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Joanne P. Estes University of Kentucky, estesj@xavier.edu

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Joanne P. Estes, Student Dr. Doris Pierce, Major Professor Dr. Richard Andreatta, Director of Graduate Studies



# OCCUPATIONAL THERAPISTS' EXPERIENCES WITH ETHICAL AND OCCUPATION-BASED PRACTICE IN HOSPITAL SETTINGS

# DISSERTATION

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Health Sciences at the University of Kentucky

By

Joanne Phillips Estes

Lexington, KY

Directors: Dr. Judith Page, Associate Professor, Communication Disorders

Dr. Doris Pierce, Professor and Endowed Chair, Occupational Therapy

2014

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#### ABSTRACT OF DISSERTATION

# OCCUPATIONAL THERAPISTS' EXPERIENCES WITH ETHICAL AND OCCUPATION-BASED PRACTICE IN HOSPITAL SETTINGS

Changes in health care delivery practices are impacting the provision of care in all venues. Occupational therapists working in hospital settings strive to meet professional mandates for occupation-based practice within a medical-model system. Ethical practice is another aspect of service provision vulnerable to contextual influences. The aims of the two studies reported here were to explore occupational therapists' experiences with occupation-based practice, and with ethical issues, in hospital settings. Grounded theory methods were employed for both studies. Data were collected via individual, semi-structured interviews with 22 participants for the first study. For the second study, nine participants participated in individual, semi-structured interviews, journaling, and follow up interviews. Data analysis resulted in four emergent themes for each study. The main themes of the first study were Occupation-based practice expresses professional identity; Occupation-based practice is more effective; Occupation-based practice can be challenging in the clinic; and, Occupation-based practice takes creativity to adapt. The four themes of the second study were Anything less would be unethical: Key issues; I trust my gut: Affective dimension of ethical practice; Ethical practice is expected but challenging; and, It takes a village. Occupational therapists negotiate challenges inherent in contemporary hospital-based practice to provide occupation-based services and to practice ethically. Occupation-based practice is perceived to be more effective than biomedical approaches to intervention. Therapists must employ creative strategies to overcome challenges presented by medical-model service delivery contexts in order to provide occupation-based interventions. In comparison to other health care professionals working in adult rehabilitation practice, occupational therapists experience both common and unique ethical issues. A discovery of this study was that occupational therapists also experience ethical tensions related to team members' and families' sometimes subtle, and less frequently explicit, requests to falsify recommendations in documentation. Experiences with ethical issues include an inherent affective component in the form of moral distress and a strong sense of caring. The impact of systemic/organizational and relational forces is a reality that contemporary occupational therapists must negotiate in order to provide occupation-based and ethical practice.

Key words: occupational therapy, ethics, occupation-based practice, virtue ethics, moral distress

Joanne Phillips Estes

December 15, 2014



## OCCUPATIONAL THERAPISTS' EXPERIENCES WITH ETHICAL

# AND OCCUPATION-BASED PRACTICE IN HOSPITAL SETTINGS

By

Joanne Phillips Estes

Dr. Doris Pierce, OTR/L, FAOTA Co-Director of Dissertation

Dr. Judith Page, CCC-SLP, F-ASHA Co-Director of Dissertation

> Dr. Richard Andreatta Director of Graduate Studies

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#### **Chapter One**

#### Background

Occupational therapy is a health care profession founded in the early 20<sup>th</sup> century with a strong moral imperative for humanistic values (Bing, 1981) and a belief in the curative power of occupation (Meyer, 1922/1977). Throughout its history, the profession's evolution has been shaped by sociocultural and political forces. Most significantly, around the time of World War II, occupational therapy leaders strategically aligned the profession with the medical profession (Reed & Peters, 2006; Reed, Hocking, & Smythe, 2013). The intent of this alignment with a more powerful biomedical model was to strengthen occupational therapy's recognition and acceptance within the health care field. Today, the profession stands "on a medical/social fault line" (Blair & Robertson, 2005, p. 275), working simultaneously in a medical model of practice and in the patients' real world (Yerxa, 1992). A biomedical model of practice is reductionistic in nature, focusing intervention on bodily impairments within patients and targeting goals of correcting physical impairments through medical means, curing disease, and extending lives (Cohon, 2004; Malec, 2009; Schmidt, 2012). In humanistic health care approaches, the individuality of the patient is valued, and care of individual patients focused on their quality of life (Burke & Cassidy, 1991; Yerxa, 1980). Because of Western society's valuing of, and faith in, curative medicine and life-saving medical technologies (Austin, 2007), the biomedical model of practice is perceived by some to be more prestigious and powerful than the humanistic paradigm of practice (Halstead, 2001; Varcoe et al., 2004). In one way, being aligned with the biomedical model of practice is



advantageous for occupational therapy, as it provides access to patients via physician referral. At the same time, this alignment with a biomedical culture and perspective has presented challenges in the form of a paradigmatic conflict for occupational therapists. In reality, this conflict requires occupational therapists to negotiate the provision of humanistic and occupation-based practices inherent in their professional identities, while delivering these services in settings where biomedical-based values predominate (Wilding & Whiteford, 2007).

Change from biomedical, impairment-driven practice to occupation-based practice has been slow to take hold (Molineaux, 2011), especially in medical settings (Chisholm, Dolhi, & Schrieber, 2000). Schell (2003) postulated that a change in clinical reasoning was necessary to promote integration of occupation-based practice into clinical sites. Clinical reasoning is a term that refers to several different modes or types of cognitive processes used by therapists to make practice decisions. To date, there is nothing in the literature addressing the influence of clinical reasoning on occupationbased practice. Research is needed to explore clinical reasoning regarding implementation of occupation-based practice in traditionally medical model settings.

Therapists employed in medical-based facilities face additional challenges that are stimulated by the dynamics of the current health care delivery system. Efforts to control spiraling health care costs in the United States resulted in dramatic changes in health care management and delivery at the end of the 20<sup>th</sup> century. Movement away from fee-for-service practices and toward prospective-payment and managed care was widespread in the 1990s (Gervais, 2004) and effects of these changes have altered the landscape of health care management and delivery. Management practices dominated by business values (Austin, 2007; Peter, MacFarlane, & O'Brien-Pallas, 2004) are



impacting service delivery at the practitioner level. Health care providers are governed by third party reimbursement policies and practices that have resulted in reduced hospitalization lengths of stay (Dobrez, Heinemann, Deutsch, Manheim, & Mallison, 2010), increased demands for evidence-based interventions (Carpenter, 2005), increased requirements for documentation of functional gains (Conroy, DeJong, & Horn, 2009), and diminishing coverage by third party payers who supersede therapists' recommendations for treatment and deny reimbursement for needed therapy (Krusen, 2010; Lopez, Vanner, Cowan, Samuel, & Shepherd, 2008). Service delivery environments are stressful for therapists as they strive to meet patients' needs within the constraints of a business-oriented delivery system (Freeman, McWilliam, MacKinnon, DeLuca, & Rappolt, 2009; Mackey, 2014).

Since the early years of the profession, occupational therapy has had a strong presence in physical rehabilitation services (Bing, 1981). Rehabilitation is a relatively new medical sub-specialty, born to address the needs of disabled soldiers from World War II who survived previously fatal injuries (Banja, 2004). Contemporary rehabilitation practice, while impacted by the managed care practices described above, also has characteristics that differentiate it from the practice of mainstream, acute medicine. Patients are admitted to rehabilitation facilities following acute hospitalization for major trauma, illness, or disease. To qualify for admission, they must be medically stable, able to tolerate three hours of multi-disciplinary therapy regimes per day, and meet the expectation for discharge to home (Conroy et al., 2009). Patients are expected to be active participants and thus need to be motivated, engaged, and invested in order to maximize their potential (Conroy et al., 2009). Furthermore, the rehabilitation ethic reflects the Protestant work ethic: independence, effort, and belief that pain is necessary



in order to achieve gains, all to reach performance-based goals (Wegener, 1996). In fact, it is the patients' values and personal conceptualization of quality of life that determine both treatment intervention and success (Caplan et al., 1987).

Other defining features of rehabilitation include that service delivery by an interdisciplinary team consisting of multiple health care providers, including the patient and the patient's family and/or significant other(s). Team members also bring individual and collective values into the relationship dynamic, fostering opportunities for disagreement and conflict in decision-making regarding goal setting, treatment, and discharge planning (Engle & Prentice, 2013). Additionally, patients' lengths of stay in rehabilitation settings, although decreased in the recent past, are longer than those of patients in acute hospitalizations, and tend to promote closer relationships between health care providers and patients (Poulis, 2007). The final unique feature of rehabilitation is that the decision regarding when to discharge a patient is driven by a combination of forces that include third party reimbursement, team determination of end point, and to a lesser extent, the patient's and/or family's desire to terminate treatment. Third-party payers may stop reimbursement when a pre-determined monetary benefit is reached, or when a patient "plateaus" (i.e. no longer demonstrates functional gain). Team or physician determination of a patient reaching his/her plateau can be subjective and problematic, especially in circumstances where it is difficult to determine whether or not a patient will continue to benefit from rehabilitation (Poulis, 2007). Such a situation is ripe for disagreement between health care providers and third party payers, among health care team members, and between the team and the patient.

Occupational therapists working in rehabilitation settings face many challenges that stem from the current state of health care delivery and from the characteristics of



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rehabilitation practice. Often, these challenges appear in the form of ethical dilemmas, requiring therapists to make difficult decisions and leading to experiences of moral distress. Moral distress occurs in situations where one must compromise personal and professional values due to organizational practices (Varcoe, Pauly, Webster, & Storch, 2012). Therapists' personal and professional values may be challenged as they negotiate decisions that require them to meet standards and expectations from multiple sources, including society, their profession, their employer, reimbursers, other team members, and, perhaps most importantly, their patients and their families (Clark, Cott, & Drinka, 2007; Mackey, 2014). Studies related to ethical issues encountered by occupational therapists in contemporary rehabilitation practice are under-represented in empirical literature.

However, researchers of one study concluded that occupational therapists frequently encounter ethical issues in routine practice. They identified major issues, in descending order of prominence, as reimbursement pressures, conflicts around goal setting, and patient/family refusal of team recommendations (Foye, Kirschner, Wagner, Stocking, & Siegler, 2002). In general, occupational therapy's conceptual and theoretical literature related to ethics is sparse and dated. Research is needed to identify current ethical issues encountered by occupational therapists practicing in adult rehabilitation settings.

#### **Statement of the Problem**

Contemporary occupational therapists practicing in medical-model, rehabilitation settings face several challenges, about which there exists little information. The first challenge centers on how therapists negotiate meeting the profession's moral mandate



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for humanistic, occupation-based intervention while providing services at a pediatric medical center setting. The second challenge centers on the identification of salient ethical issues inherent in practice, along with contextual factors that facilitate and/or impede their practicing according to the profession's prevailing ethical standards.

#### **Statement of Purpose and Research Questions**

The purpose of this two-part study was to explore with occupational therapists employed at medical-model based settings their perceptions of the dynamics of doing occupation-based practice, and of ethical issues inherent in their practice along with factors that promoted and impeded ethical practice. It was anticipated that, through a better understanding of these factors that influence everyday practice, therapists could positively influence policy formation in order to better promote occupation-based and ethical practice. To illuminate this problem, the following research queries were addressed:

Study 1/Research query 1: What are the supports and barriers to occupation based practice experienced by occupational therapists at a pediatric medical facility?

Study 2/Research queries 2 and 3: What are occupational therapists' experiences with ethical issues in contemporary adult rehabilitation practice? What are supports and barriers to ethical practice by occupational therapists working at an adult rehabilitation facility?

#### **Research Approach**

The design of these studies was qualitative, in the tradition of grounded theory (Charmaz, 2014). I chose qualitative inquiry because I wanted to explore in depth issues related to occupation-based practice and ethics in practice with therapists who



experienced these in their natural work environment (Creswell, 1998). Qualitative inquiry assumes that reality is socially constructed (Glesne, 2006) by research participants. By entering the therapists' world, I was able to generate authentic knowledge about the realities of their day-to-day practice. In conducting grounded theory studies, researchers enact a "systematic, inductive, and comparative approach for conducting inquiry" (Bryant & Charmaz, 2007, p. 1) in order to produce a theory that is grounded in the data that is collected. Thus, I gathered data through individual, semistructured therapist/participant interviews, participant reflective journaling, and follow up telephone interviews. In the tradition of grounded theory, data collection and analysis occurred simultaneously (Charmaz, 2014) and culminated in the development of emergent themes of meaning in the form of substantive theory that can inform occupational therapy practice.

#### Assumptions

I held five primary assumptions prior to commencing data collection for each study. These assumptions stemmed from my doctoral studies, professional experience, review of the literature, and attendance at professional conferences. The first two assumptions relate to research query 1. For this study, I assumed that participants were familiar with concepts related to occupation-based practice. This assumption was based on an in-service presentation I provided to potential study participants at the pediatric medical facility, introducing them to this topic. I also assumed that participants in that study would be able to articulate experiences of both supports and challenges related to implementing occupation-based practice at that facility. The last three assumptions relate to research queries 2 and 3. For this study, I assumed that participants would be



knowledgeable of their ethical responsibilities based on their professional education and state licensure continuing education requirements. Second, I assumed that the dynamics of contemporary rehabilitation service delivery produced ethical issues for study participants. Third, I assumed that, with the prompts provided by participation in the study, participants would be able to identify factors that both supported and challenged their meeting the prevailing professional ethical standards.

#### **The Researcher**

At the time of conducting these studies, I had completed coursework in the Rehabilitation Sciences Ph.D. Program at the University of Kentucky. Along with core rehabilitation science coursework, my studies centered on qualitative research methodology, health care ethics, and discipline-specific coursework in occupational therapy (i.e. occupation-based practice and clinical reasoning). I am a faculty member in Xavier University's Department of Occupational Therapy Master's Program, having served in the capacity of consultant (i.e. designed both the Bachelor of Science and Master of Occupational Therapy curricula), Department Chairperson, and faculty member since 1995. My current responsibilities include teaching coursework related to human occupation across the lifespan, research methods, and professional issues and ethics, along with serving as faculty tutor for graduate student capstone research projects. My doctoral education and professional experience prepared me to carry out these research projects.

My fascination with, and passion for, occupation-based practice and clinical ethical issues provided intrinsic motivation for completing these research projects. As an occupational therapist, I hold a firm belief in the complexity and healing power of



human occupation. This belief supported my practice as I provided client intervention in my past role as a clinician; as I educate future occupational therapists; and as I conduct research to contribute to the profession's knowledge base. In clinical practice, I experienced first-hand how occupational participation transformed clients' lives. As an educator, I strive to ignite in my students my own passion for occupation-based practice. And, as a researcher, I hope that my work will produce knowledge to support and expand occupation-based practice.

It was this last hope that led to my conducting a study on the provision of occupation-based practice at a medical-based facility. Occupational therapists operate within a moral mandate for intervention that is firmly based on occupation (American Occupational Therapy Association, 2010). Occupation is the reason our profession exists and without it, as was so eloquently stated by one of the study's participants, we are not doing occupational therapy. While I have always believed in the power of occupation as a foundation for practice, somewhere along the course of my professional life, "occupation" moved out of my foreground. It did not disappear, but rather was buried. Then, I took two courses about occupation and occupational therapy as a part of my doctoral studies and they changed my professional life. The spark that was my passion for occupation was re-ignited in a big way. These courses reminded me why I became an occupational therapist and why I remain passionate about my chosen profession. Our professional ethos once again became clear to me and created a renewed excitement for learning more about and teaching concepts related to human occupation. I became curious as to how occupational therapists do occupation-based practice: what factors make it easy, and what factors make it difficult? Again, it was my hope that the



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answers to these questions will lead to more occupation-based and therefore higher quality interventions for occupational therapy recipients.

Conducting the first study, learning how powerfully the service delivery context can impact practice, inspired to conceptualize of the other study. I believe that ethical practice is also at the heart of occupational therapy practice. Technical skills are important, but must be delivered ethically. If not, our clients will not receive optimal care and may actually be harmed. I have also directly observed unethical behavior by occupational therapists. As the Education Representative on the American Occupational Therapy Association's Ethics Commission, I have processed some nearly unbelievable reports of ethical misconduct. These experiences led me to questions about ethical misconduct in occupational therapy practice. That is, what causes clinicians to act in unethical ways, and what circumstances lead to their experiencing moral distress? My hope was that answers to these questions could provide a vehicle for strengthening supports and diminishing barriers to ethical practice. Ultimately, I hope that answers to these questions lead to more competent and caring interventions for the recipients of occupational therapy services.

#### **Rationale and Significance**

The rationale for these studies stems from my desire to contribute to professional knowledge in two areas that are currently lacking in the literature (i.e. dynamics of occupation-based practice and ethical issues in practice). Knowledge gained from these studies could serve as affirmation for therapists who are experiencing similar challenges and rewards related to occupation-based practice and also to navigating ethical issues common to contemporary practice. Findings from these studies could also serve as a



foundation for shared problem-solving by therapists in order to influence policy formation that will promote occupation-based and ethical practice. Additionally, the identification of current ethical challenges faced by occupational therapists can also provide data for the American Occupational Therapy Association's Ethics Commission to update the *Occupational Therapy Code of Ethics* (American Occupational Therapy Association [AOTA], 2010) and to develop educational materials that better support occupational therapists to engage in authentic and ethical practice.

#### **Definitions of Key Terms**

Altruism: "Motivation for helping behavior or it may be considered as the behaviour [sic] itself.... being devoted to or living for the welfare of others" (Burk & Kobus, 2012, p. 318).

**Autonomy:** "The governing of oneself according to one's own system of morals and beliefs or life plan" (Veatch, Haddad, & English, 2010, p. 431).

Beneficence: Acts intended to benefit others (Beauchamp & Childress, 2013).

**Bioethics:** "All ethical issues relating to the creation and maintenance of the health of living things. . . .including medical ethics" (Dawson, 2010, p. 218).

**Biomedical model:** Prevailing foundation for medical practice; values objectivity and reductionistic approach3es that focus on finding causes of and medically-based cures for disease entities (Borrett, 2012; Lundström, 2008).

**Clinical reasoning:** Thinking and perceiving processes that occupational therapists use in making practice decisions (Mattingly & Fleming, 1994).

**Conditional reasoning:** Reasoning process used by occupational therapists as they "attempt to understand the 'whole person' in the context of the life-world, given the



influence the disability may have on the person's future" (Mattingly & Fleming, 1994, p. 197).

**Confidentiality:** "Involves those who have legitimate access to private information not brining it out of that sphere and sharing with others without permission" (Mappes & DeGrazia, 2006, p. 168).

**Distributive justice:** "The just allocation of society's benefits and burdens" (Veatch et al., 2010, p. 432).

**Ethical:** "An evaluation of actions, rules, or the character of people, especially as it refers to the examination of a systematic theory of rightness or wrongness at the ultimate level" (Veatch et al., 2010, p. 432).

**Ethical climate:** "The influence of organizational practices and procedures on the ethical beliefs and behaviors of employees" (Olson, 1998, p. 348).

**Ethical reasoning:** "Reasoning directed to analyzing an ethical dilemma, generating alternative solutions, and determining actions to be taken; systematic approach to moral conflict" (Schell & Schell, 2008, p. 7).

**Fidelity:** "The state of being faithful, including obligations of loyalty and keeping promises and commitments. Also the principle that actions are right insofar as they demonstrate such loyalty" (Veatch et al., 2010, p. 432).

**Grounded theory:** "A method of conducting qualitative research that focuses on creating conceptual frameworks or theories through building inductive analysis from the data" (Bryant & Charmaz, 2007, p. 608).

**Interactive reasoning:** Form of clinical reasoning employed by occupational therapists in order to understand their patients as individuals; understand patients' perspective of illness experience (Fleming, 1991).



**Justice:** "A group of norms for fairly distributing benefits, risks, and costs" (Beauchamp & Childress, 2013, p. 13).

**Managed Care:** "Organization that combines health care insurance and the delivery of a broad range of integrated health care services for populations of plan enrollees, financing the services prospectively from a predicted, limited budget" (Buchanan, 2006, p. 653).

**Moral dilemma:** Situation where two (or more) moral convictions or right courses of action conflicts with one another; there is not one, clearly correct course of action (Jameton, 1984).

**Moral distress:** Feelings that ensue in situations where an agent is constrained from acting accordance with the correct moral course of action by external constraints (Jameton, 1984).

**Moral:** "An evaluation of actions or the character of people, especially as it refers to ad hoc judgments by individuals or society" (Veatch et al., 2010, p. 432).

**Moral theory:** "Concerns questions about the morality of actions (what to do) as well as the morality of persons (how to be) (Timmons, 2002, p. 7).

**Moral uncertainty:** Scenario in which an agent is uncertain about whether a moral problem exists, and if so, which moral principles are relevant (Jameton, 1984).

**Narrative reasoning:** "Reasoning process used to make sense of people's particular circumstances, prospectively imagine the effect of illness, disability, or occupational performance problems on their daily lives, and create a collaborative story that is enacted with clients and families through intervention" (Schell & Schell, 2008, p. 7).

**Nonmaleficence:** "The state of not doing harm or evil; cf. beneficence. Also the moral principle that actions are right insofar as they avoid producing harm or evil" (Veatch et

al., 2010, p. 432).



**Occupation:** "Daily life activities in which people engage. Occupations occur in context and are influenced by the inter-play among client factors, performance skills, and performance patterns. Occupations occur over time, have purpose, meaning, and perceived utility to the client; and can be observed by others . . . or be known only to the person involved" (AOTA, 2014, p. S43).

**Occupation-based practice:** Using occupation as the focus of intervention either as occupation as means (i.e. "use of therapeutic occupation as the treatment modality to advance someone toward an occupational outcome") or, occupation as ends (i.e. "over-arching goal of all occupational therapy interventions") (Gray, 1998, p. 358; p. 357).

Organizational ethics: Ethical issues related to management of health care organizations, including implications of decisions for key stakeholders (Gibson, 2012).Pragmatic reasoning: "Practical reasoning used to fit therapy possibilities into the

current realities of service delivery" (Schell & Schell, 2008, p. 7).

*Prima facie* duty: "[An] obligation that must be fulfilled unless it conflicts with an equal or stronger obligation" (Beauchamp & Childress, 2013, p. 15).

**Procedural reasoning:** Reasoning process used by occupational therapists in defining a patient's problem(s) and deciding on treatment procedures to remediate the problem(s) (Fleming, 1991).

**Virtue ethics:** "Focus on the agent; on his or her intensions, dispositions, and motives, and on the kind of person the moral agent becomes, wishes to become, or ought to become . . . the normative standard is the good person, the person upon whom one can rely habitually to be good and to do the good under all circumstances" (Pellegrino, 1995, p. 254).



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# **Chapter Two**

Pediatric Therapists' Perspectives on Occupation-based Practice Manuscript published in the *Scandinavian Journal of Occupational Therapy* 

#### ORIGINAL ARTICLE

# Pediatric therapists' perspectives on occupation-based practice

# JOANNE ESTES<sup>1</sup> & DORIS E. PIERCE<sup>2</sup>

<sup>1</sup>Department of Occupational Therapy, Xavier University, Cincinnati, Ohio, USA, and <sup>2</sup>Department of Occupational Therapy, Eastern Kentucky University, Richmond, Kentucky, USA

#### Abstract

Aims: The aim of this study was to describe the perspectives on occupation-based practice of 22 pediatric occupational therapists in a medical facility in the Midwestern United States. *Methods:* The study used a grounded theory approach to analyze the individual, semi-structured interviews of 22 pediatric occupational therapists. Transcripts were initially coded using Ethnograph<sup>T</sup> 5.0 software and analysis continued using constant comparison techniques and memo writing to produce emergent themes of meaning. *Findings:* The doing of occupation-based practice was based in personal identity and influenced by professional education. Occupation-based practice was more satisfying and rewarding for therapists, and they found it more effective and individualized. Patients and families were perceived by therapists to find occupation-based practice more motivating, understandable, valuable, and easily generalized to everyday life. However, occupation-based practice was seen as more difficult in a medical-based facility because pragmatic factors and contextual forces exerted strong influences. *Conclusions:* Therapists used specific creative strategies to negotiate between competing paradigms to maximize occupation-based practice within constraints.

Key words: grounded theory, occupation-based practice, pediatric practice, qualitative

#### Introduction

In the United States, the scientific discipline of occupational science is interested in understanding how occupational therapists use occupation in practice (1,2). Research on occupation-based practice can also inform the profession of occupational therapy. The purpose of this study was to describe the perspectives on occupation-based practice of 22 pediatric occupational therapists in a medical facility in the Midwestern United States.

#### Occupation-based practice defined

Occupational therapy was founded upon the premise that participation in occupation influences one's health and well-being. Yet, a tension exists in the field between intervention based on a biomedical orientation and a more holistic, occupation-based perspective (3). Contemporary occupational therapy leaders and scholars have called for a return to a stronger occupation base for practice (4,5). In the words of a therapist in a previous study, occupationbased practice is "using occupation as the framework for intervention" (6) with another author specifying that occupation can be used as a means or as an end of therapy (7). Schell (8) postulated that a change in clinical reasoning is necessary to promote integration of occupation-based practice into clinical sites.

#### Occupation-based practice research

Considering the centrality of applications of occupation to the profession, research on occupation-based practice is surprisingly limited within occupational therapy (9). For adult populations, a 1997 landmark randomized control trial demonstrated significant benefits of a nine-month occupation-based wellness

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Correspondence: Joanne Estes, MS OTR/L, 8659 Hetheridge Lane, Cincinnati, OH 45249, USA. Tel: +513 745 3018. Fax: +513 489 2517. E-mail: estesj@xavier.edu

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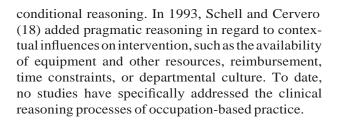
program for the elderly (2). An Australian study concluded that while doing occupation-based practice at an acute medical facility can be challenging, participants were inspired to make changes (10). Recent literature on occupation-based practice with pediatric populations showed that some pediatric therapists used an occupation-based approach and others a biomedical approach and concluded that using the occupation-based focus made a unique contribution to the healthcare team (3). Humphrey et al. (11)echoed the call for promoting occupational therapy's unique focus by advocating for an occupational perspective of child development and surmised that intervention based on "interconnectedness of elements of a situation, a person, and an occupation..." (p. 265) is more effective in promoting participation.

Other recent literature on pediatric occupationbased practice explored intervention directed at facilitating co-occupations of mothers and children. In two separate case presentations, authors demonstrated how an occupational therapist negotiated occupation-based practice simultaneously with biomedical intervention in a neonatal intensive care unit, a traditionally strong biomedical context (12,13). These articles described how the occupational therapists' intervention extended beyond the infants' physical needs by involving parents as clients and employing therapeutic use of self (12) to develop co-occupations and address development of a family unit (13). Price et al. (14) extended the focus on co-occupations in occupation-based intervention with a pre-school child and concluded that co-occupations between a parent and child were important for child development and for relationship development.

Occupational performance coaching (OPC) is another form of occupation-based practice with children. OPC is a family-centered collaborative process whereby parents are guided by occupational therapists to identify occupational performance-related goals and solutions to performance barriers (15). Goals may be related to occupational performance of the child, the parents, or the family (15). Recognizing, enabling, and modifying limiting elements of the performance environment constitutes the focus of the problem-solving processes (15). Preliminary research with three parent–child dyads showed OPC to produce positive changes in the childrens' and parents' activity-, task-, and routine-related goals (16).

#### Clinical reasoning

Clinical reasoning is a (8) "process used by therapists to plan, direct, perform, and reflect on client care" (p. 131). In their pivotal study, Mattingly et al. (17) described clinical reasoning as several levels of thinking, including procedural, interactive, and



#### Methods

#### Design

Since the perspectives of pediatric therapists on occupation-based practice have not been thoroughly explored, a qualitative grounded theory approach was used to generate a substantive theory of sufficient detail to be useful in practice (19,20).

#### Participants

Twenty-two occupational therapists at a Midwestern children's hospital medical center served as a purposive sample (21). This facility was chosen because they desired to increase their occupation base of practice and study findings would inform this goal. Therapists worked at the main hospital, as well as at four suburban outpatient satellite facilities. Participants included four males and 18 females, with a range of one to 35 years of experience as a therapist, and one to 17 years in that setting. Therapists treated children from newborn to 20 years of age in inpatient and outpatient settings. Diagnoses included the broad spectrum of pediatric conditions typically treated by occupational therapists.

#### Data collection

As requested by the research site, the first author presented an in-service overview of occupationbased practice to therapists of the setting as an exchange of value for the site's willingness to participate in the study, as an introduction to topics that might be addressed in interviews, and as an invitation to therapists to participate in the study. Topics included in the presentation included the Occupational Therapy Practice Framework (22); definition of occupation-based practice as the use of occupation as the means and ends of intervention (7); differentiation between occupation-based practice and componentfocused practice (23); occupation-based assessment, e.g. Canadian Occupational Performance Measure (24); the therapeutic power of occupation (5); and change theory (25).

Fifteen months following the presentation and after the human subjects review approval, semi-structured interviews of 30 to 45 minutes in length were



conducted with each therapist. Interview questions asked about supports and barriers to occupationbased questions with probing used to expand depth and breadth of responses. Interviews were transcribed verbatim, producing 268 double-spaced pages of data.

#### Data analysis

Grounded theory research, developed by Glaser and Strauss in the 1960s, produces theory that is grounded in or built from data (26). Since its inception, grounded theory research has evolved and diversified in terms of how structured analytic procedures should be or how general or abstract resultant theory should be (20,26–28). According to Charmaz (28), grounded theory methods, e.g. constant comparison, multiple levels of coding, memo-writing, and theoretical saturation, are flexible guidelines rather than prescriptive rules.

Analysis was collaborative. The first author immersed herself in the data, repeatedly reading each transcript to develop the initial 60-category draft coding scheme (19,29). The second author used a return to the data to condense and test the coding scheme. Data were fully coded, using Ethnograph 5.0. Data analysis used constant comparison to develop full descriptive memos for each code (20). Then, categories expressing factors that crossed the previous set of codes, often called secondary or axial codes, were identified and used to develop second-level interpretive memos. Again, new relationships were identified and third-level descriptions of several emergent themes were crafted, as reflected in the following results. At this point, the researchers determined that they had reached theoretical saturation. Themes were highly descriptive of the dynamics and factors of occupation-based practice. The desired degree of detail enabling the substantive theory to guide daily practice had been reached. Substantive grounded theory is specific to groups and place (30) and is "a theoretical interpretation or explanation of a delimited problem in a particular area" (28, p. 89), as opposed to formal grounded theory, which is based on substantive core concepts but is extended in depth, breadth, and abstraction (31). The researchers then moved into research completion activities, including member check and write-up (20).

# Trustworthiness and limitations

The trustworthiness of the study was supported by multiple analysts, expert peer review, and a member check with 10 occupational therapists employed at the research setting (21,32). The use of interviews as the



sole source of data is acknowledged as a limitation to its findings. Also, since the perspectives of this group of pediatric occupational therapists may not fully represent those of other occupational therapists, generalization is necessarily limited.

## Results

Data analysis produced multiple related themes with regard to the therapists' perspectives on occupationbased practice. To this group of 22 pediatric occupational therapists, occupation-based practice expressed professional identity, was more effective, could be difficult in the clinic, and required "creativity to adapt".

# Occupation-based practice expresses professional identity

Identity grounded in occupation. Intrinsic perceptions of what it meant to be an occupational therapist drove the degree to which therapists used an occupation-based practice approach. Almost half of the participants indicated that they incorporated occupation-based practice because it was central to their professional identity. "It's a very basic principle of occupational therapy.... If you're not using occupation then what are you doing? ... that's our strength and we should point to it".

*Educational background.* A few participants mentioned the degree to which academic and fieldwork portions of their educational programs shaped their occupation-based approach to practice. "(My school) was very occupation-centered.... It was 'don't be the therapist that sits there and stacks cones'." Some participants described how educational histories emphasizing biomechanical practice resulted in their not presently using an occupation-based practice approach. "Educationally, that's where I come from, twenty years ago... NDT types of [approaches] ... it's not occupation-based ... and in this clinic environment it works really well".

# Occupation-based practice is more effective because

It is more enjoyable and rewarding. Some participants stated that their use of occupation-based practice is further reinforced by the fact that it was more enjoyable. Customizing interventions, being creative, changing and adapting for each child, and playing with the children makes work as an occupational therapist more interesting.

I don't have a bag of 10 creative tricks to use, I feel like I am constantly changing and adapting for each child and it's always completely different. I think

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it's less burn-out that way because I am not doing the same thing over and over.

*It is highly customized.* Half of the participants observed that the individualized design of intervention was a key component of occupation-based practice, matching interventions to the interests of each child. To this end, four participants stated that they let the child guide what will be done in treatment. Similarly, some participants said that they must set aside their own agendas for the child, or enfold their objectives into the child's agenda, in order to produce successful results.

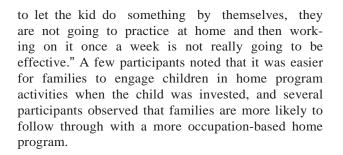
I think OTs have to be creative.... I just don't think any of [the kids on my caseload] would be progressing as well if I used the same exact same thing with each one of them. So, since I have to make it more occupation-based and individualized, I really have to be creative and if I weren't I don't think they would be making nearly as much progress.

It is valued and understood by children and families. A key finding of this study was the strong perception by therapists that, because children and families value and understand occupations, occupationbased practice is more family-centered, is more motivating for children, and generalizes better to everyday life. When communicating about desired goals or outcomes for intervention, the patients' and families' goals were usually expressed in terms of desires for success in performing specific occupations, rather than as desired gains in component functions.

A lot of times the parent's goal is an occupation and that is what you want to be accomplishing. So why not just work on the occupation and break it down even into its small [steps] ... and have them do ... what they are wanting to do?

Many participants observed that children were more motivated in therapy when treatment revolved around valued occupations. Similarly, as some participants noted, the children seemed more engaged when working on something in which they had interest, rather than on something imposed upon them. A couple of therapists noted that there was no power struggle when occupations were designed to meet the unique needs of each child.

According to the therapists, when intervention was occupation-based, not only were children more motivated to participate but families were too. Implementation of home programs was perceived to be better when treatment consisted of valued occupations. "If [the family is] not motivated



# Occupation-based practice can be challenging in the clinic because

It takes more time. The primary issue identified as impeding occupation-based practice was time constraints. Almost all of the 22 participants noted that occupation-based practice takes more time. Extra time is required to plan, prepare, implement, and clean up, and no time for that was built into the therapists' daily schedule.

I think it goes back to the time. You know, there are a lot of meaningful activities that I could do but I would need to prepare and plan for that ahead of time so that I had the supplies and equipment and those things readily available when that patient walks in the door. And you know we have patients back to back.

The clinic environment is too "artificial". Most of the participants noted that the artificiality of the clinical context limited occupation-based practice, in an interesting variety of ways. Over half of the participants specifically stated that it is difficult for therapists to observe authentic child behavior because the influence of the clinic setting on the behavior of interest is different than that of home or community contexts. The clinic is structured for success, which is quite different from the child's natural context. Replicating a natural performance in a clinic setting can also be difficult. The real problem may not even appear in the context of the clinic.

Because the "artificiality" of the clinical context impedes the quality of occupation-based practice, almost half of the participants voiced the desire to be able to go into the child's natural context: his/her home, school, and community. They believed direct observation of the child's performance would assist them in identifying key issues and planning more effective interventions.

So I think that it would be interesting too to spend ... a day with some of our clients in their world, like really in their world, and seeing all the little things. They come to us in the clinic saying "Oh, they can't get dressed", but you could come up with, if you watch them in their home, maybe



five or six other little things that you can give real simple suggestions and that might make them feel much more successful.

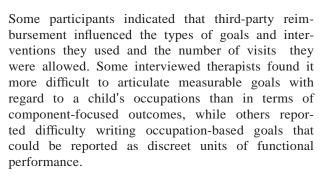
Similarly, a few of the participants pointed out that it can be difficult for parents to implement interventions demonstrated in clinic in the home environment.

*Clinic space and object availability limit practice.* Most of the participants described spatial constraints to occupation-based practice, including lack of easy availability of designated spaces, crowding (and its influence on patients' behavior), and lack of storage. Although interviewees agreed that toys, equipment, and supplies were plentiful at this facility, there were still problems with object availability. Some participants made the point that available toys might not be appropriate for older children, might be worn and dysfunctional, or might not be suitable for more highly involved children. A few participants stated that, although equipment could be easily purchased, a lack of storage space was a problem. Biomechanical or medical equipment could also be a barrier to occupation-based practice and, for a therapist working in patient rooms, equipment and supplies were not easily accessible.

It requires good parent involvement. A lack of active parent involvement was considered a barrier to high-quality occupation-based practice. A couple of participants indicated that it may be difficult for parents to implement the home program, due to competing demands for their time. Some participants noted it could be difficult to communicate with families regarding treatment and home programs as some parents were not able to attend therapy sessions.

It can be supported or impeded by clinical culture. While discussing their crafting of occupationbased practice, almost half of the participants described the culture of their occupational therapy department as supportive through both a general atmosphere of support from department administrators and supervisors and specific support for occupation-based practice. Several participants noted direct support for occupation-based practice from peers and co-workers.

Traditional medical culture was generally viewed as impeding occupation-based practice. A few participants commented that physicians' control of access to patients was problematic when physicians were not aware of the services occupational therapy offered, were reluctant to refer due to a perceived lack of evidence of efficacy, or when a referral was written specifically for biomechanical interventions.



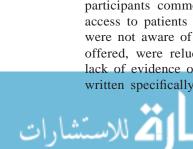
"*Mind shifting is too hard*". Professional preparation that was not structured around occupation-based practice was described as a barrier to occupationbased practice. A few participants noted that in order to implement occupation-based practice, they would have to "change" their thinking process regarding treatment planning and implementation, or make a "mind shift". A couple of participants noted that it is easier to fall back on component-focused intervention because they are more familiar with that type of intervention and it is quicker and easier to implement. One participant noted that his/her lack of experience also serves as a barrier to implementation of occupation-based practice.

Over half of the participants reported that, although they use a component-focused approach, they are targeting the occupational needs of the child. These participants noted that it was important that the "end goal" or "big picture" be kept in mind when doing component-focused interventions. One participant noted that there might be multiple component deficits causing occupational dysfunction and solely using occupation as intervention would not necessarily target all of the components and subsequently produce occupational functioning.

I'll do some repetitions with people, but it's ultimately about the security of the joint, the how it's going to work when I am trying to get them to do a certain function in the end. So whether it's homemaking, whether it's wheeling the wheelchair ... it's got an end goal to it.

#### Occupation-based practice requires "creativity to adapt"

One participant described his/her efforts to maximize the degree to which he/she was able to provide occupation-based practice within clinical realities as "creativity to adapt". Others also described this ability to generate innovative solutions and treatments and to work outside the constraints of the clinic environment. They perceived the culture of their department as supporting this creativity; several participants stated that they have the freedom to be as creative as they would like to be.



Therapists also used creativity in treating children confined to their rooms. They adapted the environment as much as possible, such as bringing in mats to allow out-of-bed play. One participant said that, when doing bedside treatments, he/she may have to "make something out of nothing". Another noted that he/she could "do my therapy with a box of Kleenex" along with creative play.

#### Summary of results

Several dynamic forces acted simultaneously to influence the degree to which practice was occupationbased (Figure 1). Professional identity and education background grounded in occupation were a base for occupation-based practice and having creativity to adapt was a fulcrum point upon which occupationbased practice depended. Therapists' perceptions that occupation-based practice was more effective supported and reinforced its application. Effectiveness factors included that it was more enjoyable and rewarding, highly customized, and valued by children and families. At the same time, occupationbased practice was more challenging because it required more time, took place in an artificial clinic environment, was limited in space and object availability, required good parent involvement, was impeded by medical culture, and the therapists' mind-shifting to an occupation-based approach was too hard.

#### Discussion

#### Key findings

The combined practice experience of this group of pediatric occupational therapists has, through this study, resulted in the following perspectives on occupation-based practice. Using an occupationbased approach was strongly tied to professional identity, which was in turn shaped by educational background. In congruence with their professional identities, the therapists found occupation-based practice more enjoyable, rewarding, and effective, due to several specific factors. First, it is customized to the needs of each child. And second, because children and families value and understand occupations, occupation-based practice is more family-centered, is more motivating for children, and generalizes better to everyday life. Participants in the study also viewed occupation-based practice as difficult to implement in the clinic because it takes more time; the clinic environment is too artificial; clinic space is limited; needed objects may not be available; and parent involvement may be limited. Clinical culture can support or impede occupation-based practice. And "mind-shifting" from a more biomedical approach may be too hard for some therapists. Lastly, therapists felt that occupation-based practice required "creativity to adapt", or the ability to generative innovative solutions to overcome challenges to occupation-based practice.

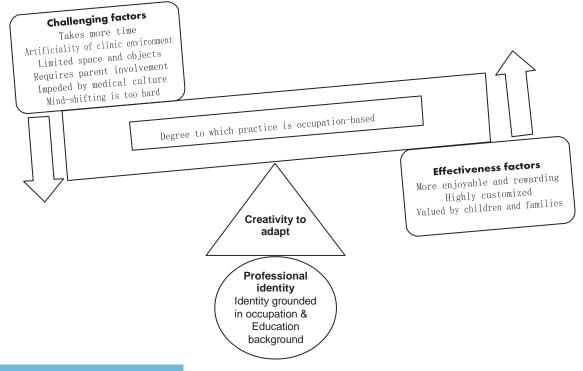


Figure 1. Dynamic balance in the doing of occupation-based practice.

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# Occupation-based practice, professional identity, and work satisfaction

Among the primary results of this study, some aspects bring to light new considerations with regard to occupation-based practice, while others are congruent with previous studies. The ties of occupationbased practice to professional identity, education, and work satisfaction have not yet been studied, although educators and others have certainly identified their importance to the profession (4,33).

#### Effectiveness of occupation-based practice

The therapists' perspectives on the greater effectiveness of occupation-based practice, which was grounded in their everyday practice experiences, provide an interesting contrast to current discourse with regard to the evidence base of the profession. Instead of research that demonstrates the effectiveness of practice, such as clinical trials or meta-analyses regarding specific populations and approaches, this group of participants described active dynamics of daily practice that improved their observed intervention results, such as treatment customization and the degree to which the valuing and understanding of occupations support family-centeredness, client motivation, and generalization. Although many of these findings open new avenues of thinking regarding the efficacy of occupation-based practice, they are also congruent with the venerable record of research by Nelson (34) and others (35) on the greater efficacy of purposive versus rote activities in intervention. A greater development of research into the tie of client/family understanding, and generalization to home, of occupation-based interventions would also be a strategic contribution in this area.

#### Family-centeredness and occupation-based practice

According to contemporary literature, best practice in pediatric occupational therapy is characterized as being occupation-based and family centered (15). Therapists in this study related their observations concerning the success of occupation-based practice to the fact that it is inherently occupation-based. Family-centered care acknowledges the collaborative role of family involvement in all phases of the intervention process (36). Interventions based on familycentered care target occupations that are meaningful and important to the family (37). Findings of this study indicate that parents' goals are communicated in occupational terms and as such forge a natural connection between occupation-based and familycentered care. The better therapeutic outcomes and increased parent satisfaction associated with



occupation-based practice in this study are consistent with the findings of family-centered care research (24,38).

# *Clinical setting limitations to the effectiveness of occupation-based practice*

In this study, many aspects of the clinic setting were identified as limiting to occupation-based practice. The importance and use of context in occupationbased practice has been described by Pierce and colleagues (5,6,39). Pierce (39) has argued that the power of occupation-based practice is impacted by the degree of the "intactness" (p. 249) of the occupation used as intervention. In other words, the degree to which usual contextual conditions in which that occupation would occur if not used as treatment are present, or the lack of artificiality, is key to the therapeutic effectiveness of an occupationbased intervention. The concept of intactness refers to many of the factors named by the study's therapists, especially parent involvement, intervention space, and availability of objects. The therapists desire to see clients in their usual contexts also supports this recognition that the quality of occupation-based practice depends on the intactness of intervention.

It is also at this juncture that findings of this study with regard to occupation-based practice most closely intersect with research on clinical reasoning. The findings reflect that pragmatic reasoning strongly influences the doing of occupation-based practice. Pragmatic reasoning is concerned with the influence of contextual factors on practice. Similar to other research (40,41), pragmatic factors were barriers to practice. Specific barriers were in the form of time pressures, equipment and space availability, caseload issues, and reimbursement (40–42).

#### Implications for future research and practice

The implications of this study for future research are several. It is important to continue to tap the wisdom of therapists in practice, through research designs that give them voice. Areas of occupation-based practice that call for research attention include the following: the tie of occupation-based practice to therapist identity and work satisfaction; client and family perceptions of occupation-based practice; the spatial and temporal contexts of occupation-based practice; exemplars of occupation-based practice that deliver intervention to those clients usually seen in medical settings but still exceed the degree of artificiality of usual clinical context; clinical reasoning with regard to specific approaches and mind-shifting between approaches; and therapist creativity.

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The study's findings can be especially useful in guiding improvements in occupation-based practice. Therapists can transcend medical-model-based practice by maintaining a strong intrinsic professional identity centered on core constructs of occupation. This identity is formed and sustained through socialization during professional education and/or reading current literature on occupation-based practice. A strong occupation-based identity can stimulate shared problem-solving to influence institutional policies and procedures and promote changes to strengthen the occupation base of practice. Therapists can be creative in infusing occupationbased practice strategies such as finding ways to treat children in their natural environment. Creative changes in space design, object choice, and practice-management strategies can also promote occupation-based interventions.

#### Conclusions

The importance of this study is that it examined the defining concept of occupational therapy, that it extended current understandings of occupationbased practice, and that it illuminated the intersection between occupation-based practice and clinical reasoning. The voices of these occupational therapists tell what it is like to "do" occupation-based practice in a hospital clinic setting. Pierce (5) asserted that, in order for the knowledge produced by occupational science to be applied in practice, three bridges must be built between occupational science and occupational therapy: a generative discourse, educational programs, and demonstration programs, all focused on occupation-based practice. Findings from this study contribute to the generative discourse that is refining our understanding of occupation-based practice.

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المنسارات

# **Chapter Three**

It would be easy if I didn't care: Ethical Issues in Rehabilitation

A Manuscript for submission to the Canadian Journal of Occupational Therapy



#### Abstract

**Background.** Health care providers in the adult rehabilitation sector face a variety of ethical issues, however, the literature related to ethical issues encountered by occupational therapists is dated and limited in scope. **Purpose.** The aim of this study was to explore occupational therapists' experiences with ethical issues in adult rehabilitation practice. **Methods.** A qualitative grounded theory study was conducted. Nine participants shared their experiences in individual semi-structured interviews, participant journaling, and follow-up interviews. Data analysis resulted in two emergent themes described here. **Findings.** The first theme, *Anything less would be unethical: Key issues*, included six sub–themes. Theme 2, *I trust my gut: Affective dimension of ethical practice* included five sub-themes. **Implications.** Being a moral agent is a key responsibility for occupational therapists working in adult rehabilitation settings.

Key words: occupational therapy ethics, ethical issues, rehabilitation.

# Introduction

Health care professionals face dramatic and highly publicized ethical issues arising from current societal and health trends. Rehabilitation practitioners face less dramatic ethical issues more frequently and in everyday practice, i.e. issues specific to admissions, intervention, and discharge policies and procedures. Recent studies addressing ethical issues related to nursing, physical therapy, and speech and language therapy are published in the literature. However, current research addressing these same concepts as related to occupational therapists is lacking in scope and depth. In a response to this gap, the researcher conducted a qualitative study in the tradition of grounded



theory that addressed the query, "What are occupational therapists' experiences with ethical issues in adult rehabilitation practice?"

Data collection and analysis occurred simultaneously using ground theory methods. Nine occupational therapists employed at three different facilities participated in various combinations of individual, semi-structured interviews; reflective journaling; and follow up telephone interviews. Final analysis produced four emergent themes: Theme 1, *Anything less would be unethical: Key issues;* Theme 2, *I trust my gut: Affective dimensions of ethical practice*; Theme 3, *Ethical practice is expected but challenging*; and, Theme 4, *It takes a village*, with this article addressing the first two themes. In conclusion, occupational therapists clearly experienced ethical issues with accompanying emotional aspects; as moral agents, occupational therapists needed to be sensitive to subtle issues and enact moral courage to deal with these; and, these findings may support individual therapists in practice as well as shape policy at institutional, state, and local levels.

#### Background

#### **Bioethics Issues Today**

Escalating health care costs (Fuchs, 2011), advances in technology (Entwistle, Sade, & Petrucci, 2011), and current trends in health care management and delivery (Scheunemann & White, 2011) intersect to produce high profile and at times controversial contemporary health care-related ethical issues. Bioethicists, health care professionals, and the public express concern about issues such as electronic medical records and confidentiality (Rothstein, 2012); stem-cell research and transplantation



(Robertson, 2010); reduction in wasteful spending (e.g. overtreatment; administrative complexity, and fraud and abuse) (Berwick & Hackbarth, 2012); limited resource allocation (Tiburt & Cassel, 2013); genetic testing (Klitzman, 2012), including testing of human embryos (Kolata, 2014); organ transplantation (Belkin, 2012); and life support use in medically futile cases (Magnus, Wilfond, & Caplan, 2014). Most health care professionals do not face such dramatic issues on a day-to-day basis, but they do negotiate ethical issues that have important implications for their patients, colleagues, and even themselves. Inpatient rehabilitation is one branch of medicine that gives rise to ethical issues, many due to the characteristics of its service delivery model, which providers face on a day-to-day basis.

# **Clinical Ethics for Rehabilitation**

Service delivery model. Ethical issues arise in each of the three phases of rehabilitation service delivery, i.e. admissions, intervention, and discharge. In order to be deemed a rehabilitation candidate and admitted to a rehabilitation facility, patients must meet specific criteria driven by Medicare reimbursement regulations (Braddon, 2005; Conroy, DeJong, & Horn, 2009). These criteria include the ability to tolerate three hours of therapy per day; a need for more than minimal assistance for several self-care tasks; a potential for reducing the level of disability; and the presence of a psychosocial support system (Conroy et al., 2009). Known as cherry picking, facilities can potentially select patients with fewer additional medical conditions in order to minimize extended and more costly lengths of stay (Stein, 2012), thus raising issues of justice and equal access to services.



Intervention-related issues center on expectations for patient active participation; an interdisciplinary team model of service delivery and family involvement; and decreased lengths of stay. Patients are expected to actively participate in 180 minutes of therapies per day, typically 60 minutes in each of occupational therapy, physical therapy, and speech and language therapy, five to six days per week (Conroy et al., 2009; Stein, 2012). This requirement raises issues related to patients' rights to autonomous decisionmaking, e.g. their right to refuse to participate. Rehabilitation is also characterized by interdisciplinary team service delivery in which effective functioning is important to optimal patient outcomes (Neumann et al., 2010). Families and caregivers are considered members of the treatment team and are actively involved in the patients' therapies (Conroy et al.). Conflicts related to intervention goal formation or discharge planning can generate ethical issues for both professional and family members of the treatment team. Finally, although traditionally longer than in acute settings, patients' lengths of stay have significantly declined in recent years for rehabilitation patients (Dobrez, Heinemann, Deutsch, Manheim, & Mallison, 2010; Meyer, Britt, McHale, & Teasell, 2012; Qu, Shewchuk, Chen, & Deutsch, 2011). Oftentimes, it is not the patient's needs, but rather the patient's anticipated length of stay, that determines rehabilitation goals (Stein), producing concerns about quality and effectiveness of care.

Two main issues arise related to discharge. One is in regards to defining therapeutic endpoints for discharge determinations (Stein, 2012). Unlike acute medical care where objective endpoints are clear (e.g. ending a course of antibiotics), rehabilitation endpoints are more soft, or subjective (Stein). It can be difficult to determine the point at which a patient's capabilities have improved enough to function at



home or in the community, and to predict whether extending a patient's length of stay will produce gains sufficient to justify the added costs. Typically, length of stay is determined by reimbursement sources rather than patient needs, raising questions of just allocation of resources. The other issue concerns tensions that occur when staff members recommend that a patient not discharge to his or her home due to safety concerns, yet the patient exerts his or her right to autonomous decision making and discharges to home against staff recommendations (Levack, 2009).

Interdisciplinary team. Research examining ethical issues experienced by rehabilitation team members, including nurses, speech and language pathologists, physical therapists, and occupational therapists, reflects the concerns described above. Although somewhat dated and limited in number and scope, this literature primarily includes studies of issues experienced by whole rehabilitation teams, along with a few discipline-specific studies. Three studies exploring single site rehabilitation staff perceptions of ethical issues were conducted, two based in the United States (US) (Kirschner, Stocking, Wagner, Foye, & Siegler, 2001; Mukherjee, Brashler, Savage, & Kirschner, 2009)] and one in Canada (Young & Sullivan, 2001). The top ethical issues identified in both US studies were related to reimbursement policies; conflicts in goal setting among team members, patients, and families; and impaired patient decisionmaking capacity leading to unsafe choices (Kirschner et al., 2001). Additional issues identified in the more recent study included those related to corporate culture, preferential treatment of patients, conflicts of interest, withholding information from patients, and patient confidentiality and privacy (Mukherjee et al., 2009). Staff in the Canadian study also identified risky client behaviors, such as clients choosing an unsafe discharge



destination; issues related to staff autonomy versus client autonomy, such as clients desiring unnecessary equipment; and client' challenging behaviors, such as verbal abuse toward staff (Young & Sullivan, 2001). Issues identified in each of these studies mirrors characteristics of the health care system in the two countries of origin, which can also explain the lack of overlapping issues in the studies. International single discipline research indicates that, while some experiences with ethical issues are cross-disciplinary, others are unique to the health care profession within the context of its respective country's health care system.

**Nursing.** The nursing literature is extensive in regard to ethics and nursing practice, but includes only one study addressing rehabilitation nurses' experiences with ethical issues (Stabell & Naden, 2006). The aim of this Norwegian study was to explore nurses' perceptions of challenges in maintaining patient dignity. In doing so, the participants described ethical concerns related to dealing with patient decisions that lead to health and safety risks, including unsafe discharge destination, unrealistic family expectations, patients who are too medically fragile for rehabilitation, and high workload demands and scarce resources that impede quality of care (Stabell & Naden).

Speech and language pathology. In an Australian study exploring experienced speech and language pathologists' responses to ethical dilemmas, five of the ten participants worked at inpatient hospital/outpatient rehabilitation facilities (Kenny, Lincoln, & Balandin, 2010). Similar to Stabell and Naden's (2006) findings, these participants reported dealing with ethical concerns of patient autonomous decision-making associated with risks to safety and the impact of limited resources on their ability



to provide adequate quality and quantity of services (Kenny et al., 2010). In describing approaches they used to deal with ethical dilemmas, participants reported additional ethical issues related to functioning as a member of an interdisciplinary team, advocating for patients, and focusing on patient well-being in ethical decision-making (Kenny et al., 2010). Due to parallels in professional roles, physical therapists' and occupational therapists' experiences are similar to these.

**Physical therapy.** Three studies, two Canadian (Carpenter, 2005; Finch, Geddes, & Larin, 2005) and one from Finland (Kulju, Suhonen, and Leino-Kilpi, 2013), explored ethical dimensions of physical therapy practice. Issues related to health care system and administrative policies were identified in all three studies. Lack and/or misuse of resources, discriminatory admission and discharge practices, and interdisciplinary team pressures and conflicts were issues identified in all three studies (Carpenter, 2005; Finch et al., 2005; Kulju et al., 2013). Each study presented additional issues, with Kulju and colleagues' survey-based findings also including issues related to lack of patient selfdetermination, therapists' difficulty in maintaining professional attitudes, and conflict between individual and organizational values. Additional findings of Carpenter's (2005) qualitative study concerned ethical ramifications of evidence-based practice and also participants' experiences of moral distress stemming from lack of trust in the integrity of the institutions where they work and in other health care professionals in their work settings. Although only three of the ten participants in Finch and colleagues' (2005) qualitative study worked in publicly-funded hospital settings, findings reflected rehabilitation practice issues, such as practice decisions driven by funding, patient



autonomous decisions conflicting with physical therapy recommendations, and the importance of advocating for patients' welfare.

**Occupational therapy.** Issues discussed in the occupational therapy literature parallel those described above. Internationally-based studies have explored ethical dimensions of occupational therapy practice. Canadian researchers deconstructed ethical ramifications of the discharge process using a single case study design (Durocher & Gibson, 2010). Researchers in the United Kingdom examined ethical implications of occupational therapists' discharge practices as part of a larger study examining discharge planning and team functioning (Atwal & Caldwell, 2003). Using a qualitative design, researchers explored Swedish occupational therapists' experiences with ethical dilemmas in rehabilitation with adults with developmental disabilities (Kassberg & Skar, 2008). And in the US, researchers extracted, analyzed, and published occupational therapists' responses from Kirschner et al.'s sample (Foye, Kirschner, Wagner, Stocking, and Siegler, 2002). Despite each study originating in a different country, several common issues were identified. Similar to other disciplines, occupational therapists experienced issues related to risky patient discharge decisions and patient/family/team conflicts (Atwal & Caldwell, 2003; Durocher & Gibson, 2010; Foye et al., 2002; Kassberg & Skar, 2008). Issues related to limited resources, practice driven by funding policies, and pressures to discharge patients are included in three of the studies' findings (Atwal & Caldwell, 2003; Foye et al., 2002; Kassberg & Skar, 2008). While these studies addressed various aspects of ethical issues experienced by occupational therapists, the only study directly exploring the experiences of US rehabilitation-based occupational



therapists (Foye et al., 2002) is dated and findings were limited to responses to openended survey questions.

#### **Importance of Ethics Research**

Knowledge of current ethical issues in practice can benefit occupational therapists at the individual, institutional, state, and national levels. At the individual level, such information can support occupational therapists in practice: therapists can find validation in knowing that others share similar experiences. Knowledge of shared experiences may also create learning opportunities by enabling therapists to reach out to peers for advice and affirmation. Doing so can lead to shared problem-solving to facilitate strategies that result in the most ethical outcomes possible when faced with difficult issues (Kenny et al., 2013). At the institutional level, identification of current ethical experiences could stimulate administrative changes to ease therapists' dealing with certain issues. Similarly, this information can inform policy formation at state (e.g. licensure boards) and national (e.g. professional organization code of ethics) levels. State and national policy based on current practice issues provide a public statement of standards of ethical behaviors that consumers and other stakeholders can expect of occupational therapists.

#### Summary

Current societal and health care delivery trends, along with the unique characteristics of its service delivery model, are producing ethical issues for rehabilitation professionals. Results of international research concerning nursing, speech and language pathology, physical therapy, and occupational therapy professionals' experiences with ethical issues describe several cross-disciplinary issues. The most common issues



include those related to resources and funding, specifically lack of and unfair allocation of resources and practice decisions driven by funding sources. Another issue is related to interdisciplinary team pressures and conflicts, especially concerning patient goal setting. The final issue concerns patients with or without impaired judgment asserting their right to autonomous decision-making, the consequences of which can threaten their safety and well-being. The occupational therapy literature reflects these same issues. However the occupational therapy studies are few in number, dated, and limited in scope and depth, leaving a knowledge gap. Research exploring ethical dimensions of current occupational therapy practice in rehabilitation can support therapists at multiple levels and also inform policy formation to reflect current practice issues. To address this knowledge gap, the focus of this study was on contemporary occupational therapists' experiences with ethical issues in rehabilitation.



#### Methods

The research query asked, What are occupational therapists' experiences with ethical issues in adult rehabilitation practice? The aim of the study was to explore ethical issues typically encountered by occupational therapists in contemporary adult rehabilitation practice. The researcher chose a qualitative research design using a grounded theory (Charmaz, 2014) approach in order to gather rich data from which to develop substantive theory to inform occupational therapy practice.

# **Human Subjects Approvals**

Prior to implementing study activities, the researcher secured Institutional Review Board (IRB) approval for human subjects' protection from six institutions, three from relevant academic institutions (researcher's degree-granting institution, researchers' employer, dissertation advisor's employer), and one from each of the three data collection facilities. Attaining approval from six institutions was a complex and time-consuming process, since the agreements had to match and each institution had unique requirements. One potential data collection facility withdrew agreement to participate due to an organizational merger before all necessary approvals could be attained. Ultimately, several institutions agreed to approval via IRB Authorization Agreements that granted overseeing authority to the degree-granting institution. The researcher began recruitment activities at each facility once all necessary approvals for that facility were secured.

### Recruitment

The researcher used convenience sampling (Morse, 2007) to identify three facilities for participant recruitment that offered adult rehabilitation services in the Mid-



Western US. Recruitment from three facilities provided triangulation of data sources (i.e. three data sites) and promoted completeness and confirmability of findings (Krefting, 1991). Facility A was an urban, free-standing rehabilitation hospital. Facility B was the rehabilitation unit of a large, urban, not-for-profit, acute care hospital. Facility C was the occupational therapy department of a small, suburban, general medical and surgical hospital. Inclusion criteria were: occupational therapist, at least one year of experience working with adult rehabilitation patients, and working at one of the three participating facilities. Occupational therapy assistants and therapists employed by contractual agencies assigned to the facility were excluded. The researcher met with staff members at each facility to recruit participants.

For Facility A, the researcher sent an email to all of the staff occupational therapists, introducing the study and notifying those interested of the date, time, and room location where they could meet with her for additional information. At Facilities B & C, the researcher met with each facility's staff occupational therapists as a group for approximately 30 minutes, presented an overview of the study, and invited those interested to participate. At all three facilities, the attendees were given a recruitment flyer providing information about the study and contact information. At one and three weeks after each recruitment meeting, the researcher sent follow-up email notifications to those who attended, reminding them about the study and inviting their participation. Occupational therapists interested in participating in the study contacted the researcher via the email address provided on the recruitment flyer.



# **Participants**

In total, nine female occupational therapists (i.e. Facility A, n = 4; Facility B, n = 3; and Facility C, n = 2) consented to participate in the study. Participants' duration of experience working in adult rehabilitation practice ranged from 2 to 24 years, with a mean of 10.8 years. The participants shared their experiences with ethical issues in practice via one, two, or three data collection activities (see Table 1).

#### **Data Collection and Analysis**

Throughout the study, the researcher documented study activities in several formats. Starting with seeking IRB approvals, she recorded individual study events (for example, sending and receipt of email communications; recruitment activities) in a chronological log in order to create an audit trail to enhance trustworthiness of the research (Shenton, 2004). The log was supplemented with narrative entries in a procedural research journal. Prior to data collection, the researcher recorded reflective journal entries, a process known as bracketing, to elucidate preconceptions and thus mitigate their influence during data collection and analysis processes (Tufford & Newman, 2010) in order to further strengthen trustworthiness. Expert review (Krefting, 1991) was provided throughout the research process by the researcher's dissertation advisor, an accomplished qualitative researcher with an extensive publication record.

Consistent with grounded theory methods, data collection and analysis were simultaneous (Charmaz, 2014). This iterative and dynamic process was a journey of back and forth exploration of the data as it was collected and levels of interpretation of the same, culminating in the final stage, that of writing the report (Dickie, 2003). The



process began with initial data collection activities: individual face to face interviews and/or participant weekly journaling. For the interviews, the researcher developed a semi-structured interview guide comprised of eight questions based on the literature and the researcher's expectations in regard to likely issues. Questions targeted participants' experiences with common, challenging, and distressful ethical issues and dilemmas; with moral distress; and with specific topic areas not previously discussed in the literature, including issues related to health care delivery system, rehabilitation practice model, and working within a team and with families). The duration of the initial interviews ranged from 45 minutes to 110 minutes, and averaged 60 minutes.

Immediately following each interview, the researcher recorded reflexive field notes consisting of impressions from the interview, concepts repeated over interviews, and potential topics for exploration in future data collection activities. All interviews were audio recorded and transcribed verbatim within five days of the interview by two paid transcriptionists. The researcher randomly selected one transcript completed by each transcriptionist, checked it against its respective audio recording, and determined that the transcripts did represent participants' words verbatim.

Simultaneous to the conducting of initial interviews, volunteers were recruited to participate in data collection via journaling. Two therapists submitted answers to weekly reflective journal questions. The researcher emailed the questions to the journaling participants once a week for eight weeks and participants emailed their responses. The same questions were sent each week and asked about participants' experiences with ethical issues and moral distress for that week. Combined, the two journal participants



returned nine entries describing ethical issues and reported no ethical issues during the other seven weeks. The researcher copied each participant's entries into a separate Word document for analysis.

As each transcript was completed, the researcher studied a hard copy and began initial coding, a process of sorting and defining the data by labeling lines, segments, and incidents in the margins (Charmaz, 2014). Throughout this process, the researcher employed a strategy known as constant comparison whereby she compared data to data, and data to codes (Charmaz, 2014). From initial coding processes, she developed an initial code book consisting of 33 code words and an operational definition for each. Then, using these code words, she coded each transcript and the participant journal entries using HyperRESEARCH<sup>TM</sup>, a code-and-retrieval software program. She then wrote a descriptive memo (Charmaz, 2014) for each code word that consisted of its definition, followed by the coded raw data, and then a summary describing the characteristics of the data according to that code word. For the next phase, the researcher diagrammed (Charmaz, 2014) the code words to organize them according to similarity in relationship or patterns. From these patterns, the 33 code words were shaped into 6 categories. Again, using constant comparison, the researcher returned to the data and reflexive journal entries to look for consistency between those data sources and the newly-formed categories. Being satisfied that there was a sufficient level of consistency, the researcher wrote an analytic memo (Charmaz, 2014) for each category. Each analytic memo consisted of summaries of code words that formed the category and a category summary. The category summaries describe how the data merges together to form new patterns and explain characteristics of the category at a more abstract level (Charmza,



2014). Throughout this process, the researcher made note of areas of inquiry for participant follow-up interviews.

All individual interview and journaling participants were contacted via email (and two reminder emails) and invited to participate in follow-up interviews conducted via telephone. For these, the researcher developed a new semi-structured interview guide that asked participants to conceptualize what ethical practice means, and to describe supports and barriers to their ethical practice. Eight of the nine participants took part in phone interviews that ranged in duration from 18 minutes to 53 minutes, and averaged 37 minutes. As with the initial interviews, these interviews were audio-recorded and transcribed verbatim. The researcher also recorded reflexive journal entries following each interview.

After completing the follow-up interviews, the researcher re-coded all data (i.e. initial interviews; participant journal entries; follow-up interviews) using the previouslydeveloped categories as code words. From this coding, the researcher wrote five analytic memos (note, two of the six categories were merged, reducing the number of categories from six to five). Each memo consisted of its category's raw data and a category summary describing patterns of relationships among concepts embedded in the data. At this point, the researcher emailed the category summaries to the participants and asked them to review the information for resonance of accuracy based on their participation. This process, known as member checking (Krefting, 1991), enhanced trustworthiness by ensuring participants' perspectives held true in the findings.



Having received no participant feedback of inaccurate representation of their data, the researcher returned to analysis. For this, she wrote individual concepts from each category on post-it notes, color-coded according to category. Over several iterations, she rearranged the post-it notes, seeking any new patterns and relationships, out of which emerged three final themes of meaning. The researcher then wrote a final analytic memo consisting of descriptions of each theme and its accompanying sub-themes, along with participant quotations to support the same. Content of this memo is represented in the Findings.

#### **Positionality of the Researcher**

As an occupational therapist, I have had a long-standing fascination with the ethical realm of clinical practice and how it intersects with and impacts the quality of patient care. This interest led me to pursue doctoral studies on the topic. However, in conducting this research, I held an etic (i.e. outsider's) perspective as one who was an experienced academician, but without recent clinical practice experience. From my doctoral studies and teaching responsibilities, I had a strong working knowledge of theoretical and empirical literature related to bioethics, literature related to clinical ethical issues, and ethics terminology. Additionally, during the time period this study was conducted, I served as the Education Representative to the American Occupational Therapy Association's Ethics Commission. Through reflexive journaling, I revealed preconceptions that included, but were not limited to, that participants would (a) report observations of unethical behavior by peers and colleagues; (b) report being pressured by team members to behave unethically; and, (c) describe ethical and/or unethical experiences in behavioral terms and not use ethics terminology. Awareness of these



preconceptions enabled me to not force them onto the participants during interviews (Charmaz, 2014).

### **Findings**

These methods resulted in four emergent themes describing participants' experiences with ethical issues in rehabilitation practice. One theme centers on the negotiation of specific ethical issues in meeting professional responsibilities, with the second theme describing affective experiences elicited in doing so. The third and fourth themes are related to system and human supports and barriers to ethical practice and will be reported elsewhere. Theme 1, *Anything else would be unethical: Key issues*, includes six sub–themes focusing on various realms of these responsibilities. Theme 2, *I trust my gut: Affective dimension of ethical practice*, includes five sub-themes describing the range of emotional experiences elicited by meeting professional responsibilities. Participant quotations are provided to support the sub-themes and are represented by pseudonyms to protect participants' identities.

#### Anything Less Would be Unethical: Key Issues

Therapists' meeting of ethical and professional responsibilities was guided by ethical principles of not only benefitting patients, but more importantly, not harming them. They were also guided by ethical mandates to be honest, respect patients' decisions, advocate for patient rights, be culturally competent, and adhere to confidentiality regulations. These principles guided ethical practice for issues that arose on a day-to-day basis.



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*First do no harm.* All of the therapists stated that their *prima facie* duty is to protect their patients from harm and preserve their safety and well-being. They met this responsibility by erring on the side of providing more conservative interventions in situations where they are not sure of patients' status, and/or are unfamiliar with a new diagnosis. They also respected recipients' humanity to the utmost, doing everything in their power to provide the best possible care to each, saying "anything less would be unethical."

I think it's about, treating all clients with the same amount of respect, being willing to... give them the absolute best standard of care.... I have to make sure that I, you know, do as much as I can and so to do any less I, I feel like that's unethical (Lila, follow up interview).

*Honesty is the best policy*. Therapists met their duty for veracity in being honest in their discharge recommendations and documentation, at times despite patient, family, or team subtle (and less frequently, explicit) requests to emphasize certain aspects of patient functioning, subtly misrepresenting the truth. They were asked to do this in order to realize a certain discharge destination, likely one for which the patient didn't necessarily qualify. For example, they may be asked to paint a picture that the patient is in need of skilled therapy services so he or she can be discharged to a skilled nursing facility. Families might ask therapists to falsify documentation in order to obtain certain equipment that the family wanted but the patient didn't need (for example, a hospital bed) or falsely deem a patient was eligible for admission to a skilled nursing facility because the family did not want to care for the patient at home. The therapists also protected the



system by honestly appraising potential patients' ability to benefit from services and refusing to treat those who do not have potential to benefit, thus preserving resources such as their own time that could be better used to treat appropriate candidates. All therapists reported that they do not succumb to these pressures, that their documentation is honest and accurate, and that they are not willing to put their license on the line for fraudulent documentation.

Often our recommendations were, uh, asked to be modified, changed, enhanced, and based on usually reimbursement issues or appeasing family member issues or what have you [by] docs, nurse, social worker. . . . Usually it was along the lines of, could you focus your note more heavily on the positive aspects, if they were aiming for rehab, or can you focus your note more heavily on the deficits, if they were trying to explain something to a family member. Or, and influence—some of it was not falsify but influence, but some was outright falsify (Abril, initial interview).

Patient autonomy – the emperor's new clothes? Therapists agreed on the importance of respecting patient autonomy. At the same time, however, they acknowledge that patients in rehabilitation do not really have the right to refuse to participate, as they ostensibly agreed to participate upon admission to the unit. Respecting patient autonomy was difficult when treating patients who have a brain injury or dementia. Due to cognitive impairments, these patients may be unable to understand or appreciate therapy. As a result, they could become physically combative, placing the safety of both therapist and patient at risk. Other ethical tensions related to patient



autonomy primarily arose when patients decided to discharge to home against occupational therapy recommendations that doing so would be unsafe for the patients or the caregivers. This occurred when patents lived alone or with caregivers who were incapable of providing safe and effective care due to their own physical or cognitive deficits.

So we do try to convince people, and of course you still have the issue of patient autonomy, they have the right to refuse, but they kind of don't on rehab. They kind of, I mean they agreed, right, they agreed to the three hours a day, five days a week. And then it comes down to the people that didn't necessarily agree, like maybe their family member agreed, or the doctor strongly recommended it, and we, you know, our admissions people are very like clear about what the expectations...but you still get the patient who's like, I didn't know that this is what it was gonna [sic] be (Addie, initial interview).

*Advocate, advocate, advocate.* Therapists met their duty to prevent harm primarily by advocating for their patients. They advocated when families expected too much and wanted to push patients beyond their capabilities. They advocated when families unrealistically believed they could care for their loved ones at home, in which case therapists advocated for safer discharge destinations. Therapists advocated for patient's rights to refuse therapy to physicians who professed that patients do not have the right to do so. They also advocated for patients when nursing staff provided substandard care and when physical therapists seemed over-aggressive or appeared uncaring during



interventions. Finally, they advocated for best practice by suggesting more effective intervention options to other occupational therapists.

You know, when you see a therapist who never, I don't say never, but one who would just prefer to keep a patient in their wheelchair the whole time, instead of getting them up and doing things . . . um, but just kinda [sic] seeing those kinds of things, when it would be better for the patient if they did X activity" (Carleen, initial interview).

*You have to be culturally competent*. Therapists dealt with ethical issues centering on cultural issues and language barriers. They certainly respected patients' unique culturally-based situations and needs, but providing culturally-competent care could be a challenge. Therapists were sometimes concerned that patient well-being may be at risk due to communication barriers. All three facilities provided interpreters; however, some patients refused these services. Additionally, therapists sometimes had the sense that interpreters were not effectively relaying patient communications, which was particularly distressing in situations where patient safety was at risk.

I had a patient with limited English proficiency . . . this patient did not wish to use the phone interpretation service . . . Compounding this, I have reason to believe the patient had some level of cognitive impairment . . . however, this was difficult to fully assess given the language barrier and the patient's unwillingness to use the phone interpreter. . . . Finally, I ended up overriding the patient's wishes and using the phone interpreter. . . . I felt that this was the right thing to do, even if it wasn't what the patient wanted. I believe that, by not using the interpreter, I could



*be putting the patient at risk of harm, as the patient would not be able to communicate effectively to me*....*It's frustrating every time it happens* (Nell, journal entry).

*Keep it confidential*. Therapists received facility-based training about privacy and confidentiality regulations and were cognizant of their responsibility for respecting the same in regard to patient information. Some therapists talked about being tempted to look up information on former patients, personal acquaintances, or high profile patients, which was made easier by electronic medical records, but avoided doing so. One therapist pointed out a difficulty in respecting patients' privacy and confidentiality when treating in the gym due to the close proximity of patients, coupled with between-patient conversations that were typically related to their conditions.

As far as ethical, yeah, we've been trained in this, so it's been brought to our attention. You know, if I was to look up anybody that I didn't have as a patient that day, that's an ethical overlapse [sic].... I think the opportunity to do something like that is very easy, where with paper charting obviously that was a lot harder, because I don't have that information in front of me.... But now with that electronic charting, a lot more information's flooded to me, now I've got to make decisions about that, and we've been, now we've been, since we've started Epic, I mean, they trained us that, they educated us that these are ethical violations, you're not allowed to do this, can't go into somebody's chart... so we know that, but sure, it's tempting. (Macie, initial interview).



#### I Trust My Gut: Affective Dimensions of Ethical Practice

Ethical practice elicited a range of positive and negative affective responses for therapists. Indeed, they relied on these affective reactions as their own internal compasses to guide ethical practice. Negative emotions in the form of moral distress, frustration, and feeling stressed occurred regularly. However, the negative emotions were counteracted by positive feelings of gratification, stimulation, and creativity.

*Trust your gut.* The therapists listened to and relied on their internal moral compasses to identify and deal with ethical issues. They trusted their gut instinct as a cue that something wasn't right and they needed to reflect on the most ethically sound course of action. Most attributed the source of their values and high standards primarily to their upbringing. They viewed themselves as raised in families who valued moral behavior. Some also attributed their value formation to their professional education. In general, several talked about having multiple opportunities to be unethical, but choosing to stay true to their values and high standards of behavior.

I don't know, I guess it's kind of you know, moral compass . . . just a good general gut feeling about if something just doesn't look right or smell right, you know, having a good gut feeling about . . . if there could be an ethical concern about something (Nell, follow up interview).

*It would be easy if I didn't care so much.* Being ethical or being constrained from providing best care could elicit strong negative affective responses for therapists. Perceiving oneself as lacking control was distressful when related to negative impacts on



quality of patient care, or when required to treat an agitated patient when doing so is unsafe. Centralized scheduling that took timing of treatment sessions out of the therapists' control was distressful when therapists could not choose the optimal time to treat their patients. It was also distressful to therapists when peers or team members did not treat patients according to the therapists' high standards, making therapists feel powerless to influence change. In respecting patients' autonomy, they worried about patient safety and well-being when patients decided to discharge to home rather than following therapists' recommendations for alternate and safer discharge destinations. It was distressing for therapists when they perceived that their patients would not receive good care at home or that families would neglect patients. Therapists also felt badly when families or physicians expected too much in terms of participation in therapy and they wanted the therapists to push patients too hard. Similarly, they felt badly when they themselves pushed patients too hard. At the same time, therapists felt badly when they could not respect patients' autonomy in circumstances where doing so would have been harmful to the patient (for example, a patient with dysphagia wanted the therapist to give her water, or a patient with dementia and post-hip fracture needed to get out of bed to promote healing, but doing so was painful and the patient becomes combative). Ultimately, having professional experience helped therapists cope with these situations and feelings: they can sleep at night when they know they have done their best and the situation is out of their hands.

I think it would be [most upsetting] having to document, um, of somebody's very agitated, um, why they have to stay, why they should still be getting acute services, and documenting in my notes how agitated they are, how they're not



appropriate because they cannot be redirected to be a participant. So, um, and how unsafe that is. And what's so emotionally upsetting about that is we would get put into dangerous situations, um, and then we would have to make up the time, so they would just keep sending up back to this person at the end of the day, or sometimes 3 or 4 times a day to try to make up the time" (Daria, initial interview).

A lot of things like that stay in your head. Each of the participants described at least one particularly distressful patient-related experience that has stayed with her. The scenarios all had underlying ethical ramifications and served as learning experiences. Some of the scenarios involved patients who were terminally ill and the therapist had to advocate for humane treatment. One scenario involved a patient who committed suicide, using muscle strength derived from therapy: this therapist felt badly that she helped him end his own life. Another scenario involved a patient who discharged to her home against occupational therapy recommendations, fell her first day home, and lay on the floor for four days. Other scenarios involved hindsight revealing the therapist had pushed the patient too hard, worked with an incompetent peer, and knew that a patient would not receive adequate care from family members upon discharge.

We got a nasty note from .... well the letter was sent to the hospital from the wife, honestly I can't say that I blame her. And I can remember too, um, and I think this is kind of in my mind too, a friend of the family where, um, the gentleman was ill and I don't remember what his illness was, but I remember her saying that you know, and this was at a different hospital too. The therapist



would come in and make him get up and you know he was just so sick, so tired, and died a couple days later, and she just really wished they wouldn't have done that to him. Yeah, 'cause it just made him miserable...and you know there's a lot of things like that that stay in your head too (Dixie, initial interview).

*But it's worth it in the end.* Despite these negative feelings, being an occupational therapist was personally rewarding for these therapists. They described holding themselves to high standards and being proud of doing so. They told stories of feeling gratified in situations where they creatively crafted meaningful interventions for patients who were perhaps not therapy candidates but were pressured by physicians and/or families to provide treatment. They enjoyed the relational aspects of working with their patients and co-workers. They were pleased when they made a difference in patients' lives, especially when patients returned long after discharge to thank them and show the therapists how well they were functioning, and also send annual greeting cards. They enjoyed the daily creative problem-solving opportunities that presented challenges and provided stimulation to their work lives. This aspect of their work prevented boredom and made every day (and every patient) different and interesting. The therapists appreciated opportunities to continue to learn and grow through their work as occupational therapists.

I love to work with people. I love to see them get better and meet the goals, you know, to [reach] their desired participation . . . . I feel that I have challenge in what I'm doing and that I can do my job well, um, which keeps me doing it. I guess just, you know, the general, the gratification of being an occupational



therapist and, and um, providing quality care for my clients even in a stressful environment (Anastasia, follow up interview).

# Discussion

Findings of this study reflect two themes representing aspects of occupational therapists' experiences with ethical issues, one related to meeting professional responsibilities, and the other to the affective implications of doing so. Under the first theme, *Anything less would be unethical: Key issues*, six sub–themes describe various ethical issues therapists encountered in meeting their professional responsibilities. These issues centered on having a primary duty to protect patients from harm, being honest in documentation, respecting patient autonomy, advocating for patient well-being, being culturally competent, and respecting patients' privacy and confidentiality. The second theme, *I trust my gut: Affective dimensions of ethical practice*, includes four sub-themes depicting the emotional aspects associated with meeting these professional responsibilities. For the participants, these emotional aspects consisted of trusting their gut instincts to guide ethical practice, a sense of caring that led to feelings of distress and frustration, incidents that were particularly memorable, and positive features of being an occupational therapist that counteracted the negative aspects.

### **Ethical Issues**

These occupational therapists faced several ethical issues to which they responded as moral agents. An ethical issue is a situation with inherent moral challenges (Purtilo, 2005), i.e. challenges related to one's personal and professional values and duties (Purtilo & Doherty, 2011). In thinking about and acting on these challenges, the therapists served



in the role of moral agents. Carpenter (2010) defines a moral agent as "someone who is capable of deliberating, thinking, deciding, and acting in accordance with personal and professional moral standards and principles" (p. 69). Participants served as moral agents as they negotiated several types of ethical issues, with the most salient concerning veracity; social justice (cultural competence and advocacy); and patient autonomy.

Veracity. Participants upheld their ethical responsibility to accurately and honestly document their recommendations despite occasional pressures, usually subtle and occasionally explicit, requests by family or team members to do otherwise. These requests were typically related to others' desires to qualify a patient for a discharge destination (usually a SNF, for which the patient did not actually qualify) by asking the occupational therapist to misrepresent the patient's actual status in her documentation. Although not prevalent in the literature, therapists feeling pressured by other professionals or patients to falsify recommendations has been reported by occupational therapists (Freeman, McWilliam, MacKinnon, DeLuca, & Rappolt, 2009), and physical therapists (Finch et al., 2005) in Canada. Its ostensibly recent appearance may stem from increasing health care systematic pressures to discharge patients as soon as possible so as to contain costs. Occupational therapists may experience tensions in refusing such requests, especially in situations of perceived power differentials between themselves and the persons making the requests. Situations like these call for therapists to draw upon moral courage to support their ethical response to refuse to falsify documentation. Moral courage is a readiness to respond in situations inherently anxiety-provoking in order to uphold moral values (Purtilo, 2000), and requires knowledge, confidence, energy, and



passion (Spence & Smythe, 2007). As this study's participants experienced, moral courage is often most necessary in times of change (Purtilo, 2000).

Social justice. Therapists also drew upon moral courage when negotiating two issues related to social justice: providing culturally appropriate care, and advocating for patients' rights and well-being. Immigration patterns are changing the fabric of US society in producing increased language and diversity clusters in both large and small metropolitan areas in the US. According to the U.S. Census Bureau, the number of people who spoke a language other than English at home increased 158% between 1980 and 2010 (U. S. Department of Commerce, 2013). In 2011, 21% of the population spoke a non-English language at home, with 22% of those individuals reporting that they spoke English either not well or not at all (U. S. Department of Commerce, 2013). The participants acknowledged the importance of being sensitive to their patients' unique cultural needs, affirming that providing culturally appropriate care is a current reality for them. Consistent with reports in the literature, uncertainty and frustrations arose when participants had difficulty communicating with non-English speaking patients that raised concerns about whether or not they were providing safe and effective interventions (Pooremamali, Persson, & Eklund, 2011). Using either facility-provided or patientgenerated translators was at times problematic as the participants questioned the accuracy of the translation. Indeed, empirical literature validates their perceptions that high rates of errors occur in translation services (Flores, Abreau, Barone, Bachur, & Lin, 2012).

Advocating for patients' safety and well-being was the other issue related to social justice. Advocacy responsibilities are within the scope of occupational therapists' roles (Dhillon, Wilkins, Law, Stewart, & Tremblay, 2010). Occupational therapists



advocate for a variety of reasons (Dhillon et al., 2010) and at multiple levels, including personal, professional, and societal (Sachs & Linn, 1997). This study's participants advocated at the personal and professional levels, and did so primarily to protect patients' rights and promote their safety and well-being. Like the Israeli occupational therapists in Sachs and Linn's (1997) study, these participants were "guardians of morals" (p. 210). They interceded on patients' behalf when other health care professionals provided substandard care, were too aggressive with patients, or did not respect patients' autonomous rights to refuse to participate in therapy. Indeed, negotiating issues related to patient autonomy was challenging for these participants at times.

**Patient autonomy.** Promoting patients' autonomous decision-making is one ultimate aim of rehabilitation, and a pre-requisite for the level of active participation expected of patients (Cardol, de Jong, & Ward, 2002). However, this right can turn in to a double-edged sword when patients make decisions that place their safety and well-being at risk. Participants experienced this issue at times when their patient chooses to discharge to his/her home, despite staff recommendations that he/she does not possess the requisite abilities to function safely and independently there. This classic dilemma of beneficence (i.e. protecting patients' well-being) vs. respecting patient autonomy is well-documented in both theoretical (Cardol et al., 2002; Frost, 2001; Hunt & Ellis, 2011) and empirical (Atwal, McIntyre, & Wiggett, 2011; Durocher & Gibson, 2010; Finch et al., 2005; Foye et al., 2001; Kenny et al., 2010; Moats, 2007; Mukherjee, et al., 2009) literature. This and other scenarios elicited an emotional dimension inherent in ethical practice.



# **Affective Dimension**

Participants' experiences with ethical issues included several important emotional aspects. They all talked about using visceral reactions to guide ethical decision-making and practice. In other words, they trusted their gut reaction to serve as a personal moral compass. The participants also described situations that elicited feelings of moral distress, feelings of frustration that stemmed from the perception that they were being constrained from acting according to their moral values. A sense of caring can underpin these feelings of moral distress.

Moral distress. Participants in this study described several scenarios that elicited feelings of moral distress, such as patients choosing an unsafe discharge destination, but did not name these feelings as moral distress. First appearing in the nursing literature in the 1970s and 1980s, Jameton (1993) coined the term moral distress to describe feelings related to situations whereby a nurse knows the morally correct course of action, but is constrained in actions by institutional structures or co-workers. Contemporary conceptualizations of moral distress are complex (Hamric, 2012), however, its characterizations include personal experiences of moral compromise stemming from organizational practices and a compromise of personal and professional values that can threaten one's identity and integrity (Varcoe, Pauly, Webster, & Storch, 2012). In the last decade, there has been a burst of interest in exploring this concept as related not only to nursing but to other disciplines as well (Carpenter, 2010; Hamric; Kälvemark, Höglund, Hansson, Westerholm & Arnetz, 2004). While physical therapy literature includes empirical (Carpenter, 2005) and theoretical (Carpenter, 2010) articles related to moral distress, the same is scarce in occupational therapy literature. Occupational



therapists' experiences related to moral distress are embedded in empirical research exploring intervention team members' experiences with moral distress, i.e. in homebased palliative care (Brazil, Kassalainen, Ploeg, & Marshall, 2010), and adult rehabilitation settings (Kirschner et al., 2001, Mukherjee et al., 2009). One study specifically explored occupational therapists' level of moral distress using a survey design and administering the Moral Distress Scale-Revised (Penny, Ewing, Hamid, Shutt, & Walter, 2014). Respondents in this US study worked primarily in geriatric and physical disability settings and reported experiencing moderate levels of moral distress. The issues reported most frequently were diminished quality of patient care due to poor team communication, to pressures to reduce costs, and to lack of provider continuity; working with health care providers not competent to meet patient care requirements; and working with unsafe levels of nurse or other provider staffing levels.

**Caring.** A strong sense of caring for and about their patients permeated participants' discussions of ethical issues. Consistent with reports from other health care disciplines, for example, speech and language pathologists (Kenny et al., 2010) and physical therapists (Finch et al., 2005), these participants described a moral imperative to protect their patients' safety and well-being. Each participant described a particularly memorable scenario for which feelings still linger, a phenomenon known as moral residue (Epstein & Hamric, 2009). It is not surprising that therapists function from a foundation of caring. The profession grew from roots based in the moral treatment movement. Caring was a key characteristic of founding occupational therapists (Bing, 1981). Contemporary professional leaders affirm that caring is inherent in occupational therapy's ethos (Peloquin, 2005) and that caring provides a moral motivation for practice



(Wright-St. Clair, 2001). Indeed, as with these participants, caring about their patients and helping them overcome their disabilities is associated with job satisfaction (Randolph, 2005).

## **Clinical Implications**

These findings provide important information for occupational therapists working in the complex and dynamic adult rehabilitation practice arena. Therapists need knowledge and skills that extend beyond those for patient treatment. Being a moral agent is a key aspect of practice. Occupational therapists experience, and need to be alert to, sometimes subtle ethical issues that surface in everyday practice. Some of these issues are related to protecting and advocating for patients' well-being and rights; having moral courage to withstand subtle pressures to falsify documentation; effectively dealing with patients from diverse backgrounds; and adhering to privacy and confidentiality standards, especially as related to electronic documentation. At times, therapists may be constrained from acting on their moral beliefs, leading to feelings of moral distress. Because dealing with these issues and pressures can be stressful, therapists should actively develop effective coping strategies and support systems to protect their own well-being.

#### Limitations

Limitations of this study are related to the sample characteristics. Having more than two therapists record journal entries could shed more light on the prevalence of certain ethical issues. Similarly, equal representation of interview participants from each of the three facilities might have strengthened the triangulation of data collected. Finally, the study was limited by an all-female sample: the addition of male participants may have expanded the scope of the findings.



# **Future Research**

Knowledge related to ethical dimensions of occupational therapy practice could be expanded in future research. The current study could be validated through a large scale survey-design study with instrument questions developed from this study's findings. This same study could also be replicated within other occupational therapy practice areas, including service provision related to children and youth, mental health, or productive aging, to ascertain the universality and variety of ethical experiences across the profession. Studies could explore in greater depth specific aspects of ethical practice revealed in this study, such as occupational therapists' role in advocacy, the impact of electronic medical records on practice, knowledge and skills that support moral courage, or prevalence and situations related to moral distress. Finally, research exploring the ethical dimensions of practice should be repeated every few years, as the health care delivery system and occupational therapy's roles within it continue to evolve.

#### Conclusion

Like other health care professionals working in adult rehabilitation practice, occupational therapists experience common and unique ethical issues. Some of the common issues are related to protecting patients' safety and well-being; advocating for patients; respecting patient autonomy; providing culturally competent care; and respecting confidentiality of patients' private health-related information. Unique to this study, occupational therapists also experience ethical tensions related to team members' and families' sometimes subtle, and less frequently explicit, requests to falsify recommendations in documentation. Experiences with ethical issues include an inherent affective component in the form of moral distress and a strong sense of caring.



Occupational therapists' sense of caring and making a difference in patients' lives reinforces their commitment to their profession.



# **Key Messages**

1. As moral agents, occupational therapists in rehabilitation practice need to be sensitive to the sometimes subtle ethical issues that occur in day-to-day practice, some of which can lead to feelings of moral distress.

2. Therapists must also possess knowledge, skills, and moral courage necessary for appropriately and effectively dealing with these issues.

3. These findings can be used to inform policy formation at institutional, state, and national levels.



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Table 3.1

# Participants

# Participation Activities

Pseudonym	Years Experience	Initial Interview	Journal	Follow-up Interview
Anastasia	35	Х	Х	Х
Carleen	7.5	Х		
Daria	2	Х		Х
Lila	2	Х		Х
Macie	24	Х		Х
Nell	3		Х	Х
Addie	3	Х		Х
Dixie	24	Х		Х
Abril	12	Х		Х

Note. Years experience represents number of years working in adult rehabilitation. Twenty months of experience rounded up to two years, and 33 months rounded up to three years.



# **Chapter Four**

Systemic and Relational Dynamics of Ethical Practice:

Occupational Therapists' Experiences in Rehabilitation

A manuscript for submission to the

Journal of Allied Health



#### Abstract

**Background.** Changes in health care delivery practices are affecting the provision of care in all venues, including adult rehabilitation practice. Ethical decision-making and behavior is one aspect of service provision made vulnerable by these changes. The aim of this study was to explore how the rehabilitation practice context impacts occupational therapists' ethical practice.

**Method.** Using a qualitative approach in a grounded theory tradition, nine occupational therapists employed at three different rehabilitation facilities participated in various combinations of data collection activities. Through initial individual interviews, recording weekly journal entries, and follow-up telephone interviews, participants described their experiences related to ethics in practice. Data were collected and analyzed simultaneously using grounded theory methods.

**Results.** Two main themes emerged from data analysis. Theme 1, *Ethical practice is expected but challenging*, includes four sub-themes describing one support and three challenges to ethical practice. Theme 2, *It takes a village*, includes four sub-themes related to relational dynamics that mostly support but sometimes challenge ethical practice.

**Conclusions.** The impact of systemic/organizational and relational forces is a reality of ethical adult rehabilitation practice. Systemic/organizational forces produce more barriers than supports and organizational leaders should implement practices to better support expected ethical behaviors. Relational forces produce more supports than



barriers, with individual practitioners' personal moral values providing a strong support to ethical practice when systemic forces pull therapists toward unethical actions. Key Words: rehabilitation ethics, occupational therapy ethics, rehabilitation ethics.

#### Background

Adult rehabilitation is a branch of medical care expected to increase in importance. Unique features of rehabilitation service delivery combined with characteristics of contemporary health care delivery practices create a complex practice environment for rehabilitation professionals. Ethical practice is one aspect of service delivery that is relational and contextualized. While empirical literature includes reports of rehabilitation professionals' experiences with ethical issues in practice, no research has investigated how contextual forces impact ethical practice. To address this gap, the researcher conducted a qualitative research study in the tradition of grounded theory, addressing the query: "What are occupational therapists' experiences with ethical issues in practice?"

Data collection and analysis occurred simultaneously using ground theory methods. Nine occupational therapists employed at three different facilities participated in a combination of individual, semi-structured interviews; reflective journaling; and follow up telephone interviews. Final analysis produced four emergent themes, with the following two themes addressed in this paper: Theme 1, *Ethical practice is expected but challenging*, includes four sub-themes describing one support and three challenges to ethical practice at the system/organization level. Theme 2, *It takes a village*, includes four sub-themes related to intra- and inter-personal relational dynamics that mostly support, but sometimes challenge ethical practice. The impact of systemic/organizational



and relational forces is a reality of ethical adult rehabilitation practice.

Systemic/organizational forces produce more barriers than supports, whereas relational forces produce more supports than barriers. Employers need to implement strategies to better support ethical practice, and practitioners should rely on their personal value systems to support ethical practice, especially as systemic/organizational forces tempt them to do otherwise.

#### Introduction

Adult rehabilitation is a branch of medical care expected to continue to increase in importance (Gutenbrunnner et al., 2011). Aging populations and advances in medical care are increasing survival rates for some diseases and expanding the number of people living with chronic medical conditions, often accompanied by functional disabilities (Center for Disease Control, 2003; Motl & McAuley, 2010). Rehabilitation service delivery is characterized by several unique features as compared to acute hospitalization care. Patients need to meet certain criteria to be admitted to rehabilitation units (Conroy, 2009), their lengths of stay are typically longer (Conroy, 2009), they are expected to actively participate in their treatment programs (Stein, 2012), and families/caregivers are involved in their loved ones' care (Conroy, 2009). An interdisciplinary team that typically includes physicians, nurses, occupational therapists, physical therapists, and speech and language pathologists provides intervention. These professionals provide care within a complex and dynamic context comprised of system (i.e. health care system, organizational) and relational (i.e. team members, patients, and families/caregivers) elements. Empirical and theoretical literature includes accounts as to contemporary characteristics of these elements and their impact on service delivery.



## **Systemic Elements**

The United States' (US) health care system has dramatically transformed in the past 25 years. Changes in health care management were implemented in an effort to control escalating health costs. Health care management has shifted to a business-orientation model emphasizing cost-containment strategies along with cost-effective and efficient service delivery practices (Austin, 2007). Across the globe, health care providers are plagued by diminished resources stemming from budget cuts (Mackay, 2014); by decreased staffing levels that produce increased workloads and lack of time for staff to meet job responsibilities (Kalvemakr et al., 2004; Peter et al., 2004; Stabell & Naden, 2006); and by third party reimbursement policies/economic conditions that dictate practice decisions (Freeman et al., 2009; Kenny et al., 2012). These contextual features are producing stressful work environments for health care providers (Freeman et al., 2009); Kulju et al., 2013; Mackey, 2014; Morley, 2009), who simultaneously navigate these elements with aspects of relational contexts.

#### **Relational Elements**

Interdisciplinary team. Rehabilitation professionals provide services within a web of interconnected relationships. Key players in these relationships include interdisciplinary team members along with patients and their families/caregivers. An interdisciplinary team model of intervention is an important feature of rehabilitation service delivery (Carpenter, 2005). Integration of individual team members' interventions is driven by interests in safety and economic factors (Engle & Prentice, 2013), and produces better functional outcomes for patients (Engle & Prentice;



Gutenbrunner et al., 2011; Neumann et al., 2010). Team-based intervention is also beneficial to individual team members by providing support in making risky or difficult decisions (Atwal et al., 2012; Kenny et al., 2010; Moats, 2007), and effective team functioning is associated with job satisfaction (Eklund & Hallberg, 2000).

However, in order for a team model to produce positive outcomes, effective communication, cooperation, and collaboration between team members is essential (Clark et al., 2007; Conroy et al., 2009; Gutenbrunner et al., 2011; Suddick & DeSouza, 2007). Challenging dynamics can stem from individual team member traits, including personalities, interpersonal skills, or differing opinions and perceptions (Suddick & DeSouza, 2007). Tensions can arise from team members' perceptions that other team members either lack competency (Brooks et al., 2014) or do not perform their job responsibilities (Atwal et al., 2006). When these tensions place patient care or well-being at risk, individual team members intervene to advocate on behalf of the patient (Dhillon et al., 2010; Kenny et al., 2010; Sachs & Linn, 1997). In rehabilitation, patients and their families/caregivers are integral members of the team and play an important role in their own care.

**Patients and families/caregivers.** Patients must meet certain criteria to be accepted for inpatient rehabilitation services. Factors associated with being admitted include younger age, independent premorbid functioning (e.g. cognition, mobility, communication), and higher levels of current mobility (Hakkennes et al., 2013). Social support and current cognition and mobility issues are associated with denial of admission (Hakkennes), although selection practices vary, leading to concerns about equity in access (Ilett, Brock, Craven, & Cotton, 2010). Rehabilitation intervention is strongly



patient-centered, as patients are expected to actively participate in treatment regimens (Conroy et al., 2009), and this participation is essential for successful outcomes (Gutenbrunner et al., 2011). Motivation to participate can be affected by patients' personality traits and cultural practices, as well as characteristics of the rehabilitation environment and professionals' behavior (Maclean, Pound, Wolfe, & Rudd, 2002). Family members that press patients to make gains (Maclean et al., 2002) or expect them to return to previous levels of functioning (Stabell & Naden, 2007) can also negatively affect patient motivation levels.

Trends in rehabilitation care reflect an increasing importance of treating patients within the context of family members (Bamm & Rosenbaum, 2008; Brasher, 2006). Precipitating conditions (e.g. stroke) influence spouses/caregivers in ways that produce ramifications for the patients themselves (Visser-Meilly, 2006). The role of family members extends beyond providing hands-on care for patients. From a relational autonomy perspective, patients are viewed as individuals embedded in a social context of interdependent relationships with caregivers who provide practical and emotional support and share in decision-making processes (Hunt & Ells, 2011). While some authors advocate for family member interventions (Pellerin, 2011), clinicians perceive these to be a lower priority, perhaps due to time pressures inherent in providing patient care, or to logistical constraints of families typically visiting during non-therapist working hours (Rochette, 2007). While family-centered care produces better outcomes, e.g. in stroke rehab (Visser-Meilly, 2006), family involvement can be problematic when family members do not act in patients' best interests (Brashler, 2006; Mukherjee, 2009), mistreat or abuse patients (Sachs, 1997), or are demanding and/or have unrealistic expectations



(Kassberg, 2008; Stabell & Naden, 2006). These relational dynamics combine with systemic forces to produce complex environments that can impact team members' service delivery in important ways.

# **Context and Ethical Practice**

Ethical practice is one key aspect of service delivery that is relational and highly contextualized (Varcoe et al., 2004). Empirical literature includes accounts of rehabilitation team members' identification of ethical issues in practice (Kirschner et al., 2001; Mukherjee et al., 2009; Young & Sullivan, 2001), along with discipline-specific studies, including nurses (Stabell & Naden, 2006), speech and language pathologists (Kenny et al., 2010), physical therapists (Carpenter, 2005; Finch et al., 2005; Kulju et al., 2013), and occupational therapists (Foye et al., 2002). Issues identified in these studies include those related to both systemic and human contexts, even though study aims did not explicitly relate to contextual factors. Most of the literature regarding the relationship between work setting and ethical issues is from empirical nursing research (Corley et al., 2005; Pauly et al., 2009; Peter et al., 2004), along with non-empirical articles related to managed care in physical therapy (Mellion, 2001), and organizational ethics in occupational therapy (Slater & Brandt, 2009). A few international empirical studies exploring the impact of context on occupational therapy service delivery included findings associated with ethical practice.

Using an institutional ethnography design, Krusen (2011) explored how the practice environment plays a part in shaping the culture of practice at four different types of practice settings in the US. Findings centered on issues related to reimbursement dictating practice decisions; therapists needing to balance ethical responsibilities with



meeting billing and productivity expectations; and some therapists relying on their professional value systems when dealing with changes (Krusen, 2011). Similar contextual constraints appeared in a Canadian study that explored how occupational therapists' met their accountability expectations at a variety of contemporary practice settings (Freeman et al., 2009). Additionally, these therapists relied on their internal motivation in meeting accountability expectations, and were unwilling to compromise their standards when asked to do something unethical, such as change their recommendations (Freeman). Finally, a study from the United Kingdom explored experiences of occupational therapists' professionalism within contexts impacted by health care reform, including participants' struggles with balancing their commitment to professional values with employer's business-oriented values (Mackey, 2014).

# Summary

Adult rehabilitation service delivery is provided by an interdisciplinary team in and takes place in a complex and dynamic practice environment. Contemporary features of both systemic and relational aspects of this context impacts practice in important ways. Systemic aspects related to diminished resources and business-oriented management practice challenge the quality of care provided. Relational aspects stemming from team dynamics, patient characteristics, and family involvement contribute to the web of practice challenges. Ethical practice is one key aspect of service delivery that is contextual and relational. Nursing literature includes empirical articles exploring the relationship between organizational contexts and ethical practice. Non-empirical literature describes the impact of systemic forces on practice in physical therapy and occupational therapy, and a few empirical studies exploring the impact of context on



occupational therapists' service delivery include findings related to ethical ramifications. None of these studies focused on the rehabilitation practice context. To date, no research has investigated how systemic and relational contexts affect occupational therapists' ethical practice. Towards addressing this knowledge gap, the focus of this study was occupational therapists' experiences with ethical issues in adult rehabilitation practice.

#### Methods

This study was guided by the query, What are supports and barriers to ethical practice by occupational therapists working in adult rehabilitation settings? The researcher used a qualitative grounded theory design (Charmaz, 2014) to guide data collection and analysis activities and resulting in a substantive theory addressing this query. Prior to study implementation, human subjects protections' approval was obtained from all participating organizations' institutional review boards or research committees.

# Recruitment

Inclusion criteria for study participation consisted of being a registered occupational therapist with a minimum of one-year of professional experience working with adult rehabilitation clientele. Individuals who were certified occupational therapy assistants, or not directly employed at recruitment facilities, were not eligible to participate in the study. The researcher recruited study volunteers at three Midwestern hospitals. Facility 1 was a freestanding rehabilitation facility. Facility 2 was a rehabilitation unit at a large urban hospital. Faculty 3 was the occupational therapy department at a small general hospital. Participants were recruited via an in-person introductory meeting at each facility. An overview of the study was presented, including background information and options for participation, and attendees were given a flyer



and the researcher's contact information. Meeting attendees also received study reminder emails at one and two weeks after each recruitment meeting.

# **Participants**

These recruitment efforts produced nine study participants. This all-female sample consisted of four occupational therapists employed at facility 1, three employed at facility 2, and two employed at facility 3. Years of experience in a rehabilitation practice setting ranged from 2 to 24 years, with an average of 10.8 years. These nine participants took part in a combination of one, two, or three data collection activities.

## **Data Collection**

**Initial data collection.** The researcher initially collected data using two simultaneous methods, one via individual, semi-structured interviews, and the other via participant journaling. Eight of the nine participants completed an initial interview. These interviews lasted 60 minutes on average, with durations ranging from 45 to 110 minutes. An interview guide was used, with questions asking participants about their perceptions related to specific ethical challenges in practice, including those associated with moral distress and those related to organizational and system characteristics. Interviews were audio-recorded and transcribed verbatim by one of two paid transcriptionists.

Two participants (one of whom also completed an initial individual interview) provided weekly journal entries for eight weeks. The researcher emailed the same questions each week to these two participants, who then responded via email. The questions asked about ethical issues they experienced that week. Out of the potential total of 16 weeks, these participants returned a combined total of nine weeks' entries, and



had nothing to report the other seven weeks. The researcher copied these journal entries into a Word document for data analysis.

**Follow-up interviews.** After initial data collection and preliminary data analysis, the researcher emailed the nine participants and invited them to participate in follow-up telephone interviews. Eight therapists took part in these interviews, which lasted between 18 and 53 minutes, and averaged 37 minutes. A new set of questions derived from preliminary data analysis guided these interviews, which were also audio-recorded and transcribed verbatim by one of two transcriptionists.

#### **Data Analysis**

In grounded theory tradition, data was collected and analyzed simultaneously (Charmaz, 2014). The process began with initial coding, which consisted of repeatedly reading transcripts and labeling chunks of data (Charmaz, 2014). This produced an initial codebook comprised of 33 code words and corresponding definitions. Using HyperRESEARCH <sup>TM</sup>, a computer-aided analysis program, transcribed interview and journal data was reduced and sorted according to initial code words. Several iterations of memos were written as part of the analysis process (Charmaz, 2014). The first iteration consisted of descriptive memos comprised of the raw data and a narrative explanatory summary for each code word. At this point, and throughout the analysis process, the researcher used constant comparison to review coded data (Charmaz, 2014).

Next, the code words were reduced into related chunks of information to form six categories. The researcher then reviewed the original transcripts and personal reflections to confirm an acceptable level of consistency between the data and the categories. Following this constant comparison process, a second iteration of memos known as



analytic memos were produced (Charmaz, 2014) for the new categories. The analytic memos were more abstract than the descriptive memos. Each analytic memo summary accounted for the new arrangements and relationships that the data formed to produce each category. At this time, the researcher also noted potential topics for the follow-up interviews' interview guide during this process.

The next phase of analysis occurred following completion and transcription of the eight follow-up interviews. In this phase, the researcher again used HyperRESEARCH <sup>TM</sup> to re-code all data sources using the six categories. She then wrote analytic memos, i.e. the third iteration of memo writing, to illuminate relationships between chunks of data. Participants validated these preliminary findings through a member checking process (Krefting, 1991). Then, in the ending stages of analysis, the concepts were further reduced and re-organized from the categories to produce four emergent themes. This process culminated in the fourth iteration of memos, producing one for each theme. These memos included a narrative description for each theme, along with sub-themes and their descriptions, as well as direct quotations that supported each sub-theme. Final analysis continued during write up of the findings (Charmaz, 2014). Here, the researcher returned to the data to check that the findings reflected salient points in the data.

#### Trustworthiness

The researcher implemented several strategies to enhance trustworthiness. A research log of study activities was maintained, along with narrative procedural and postdata collection reflective journal entries to produce an audit trail (Krefting, 1991). Prior to data collection, she also recorded reflections focused on her preconceptions in order to



illuminate these concepts and minimize their influence during study procedures. This process is known as bracketing (Tufford & Newman, 2010). For triangulation of data sources (Krefting, 1991), participants came from three different facilities, and different methods of data collection were used. Study participants also reviewed preliminary findings for accuracy, a strategy known as member checking (Krefting). Finally, the researcher's dissertation advisor provided expert review throughout the study (Krefting).

#### Results

Four themes of meaning related to occupational therapists' experiences with ethical issues in adult rehabilitation practice emerged from the data. Themes one and two center on the systemic/organizational and the relational supports and barriers to ethical practice. The third and fourth themes describe ethical issues experienced by occupational therapists as they meet their professional responsibilities, and the accompanying affective experiences in doing so, and will be reported elsewhere. Theme 1, *Ethical practice is expected but challenging*, includes four sub-themes describing one support and three challenges to ethical practice. Theme 2, *It takes a village*, includes four sub-themes related to relational dynamics that support and sometimes challenge ethical practice. Participant quotations are provided to substantiate the sub-themes, and are represented by pseudonyms to protect their identities.

# **Ethical Practice is Expected but Challenging**

Employers' expectations for ethical practice served as an important support, as well as the only support, stemming from systemic/organizational sources. Financial considerations in the form of budget cuts, third party reimbursement policies, and productivity standards intersected with ethical practice in important ways. Meeting



regulations and standards and working within constraints of third party reimbursement defined practice patterns, provided opportunities for unethical practice, and required therapists to develop creative strategies to provide best practice interventions. Therapists had to be knowledgeable about regulations and self-directed in meeting them in ethically sound ways.

**Employers expect ethical practice.** Participants from all three facilities affirmed that their supervisors/managers/employers expected them to be truthful and ethical in performing all aspects of their job duties. For example, employers provided explicit policies and guidelines that dictated honest and accurate billing practices, as they clearly expected therapists to provide not less than 60 minutes of skilled treatment and to bill for the same. Electronic documentation raised therapists' awareness of adhering to legal and ethical regulations concerning privacy and confidentiality of medical records. Therapists discussed the easy access electronic medical records provides to all (i.e. not just their) patients' protected health information and personal records. Although the use of laptops for documentation made accessing records of people they were not treating even easier, employers provided explicit education regarding confidentiality boundaries and emphasized that accessing records of individuals who are not one's current patients violated these boundaries and regulations.

I would also say having management who supports ethical practice as well is very helpful. For example today I had sort of a dilemma with regard to billing, I went and talked to my manager about it, you know, she was, you know, very much oh you know we need to reimburse them. . . . My manager just did the right thing. So



*I think having a management culture that supports ethical practice is a big help* (Nell, follow-up telephone interview).

Money drives practice. Budgetary and reimbursement factors impacted practice and related decisions. Budget cuts impacted staffing levels. Therapists at one facility no longer had therapy aids to assist with patients, including those with brain injury who were agitated and combative. Third-party reimbursement also dictated practice and was a source of ethical tensions. Length of stay was dictated by reimbursement rather than therapists' determination of patient ability to function safely at home and patients were often discharged despite needing more therapy. In these cases, therapists employed creative strategies to offer the best possible outcome for patients, such as involving caregivers sooner or seeking community resources. Additionally, patients transferred to rehabilitation were generally more medically unstable than in the past, diminishing therapists' ability to provide skilled services that could benefit these patients. Therapists also talked about unequal distribution of resources such that patients with good insurance coverage received better services. For example, patients with worker's compensation and Medicaid tended to get better services because those payer sources provided better reimbursement.

I think the biggest barrier is the insurance/financial portion, I would say that far exceeds any other barrier . . . you know, wanting to provide service for someone who can't afford it, and just wanting to document less than you've done but know that that's not ethical . . . it's just such a challenge...to provide good care in this day and age . . . (Abril, follow up telephone interview).



**Every minute counts but not everything counts as minutes.** Due to Medicare's 60 minute rule, therapists were expected to provide and bill for exactly 60 minutes of skilled therapeutic intervention per patient in order to attain maximum reimbursement. Ethical tensions arose when therapists were tempted to round up therapy minutes and bill for 60, despite having provided less, to meet productivity standards. In spite of this lure, therapists were conscientious in counting and providing exactly 60 minutes due to unexpected disruptions, such as patients becoming ill or incontinent, nurses providing interventions, or families asking questions or showing up unexpectedly for education. They employed creative strategies in doing so, such as providing an education-based intervention while transporting the patient, but experienced ethical tensions in determining whether certain interventions qualified as skilled therapeutic treatment.

And that's a stress, because I'm always looking at my watch. And I'm always counting. OK the nurse was in, did I say if I can keep that person in conversation, about energy conservation, or, you know, medicine management, or if it's something that I can relate back to a goal, then I can charge for that time, if not, then I can't. And so, that's just a, that's just a bit of a stress (Anastasia, initial interview).

**Productivity standards count.** Medicare's 60 minute rule combines with high productivity expectations to limit flexibility in therapists' daily schedules as patients were scheduled on the hour and back-to-back. Therapists had difficulty transitioning between patients, taking time to thoroughly clean equipment, using the restroom, or reviewing patient charts prior to treatment. They also had difficulty employing art of therapy



processes such as therapeutic use of self, clinical reasoning, or peer consultation about patient treatment issues. Furthermore, productivity standards influenced therapists' practice decisions, such as those related to patient autonomy. Therapists acknowledged patients' right to refuse treatment, but pressures to meet productivity standards may have influenced therapists to work a little harder to convince patients to participate.

I guess sometimes the question comes up as to the, are we trying to meet productivity standards, or are we doing again what's to the benefit of the patient? Does the patient need more time or less time, or are we choosing less time so we can meet a standard? And I think that's a question. Now I'm not saying that occurs all the time, I have no idea, but I think it comes up for question, just I think it is an ethical something we need to evaluate as therapists when we're treating somebody (Macie, initial interview).

# It Takes a Village

Interactions and relationships with several key individuals influenced therapists' experiences in ways that simultaneously supported ethical practice and created ethical tensions. Most people supported ethical practice most of the time. At times, thought, these same individuals challenged ethical practice. Key individuals included the therapists themselves, peers, professional team members, and patients and their families/caregivers.

**It's who I am.** Characteristics stemming from therapists' personal context supported ethical practice. One key support voiced by all of the participants was their own intrinsic value systems. They had a strong sense of responsibility to meet high



personal standards of conduct as guided by their own core moral values. The therapists attributed the formation of these values to their upbringing, education, and professional experience. Several talked about being raised according to strong family and Christian values that shaped them to be ethical persons in both their professional and personal lives. Their professional education coupled with participating in continuing education opportunities strengthened their commitment and ability to be ethical practitioners. Finally, the more experienced therapists noted that professional experience enhanced their confidence in making difficult ethically-based decisions, their courage to act on these decisions, and their ability to accept frustrating circumstances that they could not control.

Well, I mean that's part of how I grew up. You know, you do the right thing, you take care of people. We're a very medical family also, yeah, I mean it's all in who you are I guess (Addie, telephone interview).

I get by with a little help from my friends. Occupational therapy peers and supervisors generally created a culture of valuing ethical practice. Therapists looked to their peers as a support system in dealing with stresses related to the realities of clinical practice. Peers and supervisors/managers were ethical themselves and served as important resources. When the situation allowed time to do so, therapists sought information and advice from these individuals. Therapists often knew the correct ethical course of action, but appreciated affirmation from others that they were doing the right thing. Observations of unethical conduct by peers were rare, but therapists in the study provided four examples of blatantly unethical behaviors they observed. These included surfing the Internet on work time; taking hard copies of treatment notes home; treating



using modalities for which there was no physician order; and providing sub-standard treatments. Some therapists noted that the environment provided opportunities for unethical conduct, and they sometimes wondered how accurate some peers were when billing for therapy minutes.

So I think I used to consult with my peers, I mean these are OTs that have been practicing for twenty years, and I think I kind of almost know what they're gonna say, and they're just kind of like well, you know, don't take any chances, just do whatever is right. And it just seems like they will always say, 'If you just do, you know, do what you believe is right then our supervisor will stand behind us'. And so they pretty much assure me of that (Lila, follow up telephone interview).

There is an 'I' in team. All of the therapists talked about valuing the highly effective and positive team interactions and functioning at their facilities. They felt respected by team members and appreciated how the team worked together for the good of the patient. Team members typically supported occupational therapist recommendations that patients were unsafe to discharge to home, and provided a united front and consistent information to patients. At the same time, therapists talked about situations where they had ethical obligations to advocate for patients based on team members' behaviors. Physicians referred individuals for therapy who were not appropriate candidates, raising concerns for the therapists about resource allocation. Nursing issues centered on ramifications of staff-shortages that resulted in stress and burned out nurses, leading to concerns related to safety and diminished quality of care. Subsequent ethical issues included some observations of unprofessional behavior, such as nurses rolling their eyes at patients, and patients not receiving medications or other care



in a timely manner. At two facilities, therapists reported instances of nurses expecting therapists to perform nursing tasks, which led to negative feelings on the part of the therapists. A few participants talked about nursing's lack of follow-though with occupational therapy recommendations, especially if doing so would have been time consuming; for example, it was easier for nurses to give a patient a bed pan than to take the time to assist him/her to the bathroom, which interfered with patient progress.

A few therapists talked about isolated observations of physical therapists who lacked empathy in patient interactions, provided overly-aggressive or ineffective treatments, or co-treated with occupational therapists for the benefit of the therapists and not the patient. Therapists also talked about some team members' (e.g. social workers, case managers, physicians) indirect (and, at times, explicit) requests for the therapists to fudge documentation/recommendations to benefit the patient or facility. Such requests came in the form of asking therapists to emphasize certain aspects and de-emphasize other aspects of patients' functional status in their documentation in order to support a certain discharge destination. Most commonly, others asked the therapists to indicate that a patient met qualifications to be eligible for transfer to another facility. All therapists responded that they did not produce fraudulent notes because they were not willing to risk their license.

I was honest in my documentation, even though the staff was asking me not to be. They didn't directly ask me to not be, but they said, oh we have to figure out how he can stay here this long, because they will pay for him to stay here this long" (Daria, initial interview).



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Patients and families. Therapists appreciated supportive and caring family members who were willing and able to provide the care patients needed. Ethical tensions arose when this was not the case and therapists needed to intervene to ensure patient well-being and/or negotiate family demands. Therapists were concerned for patients' well-being when they knew that their patients were going home to be cared for by neglectful or abusive family members. They also advocated for their patients when family members had unrealistic expectations of patient ability and pushed the patient too hard. At times, family members interfered with therapeutic goals by enabling unhealthy patient habits, by doing for the patient rather than allowing patient to do for himself or herself, by speaking for the patient, or by expecting patients to do certain activities that the patient did not wish to do. Some families were unable to accept a plateau in patient functioning and demanded continued treatment. Other families asked therapists to falsify documentation in order to obtain certain equipment that the patient didn't need, or to falsely deem a patient eligible for skilled nursing facility admission because the family did not wish to care for the patient at home.

I had a wife, her husband had dementia, she pushed and pushed for me to say he was OK to drive, when in fact he wasn't, and it was because she still worked. And he still wanted to go to the McDonald's every morning and eat with his friends, but, you know, from my standpoint, I just couldn't approve him. And that's upsetting (Carleen, initial interview).



#### Discussion

Findings of this study are organized around two emergent themes describing how systemic and relational contexts support and challenge ethical practice for occupational therapists in adult rehabilitation practice settings. The first theme, *Ethical practice is expected but challenging*, includes four sub-themes. The second theme, *It takes a village*, includes four sub-themes associated with relational factors that support and challenge ethical practice.

#### **Systemic Factors**

Under the first theme, *Ethical practice is expected but challenging*, four subthemes explain how systemic factors impacted ethical practice. The first sub-theme refers to employers' expectations for ethical practice serving as the only systemic support. The other three sub-themes refer to challenges to ethical practice in the form of budgetary issues, reimbursement standards, and productivity expectations.

Ethical climate. Employers' expectations of ethical behavior served as the single systemic support of ethical behavior for this study's participants. This phenomenon, known as an ethical climate, refers to how employees' perceptions of their organization's ethical character, policies, and practices influence the employees' ethical behavior (Cullen, Parboteecah, & Victor, 2003; Mulki, Jaramillo, & Locander, 2007; Olson, 1998). Empirical work related to the impact of organizations' ethical climate on their employees is prevalent in business literature, but appears to a lesser degree in health care literature. Studies of business organizations (Andreoli & Leftkowitz, 2009), retail salespersons (Jaramillo, Mulki, & Solomon, 2006; Mulki, Jaramillo, & Locander), and marketing professionals (Valentine & Barnett, 2007) have shown associations between positive



ethical climate and employee job satisfaction. Consistent with this study's findings, empirical literature supports a positive association between an organization's ethics climate and its employees' ethical behavior (Andreoli & Leftkowitz, 2009; Baker, Hunt, & Andrews, 2006; Valentine & Barnett, 2007).

Ethics climate and health care. Despite unique features of hospital-based service delivery (e.g. dealing with rising costs; requirements to meet standards of external credentialing agencies and federal and state regulations), the ethical climate of hospitals is associated with employee job satisfaction (Deshpande, Joseph, & Prasad, 2006; Valentine, Godkin, Fleischman, & Kidwell, 2011). Furthermore, peer and managerial ethical behaviors provide positive and influential role modeling that promotes ethical behavior in others (Deshpande et al., 2006). Discipline-specific literature reports an association between positive ethical climate and willingness to endure higher levels of ethical stress for nurses and social workers (Ulrich et al., 2007). At the same time, poor ethics climate has been shown to be associated with moral distress frequency and intensity (Corley, Minick, Elswick, & Jacobs, 2005; Pauly, Varcoe, Storch, & Newton, 2009) and turnover for nurses (Hart, 2005). This study's findings did not include the presence of moral distress due to a poor ethics climate as the ethics climates were positive at all study employment sites. These positive ethical climates provided important supports for ethical behavior, however realities related to financial implications of health care delivery simultaneously posed barriers that challenged ethical practice for this study's participants.

**Economic realities.** Ethical issues stemming from current health care management and delivery practices are well documented in the international literature



and confirmed for occupational therapists in this study. Managed care and cost containment strategies, limited resource allocation, and reimbursement-driven practice decisions are producing stressful practice environments and challenging health care providers' ability to meet personal and professional standards of care. Occupational therapists in Canada (Freeman et al., 2009), the United Kingdom (Mackay (2014), and the US (Krusen, 2011) report practice environments that mirror the stress levels experienced by this study's participants as they worked to meet productivity expectations. Limited resources and unfair resource allocation have compromised therapists' abilities to provide needed or quality services world-wide (Finch et al., 2005; Foye et al, 2002; Kenny et al., 2010; Kulju et al., 2013; Mackey, 2014; Mukherjee et al., 2009), producing issues related to distributive justice. Similarly, reimbursement and funding policies are driving practice decisions and diminishing therapists' ability to provide beneficent care (Foye et al., 2002; Mukherjee et al., 2009) as well as creating pressures to reduce services as a cost-containment strategy (Ulrich et al., 2006). These global conditions are consistent with US occupational therapists in this study. These systemic forces mostly challenged ethical practice for this study's participants, while at the same time, relational dynamics mostly supported, but occasionally challenged, their ethical practice.

### **Relational Supports**

The second theme, *It takes a village*, includes four sub-themes associated with relational factors that support and challenge ethical practice. Relational supports of ethical practice include therapists' intrinsic values, peer/supervisor and team collaboration and validation, and positive patient/family dynamics. At the same time, some team and dysfunctional family dynamics also challenge ethical practice.



Interpersonal. This study's participants looked to peers and supervisors as an important source of support when faced with ethical issues. This finding is consistent with literature reports as to the relational and contextualized features of ethical practice (Austin, 2007; Varcoe et al., 2004). Nurses and therapists frequently reach out to peers for support and advice when faced with challenging ethical decisions (Finch et al., 2005; Kassberg & Skar, 2008; Kenny et al., 2010; Zuzelo, 2007). The team model of intervention in rehabilitation practice can also be a source of support when therapists face difficult decisions. Literature reports include therapists being especially appreciative of team support in situations where patients were at risk of making decisions that threatened their health or well-being (Atwal et al., 2012; Moats, 2007). Contrary to this current study's findings, the literature reports instances of team dysfunction due to lack of respect (Atwal et al., 2003), poor communication (Penny et al, 2014), or other tensions (Finch et al., 2005). For participants in this current study, peers and team members provided an important support for participants' own ethical behavior. It was these participants' innate drive to be ethical persons, however, that provided the foundation for their ethical practice.

**Intrapersonal.** This study's findings explicitly attributed participants' dedication to ethical practice to their own value systems and high personal standards of conduct. Ethical actions stemming from one's moral character represents a branch of moral theory known as virtue ethics (Gardiner, 2003). Rather than basing an ethical decision on justice-based approaches, i.e. adhering to one of four moral principles (Beuchamp & Childress, 2014), meeting one's duties (deontological theory; Stanford & Connor, 2014), or considering the consequences of one's actions (teleological theory; Stanford &



Connor, 2014), a virtues-based approach is driven by an individual's inherent character traits (Armstrong, 2006). That is, one's character and actions are closely intertwined (Pellegrino, 1995). Virtues-based approaches offer options not available in justice-based approaches (Pellegrino, 1995), as they include consideration of relational and contextual dynamics (Armstrong, 2006). In virtues-based approaches, emotions and responsibility are regarded as important (Gray, 2010), which can serve to protect vulnerable individuals (Armstrong, 2006). Some advocate for a stronger presence of virtues-based approaches in the health care arena (Armstrong, 2006; Gardiner, 2003; Gray, 2010; Pellegrino, 1995), despite inherent difficulties in adopting a virtues-based approach. Pellegrino (1995) suggests such difficulties include a lack of action guidelines inherent in justicebased theories and a sense that attaining virtuous excellence is too high an expectation. Nevertheless, the occupational therapists in this study were well grounded in strong personal values and held high personal standards. This grounding served to strengthen their moral convictions when facing challenges to ethical practice that stemmed from interpersonal relationships.

#### **Relational Barriers**

Although not frequent in occurrence, this study's findings included the occurrence of requests by patients/families to perform unethical acts, and observations of peer and team member incompetent and/or unethical conduct. The literature reports patient/family requests for therapists to perform unethical acts as stemming from various underlying motivations. The first relates to economic factors, when a patient/family member asks therapists to falsify recommendations in order to receive equipment the patient desires, but does not necessarily need (Finch et al., 2005; Kassberg & Skar, 2008). Similarly,



families may request that therapists falsify documentation for family convenience, for example, to qualify a patient for skilled nursing facility placement because family members do not wish to care for the patient at home. The other concern stems from families pressuring therapists or physicians to continue their loved ones' therapy despite patients having no potential for functional gain (Finch et al, 2005). Resulting from experiences related to this last issue, the occupational therapists in the study were concerned with allocation of scarce health care resources.

Observing team members' incompetence or unethical acts is consistent with findings in international occupational therapy (Dhillon et al., 2010; Penny et al. 2014; Sachs & Linn, 1997), physical therapy (Kulju et al, 2013), speech and language pathology, and nursing (Jackson et al., 2010; Kenny et al., 2010). Consistent with literature reports, this current study's participants intervened in those circumstances to protect patient safety and well-being. Findings of the study reported here include additional issues specific to nursing. Participants attributed these concerns to staff shortages that led to overworked and stressed nurses. The prevalence of staff shortages and overworked and stressed nurses is well-documented in the nursing and non-nursing literature. Nurses themselves have identified that working in unsafe environments due to staff shortages is a major cause of distress (Corley et al., 2005; Kalvemark et al., 2004; Pauly et al., 2009; Peter et al., 2004; Stabell & Naden, 2006; Ulrich et al., 2010; Zuzelo, 2007). It is not surprising that these staffing patterns and resultant heavy workloads diminish nurses' abilities to meet job responsibilities (Peter et al., 2004; Stabell & Naden, 2006; Zuzelo, 2007) and that other team members recognize and feel the impact of this reality. This study's participants' experiences with nursing issues were aligned with



literature reports of lack of consistency of basic nursing care and lack of follow through with therapy goals because it may be quicker or easier for nurses to do the task than to take the time to allow the patient to do it him or herself (Atwal et al., 2006; Brooks, et al., 2014; Morris et al., 2007).

## Limitations

This study's findings are limited by two key factors related to its sample. Selfselection bias may have impacted the findings in that those who volunteered to participate may represent therapists who are firmly rooted in ethical practice or have particular concerns in regard to ethical practice. Therapists who may have tendencies to bend the rules may not have desired to partake in the study. The all-female sample could have also biased the findings, especially those related to virtue ethics. Virtue ethics is considered to be related to feminist ethics theory, the foundation of which proposes gender-based responses to ethical decision-making. Including male therapist participants may have produced findings less attributable to a single gender.

#### Implications

At the organizational level, managers who expect ethical compliance need to implement policies that better support employees' ability to meet these expectations. They need to support a positive ethical climate and provide strategies to help employees counteract systemic and organizational forces that tempt unethical practice. At the individual level, therapists should seek continuing education opportunities to keep abreast of policy changes with the potential to impact ethical practice. Therapists should also continue to seek support from peers and team members for mutual learning opportunities. Furthermore, by sharing ethical struggles, individuals can promote ethical practice and



contribute to a positive ethical climate. At the educational level, professional curricula should include content that prepares students for the realities of the system, organization, and relational ethical challenges of clinical practice. Students should also take part in self-reflection activities to develop a deep understanding of their personal values along with how their values support ethical practice.

# **Future Research**

Future research studies could explore the prevalence of specific supports and barriers to ethical practice identified in this study. A survey design could capture a large sample size and include male participants. An additional area of inquiry could explore how rehabilitation facility organizational policies and practices support and challenge ethical practice. A participatory action research (Stringer, 2013) study could be implemented within a designated therapy department to develop strategies to better support ethical practice, and evaluate their effectiveness. Finally, inquiry as to the role of virtue ethics in clinical practice could inform therapy educational content and teaching strategies.

# Conclusions

Well-documented changes in the health care delivery context are impacting rehabilitation practice on multiple levels. System/organizational and relational level concerns are being infused into clinicians' ethical practices. Systemic/organizational and relational forces provide both supports and challenges to ethical practice. Systemic/organizational level factors produce more barriers than supports. Managers who expect ethical behavior need to implement policies and practices to better support ethical practice at the employee level. At the same time, relational factors produce more



supports than barriers. A key support to ethical practice is the inherent moral character of practitioners, which leads them to make sound ethical decisions. Known as a virtue ethics-based approach, practitioners can look internally for guidance in instances when contextual forces lure them towards unethical decisions.



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### **Chapter Five**

### Conclusions

The aim of the first study, Pediatric therapists' perceptions of occupation-based practice, was to explore occupational therapists' experiences related to using occupation as a basis for intervention in a hospital setting. Findings from this first study coupled with a gap in the literature related to ethical practice to generate the impetus for the second study. Occupational therapy literature lacked current empirical works related to ethics in practice. Implementing a grounded theory study allowed me to tap in to the wisdom and experiences of contemporary occupational therapists as they navigated ethical waters in practice. The findings of these studies showed what it is like to do occupation-based practice at a pediatric medical center, and to practice ethically at adult rehabilitation facilities. That is, they described practice realities for contemporary occupational therapists in medical model-based practice settings as they strive to meet professional expectations for ethical and occupation-based practice.

Doing occupation-based practice at a pediatric medical center was easier than biomechanical-based interventions because it is supported by supervisors and peers, serves as grounding for therapists' identities, and is more effective, customized, and valued by children and families. At the same time, the artificiality and space limitations of the clinic environment, the extra time required to do occupation-based practice, service provision within a medical-based facility, and needing to shift away from the paradigm upon which their professional education was based all challenged therapists' ability to implement occupation-based practice in this group of pediatric occupational therapists.



Ethical practice at adult rehabilitation facilities required therapists to adhere to professional ethical standards in daily practice, despite challenges in doing so. Ethical practice also included emotional aspects, such as therapists needing to trust their instincts regarding the right course of action and having lingering feelings of distress when constrained from providing best care, yet feeling gratified by making a difference in patients' lives. Barriers to ethical practice stemmed from organizational and health care system policies and procedures. Employer expectations, and peer and team support generally made ethical practice easier. At first glance, the findings of these two studies can appear unrelated. Synthesizing these studies' findings does, however, reveal several primary conclusions, suggest recommendations for key players, and suggest future research.

#### **Primary Conclusions**

**Contextual forces.** Inherent characteristics of clinic, facility, and health care system environments offer supports and erect barriers to occupational therapists' ability to provide best practice. Twenty-five years ago, Peloquin (1989) warned of the dangers of contextual forces (e.g. decreased hospital stays, productivity expectations, third-party payers' documentation requirements) detracting from the humane aspects of practice. Indeed, her words were prophetic as these contextual forces drive practice today, exerting a mostly negative influence. More recently, authors have suggested a need for attention to and investigation into the relationship between institutional environments and ethical practice (Austin, 2007; Carpenter & Richardson, 2008). Findings of these current studies showed that forces at the clinic level, such as productivity expectations and availability of space and equipment, made ethical and occupation-based practice challenging. Forces at



the health care system level, primarily reimbursement issues and shortened lengths of stay, added to these challenges and negatively affected ethical and occupation-based practice. At the same time, employer expectations served as a support to practice. Beyond having these expectations, managers who support ethical and/or occupationbased practice also need to be cognizant of these forces. To the extent possible, managers and supervisors should implement policies and procedures that mitigate their negative impact. Along with these non-human contextual forces, occupational therapists negotiated dynamics of relational contexts when implementing ethical and occupationbased practice.

Human context. Occupational therapists' treatment interventions did not occur in a vacuum. That is, relational dynamics also supported and challenged practice. Supervisors, peers, and team members provided important supports, but also generated challenges to ethical and occupation-based practice. Supervisors' expectations and modeling were strong supports in promoting ethical and occupation-based practice. Peers and team members served as important resources by providing assistance with problemsolving and offering reassurance. Family members and caregivers were also important players in therapeutic dynamics. Clients need support and assistance from family members, significant others, or caretakers in order to reach the best therapy outcomes (Brashler, 2006). Occupational therapists need to be skilled in educating clients and their loved ones so that they appreciate the value of occupation-based practice, and follow through with treatment regimes in order to achieve optimal outcomes. Similarly, therapists need to educate clients and significant others about therapists' professional ethical obligations and constraints. Negotiating the non-human and human contexts is an



inherent aspect of clinical practice and involves a thinking process known as pragmatic reasoning.

**Pragmatic reasoning.** The dynamics of contemporary practice environments require occupational therapists to be skilled in clinical reasoning (Leicht & Dickerson, 2001). Occupational therapists used a type of clinical reasoning known as pragmatic reasoning to negotiate the realities of medical-model practice environments. In pragmatic reasoning, therapists consider the influence of practical considerations on decision-making (Neidstadt, 1998). Such practical considerations consist of the realities of practice, that is, the non-human and human contextual forces found in these two studies that supported and challenged ethical and occupation-based practice. Using pragmatic reasoning, therapists implemented creative strategies in effectively negotiating these realities of practice contexts.

**Creativity.** Creativity was required for occupational therapists to meet employer and health care system expectations, and professional and personal standards of practice. Creativity is an integral and consciously employed aspect of occupational therapy practice (Schmid, 2004). These studies' participants enjoyed this creative aspect of their jobs. They found that employing creative strategies brought elements of stimulation and challenge, and made their day-to-day work more interesting. Therapists should continue to propagate these reinforcing elements by drawing upon their creativity to develop strategies that promote ethical and occupation-based practice. Being creative was also rewarding when doing so produced more positive client outcomes, and reinforced occupational therapists' professional identities.



Identities. Occupational therapists' professional and personal identities served as important beacons guiding their daily practice. That is, their identities as occupational therapists drove their desire to be ethical practitioners and to ground their practice in the valued activities of their clients as a means of intervention or as desired goals. Their identities as occupational therapists meant that doing occupation-based practice differentiated them from other health care practitioners. In doing occupation-based practice, therapists provided individually tailored interventions based on occupational therapy's unique knowledge base, avoiding a duplication of services provided by other practitioners, such as physical therapists or speech and language therapists. Similarly, their identities as occupational therapists, persons who care, and persons with strong moral characters meant they were ethical practitioners, even when contextual forces challenged their doing so. Furthermore, these features of their identities reinforced their commitment to being occupational therapists. These conclusions provide impetus for recommendations at the professional, organizational, individual therapist, and educational levels.

# Recommendations

**Profession.** The findings of these studies can inform the American Occupational Therapy Association's (AOTA's) policy formation and advocacy efforts. The AOTA Ethics Commission could reflect some of these findings in revisions of the *Occupational Therapy Code of Ethics* (*Code*). Including standards related to ethical issues experienced by this study's participants will produce a *Code* reflective of the current realities of practice. For example, adding ethical standards related to responding to team and family requests to perform unethical acts, to observations of non-occupational therapy team



members performing unethical acts, or to boundaries on accessing information in electronic medical records would update the current *Code* to better guide therapists' ethical behavior.

The AOTA can also use these studies' findings to support lobbying efforts. The need for health insurance reform is well known and addressed in recent health care legislation. However, Medicare reimbursement for therapy services remains limited, and many health insurance companies follow Medicare's lead in forming policy related to reimbursement (Qu, Shewchuk, Chen, & Deutsch, 2011). Both studies' findings related to how reimbursement issues determine practice decisions and limit service provision can inform lobbyists and support their efforts to educate legislators and shape policy formation.

**Organizations.** Employers who support occupation-based and ethical practice should use these findings to better understand the factors that support and challenge employees' abilities to implement such practices. Based on this information, managers and supervisors can develop and implement creative strategies to strengthen the supports and minimize the barriers revealed by these studies' findings. Supervisors should clearly communicate their support for occupation-based and ethical practice, as well as model those desired practices. Additionally, managers should set realistic productivity standards.

**Occupational therapists.** Therapists should use the findings of these studies for purposes related to education, support, and guidance. These findings can educate therapists about subtle ethical issues inherent in contemporary rehabilitation practice and about supports and barriers to ethical and occupation-based practice. Awareness of these



issues can enable therapists to react appropriately in situations requiring quick decisions. In addition, through shared problem solving, therapists can develop proactive strategies to minimize barriers to ethical and occupation-based practice. Sharing of stories and problem solving can also serve as a conduit for team and peer support, which is an important coping strategy when therapists face these challenges. Finally, therapists should maintain their strong identities in order to transcend challenges inherent in service provision grounded in occupation-based and ethical practice. By practicing according to their identities, therapists can serve as role models for others and contribute to a positive clinic environment.

**Entry-level education.** The role of professional education is to prepare students to meet the demands of entry-level practice. Occupational therapy educators should infuse these findings into course content to better prepare graduates for the realities of practice. Curricular content should reflect current professional issues and ethics content. Such content can alert students to practice challenges and prepare them to deal with current challenges. Instructional strategies to prepare students to deal with challenges could include assertiveness training to develop advocacy skills. Self-reflection for values identification and moral development could strengthen students' identities as ethical and occupation-based practitioners. Students should also practice strategies for effectively dealing with families and significant others, perhaps using role-play and simulation activities. Finally, faculty members should guide students in their development of coping skills, perhaps by reinforcing the importance of seeking peer and team support, or by participating in shared problem-solving activities.



### **Future Research**

These studies suggest several topics for future research. The next study I plan to implement stems directly from this dissertation. I will develop a survey consisting of a variety of question formats, including demographic, Likert scale (e.g. rating level of extent to which participants experience those issues, supports, and barriers identified in my study), and open-ended (e.g. identify additional issues, supports, and barriers ) questions. I envision separate studies, each targeting a different practice setting (e.g. skilled nursing facilities, school-based practices, acute care hospitals, behavioral health facilities/units). In hopes of attaining a sample size of several hundred participants, I will distribute the surveys at a national level, perhaps by posting study invitation on the American Occupational Therapy Association's social media site, or attaining email addresses from state licensure boards. These strategies will aim at determining the prevalence of ethical issues as well as supports and barriers to occupation-based and ethical practice elucidated in my dissertation studies.

Other research could include qualitative studies aimed at eliciting occupational therapists' voices regarding their experiences related to aspects of these studies' findings. Such studies could focus on advocacy, moral courage, impact of spatial and temporal contexts on occupation-based and ethical practice, the role creativity plays in therapists' coping and job satisfaction, therapists' perceptions of how administrative/managerial policies and practices impact occupation-based and ethical practice, and the role of therapist identity inoccupation-based and ethical practice.

I would also like to implement two participatory action research (Stringer, 2014) studies, one focused on occupation-based practice and the other on ethical practice. For



these studies, I would collaborate with occupational therapists at a medical-based facility in order to develop and implement a plan to strengthen supports and minimize barriers to occupation-based or ethical practice and measure outcomes, repeating the process until desired changes occur. The overall aim of these studies would be to produce sustainable changes in practice environments to better support, and minimize barriers to, occupationbased or ethical practice.

Other studies could include replications of these dissertation studies. The studies should be repeated in five years to compare findings and estimate practice trends. Additional replication research could focus on studies that explore ethical and occupation-based practice at other types of practice facilities that service different populations. Various practice settings could include schools, long-term care facilities, psychiatric facilities, or home health care practices. Other service populations might include mental health, work and industry, or health and wellness.

#### Closing

To address gaps in the occupational therapy literature and knowledge base, I used grounded theory methods to explore two important aspects of occupational therapy practice. The professional imperative to return the focus of practice to occupational therapy's unique contribution to health care (that is, occupation-based practice) stimulated the implementation of the first study. Occupational therapists practicing in medical facilities stand in two worlds of competing paradigms. Little information was available to therapists as to how they could successfully provide occupation-based interventions within a medical-model context. Through systematic inquiry, I generated substantive theory to inform our understanding of occupation-based practice at a medical



facility. This theory elucidated both the supports and the barriers to implementing occupation-based practice, which were equally important in assisting therapists as they worked to strengthen the occupation base of their practice.

Findings related to the impact of practice context from the first study combined with a gap in the literature related to ethical practice to generate the impetus for the second study. Using a grounded theory approach, I tapped into the wisdom and experience of occupational therapists working in rehabilitation practice settings. The findings of this second study produced empirically based, substantive theory related to the complex dynamics of ethical practice. For the most part, the ethical issues my study's participants faced had been reported in earlier/dated occupational therapy studies, or in studies of ethical issues identified within other professions. One lesser-reported issue did emerge from this study. This issue relates to requests by team members and clients or their families for therapists to commit unethical acts, primarily in the form of falsifying documentation. These types of requests may be a reaction to increasingly stringent reimbursement policies and a reflection of increasingly scarce health care resources. Other barriers to ethical practice emerged from organizational and systemic forces. While study findings elicited fewer supports to ethical practice, the supports that emerged could contribute to a more optimistic future. This study's participants had strong moral characters, caring attitudes, and a commitment to the profession of occupational therapy.



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# Vita

# Joanne Phillips Estes

# Education

1988	Mercy College of Detroit Detroit, Michigan Master of Science, major in Allied Health Education
1979	Eastern Michigan University Ypsilanti, Michigan Bachelor of Science, major in Occupational Therapy

# **Professional Positions**

1995 –	Assistant Professor of Occupational Therapy
Present	Xavier University
	Cincinnati, OH
2002	Consultant to Xavier University, Department of Occupational Therapy
1997-	Chairperson, Department of Occupational Therapy
2002	Xavier University
	Cincinnati, OH
1979-	Available upon request
1994	

# **Professional Publications**

2014	Asher, A., Estes, J., & Hill, V. (2014). International collaboration from the comfort of your classroom. American Occupational Therapy Association's <i>Education Special Interest Section Quarterly</i> , 24(4), 1-4.
2014	<b>Estes, J.</b> (2014). An Advisory Opinion for the AOTA Ethics Commission: Promoting Ethically Sound Practices in Occupational Therapy Fieldwork Education.



2013	Estes, J., & Pierce, D. (2013). Pediatric therapists' perceptions of the dynamics of occupation based practice. In D. Pierce (Ed.) <i>Occupational science for occupational therapy</i> , (pp. 281-290). Thorofare, NJ: SLACK, Inc.
2013	<b>Estes, J.</b> (2013). An Advisory Opinion for the AOTA Ethics Commission: <i>Telehealth</i> .
2012	Estes, J., & Pierce, D. (2012). Pediatric therapists' perspectives on occupation-based practice. <i>Scandinavian Journal of Occupational Therapy</i> , 19(1), 17-25. doi:10.3109/11038128.2010.547598
2011	Estes, J. (2011). Diabetes. In B. Atchison & D. Dieuret (Eds.), Conditions in occupational therapy (4th Ed.). Baltimore: Lippincott Williams and Wilkins.
2011	<b>Estes, J.,</b> & Brandt, L. (2011). Navigating ethical challenges of Level II fieldwork. <i>OT Practice</i> , <i>16</i> (7), 7-10.
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2007	<b>Estes, J.</b> (2007). Diabetes. In B. Atchison (Ed.) <i>Conditions in occupational therapy</i> (3 <sup>rd</sup> Ed.). Baltimore: Lippincott Williams and Wilkins.
2005	Barrett, J., Scheerer, C., <b>Estes, J.</b> (2005). Order of information: Impact on clinical judgment. <i>Occupational Therapy in Health Care, 18</i> , 1-12.
Pre-2005	Provided Upon Request

