

# Chapter 1

## General introduction

## Introduction

Client-centredness is an approach that is not only used in corporate environments and in public services, but also in health care settings. A patient's perspective of quality of care and the ability of health systems to respond holistically to the needs of patients are nowadays salient concepts for health care participants.<sup>1</sup>

The emphasis on client-centred health care stems from the shift away from infectious diseases and single disorders toward chronic conditions and multifaceted problems. The appeal for client-centredness is concordant with the appeal to enhance a patient's autonomy.<sup>2</sup> Patients are considered to have the right to know and the right to decide. According to the World Health Organization's Declaration of Alma-Ata "...people have the right and duty to participate individually and collectively in the planning and implementation of their health care".<sup>3</sup> Hence, people nowadays expect health systems, health care organizations, and health practitioners to adopt a holistic approach to health care, where the individual who needs care is viewed and respected as a whole person with multidimensional needs.<sup>1</sup> This health care approach assumes a balanced consideration of the rights and needs as well as the responsibilities and capabilities of all health participants.<sup>1</sup>

A variety of concepts related to client-centred practice exist, such as person-centred care, family-centred care, demand-oriented care and patient-focused care.<sup>4,5</sup> Although there is much debate about the differences between these concepts, there are also areas of agreement. Lewin et al. included in his definition of patient-centred care the following features: 1) healthcare providers share control of consultations, decisions about interventions or the management of the health problems with patients and/or 2) healthcare providers focus on the patient as a person, rather than solely on the disease in consultations.<sup>6</sup> In this thesis the term client-centred practice is used as this term is operationalized within the occupational therapy. In essence, client-centred practice is seen as a process in which the patient is the central point in the treatment process and in which the patient is involved in the decision-making process. It goes well beyond simply setting goals with the patient.<sup>7</sup> Core concepts of client-centred practice include respecting the patient and the choices he or she makes, facilitating patient participation, focusing on the person-environment-occupation relationship, providing flexible and individualized service delivery, incorporating the patient's values into clinical decision making, and patient-centred communication.<sup>8</sup> In client-centred practice, patients are encouraged to manage their own health care through prevention and lifestyle changes.<sup>9</sup> This should lead to improved participation and satisfaction

both in the short and long term.<sup>9</sup> Despite the appeal of client-centred practice, questions remain about the actual effect of the implementation of client-centred practice in health care.

## Evidence on client-centred practice

A theoretical advantage of client-centred practice is that the therapy is tailored to the patient's needs. This, in turn, is assumed to result in increased patient satisfaction, increased compliance with treatment programs, decreased length of stay in a rehabilitation facility, and greater improvement in autonomy and quality of life than conventional therapy.<sup>10,11</sup>

Studies on client-centred practice have shown beneficial effects on communication with patients, patient satisfaction, patient adherence, health care utilization, and malpractice litigation.<sup>12</sup> In addition to the positive impact on process outcomes, client-centred practice also claims to have a beneficial effect on functional outcomes. However, despite the purported benefits of a client-centred approach, mixed findings about the efficacy of client-centred therapy on health care behaviour and health status have been found.<sup>6</sup>

### Client-centred practice and occupational therapy

Client-centred practice is an important component of major occupational therapy (OT) conceptual practice models (e.g., the Canadian Model of Occupational Performance and Engagement<sup>13</sup> and the Model of Human Occupation<sup>14</sup>). Client-centred practice has been part of the OT literature and educational process for over 15 years. Therefore, client-centred practice is often considered as "usual care" in OT since it is thought to be the theoretical lens through which occupational therapists think, reason, and make their intervention decisions. Practising as an occupational therapist in a client-centred manner may therefore seem logical and easy to implement. However, in reality this is often not the case. Despite the intuitive appeal of the term client-centred practice by assuming that what we do in health-care is client-centred, the actual practice shows different perceptions of client-centred practice between health professionals and patients. A study of Maitra et al. showed that the occupational therapists indicated use of the principles of client-centred practice in their therapy, while not all their patients recognized a client-centred approach in their therapy.<sup>15</sup> For example, 72% of the occupational therapists responded positive to the question if their patients participated in

setting goals for their therapy, while the majority of the clients (63%) stated little or no active participation in setting their goals.<sup>15</sup>

The implementation of client-centred practice is not only discussed in OT but in health care in general. In fact, a number of tensions and issues are experienced by incorporating the client-centred approach.<sup>16,17</sup> Barriers are presented by 1) health professionals (e.g., patient safety, capabilities, self-knowledge and values), 2) patients (e.g., cultural issues, education, problem-solving skills), 3) the environment (e.g., time to implement, confusion due to other approaches used by other multidisciplinary team members, philosophy of the staff)<sup>18</sup>, and 4) the lack of a clear definition and method of measurement of client-centred practice.<sup>4,5</sup>

To enhance the implementation of client-centred practice, a conceptual framework, the Canadian Practice Process Framework (CPPF), has been established to guide occupational therapists through a structured client-centred process.<sup>13</sup> The framework takes into account the knowledge, experiences, and personal values that both the patient and therapist bring with them into the therapeutic relationship. It also describes the need for therapists to consider the contextual factors that may influence the practice processes<sup>13</sup>. The CPPF describes eight action points in the therapy process which are directed towards enabling change in occupational performance and engagement. The first action point (*enter/initiate*) represents the first point of contact between the patient and therapist where a collaborative decision is made to either engage in or terminate the therapy. At the second action point the therapist and patient *set the stage* by determining how they work together, by clarifying expectations and assumptions and by identifying priority issues and possible goals. Subsequently action point three concerns the *assessment* or *evaluation* of personal, environmental and occupational factors that underlie the client's issues. Action point four (*agree on objectives and plan*) involves the therapist and the patient to establish goals and agree on the objectives and plan of intervention. The fifth action is to *implement the plan* with patient participation and power-sharing. Action point six includes *monitoring and modifying* by ongoing evaluation to determine if the used strategies are meeting the objectives. In the next action point the outcome of the plan is evaluated and the attainment of the goals is examined to determine whether goals are met or new goals or plans need to be established. The process *concludes* with action point eight, when the therapist and patient come to a collaborative decision to either pursue other objectives or conclude the therapeutic relationship.<sup>13</sup>

### **Client-centred practice and multiple sclerosis**

The client-centred approach is assumed to be suitable for a large patient-population varying from persons with acute problems, due to trauma or infectious diseases, to persons suffering from multidimensional chronic diseases. For the latter, the client-centred approach is supposed to be of extra value. People with a chronic disease have often lived with the accompanying symptoms for several years. Furthermore, they have become familiar how to deal with the health care system, know where to gather information, and are knowledgeable about their disease and existing interventions. This is especially the case for people suffering from multiple sclerosis (MS).

MS is a chronic progressive neurological disease. A variety of symptoms can result from MS, including sensory deficits, visual problems (optic neuritis), muscle weakness, depression, impaired coordination (cerebellar ataxia), cognitive problems and pain. One of the most prominent symptoms in many MS patients is fatigue. The incidence of MS is approximately 7 per 100,000 and the prevalence 120 per 100,000 in the Northern-American and Western-European countries. The female to male ration is about 2:1.<sup>19</sup> The average age of onset of symptoms is between 20-40 years of age. This means that MS mainly affects young adults at a stage in their lives when they are establishing careers and having a family. Consequences of MS do not only involve coping with the appearing symptoms but also the adjustment of living with a chronic illness. It may bring disability, lifestyle changes and alterations in quality of life. In particular patients with relapsing forms of MS follow treatment regimens, monitor their condition, adapt to changes, and regularly make decisions about whether they need to seek care or are able to handle their problem on their own.<sup>20</sup>

MS patients often experience severe functional disability and reduced social participation. OT aims to reduce this functional disability and to improve social participation, with the ultimate goal to increase autonomy and quality of life of MS patients.<sup>21</sup> The ability to lead an independent life has been highlighted as one of the major goals for patients with MS.<sup>22</sup> To achieve this goal, interventions have been developed that 1) preserve energy and improve time management, 2) ameliorate body mechanics and strategies for task performance, and 3) provide adequate assistive devices.<sup>23</sup> Although more scientific support on the efficacy of OT is needed<sup>23</sup>, OT is established as an integral part of care for MS patients as outlined in the guidelines for MS care from the national collaborating centre for chronic conditions.<sup>24</sup>

The mixed results in literature about the efficacy of client-centred practice, the lack of well-performed studies due to insufficient implementation of client-centred practice and the clear relevance of client-centred therapy to MS patients prompted us to conduct the studies as described in this thesis. The aim of these studies was to determine the efficacy of client-centred OT in MS. The results can be used to modify current OT, with the goal to increase its efficacy and relevance to patients with MS.

## Client-centred assessments

Client-centred instruments that assess meaningful outcomes from the patients' perspective are necessary to inventorize the components for client-centred practice and to evaluate the effect of client-centred interventions. Since it is not always possible to cure patients, the content of many assessments focus on reducing the negative impact of the disease. Clinical measures are frequently used to quantify disability. Although these measures are considered as objective and useful for health-professionals they often correlate poorly with patients' perception of their own well-being.<sup>25</sup>

Important client-centred outcomes within the occupational therapy are activities and participation. It is often claimed that it is important that these outcomes are based on the patients' own perspective including their own values, judgments, and preferences. These self-report measurements can be used as discriminative instruments to detect the health status at a certain point in time or as evaluative instruments over a period of time.<sup>26</sup> A promising client-centred outcome to measure a patient's self-perception of performance issues is the Canadian Occupational Performance Measure (COPM)<sup>8</sup>. However, the reproducibility and responsiveness of this instrument are not fully known and further study is needed. To assess if client-centred practice improves the patient's participation it is important to choose the right participation instrument. Therefore it is necessary to know how the concept participation is operationalized and measured.

### Canadian Occupational Performance Measure

Patients who receive a client-centred intervention have the right to expect that their health professional selects an appropriate intervention that is based on empirical evidence and that is effective. Furthermore, the intervention has to be appropriate to the patient's therapeutic needs and the intervention has to be

consistent with the stated goals.<sup>27</sup> However, from a client-centred perspective not all patients share the same definition of enhanced function.<sup>28</sup> OT interventions and measures should therefore be directed towards this diversity.<sup>29</sup> Questions that need to be addressed are how the patient's unique goals can be incorporated when measuring outcomes, and how patient outcomes can be compiled to allow reporting of the general effectiveness of OT interventions.

Individualized outcome measurements are supposed to be the most useful instruments to measure the effectiveness of client-centred interventions. An individualized outcome measure reflects the change in the performance aspirations and satisfaction of the patient.<sup>18</sup> The Canadian Occupational Performance Measure (COPM)<sup>8</sup> is such a measure. In the COPM, an important client-centred concept is incorporated, namely the patient's values and perspectives on their health. The COPM is developed as a non-diagnostic-specific outcome measure to evaluate change in a patient's self-perception of occupational performance over time. The COPM guides the patient to identify occupational performance issues and to evaluate their performance and their satisfaction with this performance. It is a standardized instrument, meaning that it includes specific instructions and methods for administering and scoring. It has a semi-structured interview format and structured scoring method. It has been used in more than 35 countries and has been translated into over 20 languages. The Dutch version of the COPM was released in 1999.<sup>30</sup> Although the use of the COPM is expanding, the clinimetric properties of this measure are not fully known. Supportive evidence was found for the content validity, the convergent validity and the divergent validity<sup>31,32</sup>, but several questions remain about the reproducibility and the responsiveness of this instrument. To determine whether the COPM is a reliable measure that can detect changes in a patient's self-perception over time, the reproducibility and the responsiveness of the COPM are evaluated in this thesis.

## **Participation**

Client-centred practice aims to improve the participation of the patient in the society. Several instruments claim to measure participation, but what is participation exactly and how can it be measured?

Participation is defined in the International Classification of Functioning, Disability and Health (ICF). The ICF is a theoretical framework that is used to describe and measure functioning. The framework describes body functions, body structures, activities and participation, and takes personal and environmental factors into account.<sup>33</sup> Figure 1.1 illustrates the relationships between the different

factors. In the ICF, the term disability refers to impairments, activity limitations and participation restrictions.

Participation may appear to be a simple concept to measure, but in reality problems arise in the conceptualization and operationalization. Participation is defined in the ICF as “involvement in a life situation” while participation restrictions are defined as “problems an individual may experience in involvement in life situations”.<sup>33</sup> Activity is defined as the execution of a task or action by an individual. Although there are two definitions for activity and participation they are treated as one category in the ICF.

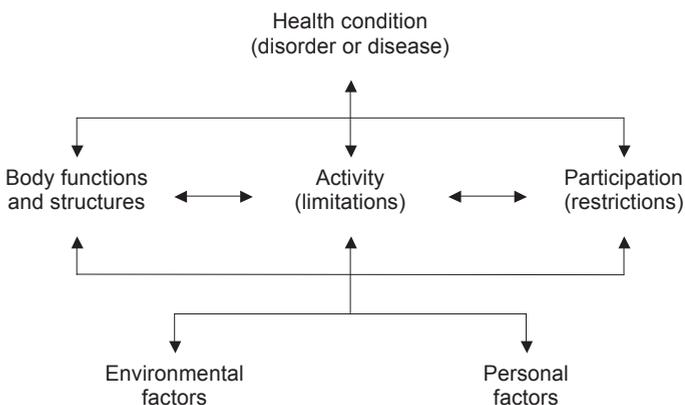


Figure 1.1 The International Classification of Functioning, Disability and Health (ICF)

Conceptual and measurement issues requiring clarification, include identifying domains of participation, ascertaining metrics appropriate to each domain, describing typical levels of each metric in each domain, and identifying the key characteristics of participation. The vague distinction between participation and activity in the ICF-definition creates ambiguity and has made the operationalization and measurement of participation a challenge.<sup>34,35</sup>

Participation is difficult to measure as both the quality and quantity of participation are affected by the environment and personal characteristics.<sup>36</sup> Nevertheless, many instruments claiming to assess participation are available in the literature. These instruments vary widely in the level of detail they assess. There are instruments that aim to measure participation as a construct that can be determined objectively. However, there are also many measures that reflect subjective aspects of participation, including autonomy, satisfaction, perceived difficulty of participation, equality with peers, experiences of inclusion, independence, and non-discrimination.

In rehabilitation and other medical and social service programs, participation is often considered as a key outcome. Participation is one of the core principles of patient-centred health care models.<sup>7</sup> Many instruments claim to measure participation, but it is questionable whether they all do so. Before the clinimetric properties of participation measures can be reviewed systematically and a well-founded decision can be made which participation measure to use, it needs to be clear how participation is operationalized.

In this thesis a systematic review is conducted to gain more insight in the concept and dimensions of participation and in the extent to which instruments that aim to measure participation indeed do so.

## Aims and outlines of the thesis

The main aim of this thesis was to assess the efficacy of client-centred occupational therapy (OT) compared to usual care OT in patients with multiple sclerosis (MS).

**Chapter 2** describes the results of a cluster randomised controlled trial on the efficacy of client-centred OT compared to usual care OT in patients with MS. This trial was conducted as no conclusive evidence was available to support the efficacy of client-centred OT in patients with MS.

**Chapter 3** reports on secondary analyses performed on the data of the clustered randomised trial. The hypothesis whether client-centred therapy spends more time on diagnostic consultation and less time on actual treatment compared to usual care was assessed in-depth.

Second, we assessed the clinimetric properties of the Canadian Occupational Performance Measure (COPM), a client-centred outcome measure that is frequently used in OT.

**Chapter 4** presents the results on the reproducibility (reliability and inter-rater agreement) of the COPM. The results are presented of 1) the inter-rater agreement of the prioritised problems, 2) the reliability and agreement of the mean performance score and the mean satisfaction score, and 3) the agreement of the performance score and the satisfaction score of the separate prioritised problems.

**Chapter 5** continues with the description of the clinimetric properties of the COPM by presenting the results of the responsiveness of the measure in a population of outpatients receiving OT. The evaluation was based on the criterion

responsiveness, the construct responsiveness, the feasibility of the COPM, and the correlation between satisfaction and performance-scores of the COPM.

Third, we reviewed systematically whether instruments that intend to measure participation actually do so and how frequently specific aspects and domains of participation are addressed. These findings are reported in **chapter 6**.

Finally, a reflection on the main issues related to the findings in this thesis, the implications for clinical practice and directions for future research are discussed in **chapter 7**.

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