‘Expert Patient’ in Health Professional Education:

Experience of OT Students

by

Jasmin Joan Cameron Duarte

A thesis submitted to the graduate program in Rehabilitation Science

in conformity with the requirements for the

Degree of Master of Science

Queen’s University

Kingston, Ontario, Canada

March, 2013

Copyright © Jasmin Joan Cameron Duarte, 2013
Abstract

Patient-centred care is the gold standard of health care, yet in practice, problems prevail. The use of the ‘expert patient’ in health professional education is one form of learning patient-centred care. A gap in the literature regarding how the use of ‘expert patient’ in health professional education promotes patient-centred care was acknowledged in current research. With Queen’s University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board approval, a sample of Queen’s University MScOT students participated in a qualitative study with the following research question: “How does the students’ experience of interacting with the ‘expert patient’ (‘XP’) relate to learning regarding client-centred practice (CCP)?” Three objectives were proposed: 1. Describe the OT students’ experience of interacting with the ‘expert patient’, 2. Describe the students’ learning regarding client-centered practice, 3. Identify the conditions particular to the ‘expert patient’ experience that led to learning regarding client-centered practice.

In-depth interviews were conducted with the students subsequent to their ‘expert patient’ experience. Analysis revealed three conditions that together provided the foundation for student experiential learning regarding client-centred practice: interaction with particular persons with stable disability known as ‘expert patients’; students’ requirement to evaluate them and thus ‘experience power’; and explicit opportunities for ‘directed reflection and discussion’. Questions were raised for researchers, health care professional educators and health care professionals regarding the potentially transformative nature of engaging in unfamiliar contexts with openness to learning. The thesis allowed insight into the lived experience of OT students learning with ‘expert patients’; and the admiration, discomfort, humility and gratefulness they experienced while gaining a sense of the meaning of collaboration, respect for autonomy and recognition of expertise. Implications of the research impact all stakeholders in health professional education.
Acknowledgements

AM, Jo, MF

SS, KK


L’Chaim
# Table of Contents

Abstract .......................................................................................................................... ii

Acknowledgements ......................................................................................................... iii

List of Tables .................................................................................................................... vi

List of Figures .................................................................................................................. vii

Chapter 1 Introduction ..................................................................................................... 1
  The Problem, Rationale & Significance ......................................................................... 1
  Statement of Purpose and Research Question .............................................................. 3
  Clarification of Terms ...................................................................................................... 4
  Researcher Reflexivity Statement .................................................................................. 5

Chapter 2 Literature Review ............................................................................................ 7
  Client-centred Practice in Context ................................................................................ 7
  Problems with Client-centredness .................................................................................. 9
  Strategies to Assist Clinicians with Client-centred Practice ......................................... 11
  Patients as Teachers ...................................................................................................... 15
  The ‘Expert Patient’ and Patient-centred Care .............................................................. 16

Chapter 3 Method .......................................................................................................... 19
  Research Design ........................................................................................................... 19
  Ethics ............................................................................................................................. 21
  Sample .......................................................................................................................... 21
  Recruitment .................................................................................................................. 22
  ‘Expert Patients’ ............................................................................................................ 23
  Final sample .................................................................................................................. 24
  Data Collection ............................................................................................................. 25
  Student Notation Sheet ................................................................................................. 25
  Interviews ...................................................................................................................... 25
  Data recording procedures ........................................................................................... 25
  Data Analysis ............................................................................................................... 28
  Trustworthiness ............................................................................................................ 30

Chapter 4 Findings ......................................................................................................... 32
  Part One: Students’ Experience of ‘Expert Patient’ (‘XP’) Interactions ......................... 32
    1. Admiration ............................................................................................................... 32
    2. Discomfort .............................................................................................................. 34
    3. Humility & Gratefulness ......................................................................................... 36
  Part Two: Students’ Learning Regarding Client-centered Practice (CCP) ....................... 39
    1. Respect autonomy .................................................................................................... 40
    2. Collaborate ............................................................................................................ 41
    3. Recognize expertise. .............................................................................................. 42
  Part Three: How the ‘Expert Patient’ (‘XP’) Experience Led to Learning Client-centered Practice (CCP) ................................................................. 43
    1. Condition of the ‘client’: ‘expert patients’ rather than patients. ............................ 44
    2. Condition of the student: experience of power ....................................................... 48
    3. Condition of setting: directed reflection and discussion ........................................ 50
  Summary ....................................................................................................................... 53
Chapter 5 Discussion

Summary of Findings

Interpretation

Implications For Research

Implications for Educators

Implications for Clinicians

Limitations

Conclusion

References

Appendix A: Research Ethics Board Approval

Appendix B: Letter of Information/Consent

Appendix C: Student Notation Sheet

Appendix D: Sample Text Horizontalization: Units of Relevant Meaning

Appendix E: Sample Themes Draft

Appendix F: Statement of OT Values and Beliefs
List of Tables

Table 1: Interview Guide........................................................................................................27
Table 2: Steps to Data Explication.........................................................................................29
Table 3: Key Findings...........................................................................................................57
List of Figures

Figure 1: A Foundation for Student Experience and Learning........................................54
“Learning which builds capability demands that individuals engage uncertain and unfamiliar contexts in a meaningful way” (Fraser & Greenhalgh, 2001).

Chapter 1 Introduction

Client-centred practice (CCP) has been woven into the fabric of occupational therapy (OT) in Canada since 1983 (CAOT, 2002). Law, Baptiste, and Mills (1995) described client-centered occupational therapy as “an approach to service which embraces a philosophy of respect for, and partnership with, people receiving services” (p. 253). This longstanding value, cherished by the OT profession, has recently been added by the Canadian Medical Association (CMA) as one of seven core principles included in the updated Canada Health Act. “All health care must be patient-centred” (CMA, 2010, p. iv). The Lancet’s global independent Commission of the Education of Health Professionals for the 21st Century (Frenk et al., 2010), recently concluded that “all health professionals in all countries should be educated to mobilize knowledge and to engage in critical reasoning and ethical conduct so that they are competent to participate in patient and population-centred health systems . . .” (cited in Horton, 2010, p. 1875). But there is a gap between what is recommended for all patients and what health professionals deliver. “The present content, organization, and delivery of health professionals’ education have failed to serve the needs and interests of patients . . .” (Horton, 2010, p. 1875).

The Problem, Rationale & Significance

While patient-centred care has been lauded as the gold standard in Canadian health care, problems prevail with its practice. Among occupational therapists, problems with client-centred practice have been identified at the level of the client, the system and the therapist (Law, Baptiste, Mills, 1995; Sumision & Smyth, 2000; Townsend, 1998; Wilkins et al., 2001). There is discussion, but research on this topic and on therapists’ experience is limited (Mortensen & Dyck,
2006; Bright et al., 2012). In order to be practiced, client-centred care must first be learned. There is no consensus in the literature regarding how this is accomplished (Bright et al., 2012).

Literature reviewed from medicine, nursing, and rehabilitation cites the utilization of ‘expert patients’ (persons with stable, chronic conditions who act as educational resources in health professional education) as valuable sources for learning patient-centred care (Barr et al., 2010; Ottewill et al., 2006; Spencer, 2010; Stacy & Spencer, 1999; Thompson, 2007; Towle et al., 2010; Wykurz & Kelly, 2002). Farrell, Towle and Godolphin, (2006) note, “The authentic and autonomous patient’s voice promotes the learning of patient-centred care” (p. 5). But little is known about how patients are being involved in health care education, [and] the effect on learning and practice (Ottewill et al., 2006; Repper & Breeze, 2007). While evidence-based practice supports the use of a client-centred approach (Sumson & Law, 2006), and literature suggests ‘expert patients’ promote learning patient-centred care, it is unclear if or how this might occur.

The utilization of the ‘expert patient’ (‘XP’) is not yet informed by theory nor supported by valid, rigorous research or investigation of behavioral outcomes: “We know too little of how to do it and how to optimize its impact . . .” (Towle et al., 2010, p. 72). More developed qualitative research methods are required (Towle et al.). “Every health care profession espouses the rubric of patient-centred care, but in order to move beyond the rhetoric . . . the autonomous and authentic patient’s voice must be a core part of the training of all health professionals” (Towle et al., pp. 72-73).

As health care in the Western world increasingly focuses on patients’ choices and professional bodies recommend consumer involvement in health education and research, active patient involvement in health professional education is increasingly prevalent. The ‘expert
patient’ is used in the education of OT students as well as other health professionals in training, yet we are not aware of what the students’ experience of the ‘expert patient’ is, whether the students’ descriptions of their experience of their interactions with ‘expert patients’ reveal any relationship to learning regarding client-centred practice, and under what conditions such learning took place. Here, “experience is considered to be an individual’s perceptions of his or her presence in the world at the moment when things, truths, or values are constituted” (Morse & Richards, 2002, p. 44).

**Statement of Purpose and Research Question**

This study described the experience of the OT students /‘expert patient’ interaction and identified the potential contribution of that experience to student therapists’ learning regarding client-centred practice. The research question was: How does the students’ experience of interacting with the ‘expert patient’ (‘XP’) relate to learning regarding client-centred practice (CCP)? The specific research objectives were:

1. Describe the students’ experience of interacting with the ‘expert patient’.
2. Describe the students’ learning regarding client-centred practice.
3. Identify the conditions particular to the ‘expert patient’ experience that led to learning regarding client-centred practice.

The research addressed health care professional educators, health care students, and health care professionals. The researcher believed that insights generated through this study could lead to making explicit the previously implicit concepts regarding learning client-centred practice apprehended in the process of student interaction with ‘expert patients’, thus further informing evidence-based practice regarding the utilization of the ‘expert patient’ in health professional education. In addition to stimulating dialogue and increasing understanding, the
researcher believed that this study might fill a void in the existing literature regarding the use of
the ‘expert patient’ as a facilitator of patient-centred care.

Findings from this research illuminated the role the ‘expert patient’ experience plays in
health care professional education and revealed an opportunity for the potentially formative and
transformative impact of the use of the ‘expert patient’ in learning regarding patient-centred care.
Findings were used to further discuss the role of the ‘expert patient’ interaction in the adoption of
therapists’ attitudes related to client-centred care and the role of the ‘expert patient’ in the
operationalization of client-centred care. Implications of the research impact all stakeholders in
health professional education. Enhanced understanding of the impact of ‘expert patient’
utilization with health professional students informs best practice – educational and clinical.

Clarification of Terms

The terms ‘client’ and ‘patient’ have been used synonymously. Those receiving care in
Canada’s health care system are generally referred to as ‘patients’ from within the system. The
word ‘patient’ is derived from the Latin *patiens* “to endure, bear or suffer” (Chochinov, 2007, p.
184). Those accessing occupational therapy services are referred to as ‘clients’ from within the
profession based on a citizenship model emphasizing agency, autonomy and self-authority
(CAOT, 2007). Controversy surrounds the choice of terminology, as many variables dictate
whether ‘patient’ or ‘client’ or a host of other terms is appropriate. Sometimes neither or both are
required: “When people become patients they want to be seen in both their agency and
vulnerability and feel unmet by interactions that emphasize one or the other” (Todres et al., 2009,
p. 266). The word ‘patient’ is used in the literature as the single most widely understood term
and is meant to encompass ‘client’, ‘consumer’, ‘service user’, ‘survivor’, etc., as preferred in
various contexts and health care disciplines (Farrell et al., 2006). Although controversial, since
no single alternative is more accepted than the term ‘patient’ (Towle et al., 2010), the term ‘patient’ was used unless the context was exclusively occupational therapy. In the OT context the word ‘client’ was used.

**Researcher Reflexivity Statement**

The researcher is a Registered Occupational Therapist and a candidate in the Masters of Science, Rehabilitation Science program at Queen’s University, Kingston, Ontario, Canada with a 25-year interest in the concept and practice of patient-centred care and health professional education. Significantly enhanced by the experience of ‘expert patients’ and their families at the Hospital for Sick Children, Toronto, Ontario; the Victoria General Hospital, Halifax, Nova Scotia; Jirapa Hospital, Ghana, West Africa and from experiences of the people of Costa Rica, Nicaragua, Guatemala, and North America, the researcher is humbled by and values opportunities to learn. With limited formal research experience, the researcher shared the learner role alongside the participants.

The entry point for the development of the research question itself was based in the researcher’s lived experience as an occupational therapist/masters student/teaching assistant witnessing first year OT students interacting with ‘expert patients’ as part of their course curriculum. Upon recently reentering the profession after a lengthy absence, the researcher was surprised to learn of the persistent therapist-related difficulties with client-centred care, a valued practice since the researcher’s first entry into the profession. The researcher posed a question that might reveal more about the students’ experience while interacting with the ‘expert patient’ and its potential relationship to their learning to become client-centred practitioners. Witnessing and learning about the ‘expert patient’ experience from the students’ perspective, particularly subsequent to reading that the ‘expert patient’ model utilized in health professional education
was promoted in literature as fostering-patient centred care, became the researcher’s interest and the focus of this study.

While the participants and the researcher were all Masters students, the considerable difference in age and experience between the researcher and participants could be seen as a factor affecting the openness of the participants in the study. The researcher’s prior experience and professional practice as an occupational therapist could have placed the students in a position of inferiority. It was made explicit at the outset of the interviews that the researcher was in a position of listening and learning (by phenomenological design) rather than teaching.

The researcher remained committed to reflexive practice throughout the study. As a novice interviewer, experience taught that less (talk from the researcher) is more. There was an inherent trust in the understanding that the outcome of the undertaking was uncertain, and that what was to be revealed was dependent on an ability to let the results of the approach and the things themselves be my guide. In the process of further collecting data, employing techniques of naturalistic observation and while initiating data analysis, the lived experience of simultaneously being producer and product continued.

Exploring OT students’ experience of interacting with the ‘expert patient’ attended to an affective aspect of health professional education previously unstudied. While the researcher role as key research instrument (data gatherer, observer, interviewer, explicator) was recognized, the primary focus of the researcher was on learning the participants’ meanings rather than the meaning that the researcher brought to the research (Creswell, 2007). It was in the dichotomous spirit of focused discipline and openness to discovery that the research process was engaged.
“A mature culture will settle on sharing power and responsibility . . . this is the culture which we should work towards -- helping each other as we go” (Kennedy, 2003, p. 1277).

Chapter 2 Literature Review

Client-centred Practice in Context

Long before patient-centred care became an agenda in the evolving biomedical model, occupational therapists maintained beliefs about the person and about client-centred practice among their core values. Canada’s first national practice guidelines, developed in 1983 (DNHW & CAOT, 1983; CAOT, 2002) described occupational therapy as client-centred, based on the work of clinical psychologist, Carl Rogers:

*It is the client who knows what hurts, what directions to go, what problems are crucial . . . It began to occur to me that unless I had a need to demonstrate my own cleverness and learning, I would do better to rely upon the client for the direction of movement in the process* (Rogers, 1961, pp. 11 – 12).

Rogers described a practice focused on assisting individuals to find solutions to problems in a nondirective manner, placing great importance on the therapist’s authenticity, congruence and transparency (Lietaer, 1993). The therapist’s being his/herself with clearly defined boundaries and egoic structures is instrumental in the client’s ability to find the same for themselves (Rogers, 1965). Of primary importance to Rogers was the attitude of the therapist toward the worth and significance of the individual:

*Do we tend to treat individuals as persons of worth, or do we subtly devalue them by our attitudes and behavior? Do we respect his capacity and his right to self-direction, or do we basically believe that his life would be best guided by us? . . . by use of client-centred techniques a person can implement his respect for others only so far as that respect is an integral part of his personality make-up.* (Rogers, 1965, pp. 20 – 22).
Rogers’ ‘core conditions’ (1951) -- acceptance, genuineness, and empathy -- form the base occupational therapy values and beliefs regarding client-centred practice.

Client-centred practice in occupational therapy is contextually framed by the clinician, the client and the environments in which they interact (CAOT, 1997). Client-centred practice in occupational therapy includes “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” (CAOT, 1997a, 2002, p. 49, 180, cited in CAOT, 2007, p.113). Respect for each person’s choices about life, recognition of each person’s right to self-determination, belief that clients are experts regarding their own occupations, and commitment that clients must be active partners in the occupational therapy process, are among occupational therapy’s core values regarding client-centred practice (CAOT 2002, 2007).

Five distinct dimensions to patient-centred care in medicine have been identified: adopting a biopsychosocial perspective (as opposed to a perspective that is narrowly biomedical); understanding the patient as a person in her or her own right, not merely a body with an illness; sharing power and responsibility between the doctor and the patient; building a therapeutic alliance; understanding the doctor as a person, not merely as a skilled technician (Mead & Bower, 2000). Yet Mead and Bower also state there is uncertainty in how best to operationalize and balance these dimensions (Duggan et al., 2006). Persistent problems and critiques of the model exist.
Problems with Client-centredness

Critiques regarding the dehumanizing aspects of contemporary medicine focus “on the displacement of the person of the patient” in an “impersonal, over-pressured health care system” (Parsons & Hooker, 2010, p. 345). And “biomedicine has brought extreme specialization and an ensuing fragmentation of services, rigid compartmentalization, and uncontrolled commoditization of the health care field resulting in neglect of patients’ particular needs and concerns …” (Mezzich et al., 2010, p. 702). Despite the World Health Organization’s long established broad definition of health as a complete state of physical, emotional and social well-being, and not merely the absence of disease (WHO, 2000), modern medicine has become disease focused.

Among occupational therapists, problems with client-centred practice exist within each of the contexts that frame the practice. Problems have been identified at the level of the client, the system and the therapist (Law, Baptiste, Mills, 1995; Sumasions & Smyth, 2000; Townsend, 1998; Wilkins et al., 2001).

At the level of the client, barriers to client-centered practice can consist of concerns related to social environment, family, level of education, culture or cognitive ability (Sumasions, 2005; Wilkins et al., 2001). An inability or unwillingness on the part of the client to participate in a partnership with the therapist was cited in Wilkins et al. (2001) as a barrier to client-centred practice. When there was a concern related to clients with cognitive problems, poor insight into their problems, language barriers or depression, often the family members became the primary client of the occupational therapist. Participants in research conducted by Wilkins et al., described the ideal client that would benefit from client-centred practice as “one who is cognitively intact, insightful with good problem solving skills.” And goes on to state “the
majority of clients who need occupational therapy do not have these characteristics” (Wilkins et al., 2001, p. 77). Some of the same participants believed their older adult clients were reluctant to admit they had ‘problems’ to the occupational therapist as they feared losing their independence. Some clients may prefer the therapist as ‘expert’. Client expectations based on prior experience were cited as a barrier to client-centred relationship (Wilkins et al.).

Many institutional systems do not support client-centred practice (Duggan, 2005; Wilkins et al., 2001; Townsend, 1998; Mortenson & Dyck, 2006). Practices and processes within systems may serve to disempower clients. Without the support of the team or the organization, client-centredness is difficult to implement in practice. “Talking the talk’ is easier than ‘walking the walk” (Wilkins, p. 106). Time pressures and resource constraints, approaches used by other team members, philosophies and policies of the organization were reported as significant barriers preventing the implementation of client-centred practice (Wilkins, 2001). Many institutional processes disempower clients (Townsend, 1998). Duggan (2005) related lack of congruence between reality and the ideal of client-centred practice suggesting client-centred practice may have been unrealistic within the health care system at the time.

Mortenson and Dyck (2006) noted that the power sharing in client-centered practice may be incongruent with the way the health care system is currently organized. Within the biomedical model, the health care professional has the power (authority, knowledge). The imbalance of power prevents partnerships based on mutual cooperation and acceptance (Kieffel, 1991 cited in Sumsion & Smyth, 2000). “For client-centered practice to be effective, therapists have to hand the power to their clients, and allow them to shape the intervention” (Sumsion, 1997 cited in Sumsion & Smyth, 2000, p. 19).
Among the reported barriers to client-centred practice at the level within the therapist, some therapists struggle with truly accepting client goals, trusting client judgment, sharing power and with recognizing client expertise (CAOT, 2007; Mortensen & Dyck, 2006; Sumsion & Smyth, 2006; Sumsion, 2000; Wilkins et al., 2001). Therapist and client may have different goals for intervention (Clark, Scott & Krupa, 1993; Sumsion & Smyth, 2000). Clinician barriers include perception of client safety, clinician confidence and clinician values (Sumsion, 1999). Sumsion and Smyth (2000) identified the top three barriers to client-centred practice (as perceived by occupational therapists) were related to goals and goal setting: “The therapist and client have different goals”, “the therapist’s values and beliefs prevent them from accepting client’s goals”, and “the therapist is uncomfortable letting the client choose their own goals” (p. 19).

Client-centred practice requires a shift in professional identity “from the role of advisor to that of partner and facilitator with expertise” (Rochon & Baptiste, 1998, p. 146). The traditional or paternalistic method of providing service would shift to service provision that emphasizes equality, sharing and partnership. Recognition of the existing power differential between clients and therapists and advancement of changes toward collaborative engagements are required at the level of the client, the level of the institution, and at the level of the therapist (Wilkins et al., 2001).

**Strategies to Assist Clinicians with Client-centred Practice**

Researchers have considered conditions in which therapists are more favorable to the implementation of client-centred practice. Various tools aimed at the facilitation of client-centred practice are available for the clinician including: the Canadian Occupational Performance Measure (Law et al., 1990; Law et al., 2005), the Canadian Practice Process Framework (CAOT,
2007), the Client-centred Strategies Framework (Restall et al., 2003; Restall & Ripat, 2008), supportive mentors (Duggan, 2005; Restall et al., 2003; Sumson, 2005), and settings (Restall & Ripat, 2008), case examples (Sumson & Smyth, 2000; CAOT, 2002, 2007; Law, 1998) and therapist reflection (Rochon & Baptiste, 1998; Duggan, 2005).

Law et al. (2005) and McColl (2006) have shown that occupational therapists more readily embrace client-centred practice when they use the Canadian Occupational Performance Measure (COPM), a recognized assessment/evaluation tool. Clinicians indicated that their priorities are often different from client priorities, and suggested that there is value in using the COPM to know the client's perspective (Law et al., 1990). Colquhoun et al. (2012) found a statistically significant and clinically important improvement in practice with administration of the COPM noting a “statistically significant practice improvement (p < .0001) across the eight dimensions, including knowledge of client perspective . . .” (pp. 125-126). Clinicians perceive that the COPM results in identifying more realistic and client-centred goals (Chen et al., 2002), as well as an increase in knowledge of client perception of improvement and the degree to which care is focused on occupation (Colquhoun et al., 2012). However, Mortenson and Dyck (2006) and Chen, Roger and Polatjako (2002) noted the lack of its use in preference to institutionally developed assessments.

The Canadian Practice Process Framework (CPPF) provides a framework to guide client-centred, evidence-based and occupation-based practice. Stages of therapist/client interaction incorporate client participation and power sharing throughout the process (CAOT, 2007).

The Client-centred Strategies Framework (CSF) was proposed as a tool to assist therapists in overcoming barriers to client-centred practice (Restall, Ripat & Stern, 2003; Restall & Ripat, 2008). Five categories (personal reflection, client-centred processes, practice settings,
community organizing, and coalition advocacy and political action) are outlined with practice enhancing strategies presented. Therapists felt comfortable implementing client-centred strategies at the level of personal reflection and client-centred processes. While the CSF is a useful tool for expanding perspectives on client-centredness, strong leadership is required to integrate an expanded view of client-centred practice at the settings, systems and policies level (Restall & Ripat, 2008).

Duggan (2005), Restall and associates (2003) and Sumsion (2005), asserted that occupational therapists embrace client-centred practice when there is a facilitator who will assist therapists in dealing with the challenges of being truly client-centred (CAOT, 2007). National support for client-centred practice included the CAOT commitment to respect client views, experience, and interests; safety was emphasized, as were the “rights of clients to live with risk and to make choices that may differ from the suggestions of professionals. Occupational therapists are strongly encouraged to collaborate in all processes with clients, and to openly make arrangements for client choice, risk and responsibility” (CAOT, 2007, pp. 100-101).

Case examples describing client-centred practice were perceived by therapists surveyed by Sumsion and Smyth (2000) as the most effective way to resolve therapist-related barriers to client-centred practice. Case examples were outlined in the COPM (Law et al., 2005) and in CAOT publications (2002, 2007).

Duggan’s action research (2005) suggested personal reflection on professional identity as it relates to client-centred practice as a means to foster client-centred practice. New learning regarding client-centred practice was reported following group reflective education sessions with a small group of participants. Rochon and Baptiste (1998) suggested the cultivation of an awareness of potential conflict of interest between therapist and client related to values, duties,
rights, principles, needs or “chosen life course” (p. 146). This awareness is cultivated through personal reflection including the clarification of one’s values and development of ethical principals to reference “... in times of crisis and self-doubt” (p. 146). Ideas as such regarding the use of reflection as a means of guiding self-knowledge are consistent with education toward emancipation and transformation (Freire, 1970; Schön, 1987; Mezirow, 2009; Cranton, 2006).

Sumsion & Law (2006) reviewed the literature from 1990 - 2005 regarding conceptual elements informing client-centred practice and their influence on practice. Emerging from the review was “the overarching theme of power” as well as “underpinning themes of listening and communicating, partnership, choice, and hope” (Sumsion & Law, 2006, p. 153). A reference tool was provided with questions related to each of these themes for occupational therapists to consider regarding client-centred practice. Suggestions were offered to improve knowledge transfer within health care. The authors acknowledged that in Rogers’ theory of diffusion of innovations, early adopters and the early majority are the keys to moving knowledge and information into practice (Rogers, 2003). Early adopters actively seek new knowledge and are eager to implement ideas perceived by them to be beneficial. The early majority display readiness to implement new information.

Tools exist for clinicians yet client-centred practice is still problematic. Sumsion and Law (2006) found those who did implement client-centred concepts in the past 20 years were likely those occupational therapists who were early adopters or part of the early majority. Occupational therapy students are representative of those likely to be early adopters and the early majority. How OT values regarding client-centred practice are learned and the possible impact of the innovation of the ‘expert patient’ on the learning of these values is the focus of this research.
Patients as Teachers

Most university-based health professional education programs include some form of contact with the patients who will eventually receive their care. In 1904, William Osler, a founding father of medical education stated, “It is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself” (cited in Towle & Godolphin, 2011, p. 496). Towle and associates assert, “The autonomous and authentic patient’s voice must be a core part of the training of all health professionals” (Towle et al., 2010. p. 73). Yet Towle and Godolphin (2011) noted that “the nature, duration, and even purpose of active patient involvement in education are enormously variable form program and country to country” (p. 496). Diverse active roles for patients in health professional education have emerged. Repper and Breeze (2007) noted, “Health policy requires consumer involvement in services, research, and education but little is known about how consumers are being involved in health care education, the effect on learning and practice, and how involvement in these initiatives are being evaluated” (p. 511). Jha et al.’s systematic review recognized that patients as teachers may enhance student experience in the short term, but concluded that research on the topic is limited as is evidence of long-term effectiveness. They stated, “The lack of evidence of any long-term benefits seriously limits any recommendations that can be made to medical educationalists trying to incorporate patient involvement into their curricula” (Jha et al., 2009, p. 18).

‘Expert patient’ (Shaw & Baker, 2004), ‘patient partners’ (Barr et al., 2010) and ‘expert patient-led approach’ (Ottewill et al., 2006) are terms used in the literature to describe similar types of patient involvement in health professional education. The recognition of patient expertise is common among the types of patient involvement described. “There is growing appreciation that the patient is as much an expert as the professional, particularly with regard to
the management of their condition on a day-to-day basis” (Ottewill et al., 2006). Wykurz & Kelly (2002) reviewed the literature from 1970 – 2001 regarding program descriptions, evaluations or research involving patients as teachers in medical education. Among their conclusions for learners is that involving patients as teachers in health professional education influences attitudes and behaviour, increases respect for patients and generates new insights.

**The ‘Expert Patient’ and Patient-centred Care**

While there is no consensus in the literature regarding how patients are best utilized in health professional education nor regarding how patient-centred care is learned, literature from medicine, nursing, and rehabilitation cite the experience and expertise of persons with stable chronic conditions (also known as ‘expert patients’) as a valuable resource for learning patient-centred care in health professional education. ‘Facilitation of patient-centred care’ is cited in the literature as one of the benefits of the utilization of the ‘expert patient’ in the education of health professionals (Barr et al., 2010; Magasi & Heinmann, 2009; Ottewill et al., 2006; Spencer, 2010; Stacy & Spencer, 1999; Thompson, 2006; Wykurz & Kelly, 2006). “Students remember what they hear from patients. The authentic and autonomous patient’s voice promotes the learning of patient-centered care” (Farrell et al., 2006).

Stacy and Spencer (1999) identified the following teaching roles involving patients: patients as ‘experts’ in their condition, as exemplars of their condition, and as facilitators of the development of professional skills and attitudes. Health professionals have observed that the expertise and experience of people with chronic conditions [‘expert patients’] is an untapped resource (Morgan & Jones, 2009; Ottewill et al., 2006; Rapport et al., 2010; Spencer, 2010; Towle et al., 2010; Wykurz & Kelly, 2002). The ‘expert patient’ approach to learning and teaching “reflects the view that expert patients are well placed to contribute to the education of
healthcare professionals and inject unique insights into the learning encounter” (Ottewill et al., 2006, p. e120). “The lived experience of disease (chronic illness or disability) is unique experiential knowledge not possessed by health professional educators” (Towle & Godolphin, 2011, p. 497). ‘Dry book learning’ was contrasted with ‘powerful’, ‘memorable’, ‘inspirational’ learning from patients that helped students put academic learning in context (Rees et al., 2007). Towle and Godolphin (2011) suggested one of the aims of such initiatives is to “shape attitudes and values” (p. 497).

“Although the educational experiment has yet to be done, there is at least a theoretical link between patient involvement in education, patient involvement in care, and improved health outcomes. However, patient-centred care is still typically framed as a set of virtues learned from professionals as role models, reinforced through structured educational input from medical educators and, paradoxically, not from patients (Bleakley & Bligh, 2008). The concept of learning with rather than about patients is only just beginning to be articulated” (in Towle & Godolphin, 2011, p. 498).

Towle and Godolphin (2011) asked how experiential knowledge of the patient might best be incorporated into a system in which the health professional is seen as expert and stated that the use of patients as educators challenges the nature of expertise and power. While involving persons with stable diagnoses [‘expert patients’] as partners in health professional education claims to foster patient-centred care, it is unclear how or if this occurs as the practice is not yet informed by theory nor supported by valid, rigorous methodology in research (Towle et al., 2010). Hence the research question: “How does the students’ experience of ‘expert patient’ (‘XP’) relate to learning regarding client-centred practice (CCP)?” And the specific objectives:

1. Describe the students’ experience of interacting with the ‘expert patient’.
2. Describe the students’ learning of regarding client-centred practice.
3. Identify the conditions particular to the ‘expert patient’ experience that led to learning regarding client-centred practice.

The ‘expert patients’ referred to this research are volunteers with stable chronic diagnoses who receive training or support for their role in contributing to the education of health care professionals. Queen’s University Faculty of Health Science students have the opportunity to learn with such ‘expert patients’ in the Clinical Education Centre’s (CEC) Volunteer Patient program. As part of their first year OT curriculum (OT 844 Cognitive Neurological Determinants) students are instructed to implement standardized and functional assessments with the ‘expert patients’ and to submit documentation of subjective and objective assessments and analysis for evaluation (SOAP notes). The students’ evolving competence may be evidenced through the videotaped sessions (psychomotor domain skills), and their SOAP notes (cognitive domain skills). However, the inner experience of the students (an aspect of the affective domain) and its potential contribution to learning regarding client-centred practice remains unknown.

In this study, consideration was given to: the students’ attention to that which they brought to the interaction with the ‘expert patient’, their preconceptions/assumptions, personal biases, values, beliefs and their attention to that which they received in the process of interacting with the ‘expert patient’, and their arising feelings and thoughts in the midst of the interactions and upon reflection. The students’ learning regarding client-centred practice was described. The unique conditions that gave rise to the students’ experience of the ‘expert patient’ and their learning regarding client-centred practice were presented. The thesis allowed unique insight into the lived experience of occupational therapy students learning with and from rather than about ‘expert patients’.
“Like Orpheus, the writer must enter the dark, the space of the text, in the hope of seeing what
cannot really be seen, hearing what cannot really be heard, touching what cannot really be
touched. Darkness is the method” (van Manen, 2006, p. 719).

Chapter 3 Method

Research Design

The research design was informed by the nature of the question, worldview assumptions, and specific methods of data collection, analysis and presentation. Also considered was the researcher’s role and the audience for the study (Creswell, 2009). The research question has been situated within the qualitative research paradigm according to the following rationale:

- The question probes *how* a shared experience is given meaning and is descriptive and exploratory in nature.
- An in-depth study of a particular experience *shared* among OT students is the focus, with quality or depth emphasized rather than quantity, amount, intensity, or frequency.
- The response sought is an understanding of a *real life experience*, situated in the moment and taking place in a ‘real-life’ or ‘natural’ setting rather than in a laboratory. Depth, meanings, feelings, significance, values and understandings are sought from the in-depth exploration of *lived experience*. Just as the question is open-ended, the products of qualitative inquiry are emergent, open-ended, richly descriptive, inductive, contextual and evolving (Taylor & Bogden, 1998; Creswell, 2007, 2009; Denzin & Lincoln, 2003).

The research question proposed an inquiry into the lived experience of OT students’ interactions with ‘expert patients’. Qualitative researchers believe that the best way to understand any phenomenon is to view it in its context (Taylor & Bogden, 1998). The participants in this research were interviewed in the Clinical Education Centre (CEC), the same setting in which
they interacted with the ‘expert patient’, and as soon after their experience as possible so as to assist them in their ability to recall and relate the depth of meaning their ‘expert patient’ interactions evoked. As phenomenological study seeks to explore the realm of lived experience (van Manen, 2006; Moustakas, 1994; Patton, 2002; Creswell, 2007), the research tradition, phenomenology, was utilized. Both a philosophy and a research tradition, phenomenology is the study of phenomena: their nature and their meanings. The focus is on the way things appear to us through experience (Finlay, 2008). The German/Czech mathematician/philosopher, Edmund Husserl (1859 – 1938), developed phenomenology with the aim to discover a foundation for all knowledge. Husserl’s inquiry emphasizes a return to the lived world, \textit{(Lebenswelt)}, the world of experience, a return to the things themselves (Cahoone, 2010; Finlay, 2008). Husserl’s mantra ‘back to the things themselves’ more specifically refers ‘back to the experience itself’, back to the basic intuitions, and back to the essential structures of those intuitions (Cahoone, 2010). It has been said that meaning is at the heart of Husserl’s phenomenology (Smith, 2007).

Since this study proposed to explore the inner experience of students and the possible relationship of the interaction with the ‘expert patient’ to the students’ learning regarding OT values, Husserl’s complex and carefully crafted return to the primary process of lived experience was fitting. The methodology has established clarity and rigor and emphasizes the provision of a rich, textured description of \textit{experience as lived} (Husserl, 1936/1970). Included were the four existentials that guide phenomenological reflection: temporality, spatiality, corporeality, and relationality (Finlay, 1999): the students’ experience of themselves, embodied, in time and space and in the midst of relating to the ‘expert patient’. Phenomenological methodology is discovery orientated, responsive to phenomena and requires that the researcher continually engage in reflexive analysis to evaluate how his/her own subjective and intersubjective elements impact the
research. Merleau-Ponty refers to the method as an attitude... an attentive awareness to the things of the world as we live them rather than as we conceptualize or theorize them (Merleau-Ponty, 1962).

**Ethics**

Queen’s University Faculty of Health Sciences Research Ethics Board (FHSREB) granted approval of the study (Appendix A). A Letter of Information and Consent (Appendix B) was circulated among the first year OT class. Participants read the letter of information before the onset of the first interview and signed their consent in the presence of a witness. Contact information of the researcher, supervisor and Ethics Review Board Chair was provided in writing for each of the participants.

**Sample**

The sample consisted of three first year Queen’s University occupational therapy students roughly half-way through their program, who were immersed in the theory and practice of OT values regarding client-centred practice, and had interacted with ‘expert patients’ in the Clinical Education Centre (CEC) component of their course curriculum. As the researcher’s epistemological position includes the belief that the data are contained within the perspectives of the students, it is with them that the researcher engaged in collecting data (Groenveld, 2004, p. 7).

All three participants in the study, Jac, Sophie, and PJ, (pseudonyms) were between twenty-five and thirty years of age. All three participants worked for one to three years in counseling types of employment after completing their undergraduate degrees and before entering the Master of Science (Occupational Therapy), MSc(OT) program at Queen's University. This demographic is typical of the students enrolled in this program and therefore is not indicative of self-selection bias.
Purposeful sampling with the plan to conduct in-depth interviews was the strategy of choice. Giorgi (2008a) recommended recruiting at least three participants so that the individual experience may be discerned from the more general experience of the phenomenon. In this way, sufficient variations were ensured in order to come up with “a typical essence” (Giorgi, p. 37). The number of students the researcher hoped to gather data from was three to five (Paterson, 2010). Schwandt (2007) advises that in sampling based on the purposive strategy the “sample is chosen not for their representativeness, but for their relevance to the research question . . . the ideal sample size is simply not quantifiable” and depends entirely on the nature of the study and the research questions investigated (pp. 269-270).

Recruitment.

The process of recruitment was as follows: With the permission of the course coordinator, the researcher introduced the study to the sixty-six first year occupational therapy students in the final class in Cognitive-Neurological Determinants of Occupation (OT 844) before the CEC sessions commenced. The researcher announced that study participants would be sought for one-to-one, in-depth interviews following the CEC sessions. Letters of Information/Consent (Appendix B) were circulated throughout the class. At the end of the three weeks of CEC sessions, the researcher once again approached the class at the end of a class session and circulated a sign-up sheet for voluntary participation in the study. Twelve students from the class signed up to be interviewed for the study. Those twelve students were sent a group email (with addresses blocked) requesting that they contact the researcher within seven days to arrange to sign consent forms and schedule the first interview. Half of the students, (6/12), responded within the stipulated time frame. Six first year occupational therapy students enrolled in the
second term of the MSc (OT) program at Queen’s University comprised the initial sample.

Students eligible to participate in the study were required to meet the following criteria:

1. They were enrolled in their first year of the Masters of Science Occupational Therapy program.

2. They were, at the time of recruitment, taking Cognitive-Neurological Determinants of Occupation Part I which includes a Clinical Education Centre component involving their direct interaction with a volunteer ‘expert patient’.

3. They were not being evaluated in any capacity by the researcher.

4. They had completed three supervised sessions with their volunteer over a 3-4 week period.

5. They had successfully completed all academic work and clinical placements from the previous term.

6. They agreed to commit the 2.5-4 hours minimum required for interviews and member checking.

Exclusion criteria:

1. Students who met inclusion criteria and subsequently discover a prior relationship with the assigned ‘expert patient’ (they met this person in a previous context).

2. Students who do not complete at least two in-depth interviews with the researcher.

3. Students who do not participate in member checking.

‘Expert Patients’.

Each of the ‘expert patients’ (‘XP’s), volunteers at Queen’s University Clinical Education Centre (CEC), was an adult with a stable neurological condition who was not currently involved in treatment or in a rehabilitation program. The students each met their ‘XP’ for three sessions
over a three-week period. In the first session the students completed a standardized assessment of postural control and mobility; in the second session the students’ task was to complete a standardized cognitive-neurological assessment; and in the third session the students completed an assessment of their choosing (a standardized assessment or a functional assessment). Coincidentally, each of the students comprising the final study sample had been assigned a different ‘expert patient’. Therefore the study described the experience of three unique participants interacting with three unique ‘expert patients’.

**Final sample.**

Half of the students, (3/6), did not meet the data collection requirements stipulated in the exclusion criterion and were therefore not included. The interview guide was refined and streamlined by conducting pilot interviews with these three excluded participants. Therefore, the final sample comprised three students who met all of the inclusion criteria, did not present with any requirement for exclusion, gave consent and participated in the interview process. Three out of twelve groups of students were represented by these three students. This provided the ideal minimum number of participants for a study of this nature (Paterson, 2010).

This sample had characteristics of homogeneity as well as heterogeneity. It was homogenous in that the participants were a subgroup of Queen’s University OT students. They had all taken the same courses for the nine months prior to the study. They had been exposed to the same OT theory and applications. Heterogeneity was also present in the sample in that individuals differ with one another in their unique response to any experience. Their mode of skill acquisition, level of understanding, mechanisms of learning and integrating, and the affective impact of experience could similarly vary. The researcher was aware that both the detailed descriptions of uniqueness despite similarity, as well as any common themes emerging
from variation, are of significant value in capturing the core experience of the participants (Patton, 2002).

**Data Collection**

**Student Notation Sheet.**

During the CEC sessions involving the ‘expert patients’, all sixty-six OT students were given a Student Notation Sheet (Appendix C) for voluntarily recording their experience. This was to provide all students an opportunity to learn from their experience, not just those who would be interviewed as research participants. This Notation Sheet served as a memory aid for the preservation of the content arising in the students’ consciousness during the interactions with the ‘expert patient’. This information was utilized in the subsequent interviews for the students who participated in the research.

**Interviews.**

Data for the study were collected in a minimum of two sixty to ninety minute, face-to-face, semi-structured interviews with each of the participants. Follow-up communication was via email and/or informally in person. The interviews followed the interview guide (Table 1) posing open-ended questions, adapted to the vernacular of the participants (Kvale, 2009) to assist in facilitating the dynamic expression of the participant’s views while remaining true to the specific research objectives.

**Data recording procedures.**

The interviews were digitally recorded on the researcher’s computer using Audacity® Digital Audio Editor Software and converted to MP3 files. Simultaneously, a VHS recording was made. Access for recording, viewing and secure storage was facilitated by the Queen’s
University Clinical Education Centre team. The high-quality recording capabilities of the researcher’s laptop made for ease of use, and because it was a familiar object sitting amongst us visible to all, it was readily accommodated and eventually ignored. The interviews took place in the same assessment rooms where the participants had met with their ‘expert patient’, allowing for the temporal and spatial elements of the experience. The process for video recording of the interview session followed the format the participants had utilized when recording their sessions with their ‘expert patient’. Researcher memos were made throughout the process. Audio and video recordings as well as the memos informed interview transcription and analysis. Video recordings were supplementary, and provided clarification or reference in the event of audio recording failure. Approximately 9 hours of audio recorded data were transcribed verbatim. 4 pages of written reflection from the students in the form of the Student Notation Sheets (Appendix C), email correspondence and follow-up informal conversation were included in their data. Confidentiality and security of data were ensured by password protecting and encrypting hard drive information. All participant identifiers were excluded from written work. Hard copy files and video recordings were secured in a locked cabinet. Confidentiality of all participants’ data was maintained through the use of pseudonyms in the interview transcription.
Table 1: Interview Guide

Initial Interview
Begin interview with a brief reminder of the purpose of the study and how the gathered information will be used. Inform participants of confidentiality and of their right to refuse to answer any questions and/or withdraw from the study at any time.

Location: CEC Assessment Room Duration: 60–90 minutes

1. You have just interacted with your ‘expert patient’: what was the experience like for you? (Objective One)
2. Describe what went through your mind in the midst of the ‘XP’ interaction. (Objective One)
3. What might have surprised or challenged you in the interaction? (Objective One)
4. What might have bothered you in the interaction? What might have brought about uncomfortable feelings or thoughts? (Objective One)
5. The ‘expert patient’ volunteer presented themselves uniquely to you as they have a diagnosis and apparent limitations, yet they have no need of your professional expertise. How did that affect you? (Objective One)
6. What was the significance for you of the client having a diagnosis yet needing nothing of you/being there entirely for your own learning? (Objective Two)
7. What was the significance for you of the client being presented as an ‘expert’ in living their life? (Objective Three)
8. What about the experience might have made you think twice about what you have learned about OT values up until this point? (Objective Two)

Reminder: the reflective process can be uncomfortable, unsettling and/or inspiring. Assure a confidential, supportive environment to explore what arises. Allow for follow-up as necessary/wished.

Follow-up Interview

Location: CEC Assessment Room Duration: approximately 60 minutes

9. Describe what went through your mind upon reflection about your ‘expert patient’ experience in the day or days following the interaction. (Open)
10. Read CAOT OT Values and Beliefs Statement (Appendix D) regarding the person and client-centred practice. How has this experience affected your integration of OT values and beliefs? (Objective Two)
11. How might this experience prepare you for practice in ways different than your other interactions with clients? (Objective Three)
12. In what way is this way of learning unique? (Objective Three)
13. What possible application might this experience have for your future experiences with clients? (Open)
14. Is there anything about your experience that you would like to add? (Open)
Data Analysis

The initial data analysis was undertaken in three parts corresponding to the three specific research objectives. For Parts One and Three an adaptation of the methodology of Stevick-Colaizzi-Keen in Moustakas (1994), Finlay (1999), and Hycner (1985) was incorporated. For Part Two *a priori* values were sought in the data. Each step in the process of data explication was outlined (Table 2).

Initially transcriptions were stored and organized in NVivo9. While it is recognized that the researcher is the main tool for analysis (Denzin & Lincoln, 2005), NVivo9 allowed for organization, data storage and development of themes using free nodes and tree nodes. Categories and themes could be efficiently compared (Bazeley, 2010) through constant comparison analysis. The KWIC (Key Word in Context) function was also utilized (Leech & Onwuegbuzie, 2011). For the novice researcher, NVivo9 and similar computer assisted qualitative data analysis software (CAQDAS) are useful mechanisms for storing and organizing data (Morse & Richards, 2002). For a study of this size, following the steps for analysis using paper and pencil proved to be sufficiently effective.
Table 2: Steps to Data Explication

1. Researcher’s prior experience with ‘XP’ and CCP was reflexively considered with the aim of explicating the essential nature of the phenomenon (époché). This experience was bracketed for the purpose of hearing the participants’ experience as if the phenomenon had never been witnessed prior, gaining clarity by distancing oneself from one’s own preconceptions.

2. The époché, bracketing or phenomenological stance was adopted throughout the research, before during and after the interviews, demonstrating commitment to it remaining part of the “…ongoing process rather than a single fixed event” (Patton, 1990, p. 408).

3. Interview transcription was completed by researcher, verbatim (including uninterpreted, non-verbal communication noted from video recordings), and was considered part of analysis. Review of video recordings allowed immersion in the data and assisted in clarification of text transcription.

4. Interview data were listened to and read with openness to whatever meaning emerged; a process continually applied throughout data explication (phenomenological reduction).

From each of the participant’s interviews the following was derived:

5. General meaning statements in the transcript were highlighted (Horizonalization). These general meaning statements were equally valued (mundane reduction, irrespective of research question).

6. To respond to research objective Part One, transcripts were reviewed highlighting statements that emerged as particularly relevant to the student’s experience (feelings, thoughts arising in the midst of the interaction) with the ‘expert patient’. The researcher listened, read, and reread transcripts allowing the text to ‘speak’.

7. These relevant statements were clustered into themes, each containing a unique aspect of the experience deemed a necessary and sufficient constituent for understanding it.

8. All themes were synthesized into a composite description that included verbatim examples that revealed the most essential aspects of the students’ experience.

9. For Part Two, interpretative analysis was required as the data was reviewed for a priori content related to learning regarding Client-Centred Practice (CCP). Three a priori values (Respect for Autonomy, Collaborate, Recognize Expertise) were sought in the data.

10. Highlighted text from each transcription containing reference to the three a priori values were synthesized into a composite description that included verbatim examples that revealed the essential aspects of the students’ learning regarding client-centred practice.

11. For Part Three, the unique conditions that gave rise to the experience (Part One) in which the students were afforded learning about CCP (Part Two) were sought in the data. The students’ transcripts were reviewed and the conditions that led them to learn the three values were noted.

12. The conditions highlighted in each transcription were synthesized into a composite description that included verbatim examples that revealed the essential conditions giving rise to the students’ experience interacting with the ‘XP’ and their learning regarding CCP.

13. The results of Parts One, Two and Three were then viewed as a whole (eidetic reduction) and emergent learning regarding the overall experience was summarized.
Trustworthiness

Trustworthiness or rigor was enhanced by the adoption of a recognized approach, that being phenomenological inquiry. Detailed methods including a rigorous approach to data collection, explication and synthesis were employed. Rich, first-person description, and fidelity to the phenomenon enhanced validity and trustworthiness of the study. Member checking was utilized by reporting findings to the participants for their confirmation and approval. The quality of a phenomenological study can be judged on its relative power to draw the reader into that which was discovered, allowing the reader to see the experience of others in new and deeper ways (Finlay, 2008).

A small sample size facilitated the researcher’s close association with the participants and enhanced the validity of in-depth inquiry (McKenzie, 2006). The person of the researcher (Salner, 1989 cited in Kvale, 2009) including his or her moral integrity (Smith, 1990 cited in Kvale) and practical wisdom was critical in ensuring validity. As validation permeated the entire research process (Kvale) ‘quality control’ throughout the knowledge production in this study was maintained. The question posed, the purpose of the study, the phenomenological stance throughout the process, the in-depth interviews, the memos and reflections of the researcher all contributed to the methodological congruence of the study (Morse and Richards, 2002). “From an ethical perspective valid research design involves beneficence – producing knowledge beneficial for the human situation while minimizing harmful consequences” (Kvale, 2009. pp. 248-9). There was trustworthiness of the participant report and in the quality of the interviewing. Careful attention was given to the meaning of what was said and “... a continual checking of the information obtained as a validation in situ” (Kvale, p. 249). The interview statements expressed the truth of the participants’ views of their experience of their interactions with the
‘expert patient’ leading to valid knowledge about them. The researcher transcribed interviews with the assistance of two forms of input (audio and audiovisual). This aided in the accuracy of translation from the oral to written language. The opportunity for triangulation was provided with continual feedback from thesis supervisor and committee. These three researchers examined the raw data, each from their differing perspectives, continually asking this question of the research: “Is the question asked of the text valid and have logical associations been made?”

It has been demonstrated that trustworthiness was embedded in each stage of the production of knowledge. In this study the stages of ensuring trustworthiness included: the research design, the researcher, the quality of the interview and transcription, multiple perspectives on analysis, supervision by an experienced researcher, feedback from an experienced committee, constant referral the research question, and continual questioning. This disciplined process led to transparency in research procedures and convincing results (Kvale, 2009).
A good phenomenological text has the effect of suddenly making us 'see' something in a manner that enriches our understanding of everyday life experience. The seeing of meaning is not merely a cognitive affair” (van Manen, 1990, pp. 345-346).

Chapter 4 Findings

The results of the study have been presented in the three parts corresponding to the three specific research objectives:

1. Describe the students’ experience of interacting with the ‘expert patient’.
2. Describe the students’ learning regarding client-centred practice.
3. Identify the conditions particular to the ‘expert patient’ experience that led to learning regarding client-centred practice.

Part One: Students’ Experience of ‘Expert Patient’ (‘XP’) Interactions

The focus of Part One was the experience of the students – what arose within them, their predominant feelings and thoughts, in the midst of their interactions with the ‘XP’. Three central themes emerged from the students’ interviews regarding their experience with their ‘XP’. All of the students described the following: 1. Admiration, 2. Discomfort, and 3. Humility & Gratefulness. A significant sense of admiration for the ‘XP’ and the ‘wholeness’ and competence he represented set the tone for the discomfort, humility, gratefulness and further learning that followed.

1. Admiration.

In each student’s interview regarding their experience interacting with the ‘XP’, they described a deep sense of admiration of ‘their’ ‘XP’. The ‘XP’’s were described as engaging individuals who demonstrated to the students their comfort with themselves, their abilities and their limitations. They pleasantly and eagerly shared their experience of living with and
managing disability. The ‘XP’ s level of satisfaction with themselves and their passionate
enthusiasm to share, impressed the students. The ‘XP’ s physical and emotional stability helped
put the students at ease which was noted and appreciated by all of the students.

1a) ‘XP’ self-satisfaction.

The students were impressed by the ‘XP’ s level of satisfaction with their lives despite
their disability. The ‘XPs’ sometimes neglected to mention their diagnosis when students asked
them: “Tell us a bit about yourself.” The students heard about their families, where they live,
how they spend their day, their pets . . . They heard what is important and meaningful in the
‘XP’ s lives. When the students heard of the ‘XP’ s strategies to accommodate their disability, it
was presented as an emotionally neutral fact of the ‘XP’ s lives. The ‘XPs’ spoke with a level of
satisfaction regarding their lives, including their living with and managing their disability that the
students described with admiration:

[The ‘XP’] is still living what seems to be a pretty full
life, he’s playing baseball, he’s doing this [being an
‘XP’], he’s performing a lot of meaningful roles, he’s
able to do a lot of the things I think he seems
interested in . . . he knows what he’s doing, and he
knows . . . how to handle everyday situations . . . I
thought that was really interesting. (Jac)

All of the students described similar feelings of admiration. Sophie related, “He has a job. He
knows what strategies work for him. He’s happy and he has a dream of what he wants to be.” PJ
observed, “He has everything sorted out . . . ”

1b) ‘XP’ enthusiasm.

The ‘XP’ s confidence in themselves and their abilities was noted by all of the students.
One participant described the ‘XP’ as “passionate”: “You can literally feel that passion in what
“they're talking about and what they're saying.” The ‘XPs’ had long-established competence and self-confidence. Their accommodations and strategies, struggles and triumphs were shared with the students. Jac’s comment that follows was echoed by all of the participants interviewed regarding the enthusiasm the ‘XP’ brought, “He was so enthusiastic to teach and interact with us . . . that was a really positive experience . . . ”

1c) ‘XP’ put students at ease.

All of the students remarked that the ‘XP’ put them at ease in their interactions. From the start, the students were made to feel comfortable by their ‘XP’, as Jac described, “I felt calm in interactions . . . it was just so easy working with him, it really was just a pleasure . . . He’s very welcoming . . . I felt relaxed. I felt really comfortable.”

2. Discomfort.

In contrast to the students’ descriptions of comfort and ease, the students’ eventual experience of discomfort was also universally reported. The students experienced discomfort with the change they observed in the ‘XP’, with what they were required to do and with the perceived ‘costs’ of their learning. The students were uncomfortable with the experience of the ‘XP’s unhappiness with his performance during the assessment. They were uncomfortable with the experience of doing assessments to reveal limitations and with learning that was afforded the students at the ‘XP’s ‘expense’.

2a) Student discomfort with witnessing ‘XP’ unhappiness.

Each of the students described awkward, uncomfortable moments when their ‘XP’ was unable to complete an expected assessment without difficulty.

It was very difficult . . . he wasn’t getting it . . . We could kind of tell that his energy level went down and
that . . . he wasn’t happy with how he was doing . . .
He was smiling a lot more at the beginning. Then he looked . . . stressed, or discouraged . . . that created discomfort for me. (Sophie)

Witnessing the person they admired struggle with the assessment and become unhappy with himself caused the students discomfort: “He’s not getting it . . . It’s not working very well. Inside I felt a little bit bad.” (Jac) Discomfort dominated the students’ descriptions when the ‘XP’ experienced what was perceived by the students to be a negative consequence as a result of his participation in the assessment.

2b) Student discomfort with their role: administering assessments to reveal limitations.

As a result of being assessed, the ‘XPs’ had deficits unexpectedly revealed. The students were concerned about the negative impact of their evaluation on the ‘XP’. Sophie questioned the assessment of their ‘XPs’ and its consequences:

> Why do we need to dig into deficits or disabilities? I didn’t see the point of doing it . . . Doing the assessment and trying to look for limitations . . . making them aware of limitations that they have . . . I felt was not how things should be.

The students described this as unsettling, uncomfortable, or embarrassing. “I felt . . . a little bit ashamed of the assumption that I was making about what kind of deficits that he might have . . .” (Sophie) The students acknowledged their discomfort. They reflected aloud, reconsidering and questioning their role.

> What are we here for? When somebody is happy, regardless if they have a disability . . . if they’re satisfied with their life, why do we need to look for deficits? That’s why I was feeling uncomfortable. (Sophie)
The students experienced the impact and responsibilities of providing intervention without input from the ‘XP’. Two of the three students reported explicitly interrupting the timed standardized assessment and even deviating from protocol. Jac described making a decision: “He’s not getting it . . . That’s enough. It’s time to move on. I had to make a choice.”

**2c) Student discomfort with learning at ‘XP’ ‘expense’.

The students each described a sense that their learning would come at a ‘cost’ to the ‘XP’. The students described their opposition to learning that would jeopardize the integrity of the ‘XP’. The nature and purpose of the student/ ‘XP’ interaction was questioned in relation to a timed standardized test:

> I don’t need to know that it’s going to take him ten minutes. I don’t need to know that. I am [here] to learn . . . But now . . . I wanted to make sure I wasn’t learning at his expense. (Jac)

Concerned with meeting the academic requirements of the course, one participant described immediate upset and disappointment when in the final session an ‘XP’ was unexpectedly unable to successfully complete an assessment of functional mobility: “Ah darn! We don’t get to see him transfer. We don’t get to see him use a walker. I wish I got a chance to see that . . . .” And an immediate reconsideration followed: “A split second after I was like: Wait a minute! I can’t think about this in terms of how it’s going to stop my agenda.” (PJ)

**3. Humility & Gratefulness.

The students described their feelings of humility and gratefulness. They observed that their ‘XP’ needed nothing. They were “surprised” or “taken [a] back” that the ‘XP’ was “just here for us” (to give) rather than to receive from the students. The students unexpectedly
adopted the role of ‘not giving’. Gratefulness for the unexpected learning the experience brought to the students was described among the feelings that concluded the sessions.

3a) Recognition students were not needed by ‘XP’.

The students described the humbling experience of ‘not being needed.’ They described reconsidering their ‘helping’ role in response to the ‘XP’s competence and their feeling of not being needed to provide anything.

*The third [session with the ‘XP’] I was a lot more quiet*

. . . I was really taking in what he was saying . . . he knew that there was a sense of hope and possibility

. . . So you don’t need that from me . . . So what do you need from me? (pause)

*I’m not sure. (PJ)*

Challenged by their experience of the ‘XP’ in a way that caused them to humbly reconsider their role, the students adopted new roles (‘not giving’). In each circumstance the students described stepping aside from the interaction (while in it) to briefly consider the ‘XP’ from a new perspective and to reconsider their next action. They described a distinct turn from ‘doing an assessment’ to listening and hearing and questioning whether there was anything at all to be done.

*In the moment you just kind of feel like this guy doesn’t really have any problems . . . He wasn’t giving us any sort of problems that he had . . . you probably don’t need anything from me. (PJ)*

*When I came into CEC I felt it was going to be a really good experience [with] practice of administering tools . . . what I got out of it too was knowing that [the ‘XP’] wasn’t there needing our help . . . [‘XP’s] don’t really need our services. (Jac)*
3b) Gratefulness that ‘XP’ was here for us (giving).

The students each came to regard their ‘XPs’ from new perspectives taking them
“[a]back” and causing them to “stop” and reconsider their roles. Not only was the ‘XP’ there voluntarily:

Knowing that they’re volunteers plays a big factor for me . . . there’s no extrinsic value to their being here . . . He wanted to give us an understanding of his daily life . . . They just want to share their experience with you. (PJ)

He was there solely for the students learning:

The first two [sessions] I think I was more wrapped up in course expectations . . . for some reason I don’t know why, it just really struck me the third time that he’s really invested in our education. And I was kind of taken back by the fact that he has put aside the fact that he has a progressive disease and he is just here for our learning. That struck home. (PJ)

All three participants reflected various descriptions of arriving at a place of ‘sitting back and taking in the opportunity’, taking in the experience of the ‘XP’ as ‘expert’ rather than the students having to show their knowledge or expertise. The acknowledgment of the ‘XP’ as “just here for our learning” as well as a person with a neurological condition, precipitated the students’ humble recognition of the role of ‘not giving’:

It’s not about what I can provide. He knows best . . . It’s not so much what I can provide for you . . . it’s not necessarily me “giving” . . . (PJ)

It’s kind of a humbling experience that, ok, sometimes I just need to let them teach . . . (Jac)

The students experienced humility and gratefulness as a result of an experience that afforded them new perspectives and opportunities to practice the role of learner.
The findings for Part One, the students’ experience interacting with the ‘XP’, included their feelings of: admiration for the ‘XP’, discomfort with the negative change they saw in the ‘XP’ and the part they played in that change, and humility and gratitude. The students wanted all of their learning to be in the best interest of the ‘XP’. It seemed the stage had been set for learning the dynamics of power and responsibility (among other things). Each of the aspects of the students’ experience was an opportunity for valuable experience-based learning regarding client-centred practice.

**Part Two: Students’ Learning Regarding Client-centered Practice (CCP)**

The focus of Part Two was the students’ learning regarding CCP. The following statements from the definition of CCP in as noted in Chapter One: CCP centres on the essential values that clients are experts regarding their own occupations, that there must be respect for each person’s choices about life, recognition of each person’s right to self-determination and that clients must be active partners in the occupational therapy process (CAOT 2002, 2007).

The question in the researcher’s mind was: ‘What statement(s) or phrases [from the ‘XP’ interactions] revealed the common experience [of learning regarding CCP]?’ (van Manen, 1997). The three *a priori* values sought in the data were the need to: 1. Respect Autonomy: ‘Client-centred practice requires respect for client autonomy’ (CAOT, 2002); 2. Collaborate: ‘Client-centred practice requires that clients be active partners in the OT process’ (CAOT); and 3. Recognize Expertise: ‘Client-centred practice recognizes clients as experts in their own occupations’ (CAOT). Experiential learning and the explicit enactment of concepts related to values and beliefs concerning the person and CCP were acknowledged and demonstrated by each of the students as a result of their ‘XP’ interactions.
1. Respect autonomy.

The students described learning the importance of respecting the client as a unique individual with their own perspectives on their goals and opinions, and learning to enact this value. The students unanimously described how necessary it was to learn about their ‘XPs’ from their perspectives on their lives, not just what assessments tell us about them. In respecting and valuing the ‘XP’ perspective, they learned to consider the unique person in their presence and not to rely only on the information provided by the standardized assessment:

> It’s really important not to just rely on standardized assessments . . . Each client is really unique and has different things that are meaningful to them. (Jac)

The opportunities for the students to ‘practice’ the essential values inherent in CCP by interacting with the ‘XP’ were described by the students. In the ‘XP’ interactions the students noted opportunities for:

> Developing the respect for the client and that collaboration of knowing that they have a lot of knowledge to offer based on what’s important to them and their experience they’ve had in the past. (Jac)

The students’ reflections on what they learned from the ‘XP’ experience regarding client-centred practice included descriptions like the following regarding the need for respect as an integral foundation upon which the client-centred therapeutic relationship is built.

> There needs to be that respect, in this case between student and ['XP'], but also between the client and the therapist, you just . . . build from the respect . . . if there’s not that respect you’re not going to respect their goals and opinions. (Jac)

The students’ ‘XP’ experience “[brought] to life” previously learned theory related to values regarding client-centred practice.
OT Statements of Values and Beliefs [Appendix F]
really come to life in terms of really trusting that patient and believing him . . . seeing that dignity that the client has . . . as well . . . you have no choice but to respect and trust their expert opinion because they have spent so much time and energy in formulating these thoughts and taking life the way they are . . . (PJ)

The opportunity to “really trust that [‘XP’]”, and to “believe in him” (PJ) was afforded the students through their interactions with the ‘XP’.

2. Collaborate.

The need to collaborate with clients was voiced in the students’ interviews and upon later reflection. The assessments and the evaluation were insignificant without the active participation and input of the ‘XP’. The resulting incongruence of information obtained from an arbitrary (non-collaborative) assessment and its applicability to the ‘XP’s life was evident. The students expressed a sense that it was inappropriate to assess without working in partnership with the ‘XP’:

Maybe the person never does that task and maybe they don’t need to do that task . . . maybe it’s not important to them . . . We really need to . . . in fact . . . understand what’s important to them . . . I think that’s one of the big things I may take away. (Jac)

By the third session the students described their ‘solution’: “giving away power”.

You’re explicitly giving away . . . your power . . . They [‘XP’s] recognize they have that expert knowledge and . . . power . . . like we’re more on an equal playing field. (PJ)

As PJ stated: “Especially in my last session with [the ‘XP’] . . . it’s not so much what I can provide for you . . . it’s a reciprocal process for sure . . .”
3. Recognize expertise.

Initially, students assumed they were needed to assess the ‘XPs’ for deficits and make necessary recommendations based on their assessments. These were roles assumed in clinical placement that were incongruent with the ‘XP’ experience. This incongruence was accentuated by the explicit understanding that the ‘XP’ needed nothing from them. In the midst of the interactions with the ‘XP’ the students were challenged to find new roles. These included a) learning to appreciate the ‘XP’ as ‘teacher’; and b) because the ‘XP’ needed nothing, the students were required to let go of some of their assumptions about ‘doing’ and to adopt the role of ‘learners’.

3a) ‘XP’ as teacher.

The students acknowledged and appreciated that the ‘XP’ could teach them.

“They have a lot of knowledge to offer based on what’s important to them and their experience they’ve had in the past. [They] are here and [they] are offering us . . . insight . . . (Jac)

Each of the students humbly expressed a sense of learning their responsibility to meet the ‘XP’ from his perspective.

3b) Learning to be learners.

Students described their adoption of the learner’s stance. Jac welcomed the change: “It was really helpful to not . . . need to ‘fix’ or ‘do’ things . . . it was a learning experience for us . . .’ The students’ unanimous acknowledgement of the ‘XP’ as an expert “here for our learning” as well as a person with a neurological condition precipitated the students’ active appreciation of their new role to “meet him there”.

“I think it’s our responsibility to meet him there. To come prepared to learn and to come with questions
and also to come with an understanding that we’re learning from him and let him talk – we’re going to sit and be receptive to his knowledge . . . it’s easy to get trapped in the perspective seeing a problem . . . I need to fix it, that sort of attitude . . . In this [circumstance] . . . this [XP] has everything sorted out . . . I’m just here to listen . . . (pause) AND learn.

[Aha] That’s it! (PJ)

The students made a choice to stop, listen and learn from a perspective that integrated the expert voice of the ‘XP’.

To summarize the findings for Part Two, the students described their learning regarding CCP as a result of their ‘XP’ interactions and their reflections that followed. They described the need to respect client autonomy, the necessity for clients to be active participants in the OT process and the need to recognize the client as expert. Through their participation in the ‘XP’ experience the students were provided novel opportunities to consider and apply concepts related to values regarding client-centred practice previously introduced in theory.

Part Three: How the ‘Expert Patient’ (‘XP’) Experience Led to Learning Client-centered Practice (CCP)

The focus of Part Three was the identification of the unique conditions of the ‘expert patient’ (‘XP’) experience that led the students to learning regarding client-centred practice (CCP). The students’ transcripts were reviewed and the conditions that led them to learning regarding OT values were noted. This section reveals what was particular about the ‘XP’ experience that led the students to learn the need to respect autonomy, collaborate and recognize expertise. There were three conditions unique to the ‘XP’ interaction that gave rise to learning regarding CCP.
1. There was a condition of the *client*: that s/he be a self-professed ‘expert’ in living his/her life as recognized by him/herself, others and the system.

2. There was a condition of the *student*: that the student was required to take an evaluative role, providing assessment and documentation of findings, thus experiencing power.

3. There was a condition of the *setting*: that inherent in the system was an opportunity for questions to be asked and topics to be discussed with the students regarding their ‘XP’ experience in the midst of it and on reflection.

1. **Condition of the ‘client’: ‘expert patients’ rather than patients.**

   The first of the three essential conditions giving rise to the experience and learning regarding CCP was the condition of the interaction with ‘expert patients’. The explicit naming and acceptance of the ‘XP’ as ‘expert’ by the ‘XP’s themselves, by the students, faculty and the staff contrasted with the students’ experience of the patient (typically with no expertise explicitly named). This emerged through the data as the most dominant of the three conditions that situated the ‘XP’/student experience. ‘XP’ as expert is the common thread woven throughout the descriptions of the students’ experience of the ‘XP’ interactions (Part One) and the experience of the students that was related to their learning regarding CCP (Part Two). The students’ experience of ‘XPs’ are different from students’ assumptions about patients or clients they encountered in their clinical placements. The ‘XPs’ received training from the CEC staff in the form of the directive: “Be yourself”. The unique autonomous role of the ‘XP’ was noted in contrast to patients the students had interacted with in clinical placement. Students’ interviews revealed that at times, in the clinical setting, the content of patient/health provider communication might have been dictated by the reason for referral, the referring source or by what the patient thinks the health care practitioner is to provide, rather than by what is important
to the patient. The ‘XP’ s presentation was void of the influence of institutional thinking that
dictated expectations of what they are to report to whom, a difference that was noted by the
students:

\[ \ldots I \text{ think the energy that the volunteer brings to this setting is so much more... seeing their genuine response} \]
\[ \ldots \text{the [XPs] thoughts are not from a place where he's saying his thoughts because he thinks you want to hear them. (PJ)} \]

The ‘XPs’ presented themselves as ‘whole’ as a matter of fact, naturally and without prompting.
The students admired the ‘XPs’ presentation of the whole rather than the part of their lives, their
capabilities as well as their challenges. The interaction afforded the students an opportunity to
view the ‘XP’ as a whole person, something that is often overlooked when the focus is on
problems.

\[ \text{They’re whole and they just want to share their experience with you...he just wanted to give us an understanding of his daily life. (PJ)} \]

How would experience and learning differ if all patients, all persons, were viewed from this
perspective? Maybe this is what all patients want. Students learned experientially, rather than
only theoretically, to respect the ‘XP’ as an autonomous person with an identity that was not
consumed by his diagnosis.

The students cited the contrast they noticed interacting with the ‘XP’ in the Clinical
Education Centre (CEC) versus their experience of patients they encountered while on clinical
placement:

\[ \text{In a hospital setting patients are in such a vulnerable state... whereas in this situation they’re not in that kind of state... The people that come to CEC are... living in the moment, like they are here in this moment} \]
to do this . . . in placement, they don’t want to be here they just want to fast forward to the future. (PJ)

Someone else with maybe a newer diagnosis, just coming to terms with their diagnosis, may not necessarily believe things will get better . . . there's a big difference. (PJ)

The contrast served to emphasize the students’ admiration for the ‘XP’ and contributed to their acknowledgement and recognition of ‘XP’ expertise.

The students’ prior experience of patients in a traditional clinical setting included an inherent power differential between therapist and patient. In a traditional clinical setting the relationship of unbalanced power is already established, reinforced and ‘institutionalized’ prior to any intervention:

In hospital, parts of them have been broken . . .
I think health care professionals and [patients] themselves [see them this way]. (PJ)

The typical patient would not come to see us to affect our learning. I believe the typical patient would most likely come to us with experience of the bio-medical approach . . . They would come to us with the label and attitude of consumer. (Jac reflection)

When the students encountered patients in their clinical placement they noted (in Jac’s words), “We were focusing on what they were not able to do . . . .” The students reported that when on placement they have their “OT hats” on – “doing assessments and writing up notes, more like an OT . . . on placement it’s working with clients that need our services.” (Jac) With patients ‘in need’ the students reported confidence readily assessing, evaluating, making recommendations and documenting in spite of and seemingly undisturbed by a patient’s negative state. “It’s how it is. Whatever is lacking we are supposed to write in the notes.” (Sophie)
In contrast, ‘XP’ presented *themselves* rather than their diagnosis or their reason for referral. They presented themselves as *persons*. This led the students to recognize ‘XP’ expertise and to honour their ability to participate as collaborative partners in their learning experience.

The students wanted to maintain the dignity and respect the ‘XP’ initially garnered. PJ humbly acknowledged, “I really did believe, especially in that last session, I really believe that ‘patient is the expert’ philosophy because I really don’t have a lot to offer.” Inadvertently, the students had an opportunity to experience the ‘XP’ as experts and to learn what it actually felt like to experience interacting with them guided by that perspective.

> [The ‘XP’ experience] prepares me to know that whatever the client . . . is . . . saying . . . trust in that . . . and . . . really believe them as an expert . . . what the ‘XP’ says, that’s what going to make the difference . . . (PJ)

> I think it [the ‘XP’ experience] really tells me that they ARE the expert. (Sophie)

It seemed the students were able to glimpse an experience within themselves of what it felt like to truly experience reciprocity with a patient -- a critical learning experience.

Finally, Jac offered this reflection that related past and present ‘patient’/’XP’ experience:

> “On placement we’re expected to be more the expert and this [‘XP’ experience] was nice because he was expected to be the expert . . . .” And this note was added regarding the future:

> “And hopefully in future practice we can both be expert together.”

‘XP’ as expert emerged from the data as the primary condition on which the students built their experience of admiration and humility, significantly contributing to the students’ experiential learning of the value of respect for autonomy, and recognition of expertise. While admired by the students for this unique presentation, the ‘XP’’s presentation as ‘persons’ rather
than ‘patients’ also created difficulty for the students during the assessment and evaluation sessions.

2. Condition of the student: experience of power.

A second condition that gave rise to learning values regarding CCP was the requirement of students to adopt an evaluative position. This created an explicit shift in the expected power relationship reinforcing an unbalanced power structure. Students learned the experience and consequence of exercising power through the institutionalized patient/professional relationship, and that did not necessarily result in a desirable outcome for either students or ‘XPs’.

The students described their first hand experience with an intervention (a standardized assessment) that afforded them the experience of an imbalance of power. When the assessment tasks presented by the students created a dramatic negative change in the mood of the ‘XP’, the students unanimously described their experience of their own power over the client. “I think it really presents how much power we have . . . how clients are made to feel [negatively] about themselves . . . I want him to feel comfortable . . .” (Sophie); “I’m not really here to make him feel bad about doing this.” (Jac)

In the ‘XP’ interactions, the ‘XP’s had findings related to their diagnoses similar to patients seen on placement but they had no needs or expectations of the students. The students described a desire for change when they adopted an evaluative role with their generous, competent ‘XP’ and the ‘XP’ experienced unhappiness as a result. For two out of three participants, their ‘XP’ struggled unhappily to complete tasks during the administration of the standardized perceptual cognitive assessment in session two or three or both. This negative and unanticipated event caused the students enough discomfort to pause and reconsider their purpose.
“I felt that, OK I’ve set him up for failure . . . That’s not what I wanted to do” (Jac). This is not what the students wanted to happen.

Finding themselves complicit in this event was also not what the students expected. Their experience gave rise to the sense that to be made to struggle without reason, to be made to feel incapable – was described as being not what an ‘XP’ deserves.

Students described a level of discomfort that compelled them to enforce limits to their learning. The students’ admiration and respect for the ‘XP’ was valued more highly than the standardized administration of the assessment compelling them to choose another course of action. In Jac’s words: “That’s enough. I had to make a choice.” The students’ interactions with the ‘XP’s challenged them with an opportunity to face their preconceived roles as ‘helpers’ ‘doing for or to others’ in a safe educational environment.

This [‘XP’ experience] is really important to help balance out . . . who has the power in the relationship . . . it helps to create an equal distribution of power between the client and the therapist and that I think will lead to better outcomes for everyone. (Jac reflection)

The students unanimously described how necessary it was to learn from their ‘XPs’ perspectives on their own lives, not just from what assessments tell us about them. The nature of the interaction and the nature and use of the tools were recognized (from Jac’s reflection): “Our attitudes as clinicians can either encourage and empower our clients or discourage and devalue them.” The students’ discomforting experiences resulting from intervention without collaboration with the ‘XP’ provided the students an opportunity to reconsider what they valued in patient/therapist interaction.

The students described their opposition to learning that would jeopardize the integrity of the ‘XP’. The difficulty the ‘XP’ experienced on assessment became a significant event that
made the students feel uncomfortable enough to challenge them to re evaluate their purpose and their actions. The students experienced the need for collaboration, from the consequences of assessing and evaluating an ‘XP’ who was not actively involved in the OT process. This was an example of situated, experiential and potentially transformative learning.

The students’ personal investment and engagement in the discomforting experience of assessing and evaluating a person with possible findings but no expressed needs, potentially revealing limitations, potentially causing the person unhappiness, led to evidence of the students’ explicit desires to respect the autonomy of the person, to collaborate in all aspects of intervention and to recognize expertise. All of the students noted the ‘XPs’ need of nothing from them. “We don’t need to tell him what his disabilities are. He knows and he deals with it.” (Sophie); He’s an ‘expert patient’, he knows what he’s doing. (Jac) The students became aware that ‘XPs’ have something to offer them . . . ‘XPs’ don’t really need our services . . . there’s a kind of putting him in the driver’s seat. (Jac) Humbled, the students adopted a new role, that of ‘not giving’. In turn, the students were given the gift of real collaboration -- learning with the ‘XP’.

3. **Condition of setting: directed reflection and discussion.**

A third condition within the ‘XP’ experience that appears to have given rise to students learning values regarding CCP, was the reflection and discussion that took place as part of the study. The students consolidated and made explicit their learning. The role of the directed reflection, the interviews and the follow-up discussions were among the researcher’s considerations regarding the experience of the ‘XP’ interaction and its potential relationship to the promotion of learning values related to CCP. One of the ways to discover what was experienced by the students interacting with the ‘XP’ was to ask them. The researcher’s act of directing the students’ attention to that which arose in the their consciousness in the midst of
their interaction and upon reflection, impacted the data. Directed reflection may have accentuated what the students may have arrived at independently. Upon reflection regarding the ‘XP’ experience as a whole, all of the students described learning that benefited them as student health professionals and proposed wider applications of the ‘XP’ model. Jac suggested: “I think that this experience would be really, really beneficial not only for OTs but for just any health professional.”

All of the students expected to learn and practice the administration of tools, but other aspects of their experience, such as their learning values inherent in CCP came as somewhat of a surprise. The potential for the ‘XP’ experience to give the students an opportunity to ‘live’ a collaborative relationship was shared among all students. This revelation was described by Sophie as an ‘aha’ moment. “Ah! . . . I think this can really teach us a mutual relationship with clients . . . they can teach us.” The ‘XP’s satisfying self-governance afforded the students the opportunity to experience mutual relationship. The significance of the need for any intervention to relate to the ‘XP’s life became clear experientially for the students. By the final session, the students’ each described a compelling desire to include the ‘XP’s ‘voice’ integrated in all of their actions – their input was necessary and valued.

All of the students described unanticipated learning.

*We were . . . doing assessments at the beginning, I was thinking that’s the main part of our session, but it turned out that’s just a small part of what we could learn . . . [I] started just to meet the expectation [of the course] and came out with something more . . . .
*(Sophie)*

All of the students described moments when they found themselves humbled and grateful – moments when their learning surprisingly illuminated them:
In the moments of humility and gratefulness that were described by the students, the ‘XP’ experience became their teacher.

When asked what changes they saw in themselves over the sessions, all of the students described their own growth as being facilitated by not only their participation in the ‘XP’ interactions but by their participation in the study. Learning was cultivated and did not take place on its own. Self-reflection and guided reflection in addition to the experience of the expert patient interactions themselves informed the students learning. When the students reflected on the ‘XP’ experience in general their comments concurred with these that highlighted this particular form of learning:

Client-centredness, these are ‘soft skills’ as opposed to ‘hard skills’... a lot of education focuses on ‘hard skills’ but the ‘soft skills’ are what eventually makes us successful. This setting is really helpful in a way for us to learn our ‘soft skills’... It really helped us to focus on our mentality. (Sophie)

Each student commented on the augmenting nature of the interview process.

Interview questions were reported to be enjoyable and facilitative. The students echoed each other with the following comments regarding the research process: “Your questions really got me to think. I enjoyed it.” PJ’s words captured what all of the students related:

This, our [research] interview, is probably as important as the [‘XP’] session[s]. Just because when I was going to the first two sessions I was like [gestures with wave of hand] I’ve done this in placement... And I think because there is so much going on this forced me to be more reflective and now in retrospect I feel like: Oh,
I learned so much! Wow, I actually learned more than I thought I did . . . It’s such a personal growth opportunity that often gets overlooked when you’re just trying to meet the components of the course . . . marks are one thing, but having that personal growth experience and putting that to practice is as important . . . (PJ)

All of the students described their growth as clinicians related to learning CCP as a result of their ‘XP’ experience. The ‘XP’ experience in general was differentiated from prior learning of theory. The opportunity to “practice” was emphasized.

I learn best when it’s real life and real people . . . you can say ‘be client-centred’ but really until you practice . . . and make mistakes and then . . . learn from the mistakes and have a chance to practice and develop those skills . . . maybe that’s why this ['XP’ experience] is a lot different than just a course on theory . . . (Jac)

The data revealed three essential conditions that allowed for the integration of students’ ‘XP’ experience and learning core OT values regarding CCP. The conditions required an ‘Expert Patient’, students experience of power, and directed reflection and discussion. The three essential conditions combined were required to create the opportunities for students to transfer theory of client-centred care into meaningful and memorable practice.

Summary

This chapter presented nine themes revealed by the study of students’ interactions with ‘XP’s and their potential learning regarding CCP. Revealed were three aspects of students’ experience, three learnings regarding CCP, and three conditions that situated the experience and led to students’ learning. The three conditions: 1. ‘Expert Patient’, 2. Students’ Experience of
Power and 3. Reflection/Discussion provided a foundation for the students’ experience of the ‘XP’ and for their learning regarding CCP (Figure 1).

**Figure 1: A Foundation for Student Experience and Learning**

The most dominant theme revealed by the study, ‘XP’ as expert, emerged from the data as the condition on which the students built their experience of admiration, humility and gratefulness, and significantly contributed to the students’ experiential learning of the value of respect for autonomy, recognition of expertise and desire for collaboration. What was evoked in the students’ interactions with the ‘XP’s was situational and revealing. While a cause of
discomfort to the students during the course of their intervention, it was the ‘XP’s awareness of
and confidence in his or her abilities and limitations that elicited in the students a spontaneous
change of plan and/or a change in attitude. As a result of their interactions with their ‘XPs’ the
students each reflected on, verbalized and enacted in their own ways, the values that formed the
basis of this change. By the end of three sessions the humbled, honestly engaged students
seemed to have nothing left but to ask, “What am I here for? He needs nothing from me . . . I
have little to offer [at this stage in my training] . . . [Maybe I could learn something]”… Aha!
“So that’s what reciprocity feels like!” Maybe it is necessary to ‘catch’ one when their learned
professional guard is down to set us just enough off balance to feel for a moment the
vulnerability that openness to integrating new learning requires.

The students’ unsettling experience seemed to afford them the opportunity to reconsider
their assumptions about their role in their engagement with the ‘XP’. The students were
introduced to learning experientially certain concepts related to values that were internalized and
practiced rather than merely accepted in theory. Perhaps the unsettling brought students to their
‘centre’, to a place of reflexively considering the values and beliefs they bring to the interactions.
Perhaps it is this subjective awareness that requires our attention.

The students’ capacity to embrace and *engage* the theoretical concepts related to values
regarding client-centred practice was augmented by their ‘XP’ experience. The significant
difference between patient experience and ‘XP’ experience seemed to be found in the
exaggeration of the concept of patient expertise – a concept *both* types of patients potentially
espouse -- to allow for learning that occurs by making explicit what is implicit in other
interactions. The potential for the ‘XP’ interaction to serve as a form of caricature of any
patient/therapist interaction and a model for the operationalization of client-centred practice will be discussed in Chapter 5.
“Understanding is an event that happens within a relationship of vulnerability to that which one seeks to understand” (Schwandt, 2007, p. 244).

Chapter 5 Discussion

Summary of Findings

This qualitative study described the experience of OT students interacting with ‘expert patients’ (‘XPs’), their learning regarding client-centred practice (CCP) and the unique conditions that gave rise to their experience and their learning. The research question was: How does the students’ experience of interacting with the ‘expert patient’ relate to learning regarding client-centred practice? The research objectives were:

1. Describe the students’ experience of interacting with the ‘expert patient’.
2. Describe the students’ learning regarding client-centred practice.
3. Identify the conditions particular to the ‘expert patient’ experience that led to learning regarding client-centred practice.

These questions were explored with a sample group of three first year OT students using in-depth semi-structured interviews. Data was explicated using qualitative methodologies to arrive at key findings (Table 3).
Interpretation

The relationship of the key findings to the current literature follows: The three conditions that emerged from the data as requirements for situating experience and learning regarding CCP (the client, the student/therapist and the setting) directly correspond with the three barriers to client-centred practice named in the literature (Wilkins et al., 2001). The data from this study do seem to indicate the potential for the students’ experience interacting with the ‘expert patient’ to be instrumental in the learning of OT values regarding client-centred practice.

Interestingly, the ‘expert patient’ has characteristics consistent with the description of the
‘ideal’ client for client-centred interaction described by Wilkins et al. (2001). The ideal client who would benefit from client-centred practice was described as someone who is cognitively intact, with good insight into how they’re functioning within their environment and good problem-solving skills. What was unique about the ‘XP’ experience was the explicit naming of the ‘XP’ as expert and the subsequent heightened potential for the active engagement of values elicited by interacting with persons who are “consciously competent” (Howell, 1982, pp. 29–33).

Valuing what patients have to offer is vital to understanding what partnerships can be (Barr et al., 2010, p. 611). The students’ descriptions of their experience interacting with the ‘expert patient’ is consistent with Rogers’ ‘core conditions’ (1951) -- acceptance, genuineness and empathy, which form the basis of occupational therapy values and beliefs regarding client-centred practice. The ‘expert patient’, a person who lives with and manages disability as a part of life, who accepts and acknowledges the role as ‘expert’ in living their life, was revealed as one of three conditions that when experienced together, can facilitate learning regarding client-centred practice.

Though the literature describes many forms of involvement of patients in health professional education, no study was found that explored students’ learning regarding client-centred practice or conditions for such learning. In this way this study was unique. While we do learn of active involvement of patients as ‘experts’, as exemplars of their condition, and as facilitators of the development of professional skills and attitudes (Solomon, 2011; Stacy & Spencer, 1999), we do not know exactly how this is demonstrated. “Service user involvement has been accomplished on an ad hoc rather than a strategic basis …” (Rees et al., 2007, p. 362). This study exposed the mechanics of how one form of utilization of ‘expert patient’ promoted learning regarding patient-centred care. The findings of this study concurred with Towle and
Godolphin (2011): The students’ experience of patients as ‘experts’ served to challenge the nature of expertise and power.

The students’ **experience of power**, found to be a key condition giving rise to experience and learning regarding client-centred practice, presented in an opposite manner in the ‘expert patient’ experience than the form presenting to clinicians. Power differential was noted in the literature as a barrier to client-centred practice (CAOT, 2007; Mortensen & Dyck, 2006; Sumsion & Smyth, 2006; Rochon & Baptiste, 1998). The literature cites the need for a shift in the therapist’s professional identity from expert to that of partner. In the ‘XP’ experience, *the opposite shift* occurred. The student/‘XP’ relationship abruptly turned from walking alongside their ‘XP’ admiring their capacity, to confronting them with an assessment. The rupture in the student/‘XP’ relationship when evaluation was imposed, afforded the students the tangible experience of the shift in power relations. In the way that Kolb (1984), described the learning cycle following a critical event, or Schön’s work with reflective practice (1983, 1987) or the work of Mezirow (2000, 2009), Cranton (2006), and Rehork & Malhotra Bentz (2008), regarding transformative learning, the students participated in learning that challenged them and brought them potential new learning. This was learning that they were able to experience, apply and discuss in a supportive setting. The students experienced meaningful, mindful learning (Mezirow, 2000). A disturbing, disorienting event is often a key element of learning transformation (Mezirow, 2009; Cranton, 2006).

The OT students’ experience of ‘expert patient’ is one example of how adult learners can undergo fundamental change when learners’ frames of reference are transformed (Mezirow, 2000; Schön, 1987; Washburn, 1995; Moss, 2007). Fraser and Greenbalgh (2001) note: “Learning which builds capability demands that individuals engage uncertain and unfamiliar
contexts in a meaningful way” (p. 800). Explicit awareness of new and challenging perspectives were brought to the students’ attention through the ‘expert patient’ experience. The students opened themselves, their attitudes and their behaviors, to being changed.

The students, all capable and mature, experienced learning that takes place in what Fraser and Greenhalgh (2001) term the ‘zone of complexity’ in which the environment and the tasks had aspects of both familiarity and unfamiliarity. The students were receptive, reflective learners (Fraser and Greenhalgh) who were able to receive feedback and adapt appropriately. **The study and the setting explicitly supported the students’ learning.** The study supported the findings of Rees et al. (2007), who described learning from patients as ‘memorable’, ‘inspirational’ learning that helped students apply academic learning. This study is supported by those patient involvement initiatives reported by Towle and Godolphin (2011) that aim to shape attitudes and values and provide students a safe learning environment.

Schön (1983) encouraged therapists to think critically about their experiences and behaviors in the midst of their interactions and when the session ended, rather than presuming total expertise (Taylor, 2008). Both reflection-in-action and reflection-on-action were explicitly promoted with the students as part of the research design and, according to the students, contributed significantly to their learning. Supportive mentors (CAOT, 2007; Duggan, 2005; Restall et al., 2003; Restall & Ripat, 2008; Sumsion, 2005) were noted to assist therapists with the challenges of being client-centered. Client-centered practice is augmented by an atmosphere of support and mentorship both for students and for clinicians. Inherent in the students’ interaction with the ‘expert patient’ were strategies that addressed each of the common barriers to client-centered practice at the level of the client, the therapist and the system (Wilkins, 2001).
The ‘expert patient’ experience **supported learning regarding client-centred practice.** The students described the need to respect autonomy, collaborate and recognize expertise. This concurs with the work of Rees et al. (2007), who noted that learning *with* rather than just *about* patients . . . reflects the “dynamic mutuality” that occurs between students and patients (p. 501). This study supports the assertion that the unique experience of interacting with the ‘expert patient’ can provide an opportunity to make explicit and practice the skills required to learn client-centredness. The three conditions that situated this opportunity for learning (Brown et al., 1989) client-centredness emerged from the data as essential aspects of this finding.

**Implications For Research**

Towle et al. (2010, pp. 71-72), suggested four categories for further research: Antecedent variables (for example, “What drives patient involvement in health professional education?”), structures (“What effect does setting have on learning?”), processes (“How are patients engaged?”, “How is curricula designed and delivered?”), and outcomes (“What are the consequences that should be examined?”). Examples for further inquiry needed were suggested in each category. One of Towle’s questions in the outcomes category inspired this study: “What are the short- and long-term effects on health care professionals (knowledge, skills and attitudes) who have been taught by patients?” While addressing only a part of one of Towle’s questions, this work contributes new learning to the body of knowledge regarding active patient involvement in health professional education. This study will be submitted to the Patients as Educators Research Collaboration (PERC) in support of moving forward their clearly outlined research agenda (Towle et al., 2010).

Husserlian phenomenology offered a methodology to encourage reflexive and reflective practice in the form of the first reduction or èpocchè. This study affirmed for the researcher that
all research, all student/patient interactions, in fact all interaction could be well served by such explicit acknowledgement of personal worldviews. Like the students who experienced significant learning when they were required to meet themselves and their preconceptions, are we as health professional educators and health science researchers open to the uncertainty an epistemological turn (Broughton, 2008) may reveal? Phenomenology is a foundation-seeking exercise that is inherently transformative. It explores what is first felt and is only later understood. Further study of the lived experience of students and health professionals may help illuminate the essence of the entrenched barriers that have persisted in the application of client-centred practice.

“Transformative phenomenology is a way of cultivating phronesis” (Rehorick & Malhotra Bentz, 2008, p. 24). Phenomenology provides a philosophical and practical framework for cultivating wisdom by challenging researchers and practitioners to look deeply into their subject matter and to themselves.

**Implications for Educators**

The learning the students experienced required their vulnerability and their openness to reflection and discussion. Their learning occurred within the particular conditions outlined, requiring the support of educators. The students’ reports of their interactions with the ‘XPs’ could be described as an experience of a crisis of conscience. Scholarly expectations conflicted with their values. They were brought back to themselves and a re-evaluation of their subjectivity – what they were bringing to the interaction. A creative process was witnessed supporting the hypothesis of Bleakley and Bligh (2008) in Rees et al. (2007), that “as a consequence [of active collaboration between health care professionals and patients], a new level of knowledge production rather than reproduction may emerge . . . ” (Rees et al., 2007, p. 502). The students’ vulnerability and openness to direction and to learning was critical to the content of what was
learned. Yet unfortunately “systems of education today . . . teach us to be proud of what we know and ashamed of ignorance” (Spencer-Brown, p. 110). How could vulnerability and openness to what is yet to be learned be cultivated in educators? Are educators prepared to support learning with unknown, indefinite outcomes?

Students complained about having to do an assessment on someone who didn’t need it. They expressed frustration that they were unable to make recommendations “like on placement”. If the course coordinator had acquiesced, allowing students their comfort zone rather than challenging them, critical aspects of the applied learning regarding client-centred practice would have been overlooked. Is directed reflection and facilitation of students’ self awareness - - pointing out the significance of the questions and challenges that arise in the moment and upon reflection (Schön, 1987) - - an important initial step in adopting OT core values related to person- and client-centred practice? Identification of and affirmation of what arises in consciousness in interaction was a necessary element in this learning. Student learning could be enhanced by the facilitation of an extension session on reflection-in-action and reflection-on-action (Schön, 1987) to make explicit what has been implicit regarding the adoption of OT values. The students are just beginning. To have the ‘expert patient’ interaction in the second term of their first year has potential to be a positive step in their formation of values related to client-centred practice.

“Situations might be said to co-produce knowledge through activity” (Brown et al., 1989, p. 41). The opportunity to experience learning regarding client-centred practice was inherent in the interactions with and the evaluation of the ‘XP’. Common educational practice may seek to make explicit as much as possible. This study allowed an alternative perspective on explicit knowledge (the students conceptual awareness of CCP theory) and implicit understanding (the
opportunity to *experience* the application of the values that are the basis of CCP) through the particularly defined activities in the ‘XP’ interactions. The opportunity to experience learning regarding CPP was inherent in the design of the curriculum. Yet the learning regarding CPP was external to the objectives for evaluation. Even the course coordinator may be surprised to learn of what was taking place within the students.

Perhaps the ‘XP’ experience could become a model to serve as a mechanism of support for learning regarding client-centred practice for the student. The autonomous, authentic patient’s voice must be a core part of the training of health professionals (Towle et al., 2010). That the ‘XPs’ presented as ‘themselves’, people with established expertise at living their lives, was a critical element of the students’ learning. The patient’s voice movement (Towle et al.) has called our attention to the need to recognize and respect their expertise in representing themselves. While this study may well inform health professional education, the researcher agrees with Rees et al. (2007) that the design, implementation and evaluation of the utilization of the ‘expert patient’ should be done in a thoughtful and considered way (p. 387). This study revealed that it is not solely the independent utilization of the ‘expert patient’ that facilitates client-centred practice: *How* the ‘expert patient’ is utilized matters.

**Implications for Clinicians**

Perhaps clinicians can learn from the experience of the students. Have they forgotten the prerequisite ignorance and vulnerability required for engaged learning? Has their subjectivity been overlooked? Perhaps renewed attention to the attitude . . . the ‘how’ that precedes every ‘what’ may assist in the navigation around therapist-related barriers to client-centred practice. According to Johnson (2010), the attitude of ‘respect’ requires a certain sort of regard of self and other (Johnson, 2010). Carl R. Rogers referred to this essential attitude of the therapist as
‘realness’ or ‘genuineness’ and of the attitude of ‘prizing’ the other. It is an acceptance of this other individual as a separate person, having worth in his/her own right. To Rogers, this attitude that facilitates learning includes a direct person-to-person encounter (Rogers, 1961). The ‘expert patient’ experience provided that. The patient, here the ‘expert patient’, but any patient, has not only not avoided discomfort – they live it! And we can learn immensely from it.

The ‘expert patient’ experience prepared the students with a lived experience of applied reciprocity. Not theory, not concept, but practice. The experience itself raised the questions: How would our practice change if the implicit ‘expert patient’ was seen in all patients? What if all patients, were ‘given’ the explicit role of ‘expert’? ‘Expert’ in what they were feeling, ‘expert’ in what was important to them . . . How would experience and learning differ if all patients, all persons were viewed from this perspective? What if they were treated as ‘expert’ even when they were unable to claim that role explicitly? What permits the therapist to have a deep respect for, and acceptance of another? “Such a philosophy is most likely to be held by the person who has a basic respect for the worth and significance of himself. One cannot, in all likelihood, accept others unless he has first accepted himself” (Rogers, 1951, p. 22). Perhaps a reminder to engage in an act of ‘centering’ on the part of the clinicians themselves is required. If only clinicians were able to recall the admiration, the humility, the gratefulness and importantly, the discomfort of the student in the ‘expert patient’ interaction . . . The moments in which they realized: “Maybe I should listen and learn . . . It’s not about me . . .”

*On placement we are expected to be the expert and this [CEC] experience was nice because he was expected to be the expert . . . And hopefully in future practice we can both be expert together. (Jac)*
Jac’s vision from the place of humility reflects the reciprocity that may be possible to all (all students, all clinicians, all relationships).

Health care providers’ reflexive consideration of their own attitudes (Chochinov, 2007), ethics and beliefs regarding their own person as well as that of another may be a neglected aspect of care requiring further attention. This study made evident the contribution of the students’ attitudes and beliefs in their ‘XP’ interactions. In our striving to be client-centred (considering of the ‘object’, the ‘other’), have we forgotten to first recognize and acknowledge the contribution(s) of the ‘subject’, the ‘self’? Perhaps ©centred-patient care and ©centred-client care is the place to begin.

Limitations

A limitation of the study was its limited scope, with only three participants in one setting comprising the final sample. The sample of students did volunteer to participate in a time and energy consuming data collection protocol in addition to their already demanding schedules. This may be indicative of the participation of particular students with an exceptional inclination toward learning, and/or a proclivity toward self-reflection and in-depth study, which may not be representative of all OT students. The study was uniquely situated at Queen’s University’s Clinical Education Centre where learning with patients is part of the health care professional education curriculum. The findings may not be transferable to other settings where such supports are not present. An additional limitation includes the fact that the effect was explored only in the short-term (immediately following the experience), rather than in the long-term. In addition to the many recommendations already cited by Towle et al. (2010), further study would be required to explore the long-term effects on students’ learning client-centred practice and the application of the ‘expert patient’ experience on future practice.
Conclusion

‘Expert patients’ can be valuable resources for learning patient-centred care. Attitudes and values of student health care professionals can be influenced. A role for experiential learning of client-centred practice has been illuminated through students’ interactions with particular persons with stable disability (‘expert patients’), with students undertaking particular evaluative tasks ‘experiencing power’, within particular conditions ‘directed reflection and discussion’. Findings from this research revealed the role that the ‘expert patient’ experience could play in health professional education and exposed an opportunity for the potentially formative and transformative impact of the use of the ‘expert patient’ in learning client-centred practice. The insights generated through this study made explicit previously implicit concepts regarding learning client-centred practice. This has the potential to inform evidence-based practice regarding the utilization of the ‘expert patient’ in health professional education.

These findings have far-reaching implications for health care professional curriculum and raise questions for researchers, educators and clinicians. While the study addressed a void in the existing literature regarding the use of the ‘expert patient’ as a facilitator of patient-centred care, much remains to be studied. This thesis allowed unique insight into the lived experience of occupational therapy students learning with rather than about ‘expert patients’ resulting in significant learning regarding client-centred practice.
References


[http://www.lindafinlay.co.uk/phenomenology.htm](http://www.lindafinlay.co.uk/phenomenology.htm) (last retrieved Jan 2013)


Appendix A: Research Ethics Board Approval

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

April 6, 2011

This Ethics Application was subject to:

☐ Full Board Review
Meeting Date:

☒ Expedited Review

Ms. Jasmin Joan Cameron Duarte
School of Rehabilitation Therapy
Louise D. Acton Building
Queen's University

Dear Ms. Duarte,

Study Title: The 'Expert Patient' in Health Care Professional Education: Experience of OT Students
Co-Investigators: Dr. Mary Ann McColl

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol and the consent form for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair’s signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

➢ Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. (see http://www.queensu.ca/vpr/reb.htm).

➢ Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

➢ Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

➢ Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair’s signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

[Signature]
Chair, Research Ethics Board

Date: April 6, 2011

Study Code: REH-493-11

➢ Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete.
Appendix B: Letter of Information/Consent

Jasmin Cameron Duarte
School of Rehabilitation Therapy
Louise D. Acton Building
Queen’s University
Kingston, ON K7L 3N6
j.cameron.duarte@queensu.ca

Dear Students of OT 844,

I am an Occupational Therapist and a Masters student in Rehabilitation Science here at Queen’s University. You are invited to participate in a research project entitled: The ‘Expert Patient’ in Health Professional Education: Experience of OT Students, supervised by Dr. MaryAnn McColl.

Purpose The purpose of the research is to explore the experience of interacting with patients as it relates to the adoption of OT values. In this qualitative, phenomenological study I propose to conduct 2-3 interviews with 3-5 OT students from Groups 6- 12 regarding their experience interacting with the volunteer patients in the Clinical Education Centre (CEC) portion of your OT 844 curriculum. All students in the class will be able to participate in the reflective aspect of the research for their own learning.

Risks and Benefits There are no foreseeable risks associated with your participation in this research. The time investment required for each interview will be approximately 60 minutes. The interviews will take place directly following your CEC experience in May 2011. The direct benefit in your participation in this study is the opportunity to gain insight about your own experience. Additional benefits include the opportunity to contribute to your profession’s body of knowledge and inform your professional practice.

Voluntary Nature of the Study Participation in this study is voluntary. You may withdraw at any time. You may refuse to answer questions at any time.

Confidentiality Participant confidentiality will be maintained through the use of pseudonyms. Transcriptions and all data in print will be stored in a locked filing cabinet. Hard drive information will be encrypted and password protected. Ethics approval from Queen’s University Office of Research will be obtained prior to the initiation of the interviews.

Compensation Your participation in my research will be greatly appreciated although no financial compensation is available.

Further Information: If you have concerns about your rights as a research participant please contact Dr. Albert Clark, (613) 533-6081.
Participant Consent Form

Please contact me if you have any questions about your participation in the research. If you would like to participate, please complete the Consent Form (below) and return this page to me in person or in my mailbox at LDA as soon as possible.

The ‘Expert Patient’ in Health Care Professional Education: Experience of OT Students

I have read and understood the information regarding participation in this study. I have had the purposes and procedures and conditions explained to my satisfaction. I have been given sufficient time to consider the above information and seek advice if I choose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my personal records.

If at any time I have further questions or concerns I can contact:

Jasmin Cameron Duarte (j.cameron.duarte@queensu.ca)

Dr. Mary Ann McColl (mccollm@queensu.ca)

Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospital Research Ethics Board (613) 533-6081

By signing this consent form I am agreeing to participate in this study, which involves approximately 2.5 - 4 hours of interview on 2-3 occasions. I understand that my participation is voluntary, that there is no financial compensation for participation and that I may withdraw my consent at any time without consequence.

___________________  __________________
Signature of Participant                  Date

___________________  __________________
Signature of Witness                  Date

Statement of Investigator
I have carefully explained the nature of the above research study to the participant. To the best of my knowledge, the subject clearly understands the nature of the study, time demands, benefits and risks involved in their participation.

___________________  __________________
Signature of Principal Investigator                  Date
Appendix C: Student Notation Sheet

OT 844 Voluntary Participation

*Name, ID # or Code Name/Symbol: ______________________________

Please:

*Use a consistent code name or symbol to allow your entries to be collated should you submit multiple entries.

*Use your name or email address if you are interested in being interviewed about your experience. Your identity will not be disclosed in the study without your consent.

1. What took place in the midst of your interaction/your peer’s interaction with the ‘expert patient’?: (Please note any challenges, reactions, thoughts, feelings, jottings, ramblings, rumblings, drawings, doodles…..)

2. What took place as a result of or subsequent to your interaction/your peer’s interaction with the ‘expert patient’?: (Please note reflections, rememberings, reminders, recurrences….)
This text from Jac arose in the midst of interacting with the expert patient during the administration of a standardized assessment, one of the curriculum requirements.

| Surprised me?.. Challenged me?... (direct eye contact) Hmmmm... (hand to chin) it was the last assessment... it had a few questions that were hard, in the first two sessions he had highlighted areas we would want to go to back to, thinking these were areas he might have difficulty in... had those possible skill deficits... that was the only challenge... (eyes and head turn down briefly) once we started doing them... inside I felt a little bit bad (facial grimace)... Ya, I felt that “ok I’ve set him up for failure” (gestures with both hands to forehead) and I felt like “Now you need to gain control of this and not make him feel bad for not being able to do it because that’s not want I wanted to do...” So at that point I like... ok 15, 20 seconds, 30 seconds, “He’s not getting it, so it’s time to move on.” “That’s enough... (raises hand in “stop” sign | Assessment questions were hard | Areas he might have difficulty in | Possible skill deficits | That was the challenge | Inside I felt bad | I’ve set him up for failure | Need to gain control and not make him feel bad | It’s time to move on | That’s enough | That one was hard | That’s one of the challenges |
presenting palm to interviewer) I was trying to trick you, **that one was hard.** It’s time to move on..” so I’d say **that’s one of the challenges**…. (direct eye contact)
## Appendix E: Sample Themes Draft

<table>
<thead>
<tr>
<th>Units of Relevant Meaning</th>
<th>Invariant Meanings (Themes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s not working very well</td>
<td></td>
</tr>
<tr>
<td>Not what I wanted to do</td>
<td></td>
</tr>
<tr>
<td>Inside I felt a little bit bad</td>
<td></td>
</tr>
<tr>
<td>I’ve set him up for failure</td>
<td></td>
</tr>
<tr>
<td>I’m not really here to make him feel bad</td>
<td></td>
</tr>
<tr>
<td>I don’t need anything</td>
<td></td>
</tr>
<tr>
<td>I don’t need to know that</td>
<td></td>
</tr>
<tr>
<td>I am [here] to learn..</td>
<td></td>
</tr>
<tr>
<td>that’s really what I’m here for</td>
<td></td>
</tr>
<tr>
<td>But now (ie in this moment)</td>
<td></td>
</tr>
<tr>
<td>I wanted to make sure I wasn’t learning at his expense</td>
<td></td>
</tr>
<tr>
<td>So I just stopped</td>
<td></td>
</tr>
<tr>
<td>It’s time to move on</td>
<td>Start With Respect</td>
</tr>
<tr>
<td>That’s enough</td>
<td>(Respect)</td>
</tr>
<tr>
<td>It’s time to move on</td>
<td>“Client centred” in practice</td>
</tr>
<tr>
<td>I had to make a choice</td>
<td>Expert Patients Don’t Need</td>
</tr>
<tr>
<td></td>
<td>Therapists/Intervention</td>
</tr>
<tr>
<td>…is it really relevant?</td>
<td></td>
</tr>
<tr>
<td>He knows .. how to handle everyday situations</td>
<td></td>
</tr>
<tr>
<td>Its really important to not just rely on standardized assessment</td>
<td></td>
</tr>
<tr>
<td>…Standardized assessments are useful but they are not necessary client-centred…..</td>
<td></td>
</tr>
<tr>
<td>Each client is really unique</td>
<td></td>
</tr>
<tr>
<td>Standardized assessments can give you good ideas but [if] it’s not relevant to the client and it doesn’t matter..</td>
<td></td>
</tr>
</tbody>
</table>
… maybe it’s not important to them…

…We can’t just rely on those types of assessments… We really need to … in fact …Understand what’s important to them

Understanding the importance of what the findings [of an assessment] mean to the individual that we’re working with

there needs to be that respect

you just kind of build from the respect… the relationship’s not going to go anywhere if there’s not that respect you’re not going to respect their goals their opinions…

…everyone has their own goals and their own aspirations so just kind of respecting that .. starting there

You can say “be client-centred” but really until you practice and develop those sills

Maybe that’s why it’s a lot different than just a course on theory

[“expert Patients”] don’t really need our services .. but X [they] are here and X [they] are offering us .. insight

We’re not really coming in with the expectation that we need to ‘fix’ things or do things
He’s an expert Patient, He knows what he’s doing and he knows .. how to handle everyday situations he wasn’t there needing our help to come up with strategies

Evaluation

Know when to stop

Positive experience

Future: Expert Together

Experience of Humility
(Learner’s Quality of Attention)
developing the respect for the client and that collaboration of knowing that they have a lot of knowledge to offer based on what’s important to them and their experience they’ve had in the past

there’s a kind of putting him in the driver’s seat… I am trying to see how you do it.. learn how you do it

A good experience
a really good experience
a learning experience for us

it was a really good learning experience

I’ve learned what I need to learn
And then know when its time to stop
So that its v beneficial for him and for the student s

It … made me feel better about OT

It makes me feel good that I’m going to be a part of a career that maybe will help people do things that they want to do… …

on placement we’re expected to be more the expert and this was nice because he was expected to be the expert… And hopefully in future practice we can both be expert together.

Its kind of a humbling experience

OK… … sometimes I just need to let them teach

<table>
<thead>
<tr>
<th>Collaboration</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Learning</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Reflection on experience: Learning</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Positive experience</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Future: ‘expert together’</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Experience of Humility</th>
</tr>
</thead>
</table>
it … helped balance that [information we know] out with better understanding, the knowledge of what the individual could provide to us…

Finding the balance between them giving us information and us gaining it

This one [this experience] is really important to help balance out…we always talk about the power sharing and who has the power in the relationship but [the EP experience] helps to create an equal distribution of power between the client and the therapist and that I think will definitely led to better outcomes for everyone.

RE the reflection on action that came with the research interview process;

I’m liking it … so I think that this experience would be really really beneficial not only for OTs but just any [health professional].
Appendix F: Statement of OT Values and Beliefs

<table>
<thead>
<tr>
<th>Table 3: Occupational Therapy Values and Beliefs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>About occupation,</strong> We believe that:</td>
</tr>
<tr>
<td>- occupation gives meaning to life</td>
</tr>
<tr>
<td>- occupation is an important determinant of health and wellbeing</td>
</tr>
<tr>
<td>- occupation organizes behaviour</td>
</tr>
<tr>
<td>- occupation develops and changes over a lifetime</td>
</tr>
<tr>
<td>- occupation shapes and is shaped by environments</td>
</tr>
<tr>
<td>- occupation has therapeutic effectiveness</td>
</tr>
<tr>
<td><strong>About the person,</strong> We believe that:</td>
</tr>
<tr>
<td>- humans are occupational beings</td>
</tr>
<tr>
<td>- every person is unique</td>
</tr>
<tr>
<td>- every person has intrinsic dignity and worth</td>
</tr>
<tr>
<td>- every person can make choices about life</td>
</tr>
<tr>
<td>- every person has some capacity for self-determination</td>
</tr>
<tr>
<td>- every person has some ability to participate in occupations</td>
</tr>
<tr>
<td>- every person has some potential to change</td>
</tr>
<tr>
<td>- persons are social and spiritual beings</td>
</tr>
<tr>
<td>- persons have diverse abilities for participating in occupations</td>
</tr>
<tr>
<td>- persons shape and are shaped by their environment</td>
</tr>
<tr>
<td><strong>About the environment,</strong> We believe that:</td>
</tr>
<tr>
<td>- environment is a broad term including cultural, institutional, physical and social components</td>
</tr>
<tr>
<td>- performance, organization, choice and satisfaction in occupations are determined by the relationship between persons and their environment</td>
</tr>
<tr>
<td><strong>About health,</strong> We believe that:</td>
</tr>
<tr>
<td>- health is more than the absence of disease</td>
</tr>
<tr>
<td>- health is strongly influenced by having choice and control in everyday occupations</td>
</tr>
<tr>
<td>- health has personal dimensions associated with spiritual meaning and life satisfaction in occupations and social dimensions associated with fairness and equal opportunity in occupations</td>
</tr>
<tr>
<td><strong>About client-centred practice,</strong> We believe that:</td>
</tr>
<tr>
<td>- clients have experience and knowledge about their occupations</td>
</tr>
<tr>
<td>- clients are active partners in the occupational therapy process</td>
</tr>
<tr>
<td>- risk-taking is necessary for positive change</td>
</tr>
<tr>
<td>- client-centred practice in occupational therapy focuses on enabling occupation</td>
</tr>
</tbody>
</table>

(Adapted from: Polatajko, 1992; and Low, Baptiste, & Mills, 1995)

Enabling Occupation: An Occupational Therapy Perspective, CAOT 1997