference Group, MOHLTC, 2000). Our findings strongly support this point.

- ◆ The role of community service providers and disease specific organizations needs to be recognized and augmented and linkages to formal rehabilitation programs enhanced.
- ◆ There is a need for programs and services that provide on-going emotional support for clients. These do not necessarily need to be professional-driven but could be provided through support groups, peers, and mentoring. The Arthritis Society and its client services

programs such as the Arthritis Self Management Program provide an excellent model for involvement of such organizations in the rehab system

### 3) Components of the Rehabilitation System

Our findings echo the need for a number of the components of the rehabilitation system identified in Managing the Seams (Provincial Rehabilitation Reference Group, MOHLTC, 2000) particularly those addressing the need for: multiple, identified access points; service coordination; and, transition out of rehabilitation services. These components all address the need for systems and processes that make navigating the system easier for clients.

- ◆ Structures and systems that facilitate transitions within the system, especially between hospital based services and community services, need to be developed. These transitions are not unidirectional. Options for re-entering or re-accessing the system also need to be available. Ideally, clients would have a key contact person or primary conduit of information across the various stages of the rehabilitation system. This will require:
    - ◆ Educational and information materials for clients and providers. Resources will be required to develop, evaluate, and distribute client and provider educational materials.
    - ◆ Systems to catalogue or monitor the availability of community services and rehabilitation programs.
  - ◆ Research to evaluate health service delivery models that address coordination and integration activities such as effective interteamwork.
  - ◆ Systems to allow sharing of client information across/between programs
- 4) In addition to system level structures and processes, organizational systems and structures that support client-centred rehabilitation need to be identified. It is unrealistic to expect Health Care Professionals to practice in a client-centred manner if they are working in a system or organization that is not client-centred. This would require:
- ◆ Resources to support in house training of clinicians in client-centred practice
  - ◆ Reimbursement systems that reward/allow time to educate the client. For example, reimbursement based on the number of visits rewards the number of clients seen and does not allow comparison of services across organizations. Reimbursement by the hour rewards clinicians for taking the time to educate clients and allows comparison of like services across organizations. This is particularly important for clients with chronic diseases where education about self-management is critical.
  - ◆ Resources to support the evaluation of client-centred care through the use of outcome measures and client satisfaction questionnaires. Personnel and structures will need to be implemented to administer this data collection and utilize data.
- 5) Further research is needed to better understand the processes and outcomes of client-centred rehabilitation.

- ◆ Experimental designs evaluating and comparing client-centred interventions are non-existent. This should be a priority for future research initiatives.
- ◆ There are few valid and reliable outcome measures that measure the construct of client-centred care. The WASCANA questionnaire was identified as the best available measure for evaluating client-centred care for the rehab pilots. Further research is required to evaluate how well this questionnaire responds in non-hospital rehabilitation settings.
- ◆ Research is needed with respect to provider and system issues around implementing client-centred rehabilitation. In this project we have focused on the perspective of adult clients with chronic disabling conditions. Although there is some research that addresses the professionals' perspective, further research is needed to identify the barriers and facilitators to client-centred rehabilitation from the professional, organization and system perspective.

## ***Reference List***

- Alexy, B. (1985). Goal setting and health risk reduction. Nursing Research, 34.(5.):283.-8.,
- Allshouse KD. (1993). Treating patients as individuals. In. Gerteis, M., Edgman-Levitan, S., Daley, L., & T. Delbanco (Eds.), Through the Patient's Eyes. (pp. 19-44). San Francisco: Jossey-Bass Publishers.
- Anderson, L.A., DeVellis, B.M., & DeVellis, R.F. (1987). Effects of modeling on patient communication, satisfaction, and knowledge. Med Care, 25(11), 1044-1056.
- Asmundson, G., & Jones, S. (1996). The Wascana Client-centered Care Survey: development and psychometric evaluation. Canadian Journal of Quality in Health Care, 13(1), 19-21.
- Asmundson, G., Hedley, P., Wilkins, A., Downes, L., Ross, B., Badley, E., Renahan, M., Badali, K., & Lineker, S. (1998). A pilot project to study a new model for physiotherapy practice review, using rheumatoid arthritis as a model. Technical report for the College of Physiotherapists of Ontario. January 1998.
- Biley, F. (1989). Treatment and care: patient participation in decision making. Senior Nurse, 9(10), 23-24.
- Brody, D.S., Miller, S.M., Lerman, C.E., Smith, D.G., & Caputo, G.C. (1989). Patient perception of involvement in medical care: relationship to illness attitudes and outcomes. J.Gen.Intern.Med, 4 (6), 506-511.
- Brown, J., Weston, W., & Stewart, M. (1995). The First Component: Exploring Both the Disease and the Illness Experience. In M. Stewart, J. Brown, W. Weston, I. McWhinney, C. McWilliam, & T. Freeman (Eds.), Patient-centered medicine: transforming the clinical method. (pp. 31-42). London: Sage Publication.
- Brown, J.B., Weston, W.W., & Stewart, M.A. (1989). Patient-Centered Interviewing Part II: Finding Common Ground. Canadian Family Physician, 35, 153-157.
- Brown, S.J. (1999). Patient-centered communication. Annu.Rev.Nurs.Res., 17:85-104, 85-104.
- Bryne P., & Long B. (1976). Doctors Talking to Patients. London: HMSO.
- Burchell, H., & Jenner, E.A. (1996). The role of the nurse in patient-focused care: models of competence and implications for education and training. Int.J.Nurs.Stud., 33(1), 67-75.
- Campbell, T. (1998). Patient-focused care: primary responsibilities of research nurses. British Journal of Nursing., 7(22), 1405-1409.
- Canadian Association of Occupational Therapists. (1997). Enabling Occupation: An Occupational Therapy Perspective. CAOT Publications ACE.

- Carroll, L., Sullivan, F.M., & Colledge, M. (1998). Good health care: patient and professional perspectives. Br.J.Gen.Pract., 48(433), 1507-1508.
- Carroll, T.L. (1999). Multidisciplinary Collaboration: A Method for Measurement. Nursing Administration Quarterly, 23(4), 86-90.
- Chaplin, E., Bailey, M., Crosby, R., Gorman, D., Holland, X., Hippe, C., Hoff, T., Nawrocki, D., Pichette, S., & Thota, N. (1999). Using quality function deployment to capture the voice of the customer and translate it into the voice of the provider. Jt.Comm.J.Qual.Improv., 25(6), 300-315.
- Chewning, B., & Sleath, B. (1996). Medication decision-making and management: a client-centered model. Social Science and Medicine, 42(3), 389-398.
- Clark, M.S., & Caudry, D.J. (1983). Evaluation of rehabilitation services: the use of goal attainment scaling. International Rehabilitation Medicine, 5(1), 41-45.
- Cockburn, J., Killer, D., Campbell, E., & Sanson-Fisher, R.W. (1987). Measuring general practitioners' attitudes towards medical care. Family.Practice., 4(3), 192-199.
- Daley J. (1993). Overcoming barrier of words. In Gerteis M, Edgman-Levitan, S., Daley, L., & T. Delbanco (Eds.), Through the Patient's Eyes . (pp. 72-95). San Francisco: Jossey-Bass Publishers.
- Damgaard, A. (1999). Planetree: a bridge between clinical medicine and public health. Journal of Health Education.30.(2.):85.-9., 124.,
- de Monchy, C., Richardson, R., Brown, R.A., & Harden, R.M. (1988). Measuring attitudes of doctors: the doctor-patient (DP) rating. Medical.Education., 22(3), 231-239.
- Deber, R.B. (1996). Shared decision making in the real world. J.Gen.Intern.Med., 11(6), 377-378.
- Deber, R.B., Kraetschmer, N., & Irvine, J. (1996). What role do patients wish to play in treatment decision making? Arch Intern.Med., 156(13), 1414-1420.
- Delbanco, T.L. (1995). Patient-centered care. Bulletin.of the New York.Academy.of Medicine,72(2.Suppl.),634.-8.,
- Department of National Health and Welfare, & Canadian Association of Occupational Therapists. (1987). Toward outcome measures in occupational therapy. Cat. H39-114/1987E.
- Ellers, B. (1993). Innovations in patient-centered education. In Gerteis, M., Edgman-Levitan, S., Daley, L., & T. Delbanco (Eds.), Through the Patient's Eyes. (pp. 96-117). San Francisco: Jossey-Bass Publishers.
- Elliott, P.F. (1980). Patient-centered care facilitates more personal contact. Mich.Hosp., 16(12), 20-21.

- Epstein, R. (1997). The patient-physician relationship. In M. Mengel & W. Holleman (Eds.), Fundamentals of clinical practice: a textbook on the patient, doctor, and society. (pp. 105-128). New York: Plenum Medical Book Co.
- Eubanks, P. (1990). Nursing restructuring renews focus on patient-centered care. Hospitals, 64(8), 60, 62.
- Fearing VG, & Clark J. (2000). Individuals in Context. A Practical Guide To Client-Centered Practice. (1st ed.). Thorofare, NJ: Slack Incorporated.
- Forbes, D.A. (1998). Goal Attainment Scaling. A responsive measure of client outcomes. Journal of Gerontological.Nursing., 24(12), 34-40.
- Gage, M. (1994). The patient-driven interdisciplinary care plan. J.Nurs.Adm., 24(4), 26-35.
- Gage, M., & Polatajko, H. (1995). Naming practice: the case for the term client-driven. Can.J.Occup.Ther., 62(3), 115-118.
- Gallagher, S. (1997). Surviving redesign: basic concepts of patient-focused care and their application to WOC nursing. J.Wound.Ostomy.Continence.Nurs., 24(3), 132-136.
- Gerteis M, & Roberts MJ. (1993). Culture, leadership, and service in the patient-centred hospital . In Gerteis, M., Edgman-Levitan, S., Daley, L., & T. Delbanco (Eds.), Through the Patient's Eyes. (pp. 227-259). San Francisco: Jossey-Bass Publishers.
- Gerteis M. (1993). Coordinating case and integrating services. In Gerteis M, Edgman-Levitan, S., Daley, L., & T. Delbanco (Eds.), Through the Patient's Eyes. (pp. 45-71). San Francisco: Jossey-Bass Publishers.
- Gillick, M., Berkman, S., & Cullen, L. (1999). A patient-centered approach to advance medical planning in the nursing home. Journal of the American Geriatrics.Society., 47(2), 227-230.
- Gordon, J.E., Powell, C., & Rockwood, K. (1999). Goal attainment scaling as a measure of clinically important change in nursing-home patients. Age.& Ageing, 28(3), 275-281.
- Greenfield, S., Kaplan, S.H., Ware, J.E.J., Yano, E.M., & Frank, H.J. (1988). Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. J.Gen.Intern.Med, 3(5), 448-457.
- Grol, R., de Maeseneer, J., Whitfield, M., & Mokkink, H. (1990). Disease-centred versus patient-centred attitudes: comparison of general practitioners in Belgium, Britain and The Netherlands. Family.Practice., 7(2), 100-103.
- Guadagnoli, E., & Ward, P. (1998). Patient participation in decision-making. Social Science and Medicine, 47(3), 329-339.

- Guinn, R.M. (1993). Operational restructuring for patient focused care: the facility implications. World Hospitals, 29(1), 21-30.
- Hackman, J., & Oldham, G. (1980). Work Design. Reading, MA: Addison Wesley.
- Harrison, P. (1982). Non-traditional clinic promotes total health care and patient involvement. Can.Doct., 48(12), 16-18.
- Hefferin, E.A. (1979). Health goal setting: patient-nurse collaboration at Veterans Administration facilities. Military.Medicine, 144(12), 814-822.
- Henbest, R.J (1985). A study of the patient-centred approach in family practice, 184-186, Master's Thesis, University of Western Ontario
- Henbest, R.J., & Stewart, M.A. (1989). Patient-centredness in the consultation. 1: A method for measurement. Family.Practice., 6(4), 249-253.
- Johnston, C.L., & Cooper, P.K. (1997). Patient-focused care: what is it? Holist.Nurs.Pract., 11(3), 1-7.
- Jones, R.A. (1997). Multidisciplinary collaboration: conceptual development as a foundation for patient-focused care. Holist.Nurs.Pract., 11(3), 8-16.
- Jones, RA P. (1998) Multidisciplinary Collaboration.. Rebecca A.P. Jones, DNSC, RN, CNAA (Homepage). <http://www.tamucc.edu/~rjones/mdcinstrument.htm>
- Joyce, B.M., Rockwood, K.J., & Mate-Kole, C.C. (1994). Use of goal attainment scaling in brain injury in a rehabilitation hospital. Am.J.Phys.Med.Rehabil., 73(1), 10-14.
- Kaplan, S.H., Greenfield, S., & Ware, J.E.J. (1989). Assessing the effects of physician-patient interactions on the outcomes of chronic disease [published erratum appears in Med Care 1989 Jul;27(7):679]. Med Care, 27(3 Suppl), S110-S127
- Kasper J.F., Mulley, A.G., & Wennberg, J.E. (1992). Developing shared decision-making programs to improve the quality of health care. Quality Review Bulletin, 18(6), 183-190.
- Kenny, T. (1990). Erosion of individuality in care of elderly people in hospital--an alternative approach. J.Adv.Nurs., 15(5), 571-576.
- Kimble, J.D.J. (1997). Issues in patient-focused care for the respiratory care practitioner. Holist.Nurs.Pract., 11 (3), 21-30.
- King, I.M. (1981). A Theory For Nursing Systems, concepts, process. Wiley, New York.
- Kinmonth, A.L., Woodcock, A., Griffin, S., Spiegel, N., & Campbell, M.J. (1998). Randomised controlled trial of patient centred care of diabetes in general practice: impact on current wellbeing and future disease risk. The Diabetes Care From Diagnosis Research Team. BMJ., 317(7167), 1202-1208.

- Kiresuk, T., & Sherman, R. (1968). Goal Attainment Scaling: A General Method of Evaluating Comprehensive Mental Programs. Community.Ment.Health J., 4, 443-453.
- Kirkpatrick, M.K., Ford, S., & Castelloe, B.P. (1997). Storytelling. An approach to client-centered care. Nurse.Educ., 22(2), 38-40.
- Krueger, R.A. (1994). Focus Groups: A Practical Guide For Applied Research. (2nd ed). Thousand Oaks, California: Sage Publications.
- Krupat, E., Hiam, C.M., Fleming, M.Z., & Freeman, P. (1999). Patient-centeredness and its correlates among first year medical students. Int.J.Psychiatry Med., 29(3), 347-356.
- Laine, C., & Davidoff, F. (1996). Patient-centered medicine. A professional evolution. JAMA, 275(2), 152-156.
- Langewitz W., Phillipp, E., Kiss, A., & Wosmer, B. (1988). Detection of Psychologic Complaints by General Practitioners. Psychosomatic Medicine, 26(10), 1009-1020.
- Lathrop, J.P., Seufert, G.E., MacDonald, R.J., & Martin, S.B. (1991). The patient-focused hospital: a patient care concept. J.Soc Health Syst., 3(2), 33-50.
- Law, M., Baptiste, S., & Mills, J. (1995). Client-centred practice: what does it mean and does it make a difference? Canadian Journal of Occupational Therapy- revue Canadienne d'Ergotherapie. 62 (5): 250-7.
- Law, M., Baptiste, S., Carswell, A., McColl, M., Polatajko, H., & Pollock, N. (1994). Canadian Occupational Performance Measure. (2<sup>nd</sup> ed.). Ottawa: CAOT Publications ACE.
- Law, M., Baptiste, S., McColl, M., Opzoomer, A., Polatajko, H., & Pollock, N. (1990). The Canadian occupational performance measure: an outcome measure for occupational therapy. Canadian Journal of Occupational Therapy - Revue.Canadienne.d.Ergotherapie. (2), 82-87.
- Lineker, S., & Wilkins, A. Practice Review of the Physiotherapy Management of Lower Extremity Musculoskeletal Diseases. (2000). ACREU.
- Luckhurst, M., & Ray, M. (1999). Person-centred standards of care. Elder.Care, 11, 29-31.
- Lumsdon, K. (1993). Form Follows Function. Patient-centered Care Needs Strong Facilities Planning. Hospitals, February 5, 22-26.
- Lumsdon, K. (1996). Patient-focused. A kinder, gentler ER. Hosp.Health Netw., 70(3), 43, 46.
- Lustbader, W. (1996). Tales from individualized care. J.Gerontol.Nurs., 22(3), 43-46.

- Malec, J.F., Smigielski, J.S., & DePompolo, R.W. (1991). Goal Attainment and Outcome Measurement in Postacute Brain Injury Rehabilitation. Arch Phys Med Rehabil, 72(February), 138-143.
- Mancini, M.E. (1995). Patient-focused care: a response to the healthcare crisis. J.Intraven.Nurs., 18(6), 307-316.
- Matheis-Kraft, C., George, S., Loinger, M.J., & York, L. (1990). Patient-driven healthcare works! Nurs Manage., 21(9), 124-128.
- McWilliam, C. (1995). Qualitative Approaches that Illuminate Patient-Centered Care. In M. Stewart, J. Brown, W. Weston, I. McWhinney, C. McWilliam, & T. Freeman (Eds.), Patient-centered medicine: transforming the clinical method. (pp. 204-215). London: Sage Publications
- Mead N, & Bower P. (2000). Patient-centeredness: a conceptual framework and review of the empirical literature. Social Science and Medicine, 51(7), 1087-1110.
- Millers, N., & Koop, A.J. (1984). A person-oriented view of patient-centred care. Aust.Nurses.J., 13(6), 38-39.
- Mitchell, T., & Cusick, A. (1998). Evaluation of a client-centred paediatric rehabilitation programme using goal attainment scaling. Australian Occupational Therapy Journal, 45(1), 7-17.
- Moughton, M. (1982). The patient: a partner in the health care process. Nurs.Clin.North Am., 17(3), 467-479.
- Myers, S.M. (1998). Patient-focused care: what managers should know. Nurs.Econ., 16(4), 180-188.
- Ockene, J.K., Quirk, M.E., Goldberg, R.J., Kristeller, J.L., Donnelly, G., Kalan, K.L., Gould, B., Greene, H.L., Harrison-Atlas, R., & Pease, J. (1988). A residents' training program for the development of smoking intervention skills. Archives of Internal Medicine, 148(5), 1039-1045.
- Ottenbacher, K.J., & Cusick, A. (1990). Goal attainment scaling as a method of clinical service evaluation. American Journal of Occupational Therapy, 44(6), 519-525.
- Pence, M. (1997). Patient-focused models of care. Journal of Obstetric., Gynecologic., & Neonatal Nursing, 26(3), 320-6.,
- Planetree Group. Planetree Components. Planetree Website. <http://www.planetree.org>
- Provincial Rehabilitation Reference Group. (2000) Managing The Seams: Making The Rehabilitation System Work For People, The Rehabilitation Reform Institute, 1-66.

- Rockwood, K. (1995). Intergration of Research Methods and Outcome Measures: Comprehensive Care for Frail Elderly. Canadian Journal on Aging, 14(supp.1), 151-164.
- Rockwood, K., Stolee, P., & Fox, R.A. (1993). Use of goal attainment scaling in measuring clinically important change in the frail elderly. J.Clin.Epidemiol., 46(10), 1113-1118.
- Rothstein, J.M. (1999). The sensitive practitioner. Physical.Therapy, 79(3), 246-247.
- Roter, D.L. (1993). The Roter Interaction Analysis System (RIAS) coding manual. Baltimore, MD: RIAS.
- Ryan, D.P., Cott, C., & Robertson, D. (1997). Conceptual Tools for Thinking about Inter-teamwork in Gerontology. Educational Gerontology, 23(7), 651-668.
- Seago, J.A. (1999). Evaluation of a hospital work redesign: patient-focused care [published erratum appears in J Nurs Adm 2000 Jan;30(1):5]. J.Nurs.Adm., 29(11), 31-38.
- Skelton, A.M. (1997). Patient education for the millennium: beyond control and emancipation? Patient.Educ.Couns., 31(2), 151-158.
- Speechley, V. (1992). Patients as partners. European.Journal of Cancer Care, 1(3), 22-26.
- Stewart, M. (1995). Methods of Scoring Patient-Centredness. In M. Stewart, J. Brown, W. Weston, I. McWhinney, C. McWilliam, & T. Freeman (Eds.), Patient-Centred Medicine: transforming the clinical method. (pp. 191-203). London: Sage Publications.
- Stolee, P., Stadnyk, K., Myers, A.M., & Rockwood, K. (1999). An individualized approach to outcome measurement in geriatric rehabilitation. Journals.of Gerontology, Series(12), M641-M647.
- Strauss, A.L., & Corbin, J.M. (1990). Basics of qualitative research: grounded theory procedures and techniques. Newbury Park, California: Sage Publications.
- Sumsion, T. (1999). A study to determine a British occupational therapy definition of client-centred practice. British Journal of Occupational Therapy, 62(2), 52-8.
- Sumsion, T., & Smyth, G. (2000). Barriers to client-centredness and their resolution. Canadian Journal of Occupational Therapy - Revue.Canadienne.d.Ergotherapie.2000.Feb., 67(1), 15-21.
- Townsend, E., Brintnell, S., & Staisey, N. (1990). Developing guidelines for client-centred occupational therapy practice. Canadian Journal of Occupational Therapy, 57(2), 69-6.
- Townsend, E., Stanton, S., Law, M., Polatajko, H., Baptiste, S., Ythompson-Franson, T., Kramer, C., Swedlove, F., Brintnell, S., & Campanile, L. (1997). Enabling occupation: an occupational therapy perspective. Ottawa: AOT Publications ACE.

- Turnbull, J. (1998). Evaluating health care using goal attainment scaling. Nursing.Standard., 12(42), 35-38.
- Verhaak, P.F. (1988). Detection of psychologic complaints by general practitioners. Medical.Care., 26(10), 1009-1020.
- Vertinsky, I.B., Thompson, W.A., & Uyeno, D. (1974). Measuring consumer desire for participation in clinical decision making. Health Serv.Res., 9(2), 121-134.
- Weisman, E., & Hagland, M. (1994). Built-in care. One hospital sees the future in patient-centered design. Hosp.Health Netw., 68(22), 54, 56, 58.
- Wensing, M., Jung, H.P., Mainz, J., Olesen, F., & Grol, R. (1998). A systematic review of the literature on patient priorities for general practice care. Part 1: Description of the research domain. Soc.Sci.Med., 47(10), 1573-1588.
- Weston, W.W., & Brown, J.B. (1995). Overview of the Patient-Centred Clinical Method. In M. Stewart, J. Brown, W. Weston, I. McWhinney, C. McWilliam, & T. Freeman (Eds.), Patient-Centred Medicine: transforming the clinical method. (pp. 21-113). London: Sage Publication.
- Wilkins, S., Pollock, N., Rochon, S., & Law, M. (in press). Implementing Client-Centred Practice: Why Is It So Difficult To Do?
- Willer, B., & Miller, G. (1976). On the validity of goal attainment scaling as an outcome measure in medical health. American.Journal of Public Health, 66(12), 1197-1198.
- Yip, A.M., Gorman, M.C., Stadnyk, K., Mills, W.G., MacPherson, K.M., & Rockwood, K. (1998). A standardized menu for Goal Attainment Scaling in the care of frail elders. Gerontologist., 38(6), 735-742.
- Zweber, B., & Malec, J. (1990). Goal attainment scaling in post-acute outpatient brain injury rehabilitation. Occupational Therapy in Health Care, 7(1), 45-53.

## Appendix A: Canadian Occupational Performance Measure (COPM) – 1<sup>st</sup> and 2<sup>nd</sup> editions

Developed by Law M, Baptiste S, Carswell-Opzoomer A, McColl MA, Polatajko H, Pollock N, 1991. 2<sup>nd</sup> Edition 1994.

Purpose of COPM is "to enable occupational therapy clients to participate in a meaningful way in determining the course of occupational therapy intervention" (Law et al 1994)

- Measure based on the model of occupational performance, and to meet ten criteria for an outcome measure as set by the 3<sup>rd</sup> volume of the guidelines (*Towards Outcome Measures*)
- individualised, standardised but not normative measure
- for use with all age spans, all disability groups, all developmental levels; targets physical and/or mental disability in occupational performance (see Townsend 1997 for definition)
- allows for proxy response when client unable to respond
- measure of change in client's (or proxy's) perception of occupational performance; measures client identified problems/concerns/issues and considers client's satisfaction with performance, rating of importance and perception of current performance

### Process:

Step 1: Problem definition – client identifies specific things they are concerned with in the areas of self-care, leisure and productivity (e.g sitting, playing golf, operating machinery)

Step 2: Weighting – client rates those concerns for importance on a 1-10 scale

Step 3: Scoring – client chooses up to five of these problems that will be addressed and measured in COPM, and rates those five out of ten on how well they think they are currently performing that activity and how satisfied they are with that performance. Overall performance and satisfaction are calculated by weighting according to importance. Intervention usually occurs following this step.

Step 4: Reassessment – client reassesses the same five problem areas as to how well they believe they are performing and how satisfied they are with that performance. These scores are then compared to the original.

Step 5: Follow-up – the client is asked if there are problems remaining, or new problems that have emerged that they would like to address. If client wishes to continue intervention, process is begun again with a new COPM form.

## **Validity:**

### **Chan and Lee (1997):**

*Content* - 9 member panel expert review found COPM inadequate in assessing occupational performance or performance components, but adequate in reflecting client's problems in occupational performance – interview processes critical, yet not standardized

#### *Criterion related evidence –*

- ▶ convergent validity not found between COPM-performance subscale and the Klein-Bell ADL (KBADL) (some correlations virtually zero or negative)
- ▶ no convergent or discriminant validity between COPM and Functional Independence Measure (FIM)
- ▶ there was convergent validity between COPM-performance subscale and FIM motor subscale, as well as discriminant validity between FIM cognitive subscale and COPM performance.
- ▶ There was no convergent validity observed between the initial assessment of COPM satisfaction subscale and the Satisfaction with Performance Scale Questionnaire (SPSQ); there was a stronger relationship in the pre-discharge assessment
- ▶ significant and positive relationship between both subscales of COPM and Social/Community subscale of SPSQ; however there was no differentiated convergent, discriminant validity between them or between COPM and Home Management subscale

Chan and Lee feel that research should be directed to improving the instrument, that currently it is good at reflecting client's problems in occupational performance (and according to McColl et al 2000 may bring out a wider variety than simply asking client), but less desirable in facilitating therapists to make meaningful clinical decisions when client's performance is dependent on competence in performance components

### **McColl et al (2000) –**

#### *Construct validity:*

- ▶ COPM performance subscale not significantly correlated to any of the three other scales (SPSQ, the Reintegration to Normal Living Index (RNL) or Life Satisfaction scale (LSS))
- ▶ Significant but low correlation between COPM -satisfaction and SPSQ, RNL, LSS
- ▶ Significant and high correlation between COPM Satisfaction and Performance subscales

### *Criterion Validity:*

- ▶ concordance between problems generated on COPM and in Perceived Problems Checklist (PPCL) modest (PPCL generated for this study - asking clients to spontaneously state 5 most important problems) – 24% of items on PPCL and 21% of items on COPM mentioned on both. Most on PPCL were self-care - more variety on COPM

The authors mention a relationship between the RNL and LSS and the COPM performance subscale in their discussion, but in their table it is a non significant correlation. They criticise Chan and Lee for using SPSQ in criterion validation, saying that they are not the same domain but related. They consider the COPM to be duly validated.

### **Reliability:**

- ▶ .84 for Performance subscale and .63 for Satisfaction (McColl et al 2000 quoting Law et al 1994)

### **Utility:**

Client level –

Law et al 1990 have said that OT's working in specialized areas i.e assessing primarily performance components and not occupational performance may not find COPM useful

No serious problems found with utility in community study (McColl et al 2000) or in mental health use (Cresswell, MKM 1998) – other populations no problem using

Time to administer can vary - from 10 to 180 minutes in one study (Law et al 1994)

System Level –

Has been proposed that this measure could be used as quality measure on system level (Law et al 1990)- to measure one aspect of quality in care – effectiveness of treatment though change of client's perception of performance.

### **References:**

Chan CCH and Lee TMC. Validity of the Canadian Occupational Performance Measure. *Occupation Therapy International* 1997; 4(3): 229-247.

Cresswell MKM. A study to investigate the utility of the Canadian Occupational Performance Measure as an outcome measure in community mental health occupational therapy [abstract]. *British Journal of Occupational Therapy* 1998; 61(5): 213.

Law M, Polatajko H, Pollock N, McColl MA, Carswell A, Baptiste S. Pilot testing of the Canadian Occupational Performance Measure: clinical and measurement issues. *Canadian Journal of Occupational Therapy* 1994; 61(4): 191-197.

McColl MA, Paterson M, Davies D, Doubt L, Law M. Validity and community utility of the Canadian Occupational Performance Measure. *Canadian Journal of Occupational Therapy* 2000; 67(1): 22-30.

Townsend E (editor). *Enabling Occupation: an occupational therapy perspective*. Ottawa: CAOT Publications, 1997.

## **Appendix B: Components of Goal Attainment Scaling (GAS)**

### **Conceptual Basis of GAS:**

Goal Attainment Scaling, which was originally devised by Kiresuk and Sherman (1968), is a process used to evaluate therapeutic outcomes with patients. GAS consists of a series of steps:

- goal setter or team (amongst which the client may or may not be a member) identifies client's desires, needs and present situation) (Kiresuk and Sherman, 1968).
- goal setter/team and client reach a mutual agreement as to which goals are attainable (Kiresuk and Sherman, 1968; Clark & Caudrey, 1983 ).
- goals are assigned weights according to their importance (Clark & Caudrey, 1983).
- outcomes for each of the goals specified are established (Clark & Caudrey, 1983).
- a scale (ranging from -2 to +2) is assigned to each goal . Each point on the scale represents an outcome. -2 is assigned to the most unfavorable outcome, while +2 is assigned to best possible outcome (Kiresuk and Sherman, 1968).
- following a specified period of time, an independent team or person will evaluate the outcomes (Kiresuk & Sherman, 1968; Clark & Caudrey, 1983).
- the success of the program is evaluated by determining the score for each goal (Kiresuk and Sherman, 1968).

### **Study Settings:**

GAS has been used in in/outpatient rehabilitation, home health care, and nursing home settings. The types of clients that have participated in GAS include the following:

- brain injury patients (Zweber & Malec, 1990; Joyce, Rockwood & Mate-Kole, 1994)
- elderly patients (Rockwood, Stolee & Fox, 1993; Stolee, Stadnyk & Myers, 1999)
- mental health patients ( Willer & Miller, 1976)
- pediatric patients (Mitchell & Cusick, 1997)

## **Advantages of GAS**

GAS is beneficial as an evaluation of therapeutic outcomes for a number of reasons. Such reasons include the following:

- GAS outlines a patient's progress and change in therapy (Ottenbacher & Cusick, 1990; Joyce, Rockwood & Mate-Kole, 1994 ; Forbes, 1998; Stolee, Stadnyk, Myers & Rockwood 1999; Rockwood, Stolee, & Fox,1993)
- GAS allows for the mutual negotiation of goals between interdisciplinary team members and client (Gordon, Pwell, & Rockwood, 1999; Forbes, 1998; Mitchell & Cusick,1998)
- GAS is a tool that is not restricted to any particular outcome/treatment measure (Ottenbacher & Cusick, 1990)
- GAS allows patients to gain a better sense of self-awareness (Mitchell & Cusick, 1998 ; Zweber & Malec, 1990)

## **Problems with GAS**

- the subjectivity of goals set by clinicians which makes comparison of GAS difficult (Forbes,1998)
- clinicians setting goals that are too easy to attain (Rockwood, 1995; Turnbull, 1998)
- the problem of assigning weights to goals (Clark & Caudrey, 1983)

## **Validity of GAS**

Various studies have provided support for the validity of GAS. Validity has been supported in the following ways:

- significant correlations between GAS scores and other evaluation outcome measures (Malec, Smigielski & Depompolo,1991; Stolee, Stadnyk, Myers & Rockwood, 1999).
- significant correlations between scores of patients before and after GAS application (Malec, Smigielski & Depompolo, 1991)

## **Reliability of GAS**

- study involving GAS of brain injury patients showed inter-rater reliability between admission (.92) and discharge (.94) (Joyce, Rockwood & Mate-Kole, 1994)

## Appendix C: Picker Institute

1295 Boylston Street, suite 100

Boston, MA 00215

[www.picker.org](http://www.picker.org)

- non profit affiliate of Care Group in Boston, Massachusetts
- international leader in the field of healthcare quality assessment and improvement strategies through the patients' eyes
- mission is to improve quality of healthcare through the eye's of the patient
- Picker seeks to help caregivers and others to understand issues that are most crucial to patients
- believes that patient centred approaches will make healthcare more humane and improve patients' experiences
- 1987 started as a grant funded project through the Commonwealth Foundation
- founders conducted focus groups around the country with patients and their families
- early work is summarized in a book entitled "Through the Patients' Eyes" (Gerteis et al, 1993)
- **does not focus on goal setting**

**Picker Methodology:** focus groups, focused interviews, national surveys

Clinical settings: hospitals, clinic's and doctor's offices

Broad range of ages, ethnicities, geographical locations, medical conditions

**Validity** The validity of the surveys is addressed throughout the whole development process to insure that survey measurements correspond to some true or real value. The discriminant validity of their instruments is tested by the observed differences in problem rates between institutions.

**Reliability:** The very nature of Pickers face-to-face development process with patients and health care workers insures that there is consistency across respondents (ie. the questions mean the same thing to every respondent).

Based on over ten years of research and more than 400 000 patient survey interviews, the Picker Institute has identified eight **dimensions of care** that patient's value:

*[Eye on patients: A report by the Picker Institute for the American Hospital Association]*

1. Access to care
2. Respecting a patient's values preferences and expressed needs
3. Emotional support
4. Information and Education
5. Coordination of care
6. Physical comfort
7. Involvement of family and friends
8. Continuity and transition

Picker survey data indicates **problem areas** to be addressed

- the system is a nightmare to navigate
- caregivers do not provide enough information \*
- patients are not involved in decisions about their care
- caregivers are not emotionally supportive
- the system's gatekeepers set up too many barriers

\* Clinicians routinely underestimate the importance of giving information to patients and overestimate the amount of time they spend giving information. [Waitzkin, H (1985) Information giving in medical care, *Journal of Health and Social Behavior*, 26: 81-101]

**Surveys Measure:** The Picker surveys measure patient satisfaction and experiences with care in a variety of inpatient and ambulatory settings. All surveys use a combination of reports and ratings to assess patients' experiences within important dimensions of care, their overall satisfaction with services, and the relative importance of each of the dimensions in relation to satisfaction.

**Response Rate** Picker uses a three-stage mailing process, which consists of a mail-out/mail-back questionnaire, a reminder postcard, and a second questionnaire over a six week field period. With this method, our mean response rate for all institutions currently using the adult inpatient survey is 50%.

**Picker survey products:** Adult Inpatient; Pediatric Inpatient; Adult Office Visit; Rapid Cycle Adult Office Visit; Pediatric Office Visit; Adult Emergency Services; Adult Ambulatory Surgery; Adult Inpatient Rehabilitation; Adult Home Care; Neonatal Intensive Care Unit; Adult Cancer Care; Hip Replacement; Acute Myocardial Infarction.

### **Adult Inpatient Rehabilitation Survey Instrument** (Developed 1997)

Asks patients to report on as well as rate their care.

Assess patient's experiences across **seven** key dimensions of care:

- access to health professionals
- coordination of care
- information and education
- physical comfort
- respecting a patient's values preferences and expressed needs
- continuity and transition
- emotional support

## **Sampling Strategy**

*Hospital patient volume:* Hospitals with a minimum annual adult inpatient rehabilitation discharge volume of 1500

*Sampling time frame:* Sample drawn from 3 previous months

*Sample strategy/volume:* Obtain 300 completed surveys per hospital / centre

## **Survey Program**

*Survey Frequency:* monthly (maximum), quarterly, semi-annually, or annually

*Average response rate:*

45% for three wave option (response rates will vary among clients)

20-30% for the one wave option (response rates will vary among clients)

Questionnaire divided into sections asking patient regarding their experiences with:  
starting rehabilitation program

therapists

nurses

rehabilitation doctors

social worker

psychologist

rehabilitation team

family of friends

going home

overall impression

patient's background

## **Adult Home Care Survey Program (Developed 1997)**

Assess patient's perceptions of care across **eight** key dimensions of care:

- access to care
- nurses
- therapists
- home care aides
- home care equipment
- involvement of family and friends
- agency services
- continuity of care

## **Sampling Strategy**

*Hospital patient volume:* Hospitals with a minimum annual adult home care visit volume of 4000

*Sampling time frame:* Sample drawn from previous 4 weeks

*Sample strategy/volume:* Obtain 300 completed surveys per hospital / centre

## **Survey Program**

*Survey Frequency:* monthly (maximum), quarterly, semi-annually, or annually

*Average response rate:*

45% for three wave option (response rates will vary among clients)

20-30% for the one wave option (response rates will vary among clients)

## **Hip Replacement Survey**

Surveys offered: 1, 3 and 12 months post hospitalization

Questions focus on hospitalization (1 month) and recovery after hip replacement surgery

## Appendix D: CAHPS<sup>TM</sup> – Consumer Assessment of Health Plans Study

**Conceptual basis:** to produce a rating of health care plans based on information only consumers could provide, to assist in consumer choice of health plans in the United States.

Sought to create surveys that are suitable for and allow valid comparisons across wide range of potential consumers and with all types of health care delivery systems

Research mainly funded by Agency for Health Care Policy and Research. who gave three cooperative grants to consortia headed by Research Triangle Institute, RAND and Harvard Medical School – each consortia took different elements of survey development, and report creation

- ▶ produced surveys: adult core (published in *Medical Care* in English and Spanish), child core and supplements, and implementation handbook, as well as other supports such as drafts of respondent letters, SAS program for analysis
- ▶ also produced reporting products: two versions of a poster and one brochure advertising CAHPS reports, print guide, "Compare your health plan choices," and computer guide, "Decision Helper"

### Adult core consists of:

- ▶ Yes/No and Never/Sometimes/Usually/Always reports on aspects of health care (e.g "Your personal doctor or nurse," "Getting care from a specialist")
- ▶ 4 global ratings on 1-10 scale ("Personal doctor or nurse," "Specialist," "Health Care" and "Health Insurance Plan")

to which supplemental subscales can be added on communication, interpreter, dental care, mental health, chronic conditions, pregnancy care, prescription medicine, transportation, claims processing, medicaid enrollment, cost sharing, covered by multiple plans, relation to policy holders, well child care, medicare. (Some are required for certain populations, such the one on Medicare when surveying a Medicare Managed Care population).

### Populations used in

- ▶ Different forms of health plans (fee-for-service, managed care, and hybrids), and across various types of health insurance (private, Medicaid and Medicare)

- ▶ among different sub-populations (children, chronically ill adults)
- ▶ different parts of the U.S. (California, Washington D.C., Connecticut, Kansas, Michigan, New jersey, North Carolina, Oklahoma, Oregon, Washington State)

Survey packages have been specifically designed for adult and children who are in privately insured care, medicaid managed care, medicaid fee-for-service and adult version of Medicare managed care (Crofton et al 1999)

## **Psychometric properties – Validity and Reliability**

Cognitive testing of the questionnaire was conducted with parents of children, adults with chronic diseases, Medicare recipients 65 or older, adult medicaid recipients and with adults with low literacy skills to find out how well the survey was understood, and what options for question design were better.

Among other things they found that for their purposes ratings were better than reports, numeric ratings were better than adjectival (particularly for translation into Spanish), that participants preferred to be asked about a longer referent period (in CAHPS 1.0 6 months, in CAHPS 2.0 12 months) than their last visit to a health professional because they felt it to be more reflective of their experiences with the health plan. (Harris-Kojetin et al, 1999)

### **Validity**

(Hays et al, 1999)

- ▶ validity of the global rating of the health plan based on its correlation with the consumer's willingness to recommend it to family or friends ( $r=0.75$ ,  $p<0.01$ ), and their interest in signing up for the current plan if given a choice of plans today ( $r=0.77$ ,  $p<0.001$ ) in the field test sample of 313 individuals on Medicaid
- ▶ Global ratings of the health plan and global ratings on an Excellent-to-Poor response scale were significantly correlated ( $r=0.77$ ,  $p<0.01$ ) among 539 adults with private insurance

### **Reliability**

(Hays et al, 1999)

- ▶ used correlations between respondents for plan level reliability, and internal consistency for the ten domains of the questionnaire (composite ratings based on similar questions)
- ▶ Reliability generally much lower for Medicaid recipients than privately insured; global rating reliability in the adult medicaid population ranges from 0.19 (personal doctor) to 0.77 (health plan) in adult medicaid sample, as compared to a range of 0.66 (specialist care) to 0.96 (health plan) in the privately insured.

- ▶ Internal consistency still slightly lower in medicaid population, but not as low. Ranged from 0.48 (getting the care you need) to 0.79 (communication) for adults with Medicaid, and from 0.48 (reasonable paperwork) to 0.88 (customer service) in the privately insured population
- ▶ reliabilities of global ratings at plan level, and domains on internal consistency for children's care (answered by proxy by the child's parent) followed similar patterns, but were slightly lower than that for adult care
- ▶ Response rates were very low, ranging from 19% (Medicaid demonstration sites) to 61% (privately insured in field test) from random sample of 5,878 and 313 (two medicaid samples) and 11,393 and 539 (two privately insured groups). Methods of contact were phone, mail and mixed, in New Jersey, Washington State, California and Oklahoma..

The implementation manual for CAHPS recommends having a sample size of no less than 300 individuals for adequate reliability in almost all of the global ratings for health plan comparison in populations of the privately insured and adults on Medicaid; more then 300 responses are required for children on Medicaid.

### **Issues:**

- ▶ the questionnaire is very focussed on primary care and interactions with the health care plan, and may not applicable to rehabilitation without significant rewriting; also its focus on the choice of health care plans is not as applicable in Canada as it is in the United States

### **References:**

Crofton C, Lubalin JS, Darby C. Foreword. *Medical Care* 1999; 37(3 supplement): MS1-MS9.

Harris-Kojetin LD, Fowler FL, Brown JA, Schnaier JA, Sweeny SF. "The use of cognitive testing to develop and evaluate CAHPS™ 1.0 core survey items. *Medical Care* 1999; 37(3 supplement): MS10-MS21.

Hays RD, Shaul JA, Williams VSL, Lubalin JS, Harris-Kojetin LD, Sweeny SF, Cleary PD. Psychometric properties of the CAHPS™ 1.0 survey measures. *Medical Care* 1999; 37(3 supplement): MS22-MS31.