University of Alberta

Ethical practice in paediatric speech-language pathology

By

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Rehabilitation Science

FACULTY OF REHABILITATION MEDICINE

Edmonton, Alberta

Fall 2005

Library and
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395, rue Wellington
Ottawa ON K1A 0N4
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0-494-08738-2

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DEDICATION

To my daughter

Ceinwen

whose love never fails

ABSTRACT

Speech-language pathologists working with children and their families express a desire to more fully understand the ethical dimension of their practice. While codes of ethics and articles outlining ethical decision-making models are available, many of these sources do not necessarily reflect the day to day practice of the profession. This study explored the question, "What is ethical practice in paediatric speech-language pathology?"

Using an exploratory-descriptive approach, paediatric speech-language pathologists were asked to describe their perspectives on ethical practice. Individual interviews were conducted with ten participants. Data were analyzed using grounded theory techniques to explore relationships in the data and develop categories and themes relevant to ethical practice.

The resulting model of ethical practice in paediatric speech-language pathology presented the moral aim of clinical practice which is to make a difference in the lives of children with communication disorders ensuring that these children are part of their social world, that is, that they are socially connected to others. In order to achieve the good defined in this way, the ethical clinician, participants stated, must possess the characteristics of being other-focused, competent, knowing, honest, sensitive, and reflective. The ethical speech-language pathologist values the child and strives to do her best for the child and his family. Ethical action is centrally defined as providing support. Doing what is right involves a range of actions that are not just specific clinical activities.

Comparisons to nursing demonstrated similarities in perspectives on ethical practice. Speech-language pathologists, like nurses, attended to context, focussed on the relationship with the client and his family, recognized ethics as embedded in notions of good practice, and used everyday language to describe the ethical dimension of their clinical work.

This study offered a description of ethical practice in paediatric speech-language pathology from the point of view of clinicians in the field. As such it provides a descriptive base that serves further investigation of the phenomenon of ethical practice. Comparisons to nursing suggest that better understandings of ethical practice can be achieved with collaborative efforts to strengthen the discourse on ethics across health care disciplines.

Acknowledgements

I am deeply indebted to the many people who sustained me over the course of my studies. I will attempt here to name but a few knowing that I will no doubt regret that I have missed others.

First, I wish to acknowledge the funding support of the Social Sciences and Humanities Research Council of Canada. I also wish to thank my participants who gave generously of their time. I am honoured to belong to a community of health care professionals who care deeply about children with communication disorders.

I thank my examining committee, Jan Storch, Mary Ann Bibby, and Lili Liu, for their careful and insightful comments. Their generous contribution is appreciated. I wish to express my deepest gratitude to my core committee members, Sharon Warren, Glenn Griener, and Kathleen Oberle not only for their official support but also for their personal encouragement and advice. I truly would not have finished this degree without their dedication.

My friends kept me going by propping me up when I felt tired, lost, and cynical. In particular, I thank Lori, Kathy, Denyse, Anita, Wonita, Rebeccah, Jess, Judy, and Ram. I owe a special thanks to Adriano Zenari for his love and devotion.

Without my immediate family, nothing is possible. My brother, Andrew, has been a quiet but steady presence. My daughter, Ceinwen, in her most delightful way, was always there to remind me of the important things in life. My mother, Gwyneth, provided the foundation for my ability to complete my degree with her absolute faith in me. Finally, I remember my late father, Gordon, who patiently listened and guided

me. One of his gifts to me was to teach me the words of Rudyard Kipling's poem, "If". I have lost count of the number of times that I sought out the appropriate line in this poem to sustain me in my ever changing life over the course of my doctoral studies. But I know that my father served me well when he prepared me with the gift of this poem. So, in closing, on the day that I write these lines, I choose the following from Kipling:

If you can meet with Triumph and Disaster
And treat those two imposters just the same.

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CHAPTER 1: INTRODUCTION

Ethical practice in pediatric speech-language pathology

Speech-language pathologists working with children with disabilities and their families are seeking guidance for the difficult ethical problems they encounter in clinical practice in the face of rapid changes in the health care system, technological advances, and increasing survival rates of infants and children with severe disabilities. While guidelines and codes of ethical conduct exist for speech-language pathologists, my experience as a member of both provincial and national ethics committees suggests that the ethical perspectives of speech-language pathologists working with paediatric clients are not necessarily represented by the various guidelines, regulations, and codes of ethics currently available in the professional literature. Speech-language pathologists still ask what is expected of them to practice ethically in their everyday dealings with children and their families. What appears to be lacking is an overall model of ethical practice in pediatric speech-language pathology that would describe how ethics is articulated in this particular area of health care. Such is the purpose of the current study.

Introduction to paediatric speech-language pathology

In order to understand ethical practice from the perspective of paediatric speech-language pathologists that is reflected in the study which follows, the profession, its mandate, the population of children served, and the organization of service delivery are described. The major influence of the family-centred model of intervention is highlighted in this section to provide the reader with a context for the exploration of ethical practice.

Organization of the profession in Alberta

Speech-language pathologists in Canada receive their clinical education and training in university settings. Since 1992, the entry level to practice is a master's degree in speech-language pathology. There are currently 769 speech-language pathologists in the province of Alberta of whom twenty-four are male and 745 are female (Alberta College of Speech-Language Pathologists and Audiologists, March 2004). One hundred and seventy-two speech-language pathologists work in the Capital Health Authority region. Information about how many of these clinicians work with paediatric clients and whether or not those who do have a practice that is exclusively paediatric was unavailable. It is reasonable, however, to assume that a clinician may choose to focus exclusively on a paediatric population.

Registration with the Speech, Language, and Hearing Association (SHAA) was non-statutory until 2002 when, under the *Health Professions Act*, the Alberta College of Speech-Language Pathologists and Audiologists (ACSLPA) was declared. Since 2002, all speech-language pathologists in Alberta must possess a license issued by ACSLPA in order to practice. Membership in the Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) is optional. Clinical certification and continuing clinical education hours are tracked by the national organization and proof of continuing education efforts is required for maintaining a license. While many speech-language pathologists practice in education settings, speech-language pathology is considered a health care practice governed by the *Health Professions Act*.

Paediatric populations served

A wide range of communication disorders will qualify a child for speech and language services. Physical disabilities such as cerebral palsy, spina bifida, and multiple congenital anomalies affecting major developmental areas increase the likelihood that children and their families will have contact with speech-language pathologists. Sensory disabilities such as blindness and hearing impairment also affect the major developmental areas including communication. Other major developmental disabilities include Autism Spectrum Disorder (ASD), Down Syndrome, and varieties of congenital and acquired disabilities affecting communication development. For each child, there occur, over time, shifts in the concerns, priorities, and treatment plans to meet the child's evolving needs.

Service delivery

Paediatric speech-language pathology serves children from birth to age 18 years. In recent years, these services have been concentrated at the younger age range for several reasons. The accumulated research evidence indicates that earlier intervention is more effective in securing optimal outcomes for children with disabilities. Partly in response to this evidence, speech and language services, which are a finite societal resource, are funded more heavily in the range from birth through to the early elementary years. For example, Alberta Learning has designated funds, called Program Unit Funds (PUF) for preschool children, ages 2 years, 6 months to 5 years, to provide early education with input from developmental specialists such as speech-language pathologists. Government cutbacks in Alberta aimed at cost containment or reduction have forced a reorganization of speech and language services reinforcing a service delivery arrangement that favours younger children with developmental needs.

Certain agencies are designated to serve only the paediatric rehabilitation population. These agencies are organized as not-for-profit societies. Other public agencies, such as community health centres, have a broader mandate to provide speech and language services to all eligible persons living within their boundaries. Within their mandate, services to children are grouped together under one speech and language services administration.

Some clinicians choose private practice or contract their services to agencies that do not hire their own speech-language pathologists. Private practice or private contract speech-language pathologists find that many families of children with communication disorders prefer to access service through the public system despite lengthy waitlists. Families may be reluctant to pay for services when the public system has a mandate to provide services. Families seeking private therapy may not be able to afford the hourly fee or may find that only a limited number of sessions per year are covered by their private health insurance plan.

Description of practice

Speech-language pathologists provide assessment and treatment for children with communication disorders. The specific tasks within these two central activities include observing, recording, interviewing, testing, interpreting, reporting, planning, counseling, and carrying out therapeutic actions. Clinical activity is driven by a set of guiding questions that constitute the topics for clinical encounters with families. These guiding questions include:

1. Is there a communication problem?
2. What is the problem?
3. What can we do about it?
4. What resources do we have?
5. What will happen?
6. When will we be done?

In reality, clinical encounters involve, at any given point in time, one or several of these questions. For example, in an individual program planning meeting, the speech-language pathologist will often report on the nature and extent of the child's communication disorder, the test results and progress, and will discuss goals and expected outcomes.

Time frames for clinical encounters in speech-language pathology vary. Interactions with the child's parent(s) may be ongoing each time the child and parent attend a session or occur at intervals over time as the child attends a treatment or education program (e.g., parent meetings such as program planning meetings). Less frequent contacts with parents occur when the child attends a specialty clinic for follow-up or when the child attends school and the parent is contacted by telephone only. For some speech-language pathologists, contact with parents occurs in a specialty clinic setting where they meet with the parents on that single occasion only. Speech-language pathologists may interact with the parent and child together, the child individually, the child along with other children in a group, or with the parent alone or in a group of parents.

The assessment encounter

Assessing and determining the nature of a child's communication disorder involves creating an environment, observing, and guiding the child through activities designed to elicit specific communication behaviours. Assessment may occur in a number of settings including a multidisciplinary clinic, a community health clinic or a private clinic. The assessment itself may be an individual speech and language assessment or it may be a team assessment focusing on a number of developmental domains including communication, feeding, and swallowing. Assessment also involves talking with parents about their child; their child's history, their concerns, observations, and understandings. The guiding questions form the framework of the conversation with parents.

At the conclusion of the assessment encounter, the speech-language pathologist will arrive at a composite description of the child's skills that serves a number of purposes. The composite of a child's communication skill profile points to remedies from a range of available options. The child's diagnosis will determine eligibility for treatment services.

The treatment encounter

The treatment encounter is similarly driven by the guiding questions. However, in planning and carrying out treatment, the emphasis necessarily shifts to topics having to do with what will happen and decisions about steps taken. The speech-language pathologist, the parents, and others involved in the service delivery must agree upon what will be done and who will provide the treatment (e.g., the speech-language pathologist alone, with the family, or with the family and others as a consultant only). Parents may be intimately involved in the treatment process, particularly if their child is of preschool age. However, the amount of parental involvement and the availability of parents to participate varies according to setting and service mandates as well as parent factors (e.g., work schedules affecting the ability to attend).

Family-centred intervention

Beginning in the mid-1980s, a trend toward family-centred care for children with disabilities occurred. Early intervention practices for children with communication and other developmental challenges began incorporating family-centred principles developed in other areas of human services, most particularly social work (Compton, and Galaway,1984;_Hartman and Laird,1983; Institute for Family-Centered Care, 1997; Saleebey, 1996,1997). Variously labeled family-focused (Bailey et al., 1986), family-centred (Shelton, Jeppson, and Johnson, 1987), and family enablement and empowerment (Dunst, Trivette, and Deal, 1988), this approach to intervention sought to strengthen family functioning as a means of promoting the flourishing of the child. In a computer search of the electronic database for journals in speech-language pathology, over 900 citations of the term "family-centered practice" were found for the period 1991-2005 in which files were available. Family-centred practice in speech-language pathology is widely accepted as the preferred model for service delivery.

Previously, clinicians in communication disorders, along with their colleagues in other allied health and education professions serving young children with disabilities, had operated from a professionally driven model that accorded to them all decision-making authority and responsibility. Parental involvement was encouraged as it was seen as enhancing carry-over and would result in effective case management.

With the shift to family-centred practices, the child-centred, remedial based approach gave way to a model of service delivery that promoted a sociodevelopmental view of child development within the family context (Bronfenbrenner, 1979). The family-centred perspective reflected a position that the family was a social system, and that events both internal and external to the family impacted the child. It was increasingly apparent that whether intentional or not, interventions for the child had repercussions for the whole family.

Family-centred practice promoted a social systems perspective of empowerment for parents of children with disabilities. Within this perspective, practitioners were challenged to rethink their intervention practices. They were called upon to expand their definition of intervention to view the entire family as the unit of intervention, to see intervention as a vehicle for promoting family rather than solely child functioning, to recognize and work toward family-chosen goals rather than professional goals, and to provide support and resources through a social network of formal and informal family affiliations (Dunst et al., 1988).

In adopting a family-centred philosophy, agencies and institutions were to be organized in such a way that family-professional collaborations were encouraged, inherent family strengths and cultural diversity were acknowledged, family differences were honoured, communities of families were established, and interventions remained flexible and responsive to family-identified needs and concerns (Shelton and Stepanek, 1994). At the clinic level, professionals were guided to demonstrate sensitivity to families, acknowledge parents as the ultimate decision-makers for their child, and advocate for family rights and services (Summers et al., 1990).

Political and social forces in both the United States and Canada combined with research findings to lend support to the shift to a family perspective in intervention (Mahoney, O'Sullivan, and Dennebaum, 1990). This recognition of the importance of family in interventions with children with disabilities was reinforced in the United States with the enactment of the Reauthorization of the Education for All Handicapped Children Act (PL 99-457) which specified that intervention services reflect a family systems model. PL 99-457 extended the previous legislation, PL 94-142, regarding early education for children with special needs. Part H of PL 99-457 included the provision of the Individual Family Service Plan (IFSP), the document that outlined how service would address the outcomes identified by families for their children. As a result of the legislation, there were numerous initiatives, sponsored by ASHA, to educate speech-language pathologists regarding family-centred practice. Recently, the legislation was incorporated into the passage of the Individuals with Disabilities Education Act (1990) which was reauthorized in 1997. The trend in family-centred care that originated in the United States influenced changes in approaches to early intervention in Canada as well. Speech-language pathologists in this country looked to leaders in their profession for guidance in adapting the model to their practice.

Chief among the new skills to be acquired by speech-language pathologists were skills from the field of family therapy and counseling (Luterman, 1984; Andrews and Andrews, 1986). Clinicians were encouraged to acquire skills necessary for acting in the role of facilitators or consultants to families rather than as direct service providers as they had been trained (Campbell, 1989; Dunst, et al., 1988).

In speech-language pathology, family-centered practice was seen as offering a solution to long-standing challenges faced by clinicians working with children. These challenges surrounded choosing ecologically meaningful goals, promoting family involvement, and achieving generalization of newly acquired speech and language skills outside the clinical setting. Further, as the field increasingly focused on social interactive aspects of communication, there became a corresponding need to engage the child's communication partners in developing and implementing strategies designed to address social communicative deficits (Crais, 1991; Wetherby and Prizant, 1992; Wilcox, 1992).

Features of the family-centered approach adopted by speech-language pathologists included respect for the family's perspective, resources, knowledge, and abilities. They were encouraged to adopt a systemic view of their work with families. They were to incorporate notions of the interrelatedness of family members and the effects of change to one member on all members and acknowledge varieties of family structures and unique interaction styles into practice (Andrews and Andrews, 1986). Consensus building was recommended at critical junctures in assessment and treatment as a means of effectively implementing family-identified goals (Dunst et al., 1988).

This shift in perspective on who constitutes the client has had an important impact on speech-language pathology practice as communication disorders are the most common developmental problems in the preschool age group (Polmanteer and Turbiville, 2000). Therefore, speech-language pathologists were most likely to be the interventionists that families called upon to address the child's developmental needs.

By the early 1990s, family-centred practice became the preferred form of intervention model for children with communication disorders and the tenets of the approach were extended to other speech and language client groups across the lifespan (Crais,1991). Currently, speech-language pathologists in the field espouse the underlying philosophy of family-centred practice with their client families. With time, a fuller understanding of family-centered intervention has been linked to notions of cultural competence and a strengths perspective (Prelock, Beatson, Bitner, Broder, and Ducker, 2003). Challenges to the full implementation of family-centered services, as reported in the speech-language pathology literature, centered on difficulties in shifting from child outcomes to family outcomes, in including extended family members in the intervention process, in addressing family issues other than those directly associated with the child's communication development, and in the use of professional jargon to communicate with families (Polmateer and Turbiville, 2000). Therefore, while speech-language pathologists have endorsed family-centered practices in their clinical work with families with children with communication disorders, they are recognizing the need to continue to work with others to achieve full actualization of the recommended practices associated with family-centred service delivery.

Note on pronoun use

Throughout the document, female pronouns are used to refer to speech-language pathologists while male pronouns are used to refer to children with communications disorder. My choice to use pronouns in this way is arbitrary and meant to ease the flow of reading the text and, therefore, not meant to imply that there are no male speech-language pathologists or female children with communication disorders.

CHAPTER 2: REVIEW OF THE LITERATURE

In the critique of the literature in paediatric speech-language pathology that follows, I will point out the limits in how ethics has been presented to the profession and difficulties inherent in the approach to ethics adopted. Then I will argue for an account of ethics that is based in the context of the practice of paediatric speech-language pathology.

In examining the literature in speech-language pathology related to ethics and the pediatric client for the period 1995-2005, it is evident that there are limitations both in the number of peer-reviewed articles available and in the approach to ethics taken in the few articles that exist. A total of three articles specifically relating to ethics and the paediatric client was found through computerized and manual searches of the journals relevant to the field. Two articles focused on ethical decision-making in feeding and swallowing management (i.e., dysphagia management) (Lefton-Greif and Arvedson, 1997; Sharp and Genesen, 1996). The remaining article on ethics in communication disorders featured paediatric case examples (Muirhead, James, and Griener, 1995).

In conducting the search for speech-language pathology literature pertaining to ethical practice and the paediatric client, I accessed the following electronic databases: Medline, CINHAL, and PsycINFO. Since only one article, Lefton-Greif and Arvedson (1997) was cited, the search was expanded using more general search terms "ethics" and "speech pathology". The widened search resulted in a total of 14 different citations, including the article by Lefton-Greif and Arvedson, and four non-peer reviewed articles from the professional newletter, *ASHA Leader.* No other journal article cited specifically addressed paediatric concerns. The *Journal of Medical Speech-Language Pathology* contained one article by Catt (2000) that was, like other articles found, educational in focus. As such, it outlined the four principle approach of Beauchamp and Childress (1994) and the professional virtues perspective of Pellegrino and Thomasma (1993) using examples from clinical experience and the code of ethics. Generally, the articles I found in the profession's major journals presented introductory information about ethics, case studies, and analyses but none reported the findings of empirical research on the topic of ethical practice.

Medline cited four non-peer reviewed articles from the professional newsletter of the American Speech-Language-Hearing Association, *ASHA Leader*, in which members of the Ethics Board of the professional association wrote on issues pertaining to legal liability (U.S.), disclosure, consent, representation of professional abilities, scope of practice, telepractice, research, and student and supervisor disagreements. However, these articles, written by the Ethics Board, are intended to educate and report on professional ethics for the membership and are not peer-reviewed.

Further broadening the search, the website of the Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) contained the archives of the Canadian publication, the *Journal of Speech-Language Pathology and Audiology.* I found two articles relating to the general term, ethics (Eadie and Charland, 2005; Muirhead, James, and Griener, 1995). Only the article co-authored by me (Muirhead et al.) contained paediatric examples.

The CASLPA professional newsletter, *Communiqué*, contained non-peer reviewed articles by members, including an article written by me in which I presented the common critique of Beauchamp and Childress's approach (Stewart, 2003). Other articles in *Communiqué* addressed topics similar to the *ASHA Leader.*

Given that my search attempts yielded so few articles in the journals most widely read in speech-language pathology, I considered another formal source of ethics knowledge for speech-language pathologists, namely textbook used in clinical training, in order to account for their exposure to the topic. Again, I was interested in the paediatric client as that remained the focus of the research undertaken.

Of the textbooks currently in use in the graduate program in speech-language pathology at the University of Alberta, only one made reference to the topic of ethics but was not specific to the paediatric client. However, the treatment of the topic in this textbook is illustrative of much of the literature reviewed in my search. In *Aphasiology: disorders and clinical practice,* author G. Albyn Davis (2000) offers a section on "Ethical Practice" in a chapter entitled, Principles of Language Restoration. Briefly (i.e., in three paragraphs), Davis cites three of the provisions of ASHA's Code of Ethics and introduces Beauchamp and Childress's contribution by stating, "Beauchamp and Childress (1994) help us identify fundamental ethical issues, based on a construct developed in the 1970s by a national commission for the protection of human subjects." (Davis, p. 242). Davis concludes this section on ethics by stating, "Conflicts can be minimized by conducting a clinical practice with integrity and by following the ASLHA's [*sic*] code of ethics." (Davis, p. 242). The remarkable influence of Beauchamp and Childress's work was seen here and throughout the articles reviewed in the search attesting to their impact on the current understanding of ethics in speech-language pathology.

Given that ethics was not an identified topic in most of the texts, I considered whether, like my participants revealed, ethics and consideration of ethical practice was hidden in discussions of related notions of professional integrity and good clinical practice. Therefore, ethics would not be readily identifiable in traditional search methods used for research purposes. In the end, this consideration was beyond the scope of the review but worthy of future investigation.

In conclusion, I choose to retain the focus on the paediatric client in order to explicate the notions of ethical practice that exist in the literature for the purpose of this research study focusing on paediatric speech-language pathology. Therefore, the three aforementioned articles, (Lefton-Greif and Arvedson, 1997; Muirhead et al., 1995; Sharp and Genesen, 1996) remained the basis for the review of literature to follow.

Lefton-Greif and Arvedson (1997), in their article on paediatric dysphagia, state their purpose as providing practicing clinicians with general information about ethical theories and principles, exploring the obligation of speech-language pathologists working with this population, and describing a model for ethical-making. The authors, citing the work of Purtilo (1988), offer a classification of what they term "ethical quandaries" (p. 82) that consists of four types: distress, dilemmas, dilemmas of justice, and locus of authority quandaries.

The definitions of ethical distress and ethical dilemma are familiar to readers of the bioethics literature. Distress is said to occur when the clinician is aware of the right course of action but is prevented from taking this action due to barriers such as institutional rules. An ethical dilemma occurs when two or more ethically defensible but conflicting courses of action are available. Less familiar is the use of the terms "dilemma of justice" and "locus of authority". Lefton-Greif and Arvedson refer to a "dilemma of justice" as an issue of distributive justice. "Locus of authority" refers to decision-making authority. Regarding "locus of authority", the authors state that professional expertise as well as formal and informal roles play a part in determining who will make decisions. Though Lefton-Greif and Arvedson do not elaborate on these roles in their introductory material, their case examples deal most directly with this issue.

Following the description of their adopted classification system, Lefton-Greif and Arvedson present a decision-making framework developed from Purtilo (1988) and Farrell and Fost (1989). The guidelines proposed in the framework suggest that the clinician begin by sorting out the "relevant facts" from "judgments or opinions" (p.83), proceed to use the quandaries classification to identify the type of ethical problem, and then identify the principle or principles that apply. They state that the clinician should then discuss the possible courses of action and take the selected action to resolve the issue.

To illustrate their approach to ethical decision-making in paediatric dysphagia management, the authors present two case examples of children with neuromotor disability and developmental delay. Both cases illustrate the tension that arises when the parties involved have conflicting views on the appropriate course of treatment. In the first case example, a clinician, new to the agency, finds that her recommendation for nonoral feeding is met with resistance from the other team members. Lefton-Greif and Arvedson offer detailed information regarding the child's clinical presentation and the clinician's recommendation related to her findings. We do know that speech-language pathologist's recommendation was met with resistance from the team, most particularly by the paediatrician who raised a concern about the impact of the recommendation on the family's well-being. Without more information about the paediatrician's concern, the authors may have tipped the balance of perception of this case in favour of the speech-language pathologist's recommendation. However, we know that clinical decisions often involve the weighing of information from outside of the realm of clinical facts. So we are left wondering how the speech-language pathologist would handle the additional information in her ethical deliberations.

The second case example presents the tension between parents and health care professionals when parents choose a course of management other than the one recommended by the professionals. In this case example, an immigrant family resists the team's recommendation for insertion of a gastrostomy tube for their son with severe neuromotor and cognitive deficits. The child's mother is a physician. The parents and grandmother insist on continuing to feed the child orally despite the contraindications. Lefton-Greif and Arvedson state: "In our experience, decision-making tends to be most useful when caregivers are active participants in the diagnostic and management process." (p.86). However, their case would suggest otherwise since the family were actively involved and still were attempting to assert their choice for oral feeding. Indeed, among the questions posed by the authors regarding this case example is: "Can anything be done to 'make' the family understand the need for nonoral feeding?" (p. 86). How should the reader interpret this question? What implication lies within? As in the first case, we are left wondering what more there is to the mother's objection. There is inadequate information to be able to weigh and balance the concerns of the parties involved.

A closer examination of the decision-making guidelines proposed by Lefton-Greif and Arvedson reveals the weaknesses of the approach to the examination of ethics in clinical practice. The step by step approach offered by these authors suggests that its use will help us to think through ethical challenges. It is appealing to think that this can be done since so much of our clinical work proceeds much the same way; from problem identification to solution. Arras (1994) suggests that in applied ethics, a form of moral deductivism occurs in which we begin with a theory, collect the facts, feed them into the theory, and arrive at the right answer. Yet, as Arras points out, when we proceed in the deductivist manner, we will confront the ambiguity within the theory that leaves the issues unresolved or renders unacceptable answers.

It is also appealing to hold out a set of midlevel principles derived from various ethical theories, briefly described in Lefton-Greif and Arvedson's article, as objective standards. Indeed, it is the appearance of objectivity that is the initial appeal of the principle-centered approach proposed by Beauchamp and Childress (1994). As Arras (1994) points out, principlism's success is based in part on the appearance of objectivity. However, that objectivity ultimately fails to deliver for reasons having to do with the indeterminancy and incompleteness of the principle-based approach to applied ethics.

More specific concerns related to Lefton-Greif and Arvedson's guidelines are evident when each step is considered. The first step in their suggested framework asks the speech-language pathologist to decide what information is relevant. Here we encounter the difficulties of deciding on what basis to determine the relevance of information and how to distinguish facts from judgments and opinions. Determining the relevance of certain information is problematic. Certain features of a situation can be jettisoned when they do not fit under the available concepts and categories of moral norms being considered.

Further, subjectivity and objectivity are seen as exclusive categories where subjectivity is considered to lack rational foundation. On this point, Hoffmaster (1994) argues that the implication is that "the realm of subjective, arbitrary and capricious looms large" (p. 1425). In privileging objective facts over subjective judgments and opinions, we cast aside contextual information that in other areas of health care have been shown to influence moral practice (Christie and Hoffmaster, 1986; Hoffmaster, 1990, 1992; Jennings, 1990; Sherwin, 1998).

In the second step in Lefton-Greif and Arvedson's framework, the clinician is directed to the quandaries classification in order to identify the type of ethical problem. Again, the concern arises about classing by available categories. Hoffmaster (1994) also argues that moral problems do not come with predetermined labels that correspond with the principles so that we do a lot of moral work just in the process of deciding what kind of moral problem it is. It is possible that theoretical considerations must be discussed before we can proceed to address the case. For example, he asks, is artificial nutrition a form of medical treatment or is it humane care? This worry is especially pertinent to speech-language pathologists reading about ethics in dysphagia management. Hoffmaster argues that the response to this question will determine the moral norms brought to bear on the issue.

Whether or not we arrive at a final answer to such questions, we nonetheless move in our effort to reach a resolution to the case at hand. The naming step has a bias inherent in our use of readily available labels. The range of moral problems is certainly restricted to those we have labels for. Even how we talk about a case involves an available vocabulary that circumscribes what is captured in a given situation.

Lefton-Greif and Arvedson state that the third step in their process involves identifying the applicable principle. Arras (1994) argues that in the interpretation of the principles, a leap is taken to arrive at the proclamation that a principle means we must do X. This situation arises because the original principle is not completely worked out. A related concern is raised by Hoffmaster (1994) who questions the appropriateness of the norms. Using the interpretation of autonomy in chronic illness as an example, he points out that the principles spell out differently in different contexts. For this reason, Hoffmaster recommends that the concepts and norms "fit the settings and contexts in which they are invoked" (p.1158).

Similarly, Sherwin (1998) argues for a nuanced account of autonomy that recognises the social, historical, cultural, economic, and/or political forces that impact on the creation of autonomy in particular individuals. Arguing as Sherwin does, we must attend in Lefton-Greif and Arvedson's first case to the power structure of the team in which the struggle about the speech-language pathologist's recommendation will be played out. In the second case we must attend to the cultural differences of the mother who is also an immigrant physician.

The final step in Lefton-Greif and Arvedson's framework for ethical decision-making asks the clinician to select a course of action. The foregoing concerns about the previous steps will taint any decision the clinician chooses in working through these cases. Though these authors offer a set of questions for each case following their guidelines, they offer no discussion or suggested course of action. In avoiding the analysis suggested by their framework and guiding questions, these authors fail their audience. Indeed, in referring to the first case example, the authors state, "There is no single answer or decision to this dilemma." (p.84). Nor do they venture to offer examples of possible solutions using the resources they offered. In summary, Lefton-Greif and Arvedson's article leaves many unresolved issues related both to the approach taken and to their interpretation of the cases they describe.

In their article on ethical considerations in dysphagia management, Sharp and Genesen (1996) also aim to demonstrate how to proceed with ethical decision-making with the dysphagic patient. These authors state the central ethical tension in such cases involves the conflict between beneficence and nonmaleficence. Yet, they focus on cases where the patient, family, or team chose “a nonstandard management option” (p.15). Rather than describing the ethical tension as one between beneficence and nonmaleficence, it would appear that their cases turn on the issue of respect for autonomy versus beneficence. Again we should be concerned about the labeling of cases and the moral vocabulary used to engage in the ensuing discussion.

In their introduction, Sharp and Genesen (1996) propose that the role of the clinician in “facilitating ethical decision-making while maintaining good clinical care may differ from the traditional rehabilitation model and demands consideration of an unfamiliar perspective on dysphagia management.”(p.15). This separation between ethical decision-making and good clinical care would appear to be an artificial one. The authors’ reasons for the distinction are not given nor do they venture to explain how the role taken by the rehabilitation professional is altered. Other authors commenting on ethics in clinical practice note the intricate link between clinical and ethical practice (Hoffmaster, 1990; Jennings, 1990).

Sharp and Genesen (1996) propose that ethical dilemmas arise in uncertainties, misunderstandings, and conflicting values and can be guided to resolution with a decision-making model proposed by Jonsen, Siegler, and Winslade (1992). They propose that the model be used to sort out medical indications, patient preferences, quality of life, and contextual features. Again we are faced with the difficulties outlined earlier regarding sorting out relevant facts, deciding on the objectivity of information, labeling the case, and identifying the applicable principles. The introduction of quality of life and contextual information marks a departure from Lefton-Greif and Arvedson's (1997) approach. However, Jonsen et al.'s model does not spell out how these considerations will influence the outcome of ethical deliberations. In particular, clinicians working in rehabilitation will be wary of quality of life determinations since they are cognizant of the criticisms of quality of life determinations related to conceptual issues and sociopolitical implications (Oliver, 1996).

Using the model provided by Jonsen et al.(1992), Sharp and Genesen (1996) discuss three case examples, one of which is a paediatric case that involves a child with Tay-Sachs disease. As a result of the progressive neurologic decline associated with this disease, the child demonstrated a nonfunctional swallowing pattern. The child's mother, knowing that it was inevitable that her child would soon die, declined the team's recommendation for the insertion of a gastrostomy tube. Instead, she expressed her desire to allow the natural course of this disease to occur and to provide pain relief for her son.

Sharp and Genesen (1996) review the medical indications, the patient preferences noting the shift to surrogate decision-making, and quality of life issues related to artificial nutrition and hydration in the dying child. Contextual features are not introduced in their case example so we are not exposed to the workings of this part of the model. Given the details of the case, the authors state that the prolonging of the child's dying would be inappropriate. They conclude that the parent's request ought to be respected. Indeed, this case appears unproblematic in that regard.

In addressing the quality of life concerns, Sharp and Genesen (1996) discuss clinicians' fears about starving the patient. They provide information to the reader to alleviate the misperception that dying patients will experience pain associated with withholding or withdrawing nutrition and hydration. In providing this technical information, the authors effectively collapse the concern they raised in their introduction about an ethical tension related to beneficence and nonmaleficence.

The third article to discuss ethics and paediatric clients presents several paediatric cases in speech-language pathology and audiology practice (Muirhead, James, and Griener, 1995). Avoiding the explicit use of a decision-making framework, these authors present both legal and ethical analyses of a variety of cases of concern to speech-language pathologists and audiologists. These authors introduce into their analysis commentaries on contextual information that modify the range of acceptable ethical choices. In doing so, the authors do attend the contextual features of each case albeit in an implicit manner. Among the contextual information considered, these authors discuss the lack of defensible profession wide consensus on communication disorders and severity determinations, the implications for research and policy funding, the limitations of the prevailing family-centred ideology, the difference in perspective between benefit and effectiveness, and the results of the fragmentation of care in an era of increased specialization in service delivery.

By attending to contextual information, Muirhead, James, and Griener (1995) offer several possible avenues to pursue in ethical deliberations. However, in deciding to discuss several cases in one article as is customary in much of the professional literature, the detail sacrificed in the case descriptions circumscribes the scope of the discussion and ultimately the resolutions proposed. One of the authors of this article (Griener) points to this limitation in stating: "Mike's case is made difficult because we lack some of the most important information about it." (p.189). The nuanced story called for by critics of both principlism and its competitor, casuistry, an approach that uses case-based reasoning, involves a longer more detailed narrative (Arras, 1994). With a fuller account of the case to be deliberated, we might find that the moral issues are transformed by the inclusion of perspectives that move us beyond the mere clinical facts.

The three articles reviewed were instructive in providing speech-language pathologists with an introduction to ethical decision-making in clinical practice. What do speech-language pathologists take away from these analyses? How do they think about ethics in their clinical practice with children and their families?

Interpreting the literature

There are several possible interpretations of this literature for speech-language pathologists working with paediatric caseloads. They may decide that ethics has to do with only those really difficult cases, such those dealing with children with dysphagia, and consequently, does not apply to their practice with less dramatic cases in areas such as phonology and language. This interpretation can be drawn from statements such as the one made by Lefton-Greif and Arvedson (1997) in their summary: "Speech-language pathologists and other pediatric specialists who are involved in the assessment and management of children with feeding and swallowing problems face ethical dilemmas essentially every day of their professional lives."(p.86). This characterization of the work done by speech-language pathologists in dysphagia management offers a striking contrast to the day to day struggles of others in the field.

While dysphagia treatment serves as an illuminating example of the ethical issues that face speech-language pathologists who work with clients with neurological and neuromotor disorders, most speech-language pathologists working with children deal with less dramatic cases in areas such as phonology, language impairment, and fluency. The paucity of ethics information for these pediatric populations could reflect an interpretation of ethics that narrows its scope to only those cases where life and death decisions are played out. As such, the relevance of ethics to other practice areas would not be recognized. Could this be why we recognise the ethical dimension in clinical work only when a problem arises? Perhaps, as Jennings (1990) suggests, ethics is so embedded in everyday social practice (e.g., professional activities) that it becomes an invisible feature of clinical work.

Speech-language pathologists who do recognize the ethical dimension to their practice may feel frustrated by the lack of information that deals specifically with the children on their caseload or that reflects the realities of their practice. They may engage in further study of the principle-centered approach that underlies the ethical decision-making frameworks commonly presented in the professional literature. They may be unsatisfied with the resulting portrayal of ethical practice. In this regard, Jennings (1990) suggests that health care professionals may not be convinced of the "reasonableness and persuasiveness of the arguments made" in applied ethics (p.262). Speech-language pathologists might say that simply it does not work for them. The principle-based approach may work fine in unproblematic cases. But will speech-language pathologists withstand the ambiguity that results when using the approach in their own practice away from the high profile issues in dysphagia?

These speculations about the reactions or interpretations that speech-language pathologists give to the literature on ethics in their profession point out some of the criticisms of the dominant schema in applied ethics. Principlism's incompleteness and indeterminancy is exposed. We must ask: what do the principles mean, what do we do when they conflict, how do we decide the type of case we face, what do we do with issues of meaning within a case, and how do we determine moral relevancy. With no theoretical mechanisms to address contextual issues, much is left outside the realm of principlism to the judgment of individual clinicians.

Contextual ethics

The articles reviewed demonstrate ethical decision-making using the framework offered by the principle centered approach. However, they tell us little about the central ethical values characteristic of speech-language pathology as a profession or more specifically, the ethical values of clinicians that work with paediatric populations. It is reasonable to assume that, like other health care professions, speech-language pathologists hold beneficence, nonmaleficence, respect for autonomy, and justice as central ethical values. However, studies of descriptive ethics in areas such as NICU reveal the nuanced articulation of a single central ethical value guiding clinical practice (Jennings, 1990). Such studies also expose the tremendous influence of certain social variables in ethical decision-making (Hoffmaster, 1992; Sherwin, 1998) or the influence of a particular conception of the patient-health care professional relationship on ethical practice (Christie and Hoffmaster, 1986; Sherwin, 1992, 1998).

What these studies in social science offer is an understanding of how morality is realized in particular clinical contexts. By laying out the background, it is argued that we can see how certain moral issues dominate over others and how those issues are expressed in the moral language of those involved (Hoffmaster, 1990; Jennings, 1990). A descriptive inquiry on ethics will mark out the moral domain of a particular subgroup of health care professionals and their clients. We can ask what clinicians think is ethical in their practice? What facts are important and how do they deal with them? In paediatric speech-language pathology, what influence does the degree of disability created by the child's communication disorder have on ethical practice? Why do certain moral problems dominate? Hoffmaster (1992) argues that the answers to these kinds of questions allow us to account for the varieties of ethical action in clinical practice.

Summary

In the end, the literature on ethics in paediatric speech-language pathology leaves us uninformed about how speech-language pathologists themselves conceive of ethics in everyday clinical practice. The few articles available with a paediatric focus provide very little to go on. However, the available literature may set a trend, thereby locking us into thinking about ethics in a manner that ultimately does not reflect how morality is practiced in this specific arena. By attending to the concerns raised by critics of principlism as it is currently presented in health professions, we can open spaces for the integration of ethics and social science research. Attention to the context of paediatric rehabilitation, the perspectives of the individuals involved, and the need for more than received theories, leads this researcher to seek a foundation from which speech-language pathologists working in paediatric rehabilitation can recognise their ethical orientation in clinical practice and, ultimately, will allow speech-language pathologists to address their ethical issues in practice within a cohesive framework.

Statement of purpose

The literature in paediatric speech-language pathology provides a limited picture of what ethical practice is and little guidance for clinicians faced with ethical concerns. The purpose of this study is to discover what constitutes ethical practice for speech-language pathologists working in paediatric rehabilitation. The research will be guided by the question: What is ethical practice in paediatric speech-language pathology?

CHAPTER 3: METHOD

Methodology

This study aimed to offer a substantive account of ethical practice in a single profession where all participants were trained speech-language pathologists active in clinical practice involving children with a variety of communication disorders. As a result of a review of the literature, it was evident that few articles existed in the field of speech-language pathology addressing the nature of ethical practice in this sub-field of health care practice. In order to generate knowledge of what speech-language pathologists think is ethical practice, I chose a qualitative approach to research as it was deemed appropriate relative to the level of inquiry currently evidenced in the professional literature.

A qualitative research method permits exploration of a phenomenon of interest from the perspective of those who experience it. Grounded theory is the chosen qualitative research method for this study and has its theoretical origin in symbolic interactionism (Blumer, 1969, 1986). A key feature is the assumption that participants create meaning from their experience. Though multiple meanings are evidenced from the data collected, I aimed to develop an account that captures the participants' meanings in an overarching schema that is the product of grounded theory.

Research design

I employed the grounded theory methods outlined by Strauss and Corbin (1990). Data were generated for analysis from individual interviews with each participant. In the following sections, I describe the research setting, selection and recruitment of potential participants, sampling strategies, data collection and analysis procedures, ethical considerations, and credibility of this study of ethical practice in paediatric speech-language pathology from the perspective of practising clinicians.

Research setting

All participants in the study were practising speech-language pathologists who lived in a large urban region. Though they resided locally, they served children living in urban or in rural settings. One participant traveled to the rural setting to serve her client base. The participants worked in a variety of clinical settings including: community public health centres, community preschool agencies, hospitals, schools, private practice, and university affiliated clinics. The participants worked in settings that were publicly funded through provincial health or education departments, partially funded by donations, or by privately funded third party insured or fee for service schema. Each interview was conducted in a mutually agreed upon setting. Therefore, the interviews were variously held in a participant's employment setting, university research offices, or in a participant's home.

Selection criteria

I established selection criteria for the purpose of identifying speech-language pathologists who were eligible for participation in the study. These criteria were:

1. the individual must hold a professional degree in speech-language pathology;
2. be active in clinical practice and;
3. be working with a client population that is paediatric i.e., children birth to 18 years.

Recruitment

Ethical approval for the study was secured from the Health Ethics Review Board, Panel B, at the University of Alberta (see Appendix A for Letter of HREB Approval). I then contacted the designated administrative contact for speech-language pathologists employed at the various agencies serving the paediatric population in the metropolitan area (see Appendix B for Letter to Administration). Copies of the HREB approval and the research proposal were sent to the administrative contact person with a written request to meet with interested staff at a regularly scheduled staff meeting to discuss the research and recruit potential participants.

With site approval, presentations of the proposed research were made at a tertiary hospital in May 2001 and at three urban community health centres in the health region during the period October-November 2001. At each presentation, I described the study to the potential participants and answered any questions they had. The letter of information and a consent form were provided to all in attendance (see Appendix C for Letter of Information and Appendix D for Consent Form). Potential participants were encouraged to contact me by telephone to further discuss their interest in the study. Four potential participants were identified as a result.

Smaller non-profit public agencies employing speech-language pathologists were contacted by telephone in May and June 2001 and again in September 2001. I spoke with the director of each agency and, if interest was expressed, a copy of the HREB approval letter and proposal was sent for the speech-language pathology staff to review. The director then contacted me with the names of interested staff that were willing to speak with me. Three potential participants were identified in this manner.

Private practice and contract speech-language pathologists working with paediatric rehabilitation clients were contacted through the Private Practice Committee of the Speech, Language, and Hearing Association of Alberta (SHAA), a sub-group of the provincial professional association that was the predecessor to ACSLPA. I made a presentation about the proposed research at the regular monthly meeting of the sub-group in Edmonton in May 2001. Interested clinicians were contacted as previously described. Four potential participants were identified.

In order to reach clinicians who may not have had affiliations with above mentioned groups, I contacted the Speech-Language-Hearing Association of Alberta (SHAA) in June 2001 to solicit their support for the research and to request that a bulletin be placed in the quarterly newsletter (September 2001) that circulated province-wide (see Appendix E for SHAA Bulletin). From this effort, six potential participants were identified, three of whom worked in rural community health centres.

Speech-language pathologists who responded to the initial invitation and offered their names for consideration constituted a pool of potential participants from which specific individuals were chosen to meet the information needs of the study. These individuals were contacted by telephone to further discuss their participation. Potential participants indicated that they were willing to discuss ethical practice with me. Eighteen volunteer participants were identified from the recruitment efforts during the period from May to November 2001. An additional four volunteers were added to the list as a result of approaching me personally following a presentation by me about this research project or about ethics in speech-language pathology. A total of twenty-two volunteers was included in the potential participant pool.Characteristics of the volunteer pool were listed according to selection criteria that I generated from my initial speculation of relevant characteristics that might influence elements of ethical practice.

Sample and sampling strategies

The sample

The sample of speech-language pathologists for this study consisted of volunteer participants who were purposively selected from the volunteer pool because they were knowledgeable and presumed likely to reflect on the ethical aspects of their practice. They were active in clinical practice serving children with communication disorders, age birth to 18 years. These clinicians were willing to share their thoughts and ideas about ethical practice. All resided in a metropolitan area in the province of Alberta.

Sampling strategies

The provisional nature of sampling in the grounded theory approach allowed for flexibility in the selection of participants. Sampling in grounded theory refers to the sampling of concepts rather than participants. Therefore, the sampling procedures were tied to the level of analysis and were intended to serve the information needs of the emerging model.

At the level of open coding, sampling was aimed at selecting diverse participants who worked in the greatest variety of circumstances under which ethical practice could operate. A variety of practice settings, years of clinical experience, and populations of children served were sought in the selection of participants. Number of years in clinical practice was chosen for sampling as I thought that the number of years in practice may influence the clinician's sensitivity to the ethical aspects of clinical practice.

A participant's experience with certain client populations was also thought to play a part in developing notions about ethical practice. Caseload type can be divided into two categories of paediatric clients: single and varied populations. My experience suggested to me that clinicians who specialize in single disability caseloads (e.g., Autism Spectrum Disorder, Down Syndrome, spina bifida, cerebral palsy) might view ethical practice differently from those who must deal with varied or mixed caseloads.

Another consideration in the selection of participants was employment setting. Increasingly, speech-language pathologists, like other health care professionals, find employment outside of the publicly funded health care and education systems. Private practice in speech-language pathology in Alberta is a relatively recent phenomenon though increasing in both the numbers of clinicians engaged in private practice and in the demand for their services. Some clinicians find that only part-time positions are available in the public sector and therefore opt to open their practice to private clients outside of their employment setting. Still others find that they are able to contract their services to publicly funded agencies. I speculated that managing a private practice may present different ethical challenges than publicly funded practice.

The above-mentioned factors were only speculative and certainly not exhaustive of all the factors that could influence a speech-language pathologist's sense of ethical practice. As the relevance of certain factors or processes to the determination of ethical practice was unknown at the onset of the study, it was seen as advantageous to initially sample widely among paediatric speech-language pathologists. Years of experience, caseload type, and work setting provided useful beginning points. I sampled widely enough to ensure that as many factors relevant to ethical practice were considered. The initial sampling frame guided by theoretical considerations assisted in setting the boundaries appropriate to the research question. As the research progressed, no additional factors were introduced into sampling.

Relational and variational sampling was used at the next level of coding, axial coding, to uncover more details about the individual categories and subcategories that resulted from open coding. Relational and variational sampling also aimed to uncover any differences or changes in conditions, context, action/interaction, and consequences that would allow me to make statements about the relationships among the categories. With that aim in mind, I questioned participants with the intention of verifying the categories and relationships developed from previously gathered information. Specific participants who possessed experience or knowledge that related to the categories of interest were chosen for interviewing.

Once analysis proceeded to selective coding, the process of sampling became highly discriminative with the purpose of verifying the core category, testing the hypotheses derived from the interconnections in the data, and providing further detail for less defined categories. At this level, specific participants from the volunteer pool were chosen to deliberately sample for these intents.

Study participants

The final number of participants selected for the study was determined by the number necessary to create and then to validate the model of ethical practice in paediatric speech-language pathology. Grounded theorists offer no guidelines for the estimation of the number of participants needed (Morse and Field, 1994; Strauss and Corbin, 1998). However, since participants were selected on the basis of the information needs, sampling of new participants continued until no new information appeared (i.e., data saturation). Experienced researchers suggested that 6-10 participants are generally sufficient to reach data saturation (Oberle, personal communication, April 1999). Ten speech-language pathologists were interviewed for this study. Though there are male speech-language pathologists who work with paediatric populations in Alberta, their numbers province-wide are few (N= 24) making each of them potentially easily identifiable. No male speech-language pathologists participated in this study.

Data collection

Obtaining informed consent

At the onset of each interview, I discussed the purpose of the study with the participant, any known risks or inconveniences to the participant, answered any questions, and addressed any concerns which the participant brought forth. This conversation constituted the basis for confirming informed consent with the participant as the participant would have received a written copy of the consent document prior to the scheduled interview either at a recruitment presentation or in response to the participant's initial query about participating in the study.

Method of data collection

Data collection was conducted via open ended interviews scheduled at the convenience of the participant in a mutually convenient location. The first participant, henceforth referred to as T1 (as in T=transcript), was interviewed in her home, as were T5 and T6. Participants T2, T4, T9, and T10 were interviewed in research offices at the University of Alberta. Participants identified as T3, T7, and T8 were interviewed in their offices at their workplace. Interviews ranged in length from 45 minutes to two and a half hours. All but one participant were each interviewed once. Participant T9 requested a second interview as she had to leave the first interview after one hour to attend another appointment and wanted to talk further about ethical practice. Participants identified as T1, T2, and T4 had offered to assist with a second interview. All interviews were audiotape recorded. Transcriptionists prepared type-written transcripts of the audiotapes of the interviews. Transcripts were also stored in electronic form in computerized files.

Biographical information on each participant was collected at the end of each interview. Each participant's educational background including ethics education, as well as number of years of clinical experience, caseload type, employment setting, employment location, and age range was noted. Race, ethnicity, religion were listed on the form as optional responses (see Appendix F for Biographical information form).

All interviews were initiated by asking the participant to describe her clinical practice. By framing the initiation of the interview in this way, I established rapport with the participant by gathering important information while asking less threatening questions. Also, I then had information about the participant's practice context that allowed me to link further questions to the descriptions of clients and clinical activities provided. While my initial intention in asking for clinical practice information was for the aforementioned purposes, it became apparent after analysis of the first three transcripts that participants were also providing valuable information about the processes of clinical practice that contributed to understanding ethical practice in paediatric speech-language pathology. Therefore, I continued to open subsequent interviews with the question. However, my intent was then to gather clinical practice information that would later be incorporated into the development of a framework for understanding ethical practice.

After the participant completed her description of clinical practice, I asked, "When you think about your clinical work, what do you think is ethical practice?" While most participants were able to launch into their description of ethical practice with this lead question, I had been prepared to use guiding questions to elicit the participants' reflections on what they thought constituted ethical practice. These guiding questions were occasionally used to redirect the participant to the purpose of the study. The guiding questions and redirecting statements that were used during the interviews were:

a. How does that (topic, example) help you think about ethical practice?
b. What did you learn about ethical practice from that example?
c. When you think about ethics in your practice…

The interviews proceeded in an open-ended manner and it was only necessary for me to pose questions to encourage the participant to expand on a particular point or to give specific examples. In order to pursue specific themes or explore concepts in development, I prepared a list of ongoing themes and concepts in order to alert myself to important concepts, categories, and emerging themes to be explored with each participant. Each interview closed by offering the participant a final opportunity to add anything of significance to her.

Since data collection and analysis were conducted concurrently, I used newly developed questions to elicit data specific to the emerging categories. For example, T1 discussed the importance of honesty in her work assessing children with severe disabilities. Given that T2 did similar work, I pursued the idea of honesty with questions intended to elicit more details about honesty as an element of ethical practice. The questioning about honesty continued in order for me to expand the notion if possible and to fill in details of the provisional category that was created after the initial analysis of T1's interview transcript.

Immediately following each interview, I wrote field notes of my perceptions and observations of the participant, setting, and any other significant observations of the interview. Since the interviews were audiotaped, the field notes provided additional information regarding the nonverbal aspects of the participant's communication. Events or interactions that could have influenced the interaction between the participant and myself were noted in the field journal. In the field notes, I identified any interpretations of my own or any information that was recorded from recall. Field notes also contained my thoughts on my own biases or assumptions that surfaced as a result of the interview (Morse and Field, 1995). A separate notebook contained methodological notes as well as a record of all contacts and communications related to the study.

Data preparation

All of the audiotaped interviews were type-written into computerized form by one of four transcriptionists employed over the course of the study. I informed each transciptionist about the general nature of the study and confidentiality was verbally agreed upon. The transcriptionist agreed to remove the file from her personal computer once I was able to open the disk on my computer. Computerized and paper copies of each interview transcript were made and stored on my computer and in my locked files. Each transcript was identified only by a code (e.g., T1A referred to a transcript from the first participant who was interviewed for the first time-A). Each page of the transcript contained the title, "Ethical practice", the date of the interview, as well as vertically numbered lines that identified lines in the text.

Time frame of the study

The study was conducted over a three year period. Interruptions to the study were incurred due to family and health concerns. After each absence, I resumed the study by first re-reading my journal containing memoing and audit notes and then reviewing the written transcripts. On occasion, to clarify the memos or notes, I also listened to specific interview tapes. An extension to the HREB ethics approval was secured in April 2002 to allow me to continue contacting and interviewing participants until 30 April 2004.

The first participant was interviewed on 5 June 2001. Corrections to the written transcript (T1A) and initial coding were undertaken prior to interviewing the second participant on 14 June 01. The second transcript (T2A) was not returned by the transcriptionist until after the third participant was interviewed. However, on the basis of the initial analysis of T1A and the field notes from T2A, I was able to maintain a line of questioning that was consistent with the preliminary categories. The transcripts from the interviews with T3A on 4 July 2001 and T4A on 12 July 2001 were analysed in their sequential order though I had both available at the same time. Initial coding that generated twenty-seven provisional categories was completed by September 2001. I then discontinued interviewing until the fifth participant was interviewed on 25 February 2002. Four additional categories were generated from analysis of the fifth transcript, T5A. Two additional participants, T6A and T7A were interviewed in Dec 2002 and Jan 2003. In April 2003, T8A was interviewed. The final two participants, T9A and T10A, were interviewed in April 2004. The second to last participant (T9) was interviewed twice at her request. The two interview transcripts generated by these interviews were labelled T9A and T9B.

Data analysis

Grounded theory analytic procedures

Two analytic procedures characteristic of grounded theory were used throughout the analysis process. These analytic procedures were the constant comparative method and theoretical sensitivity. The constant comparative method was one of the analytic procedures used in coding the data at each level of analysis. The procedures involved making comparisons between data and asking questions in relation to the data. I approached analysis with questions such as: what is this?, what does it represent?, is it the same or different?, how does it work?, how much?, who is involved?, what if?, or when does it occur? Since the grounded theory method intends to keep the theoretical model it aims to build linked to the data on which it is founded, relationships and propositions once generated were tested by a return to the data and field.

Strauss and Corbin (1990) describe theoretical sensitivity as the ability of the researcher to recognise significant information in the data. Theoretical sensitivity involves moving beyond one's biases and assumptions regarding the data (i.e., to question one's own view). Strauss and Corbin suggest that theoretical sensitivity develops from professional and personal experience as well as from involvement in the research process. Theoretical sensitivity can be enhanced by the following techniques: questioning, analysing the language for meanings, working with opposites, and working with extremes. In this study, I found that working with opposites involved thinking about unethical rather than ethical practice. Working with extremes involved thinking about exemplary ethical practice. Strauss and Corbin refer to this technique as making "far-out comparisons" (p.90, 1990).

In the continuing process of comparing and contrasting the data, conceptual labels were provisionally grouped when they similarly related to a phenomenon of interest under a broader categorical label, also provisionally named. Following the constant comparative method, I asked, how were these data the same as or different from other data?

Coding

I began the analysis by reviewing the audiotape while simultaneously reading the written transcript. This initial step allowed me the opportunity to check the accuracy of the written transcript and make corrections where needed. This step also afforded me the opportunity to add notes in the margins, also referred to as memoing, to reflect on the participants' meanings, speculate about relationships in the data, and create a path of thought that may later contribute to the development of the model of ethical practice (Morse et. al., 1995).

I prepared a written summary of topics discussed and questions asked during each interview. This summary was used later as the transcripts accumulated in order to more easily identify where data was located.

Once the written transcript was corrected, open coding was initiated. The primary purpose of this initial analysis was to name the phenomena evident in the data. This procedure was completed by a line-by-line examination of the transcript. I searched for the words, phrases, descriptions, and expressions used by the participant to describe ethical practice itself or to describe contexts, people, or events that the participant felt were reflective of ethical practice in paediatric speech-language pathology. These words, phrases, descriptions and expressions constituted the data which were then written on 3 X 5 cards. In addition to the data, each card contained a code that identified the source. For example, I would write T4A, Lines 246-255 to identify that the quote was taken from the interview with the fourth participant, transcript 4A at lines 246-255. I then grouped cards together that appeared to express a similar idea. A provisional category name was given to this grouping. Additional reading of the transcripts permitted the opportunity to consider any attributes of the provisional category.

Open coding was the first approach to coding each transcript that was generated and was the primary means of coding for the first four transcripts. As a result of open coding, a set of thirty-three provisional categories were developed from the preliminary groupings of memos and quotes from participants.

A second review of the set of four initial transcripts was completed in order to extract attributes of concepts and to begin initial stages of comparing and contrasting data within and across transcripts. Particularly notable was the contrast provided by statements made by T4 that illustrated negative examples of ethical relationships described by the previous participants. The fifth interview transcript prompted further exploration of negative and disputed categories as the participant was selected based on characteristics that contrasted maximally with the previous four participants (i.e., rural setting/school age children/varied disorders/ generalist).

At the conclusion of open and axial coding for the first five transcripts, I was able to describe properties of categories such as “providing support” and to group categories provisionally into groups such as “characteristics of the ethical speech-language pathologist” and “putting ethics into action”. It was also possible to speculate on connections between groupings.

I resumed the study after a ten month break. Prior to the sixth interview, I reviewed all data accumulated, including journal entries, as a means of ensuring that the study resumed at the appropriate level of analysis.

After interviewing two more participants, T6 and T7, another round of memoing of the transcripts was completed with the aim of developing an integrative understanding of the phenomenon of ethical practice. Using selective coding, I attempted to develop a narrative that would encompass the data and account for emerging ideas about the core category. Once again, all memos, including narratives from my journal, were used as data to advance the conceptualization of ethical practice in speech-language pathology. At this point, I also introduced two other types of analyses. Following Strauss and Corbin (1998), these analyses aimed to attend to changes and variations in ethical practice (i.e., coding for process) and to outside influences that impact on ethical practice (i.e., through the conditional/consequential matrix).

Process

In order to capture the changes in action/interaction or transformations that are possible in ethical practice, it was necessary to examine the data for evidence of process. Strauss and Corbin offer two conceptualisations of process: as a process that occurs in phases or stages, and as a process that is "nonprogressive" but rather reflects flexibility in response to changing environments. I was interested in linking together the action/interaction sequences and following the process over time.

Theoretical sensitivity guided me to identify changes in the context of ethical practice that result in changes in action/interaction. Variations needed to be examined along its properties or dimensions. The paradigm model was used to locate where the change occurs. For example, I considered change as it was evidenced in the conditions that create ethical practice, the context in which it was supported or not supported, the intervening factors that impacted on action/interaction, or the consequences that eventually influenced future actions/interactions and conditions under which ethical practice occurs.

While the analysis of process evidenced the evolving character of ethical practice in paediatric speech-language pathology, I needed an additional analysis to determine what was necessary for the change to occur. To do so, I examined the data using Strauss and Corbin's conditional/consequential matrix.

Conditional/consequential matrix

What precipitates the change in ethical practice? To address this question, Strauss and Corbin's matrix is a set of contexts ranging from distant (e.g., national or provincial), to close (e.g., community), to within (e.g., agency or institution) that could impact on action/interaction in ethical practice. As Strauss and Corbin recommended, I limited my attention to events related to the central phenomenon in order to demonstrate the broader influences that shape ethical practice. I sought policies, initiatives, regulations, and legislation that could influence the practice of ethics in paediatric speech-language pathology. Only the creation of the Alberta College of Speech-Language Pathologists and Audiologists (ACSLPA), declared in July 2002 under the *Health Professions Act* was identified.

The Alberta College of Speech-Language Pathologists and Audiologists (ACSLPA) is responsible for governance, regulation, and discipline within the professions of speech-language pathology and audiology. Specifically, ACSLPA is responsible for regulations, by-laws, standards of practice, and codes of ethics. In choosing to adopt the existing *Canon of Ethics* of the Canadian Association of Speech-Language Pathologists and Audiologists, ACSLPA did not alter what members expect in terms of guidance in ethical matters. Correspondingly, I did not find any evidence of change in the interview data collected before and after the creation of ACSLPA.

The final three interviews allowed me to confirm and verify relationships in the conceptual schema for ethical practice that was proposed from the research.

Ethical considerations

Confidentiality

Confidentiality issues particular to this study included the potential for unintentionally identifying specific clinicians, employment settings, or speech-language pathologists who did not participate in the study. Since the practice areas of several participants were small (i.e., less than 10 speech-language pathologists involved in working with a particular paediatric population or providing a particular specialty service), care was taken to protect identities in the following ways:

1. Practice settings were described by general category and descriptions.
2. All quotes were edited to eliminate specific identifying information.
3. In situations where the participant and researcher identified a concern regarding unique and/or recognizable descriptions or discussion, they mutually discussed whether the material could be made more general or simply left aside from quotes or other descriptions provided in the final report and subsequent future publications and presentations.

Across all audio, written, and computerized records of data, including my journal, identifying information was removed. The participants were referred to by their transcript number only. Practice setting, employer, colleagues, and all other names were replaced with general labels (e.g., City Hospital became a hospital). Biographical information was collected at the conclusion of each participant's interview. However, this information was reported in general terms only. For example, participants' ages were reported in age ranges only.

Over the time frame of this study, I employed four different transcriptionists to transcribe the audiotapes from the interviews. The transcriptionists were instructed to respect the privacy of the participants by not leaving the tapes or computer record available to third parties. Once the transcript was completed and the computer disk transferred to me, opened, and copied into my files, the transcriptionist agreed to delete her computer file and return the audiotape to me. All data generated and collected in the course of the study was stored in my secured filing cabinet.

Addressing potential emotional distress

Having served on ethics committees both in my work setting and for my professional associations, I was aware that my topic and research question might elicit from the participants thoughts and experiences that highlighted sensitive issues in clinical practice. For this reason, I prepared in advance several strategies intended to deal with potential emotional distress. First, I informed each participant during the consent conversation that emotional distress might be experienced during the course of the interview and that the participant could, if she chose, end the interview at any time. Sources of support in the eventuality of emotional distress were identified both in the conversation with the participant and in the letter of information provided. Second, I began each interview by establishing rapport with the participant by inquiring about the participant's clinical practice. These early questions also served to elicit general information about the participant's practice prior to introducing the research topic.

Throughout the interview, I was alert to outward signs of emotional distress signaled by long pauses, changes in vocal qualities (e.g., higher pitch, pitch breaks, hoarseness in voice), posture changes (e.g., slumping, turning away), and crying. Though I prepared myself to observe such signals of distress, participants who demonstrated long pauses and emotional vocal qualities continued to talk about ethical practice without making note of any desire to take breaks or discontinue the interview. However, one participant in particular talked at length, displaying her distress in her voice and posture, about a stressful work environment that raised ethical concerns for her. I provided several opportunities by asking the participant if she wanted to continue. However, the participant stated that it was important to her to have the opportunity to talk about her situation and therefore she wished to continue the interview. I then asked her permission to contact her by telephone as a follow-up to the interview. A week later, I spoke with the participant by telephone. The participant reiterated that she appreciated the opportunity to talk about her situation.

Study trustworthiness

In presenting the strategies used to ensure the study's trustworthiness, I chose to utilize the criteria developed by Lincoln and Guba (1986) though I am aware of the controversy in qualitative research regarding the various terms used and their meanings (Morse and Richards, 2002). Lincoln and Guba state that a study's trustworthiness depends on credibility, transferability, and dependability.

Credibility

In Lincoln and Guba's schema, credibility refers to whether or not the study's results can be believed. In other words, what is the truth value of the study? In this study, I adopted several strategies to ensure data were collected accurately so as to preserve the participants' perspectives on the phenomenon of ethical practice in paediatric speech-language pathology. I employed purposeful sampling by setting out selection criteria that would maximize the likelihood that participants who were finally selected would be those who were most likely to contribute rich detailed information about ethical practice. Each interview was audiotaped in order for an accurate record to be created of the participants' comments on and descriptions of ethical practice. Data were verified by checking with individual participants for their responses to trends developed from earlier interviews. For example, I asked, "Is that true for you?" or "Does that seem to be the same or different for you in your clinical practice?"

Also addressing credibility, I sought negative cases that did not fit with the emerging schema of ethical practice. These cases were important as they provided the opportunity to consider more fully the range of the phenomenon and to uncover not-so-evident connections between concepts and categories. T4A proved invaluable in this regard as this transcript contained many negative examples.

I also attempted several visual and written schema in order to capture the data to its fullest and find the best fit. This process involved dismantling one explanatory model and reorganizing categories in different relationships to each other. All original and reconstituted models of ethical practice were maintained in dated files.

In qualitative research, the researcher is considered a research instrument (Piantanida and Garman, 1999). Therefore, in order to establish credibility, I offer the following as background. Since 1984, I have worked as a paediatric speech-language pathologist with children with a variety of severe communication disorders, many of whom were multiply disabled. My experience has been primarily with families of infants and toddlers in tertiary outpatient care working on multidisciplinary diagnostic and treatment teams although I also had experience in providing outreach services to similar children and families living in rural communities. At the initiation of this study, I was not working clinically. However, after an absence of five years, I returned to work part-time in October 2003 in the tertiary care setting that I had worked in since 1986. This work setting with its specific clinical population was the one shared with participants 1-3 who were all known to me. During the period of clinical work from October 2003 to June 2004, I encountered many of the constraints described by the participants and outlined in the results of this report.

My interest in ethics and ethical practice in rehabilitation professions grew from my experiences with infants who were graduates of NICUs and others who underwent major medical interventions. With active committee participation in my professional association, the Speech-Language-Hearing Association (SHAA), I became the first chair of the newly formed Ethics Committee in 1994. I served on various ethics committees locally, provincially, and nationally from 1994-2001 and presented on ethics and ethical practice at conferences and workshops during that period. In these various positions on ethics committees, I provided support and information to members of my profession and became known for my interest in ethical practice in speech-language pathology and audiology. Therefore, my profile in my professional community is linked to my professed interest in the ethical aspects of clinical practice. In order to deal with judgments about my expert role, I explained to participants that no single account of ethical practice in our field was available and that in order to develop such an account we, as a professional community, had an opportunity, through this research, to make that contribution.

Throughout the study, I wrote in a journal my thoughts and ideas as well as my experiences both as a researcher and as a clinician returning to practice. In describing my background for the reader, I am aware that any experiences and impressions of ethical practice, formed by me prior to the onset of this study could be seen as influencing the direction of the research and the findings. In order to deal with this potential during the research I documented, in my journal notes, my experiences and impressions related to the ongoing exploration of ethical practice, as a means of making them explicit and separate from the participants' viewpoints. A related concern for me was my almost exclusive experience with children with severe communication difficulties associated with a myriad of developmental concerns. In order to address this limitation, I actively sought participants whose clinical experience differed from my own and reflected the range of populations and settings that speech-language pathologists serve.

Transferability

Transferability refers to the ability of the study findings to relate to settings other than the ones offered by the participants. In other words, a goodness of fit is sought that allows for the results to be considered in another setting. At several points in the process of conducting this study, I had the opportunity to present preliminary and ongoing accounts of ethical practice in paediatric speech-language pathology. Each presentation afforded the opportunity to check if the emerging schema were recognizable to a larger audience of speech-language pathologists.

On the first occasion, at the 2001 Annual Convention of the American Speech-Language-Hearing Association (ASHA) in New Orleans, I presented a proposed schema developed from provisional categories drawn from analysis of the first four transcripts. In the question period and discussion that followed, several audience members, all speech-language pathologists in clinical practice, acknowledged that the categories and preliminary schema offered were resonant with how they viewed ethical practice in their daily clinical work. An audio-tape of this presentation was included in the audit trail materials.

As part of the Faculty of Rehabilitation Medicine seminar series, I presented ongoing updates of the study for discussion and feedback on three occasions (January 2001 and 2002, March 2003). Interested speech-language pathologists and faculty members from the Department of Speech Pathology and Audiology, as well as faculty and clinicians from other rehabilitation disciplines attended these seminars. None of the speech-language pathologists in attendance were participants in the study at that time. At all presentations, the speech-language pathology attendees commented on the familiarity of the material presented with their clinical experience. One speech-language pathology attendee noted that although she worked in adult rehabilitation, she felt that the account of ethical practice presented was also applicable to her clinical practice dealing with stroke patients.

In addition to the presentations described and to assist others in considering the transferability of the results, I endeavoured to describe the participants, their clinical experience, and their employment settings in sufficient detail that another researcher would be able to recognize similar elements in other clinical settings where ethical practice might be explored.

Dependability

Dependability refers to the ability to produce similar findings if the study was repeated under similar circumstances and conditions. I aimed to increase dependability by creating an audit trail through the use of dated memos on transcripts and journal entries regarding decisions on aspects of method such as sampling decisions and the development of lines of questioning/inquiry. Memos and the journal were originally hand written and later transferred to computerized files to permit easier access during analysis. Several drafts of the study results were completed. These drafts, which demonstrated the various levels of development toward the final completed results report, were kept in computerized dated files. All audit material was collected together to allow another researcher to follow the path of decision making and insight that led to the final version of ethical practice presented in this report.

Confirmability

Confirmability, in Sandelowski's (1986) use of the term, refers to the neutrality of findings. Though objectivity is seen as antithetical to the qualitative approach, Sandelowski offers that the researcher can make evident to the reader that the researcher's assumptions and biases were attended to.

In this study, the following strategies were used to address confirmability.

Prior to the initiation of the study, I familiarized myself with the literature on ethics in speech-language pathology both in the academic and professional publications. An update of the original literature review was reserved to the end of the study.

While conducting the study, I set aside reading of the literature on ethics in speech-language pathology and in professional and health care ethics in order to avoid unduly and/or unconsciously influencing or bringing the research to premature closure or introducing notions from other areas prior to the completion of data analysis. In my journal, I kept a record of anything read and was careful to document thoughts. Also in the journal, I identified my notions about ethical practice that I had developed from other health care sources, particularly nursing. However, I did not actively seek out comparisons prior to the conclusion of the reporting of my results. My assumptions about the participants' experiences or work were also documented in the journal.

CHAPTER 4: RESULTS

In this chapter, I present the results of the data analysis. I used a grounded theory approach to data collection and analysis, resulting in the development of categories exemplifying ethical practice and identification of a core category. Findings are representative of the integration and eventual conceptualization of all interview data, field notes, and researcher's memos.

The core category of ethical practice in speech-language pathology, evident throughout interviews with participants, is that of *making a difference.* In order to situate this core category within ethical practice in speech-language pathology, the contextual conditions that are critical to its understanding will be explored. The core category and the individual components constituent of ethical practice in speech-language pathology will subsequently be described. These components include characteristics of the ethical speech-language pathologist, ethical relationships with others, and the processes of ethical practice.

Participants in this study, all of whom are practicing speech-language pathologists working with children and their parents, described ethical practice in terms of good clinical practice, particularly with respect to the central relationship with the child's parents. In this way, participants addressed the question, "How ought I treat the people I serve?" For these participants, ethical practice is so intertwined with clinical practice as to be inseparable. In the sections that follow, I will present an account that demonstrates how ethical practice in paediatric speech-language pathology is intimately tied to clinical practice in an ongoing dialectic. However, I will first introduce the participants who contributed to the development of the grounded theory of ethical practice in speech-language pathology.

Participants

At the time of the study, the participants ranged in age from 30 to over 50 years. Their years of clinical experience varied from less than one year to more than twenty years. All are providing clinical services to paediatric clients. However, three of the participants have clients who, though initially seen as children, continue to be followed by the speech-language pathologist past 18 years. All three of these participants provide specialty services. Eight of the ten participants work full time.

In terms of clinical populations served, the participants either have experience with or are currently working with children whose communication and related disorders cover the scope of services that the profession provides. Specifically, among the participants, clinical service is being provided to children with the following paediatric communication and related disorders: speech delays/disorders, language delays/disorders, fluency, voice, resonance, feeding and swallowing disorders, and hearing impairment. The children's communication disorders range from mild to severe and included communication difficulties associated with multiple disabilities and Autism Spectrum Disorders. Often the children's communication disorder is concomitant with a large range of medical diagnoses too great to describe here in detail. However, common medical diagnoses include developmental delay, craniofacial anomalies, traumatic brain injury, deafness, and prematurity. Four of the ten participants work exclusively with children with a specific communication disorder. All other participants work with varied populations of children.

Two participants provide diagnostic services only while two others either provide only consultation service or diagnostic treatment. The remaining six participants provide primarily treatment. Two participants note that they provide intermittent service, primarily consultation, to their specialty population of children from early identification to adulthood. In doing so, these participants are in contact with the same children and their families over a period of a number of years.

Work settings include community health centres, schools, community non-profit agencies, hospitals, and a university. None of the participants is the sole speech-language pathologist in her setting though the participant working in the rural setting is one of only two speech-language pathologists in that rural area and another participant had worked as a sole clinician earlier in her career. Most participants worked in employment that is funded publicly either by departments of education or health. However, three participants work in settings that had fee-for-service schema. Of these, one worked on contract to a school district. Another participant divides her time between a public service and a part-time private practice. The third of these participants work full-time in a fee for service arrangement.

All report that they work with other professionals in health care and education. In medical settings, participants work with physicians and surgeons to consult on speech and language and issues related to feeding and swallowing. Other health care professionals with whom the participants collaborate include nurses, physical and occupational therapists, social workers, psychologists, audiologists and nutritionists. In educational settings, participants work with teachers, teacher assistants, and school administrators as well as other rehabilitation professionals employed by either education or health departments. Private practice affords the participants relatively fewer contacts with allied professionals.

All but two of the participants report that they had experience working in more than one work setting with more than one type of paediatric client population. Of the two who had worked exclusively in one setting, one had 15 years of experience working with a variety of paediatric clients in that setting while the other had five years experience in that setting and had worked with the same population of children in a different capacity in her former career.

In terms of geographic setting, one participant currently provides service to children in a rural setting. However, five other participants working in either tertiary or specialty service provide service to rural clients though not directly in rural communities.

In terms of professional education, one participant holds a bachelor's degree in speech pathology. The remaining nine participants hold clinical and research graduate degrees. Two of the participants had completed coursework in health care ethics. None of the remaining participants identified having attended any workshop or continuing education activities related to ethics in their profession. However, one participant identified conversations she had with me as a source of informal education on ethics in speech-language pathology. Three participants who speak of their religious affiliation identified membership in mainstream Christian denominations.

Through information provided in the interviews, participants who are parents are identifiable. Of the ten participants, seven are parents; two of these are parents during their professional training program. Interviews also revealed teaching duties. Five of the participants taught courses in their clinical specialties. Three of the five are also involved in clinical supervision of practicum students in speech-language pathology. An additional two participants are involved in clinical supervision. Two participants are directly involved in clinical research although two others had experience participating in clinical research.

Context for ethical practice

Contextual conditions are those conditions of the environment in which speech-language pathologists deliver service that participants identify as critical to their understanding of ethical practice. These contextual conditions prompt study participants to consider ethical dimensions of their clinical practice. In this study, three contextual conditions are identified: the changing health care and educational systems, evolving speech-language pathology practice, and shifts in the paediatric populations served.

The changing health care and educational systems

Study participants, particularly those with more experience, are well informed of the changes to the societal institutions in which they work. Those who worked in the public sector in hospitals or schools and those in private practice settings speak of the impact of changing demands on clinical practice. As in other areas of health care and education, speech-language pathologists describe lengthy waitlists, pressure to do more with less, time constraints, and lack of ability to provide service that they feel reflect best practice. The following descriptions of practice conditions illustrate the intensity of demand felt by participants:

> That's point six. [referring to part of her FTE]. That's being available twenty-four hours a day and never being sick unless you are dead [laughs]. That involves day wise probably four assessments a week or more. Plus reports, plus follow-up, lots of follow-up. Lots of digging in the first place. Lots of talking on the phone, *lots of talking* [italics added] to speech paths all over Northern Alberta. (T1A, lines 128-134).
>
> Case loads are increasing. There's [*sic*] more demands and the demands are really coming from many, many places. They're coming from teachers. They're coming from parents. (T7A, lines 445-447).
>
> So the overwhelmingness of the number of clients, and what I see happening is numbers and more difficult or complex cases..... Caseloads are overwhelming. Very complex children. (T7A, lines 465-468, 481-483).

A theme emerging from discussions with participants about their practice environment is expressed in the statement "it's out of my hands". This participant explains:

> Part of my huge challenge is ... the boundaries put on us by health care. So they don't give us enough dollars to see these kids when they should be seen. These kids are running around for a year or two on a waiting list. So what does that mean? They're going through formative years and they're not being treated by us. Parents are calling. They're going crazy because they're still waiting. It's a year later. Our hands are tied because Alberta Health and the other places are not giving us the money that we need. Even though we show them statistics and say, look, look at our waiting lists. And, to me, that is unethical practice. But it's frustrating because it is out of my hands. I am bound by our government. (T8A, lines 494-506).

This participant, like others in this study, recognizes the origin of supply/demand tension at a higher level in the system (i.e., funding bodies). Despite her recognition of system limits imposed on her clinical work, she does not feel relieved of all responsibility. She expresses tension and regret in knowing what needs to happen for her clients but being prevented from doing it. The following interchange illustrates:

> Researcher: How do you maintain what you think is ethical practice when there are those kinds of barriers?
>
> Participant: Well, that's a tough question. I guess all we can do and all that I can do is follow the list as it comes up and as they can be seen, they're seen. And I feel terrible about it. I do. I feel terrible having to tell people, here's what we can do for you, but you're going to have to wait a year. And... you see the look on their face. It's like, oh, man, I wish I could tell you you [*sic*] can come in. And you could come in tomorrow if we had the ability. So, to me that's a real frustration. And I often feel like, I feel personally that I'm letting them down even though it's something out of my control. I do feel like I've let them down. (T8A lines 585-596).

Responding to these aforementioned pressures, speech-language pathologists find themselves seeking solutions that involve off-loading tasks to others, including other professionals, workers, and parents. The move to abdicating clinical work to others is unsatisfying to speech-language pathologists who recognize that their specialized knowledge is not easily or readily transferable to others without adequate opportunity for training. Participants explain:

> When budgets are cut and we can't see these kids and are asking teachers or aides, or speech language assistants to do things that, because of our caseloads and the demands on us, things that they are not trained to do. (T8A, lines 1109-1112).
>
> These kids [with Autism Spectrum Disorder] are really hard to figure out and I'm not permitted time to figure them out before I have to start training someone else and telling them what to do. And I don't even know what to do yet. (T4A, lines 876-880).

In other cases, speech-language pathologists are simply unable to provide the follow-up service that they see as a necessary component of good practice. Participants express concern over their inability to provide not just needed treatment services for a child identified with a communication disorder but also the support from a health care professional for the parents who may be dealing with a range of emotions related to their child's diagnosis. This participant states:

> It gets dropped. You think wouldn't it be great to call back in two months time. Have them come in if they wanted to, to have some sort of mechanism so that they could feel that they are being supported. Whereas they are just not being sent out and here are five phone numbers of people, agencies that might help you. Away you go....I don't have the resources to ensure that follow-up can occur. (T3A, lines 162-181).

Also, participants note that often the division of labour in service delivery in health care and education results in their diagnostic information being handed over to another professional. Participants are wary of this practice which they feel leaves parents without sufficient explanation or opportunity to question the information received. The process of relinquishing their clinical information is offered by participants as another example of "out of my hands".

Other system-imposed changes to clinical practice include the concentration of resources to younger children or children with specific disabilities, most notably those with Autism Spectrum Disorder (ASD). This move leaves older children with continuing needs with less access to publicly funded speech and language services. As a result, it becomes imperative to use resources wisely and in a timely manner while children are eligible for publicly funded services.

The ethical use of Program Unit Funds (PUF) in education is a concern for those participants who work with PUF eligible children. Program Unit Funds are those funds made available by Alberta Learning to early education providers in schools and community-based early intervention sites for each child in attendance with a severe delay in one of more areas of development impairment(s). These funds are used to supply materials, treatment services from specialists, and classroom personnel.

Participants voice their concern over what they see as misuse of PUF by school districts or early intervention programs where speech-language pathologists are not informed of the child's available funds for speech-language services or materials or where untrained aides are hired to work with the children without the input of a qualified speech-language pathologist or other early development professional.

> Well, in the rural areas … they take the dollars. They put in the mother and they don't bring in a consulting speech-language pathologist… they just bring in any untrained person in the community who is available and then that's it. (T5A, lines 689-693).

Changes in the systems that serve children with communication and related disorders also impact on daily practice with the proliferation of service delivery models that are seen by the participants as curbing their ability to do what is necessary or vital for their paediatric clients. Most particularly, the consult model is seen as useful in a specified way but not as a substitute when treatment is indicated. The consult model is a service delivery model in which the speech-language pathologist meets with the parent and child, or in an educational setting, meets with the teacher, makes observations during interactions with the child, carries out planned activities to determine the child's level of current ability and readiness to learn a new communication skill, and makes recommendations to the parent or teacher about how to carry out the intervention in daily activities.

Participants express a range of reactions to the consult model related to their perception of the degree of match between the child's needs and the service being offered. Where a child is likely to progress very slowly, participants are supportive of the consult model as it is seen as appropriate to the level of need. However, when the consult model is promoted as the single model for service delivery for all children within an intervention service, participants feel that some children are potentially being denied the opportunities for improvement in their communication status associated with direct treatment. However, the choice of service delivery model is more often not within the clinician's purview to change as noted by this participant:

> I know that's really one of the reasons why I left [non-profit early intervention program], and I love [the program] and [the program] has wonderful things going on about it, but the frustration is that I could not do the treatment myself. And they [the administration] *absolutely refused* [italics added] to allow individual treatment because it would get out of hand. One parent would say well, yeah, why aren't I getting [direct treatment]? (T5A, lines 1829-1848).

Family-centred practice model

Another major trend in service delivery is the widespread acceptance of family-centred practice as the preferred framework for work with the families of children with developmental needs. Participants support the intent of family-centred practice. They integrate the notions about respect, sensitivity, and support that underlie this service delivery philosophy but express reservations about aspects of the model that they feel undermines their ability to achieve optimal outcomes for the children served.

Participants offer examples of their struggles with the family-centred model across assessment and intervention situations and in various clinical settings. In assessment, pursuing a family-centred agenda is seen as potentially minimizing the importance of the child's needs. In one example, when a debate with a family over the child's diagnosis appeared imminent, one participant noted how she observed the assessment team offer the family the opinion that the family's view of their child's ability might be a more accurate picture. While the team did avert a potentially difficult confrontation with the parents that also might have alienated the child from services, the participant in this case worries that a line has been crossed that would cause the child to miss important service and funding opportunities.

In treatment and intervention practice, participants also describe their struggle with family-centred practice. Participants feel concerned about parents' decision-making at times when parents are overwhelmed by other problems. As one participant states, "The parents ... are grappling with all kinds of issues which ... sometimes do not put them in a good position to make these decisions." (T10A, lines 379-380). Still, participants are cautious about imposing their view on the parents. At the same time, they express their struggle over how expert knowledge is to be regarded in the family-centred perspective that equally promotes the parents' informal knowledge.

While participants are comfortable with working with parents to develop meaningful goals that respect family preferences, there are many examples given where participants feel that something other than the specific family's concerns and goals are at stake. Participants feel that sometimes the driving force behind the promotion of the parents' interest is a strict adherence to a family-centred philosophy of service delivery. As one participant states:

> ... we have a family-centred service... in this decade and maybe in the next decade we are committed to working with our parents so... I'm not in a position to say this is never going to work and this is what I'm going to do. We do make recommendations but parents need to tell us what they want. This is the way it works now and I think in an ideal world this is not the way I would do it. (T10A, lines 369-377).

This participant, like others, worries about sacrificing goals that would positively impact the child's speech and language status. Participants understood and are able to offer examples of where they are willing to engage in trade-offs that they feel serve the child's interest at some level. However, when consensus building attempts fail, participants feel ambivalence toward the family-centred model of intervention.

Following the family's stated desires sometimes leads some participants to feel confused when the parents' stated objectives are in conflict with the parents' behaviour. For example, one participant working in a strongly family-centred agency describes the extensive interviewing undertaken to identify family goals and priorities. Then in describing a follow-up home visit, she notes, "All they want is for us to just, do play, come play with their child and go" (T2A, line 359). In such cases, the participant is left wondering how best to attend to the family's chosen objectives. She states:

> And... each [need] is a priority but it's not a priority.... when you get there for your visit, ... there's a million other things happening and it's just not set up for a visit to get the best use of that time. (T4A, lines 367-372).

Participants describe how attending to the whole family and their multiple concerns in the context of family-centred practice is, at times, overwhelming. Asking the family about their concerns and needs, opens up the possibility that the speech-language pathologist will be required to use her clinical time to locate appropriate outside resources. In such situations, the speech-language pathologist is left with less time to devote to offering help that is within her scope of expertise. One participant commented, "It takes me away from speech pathology a lot... it's way down on the hierarchy of other needs." (T2A, line 319-320).

Where participants seem particularly bound by the framework of family-centred care is when their employer espouses a strong version of the family-centred principles. Such employers are said to impose strict rules on the number of sessions offered, on the level of intervention (i.e., consult or direct treatment), and on where the intervention should be carried out (home-based versus centre-based). In other cases, where speech-language pathologist and parent disagree over the intensity (i.e., schedule) of the intervention, the speech-language pathologist feels that her professional judgment is disregarded.

In extreme cases, participants describe feeling overwhelmed by the authority of their employers in family-centred settings to manage their caseloads in ways that contraindicate clinical judgment or challenge professional standards of practice. Some participants describe settings where certain approaches are applied to all children receiving services despite what participants feel is evidence of unique needs not met by the promoted approach.

Participants express the belief that parent-driven advocacy, supported by administration and appealing to the trend to family-centred practice, takes precedence over their clinical expertise in speech-language pathology. One participant offers her view on how her expertise is challenged in predominately family-centred setting:

> It's taken you four years to get through this university program. Why do you expect an untrained parent, a parent who's not trained in the same field, to do it? It's not easy. It takes education and experience. (T5A, lines 1793-1797).

Participants worry that the potential for conflict is built into the very service delivery model. One participant laments, "...it [family-centred practice] sets us up."

(T10A, line 386). To emphasize her point, this participant offers an illustration from speech-language pathology as she witnessed it practiced outside of North America. She states:

> The one thing that I noticed there is the absence of conflict because there is the state policy about how you treat children. The parents didn't make any decisions. They sent them to the school and the school just took care of them. You know what? No conflict. (T10A, lines 391-396).

These examples, offered by participants, illustrate how family-centred care challenges their sense of the role of expert knowledge and skill. Participants express a range of frustrations arising from the prevailing model as it is currently interpreted by families, clinicians, agencies, and institutions. Ultimately, participants worry that the principles of family-centred practice have the potential to erode their contribution to the child's well-being.

Dealing with systems issues such as lack of funds, perceived misuse of funds, and the proliferation of service delivery models not seen as meeting the needs of children with communication and related disorders leaves speech-language pathologists feeling restrained in their ability to satisfactorily deliver services to children with communication disorders. Much of the changes needed to improve service to children are seen by participants as "out of my hands".

A burgeoning research literature base demonstrating treatment outcomes places a different set of demands on speech-language pathologists. Clinical researchers in speech-language pathology have responded to the need for evidence in supporting outcomes with a concerted effort to support outcomes research resulting in a body of evidence supporting key therapies in specific clinical areas. The ability of clinicians to actualize the outcomes in their particular setting however creates a new frustration.

Two issues arise from the trend to evidence based practice. First, only certain areas of speech-language pathology are currently represented in the literature. For example, participants cite the established outcomes base in fluency. There is correspondingly, a marked lack of similar level evidence in broad areas such as language intervention. Some participants express their reluctance and uneasiness in delivering service without the evidence they feel is necessary for good practice. As one participant queries, "I think that the bigger preventative thing for me is that it is working primarily with language disorders....Are we really helping them?" (T8A, lines 302-305).

Second, the proliferation of the consult model discussed previously does not assist clinicians in realizing the treatment outcomes reported in the literature where outcome research is conducted primarily in resource intensive settings such as university clinics. The following participant expresses her reservations about working in an agency that promotes a consult model for all children with severe communication disabilities. Lacking what she feels is appropriate research evidence to demonstrate the effectiveness of the consult model for her particular population, she states:

> Yeah, one question, that I have is about ethics is, is it ever, is the consultative model ever ethical?...I think [use of the consult model] is because of the funding, and funding alone. Nothing and no other reason. That's why we have all this moral distress in our job. It's funding. (T4A, lines 2412-2423).

Another participant who had worked in an agency that used a consult model:

> I think it's up to you to choose whether you find that work [consult model] satisfying or not. I don't think you should ever consult without a minimum number of years experience. (T5A, lines 1862-1865).

However, requiring a minimum number of years of experience to ensure a good match between the speech-language pathologist with specific skills and her prospective employer is not a likely scenario in public systems that can only fund a limited number of positions at specified salary levels. Speech-language pathologists may lack mobility and may not have a range of jobs to choose from in their geographic location. Despite the recognition of the need for professionals in speech and language, the number of employment positions in speech-language pathology remains small relative to the numbers of children affected by communication disorders.

The small number of available jobs in publicly funded systems has a number of implications for the consideration of ethical practice. Some speech-language pathologists find work as private clinicians. However, currently, there are fewer than 20 speech-language pathologists in private practice in the urban setting in which this research was conducted (personal communication, ACSLPA, January 11/05). Three participants in this study engage in private practice. However, none are able to sustain sufficient work in their private practice without supplementing their work with either contracts with school districts, community based agencies, or part-time work in the public health care system. Difficulty with private insurance and reimbursement are cited by participants as barriers to full time private practice.

Sometimes speech-language pathologists work out of necessity in a setting or with an administration or institution about which they have reservations. Other speech-language pathologists find themselves working with a population of children that they do not feel comfortable with nor feel prepared for. At any given time, there is a small pool of jobs to choose from. These considerations create a tension that is expressed by one participant in the following way:

> So, I guess, I struggled with the fact that I needed the job, but I personally feel like maybe I'm not the best person in this job. (T8A, lines 279-283).

Working within a small professional community affects how speech-language pathologists conduct themselves and how they deal with differences and conflicts within the profession. This is particularly true for those speech-language pathologists who work in sub-specialty areas where their profile is easily identified.

Participants note how carefully they would approach a colleague whose actions they view as unethical. One participant describes how carefully she deals with a situation where she felt another speech-language pathologist acted unethically. In the situation she describes, the participant felt that she needed to continue working together with her colleague for the family. She states:

> And the person that recommended [*the intervention*] doesn't think she's done anything wrong. How do I say, "I think what you did was unethical?" So instead I said, "...This was a very difficult situation and I understand that the child now has [*received the intervention*] and we'll be working with [*the family*] to see if it improves [*the child's skills*]...I would've preferred if this could have been done in a better way. However, I know that [*in your setting*] these decisions have to be made very quickly...I'm just sorry that [*the team*] intervened and that the parent wasn't supported." (T2A, lines 241-302).

The participant further states:

> ...if you were to take someone to task that they may have done something that wasn't ethical, you may never be able to work with them again and this whole area is so small...[that] you've slit your own throat. (T2A, lines 320-324).

Another participant preserves a collegial relationship and adjusts for the child as follows:

> This is my list for how I think these children should be grouped...and she goes, "Thank you for your information but this child is going over there". And I don't fight her on that...I want to keep our really great relationship so I run with it and try not to turn cynical. (T10A, lines 186-191).

Participants focus on ways to preserve the professional relationship while also advocating for their client. Participants are aware that their working relationships with each other remain constant though clients change. They are also aware that their collegial relationships impacted not only the family at the center of a concern but future families as well.

Shifts in paediatric population

Populations of children with communication and related disorders are changing. Children with Autism Spectrum Disorder (ASD) form a large portion of those served by speech-language pathologists (ASHA, July 2004 issue: 70% caseload). These children have complex and ongoing needs that extend across developmental domains. As research points to the centrality of the social communicative deficits in ASD, speech-language pathologists play an important role in diagnosing and treating these children. Other similarly complex populations include children with severe feeding issues that are related to a number of causes including severe neurological damage and/or behavioural-emotional disorders.

Across all participants, there is recognition that the child's diagnosis alerts the speech-language pathologist to the potential for ethical concerns surrounding diagnosis and treatment decisions. Though clinical experience among the participants varies, all are able to identify certain populations that they think need careful consideration. These areas are: feeding and swallowing disorders, autism, traumatic brain injury, severe multiple disabilities, and deafness. Participants identify language intervention, not specific to any particular population, as an area of concern. For participants, language intervention is problematic when research bases are lacking and when the outcomes are not immediate and largely not predictable. By contrast, relatively unproblematic areas are identified: articulation/phonology, fluency, and voice and resonance where as one participant comments:

> You can try it for so long. You can see it's not working. You can come to a conclusion more readily than, say, some of the more cognitive or language problems where there's always that hope that that might change. (T8A, lines 980-983).

In addressing the problematic areas of feeding and swallowing disorders, autism, traumatic brain injury, severe multiple disabilities, and deafness, participants speak of sensitivity to ethical aspects of diagnosis and treatment in the care of children with these disabilities. They are aware of the controversies in these areas and acknowledge that these controversies often play out in their setting. Some participants are able to see the difficulties through to some resolution; others not. For example, with respect to one controversial area, this participant comments about her practice setting:

> We all understand that some methods work better for some children in some families. ... There's a lot of respect, not only for people, but different methodologies that we work with in our setting. (T10A, lines 260-270).

Similarly, in referring specifically to ethical issues in feeding and swallowing, another participant observes that clinicians are well aware of the gravity of issues in this practice area:

> People think about ethics in feeding and I think every feeding therapist on our team has the extra insurance because people can die from feeding but they can't die from articulation therapy. (T2A, lines 226-229).

In order to practice ethically in a particular specialty area, the ethical speech-language pathologist needs to adjust to expectations and deal with controversies, misconceptions and misinformation. At the same time, the ethical speech-language pathologist must be cognizant of the danger of becoming too narrowly focused on the child's diagnosis and consequently not considering other aspects of the child's communication difficulties. For example, in dealing with autistic children, one participant notes how easily the diagnosis of ASD becomes central to everyone's concern while other less obvious difficulties that the child faces are relegated to the background:

> And so he's mouth breathing. So that took me six months to figure out 'cause [sic] I don't work with that. Our main focus is language. That's all we do [in her agency]. (T5A, lines 2119-2124).

Increasingly, changes in the health care and education systems, developments in sub-specialty knowledge, and shifting paediatric populations create a context in which speech-language pathologists question their day-to-day interactions in terms of what constitutes ethical practice in their field. Study participants are well informed of these external influences on their practice. They also offer that, as individual clinicians, they experience internal influences. They point to their personal growth and change in the course of their careers as speech-language pathologists. In the next section, these internal changes over the career span of speech-language pathologists are described.

Career span influences on ethical practice

Outlined in this section are the passages described by the participants as they reflect on their sources of knowledge about ethical practice over their careers. These passages are divided into the time before entering the profession, the formal education period, entering practice (the first years), and continuing practice (the later years). While participants have a variety of levels of formal speech-language pathology education and experience and, as well, possess a range of characteristics for which they are selected for this study, all acknowledge changes in their perspectives on ethical practice over time.

Prior influences

In describing the time before entering speech-language pathology, participants identified their families as a major source and influence on what they view as ethical practice in their profession. Though participants generally regard their families as a positive influence, some participants note that insights are also gained from unethical behavior among family members and friends. Another early influence on ethical practice is religious authority. As one participant, a regular church attendee, notes:

> I go to church to hear, to be reminded, of how to live an ethical life not necessarily because I'm incredibly religious. But it's the only place in my life where we talk about it. (T2A, lines 1075-1079).

Of all the participants, only one had taken a course in ethics prior to entering the profession. When asked about the course, she summarizes her learning as follows:

> I think the one thing that I carried away from that is what is ethical isn't always what we want. Or what you feel is right.... So you always have to question and think about things from an ethical, non judgmental perspective. Who has the right for what? He [referring to the professor] always used to say "Your right to swing your fists stops where my face starts." But your right to do anything stops where someone else's rights start. (T9A, lines 477-497).

Cultural values are also acknowledged as influencing the participants' views of ethical practice. This is particularly noted by participants in their discussions about interacting with families of different origins than their own or if they, themselves, had grown up in culturally different families.

Participants also acknowledge that they feel they are perhaps different from their colleagues or classmates in their orientation to thinking about ethics in their clinical practice. Participants express that as individuals they are "the sort of person" (T9B, line 1068) who would think about ethics in practice. Some think that their orientation in this way somehow separates them from some of their classmates who they think hold differing views. One participant offers that only certain people would be attracted to the profession or remain in it for any length of time (T10, line 1041).

Formal education period

Currently, formal ethics education in the speech-language pathology curriculum is delivered via clinical instruction in each of the discipline's areas of specialty. Ethics education is a newer addition to the curriculum and, as such, the choice of topics, materials and resources are the responsibility of the instructor. Five participants in this study had taught courses in their clinical specialty. Of these five, one had completed coursework in health care ethics. This participant notes that her experience in taking a counseling course also influenced her notions of ethical practice as course discussions frequently dealt with respecting families' perspectives.

All participants were asked about their familiarity with and use of the profession's Canon of Ethics. As students, all would have been instructed to familiarize themselves with the Canon as part of either classroom instruction or clinic orientation by their practicum supervisor. Participants' responses ranged from acknowledgement that they are aware of the existence of the Canon but did not consult the document, to using the document as a beginning reference when encountering a challenging clinical situation.

The more experienced participants had graduated prior to the emergence of ethics as a topic in clinical education. Newer clinicians, those with five years experience or less are able to recall in general terms that ethical practice is discussed during courses, but when asked for any specific information are unable to provide it.

One limitation is that the newer clinicians are graduates of the same university training program whereas the more experienced participants attended a variety of training programs both in Canada and the United States. Ethics in the curriculum may be more identifiable to graduates of other programs.

Though formal means of ethics education is not cited by participants as significant, they do identify the influence of mentors, either professors or practicum supervisors, during their training period. These mentors demonstrated by their character and/or their actions, what the participants, as students, took to be ethical practice in the profession. Among the experienced participants, it is notable that they returned to their early mentors, the ones encountered in their training programs, for response to the researcher's query. Their responses suggest a possible important and enduring impact of early role models on a clinician's ideas of ethical practice.

Early years

Participants speak of their early years in clinical practice with a recognition that ethical practice consists of more than their technical skills and knowledge of human communication disorders. They note the struggles inherent in the beginning of one's career. One young participant exclaimed, "Caseload management! What course is that?" (T4A, line 1184).

If support is needed, one new clinician states that she actively sought guidance in ethical matters from her training program. If the training experience is positive and mentors upheld ethical standards, then a graduate clinician could seek ongoing support in the early years of practice. This source of practical support for ethical matters diminished over time as the clinician became more experienced and positive relations with other colleagues are established. However, if the training experience is perceived as negative, the training program is not seen to offer support for ethical challenges in the early years of the new clinician's career.

For participants who are recent graduates, the Alberta College of Speech-Language Pathologists and Audiologists (ACSLPA), declared in July 2002 under the *Health Professions Act,* is a readily identifiable resource for assistance in ethical concerns. Participants who are newer clinicians referred to the College in their discussion of resources for ethical practice. More experienced clinicians who participated in the study did not mention the College, preferring instead to describe how they consulted with their colleagues.

Events in participants' personal lives during the early years of their clinical practice interact with experience to inform the development of ethical practice. Participants point to events and experiences in their lives as contributing to the development of their notions about ethical practice. Because the study focused on clinicians working with paediatric populations, participants would offer that parenting their own children influenced their approach to working with families. One participant offers that as the parent of young children in her student years, she questioned the dominant model of intervention for young children and their parents. In her example, her life experience prevailed over her formal clinical training.

Experiences in the early years are varied. Some participants recall particularly bad experiences that they feel shaped their views of ethical practice. Other participants feel that their simple lack of experience contributes to vulnerability in ethical aspects of clinical practice. Feeling vulnerable precipitates a reaching out to others. Reaching out becomes a point of particular vulnerability if met with negative feedback, as in the case of one participant who subsequently fostered a reluctance to expose herself in future.

The early years are also marked by short periods of employment in a variety of settings. Participants later settle into a specialty area or a preferred work setting. These varied work experiences serve to instruct participants on elements of ethical practice. One participant notes:

> Definitely seeing how agencies, established agencies, provide service….And getting a feel from different agencies. And I think that's when your own ideas of the best way to provide service begin to form is after you've worked for several different places and you see how different service provision is offered. And then you start saying well, this is good about that program [and] this is good about this program. (T5A, lines 1202-1220).

Later years

As experience grows, both clinical and ethical practice is further developed, accumulated, and continuously modified. The more experienced participants offer a longer horizon that traces their evolution of notions about ethical practice. Though they feel that they remain true to the underpinnings expressed in their versions of the ethical clinician and ethical practice presented elsewhere in this report, they offer reflections on nuanced changes over time. In other instances, these participants are willing to self-critique.

> I look back on a couple of kids that if I hadn't been so rigid because I knew augmentative communication is the way to go and had actually treated the kid for speech for six months, this family might have moved beyond. (T2A, lines 749-752).

Throughout, these participants note the continuing influence of interacting with others and, at times, confronting different values as evidenced in challenges around particular situations, events, or clients. Some participants note that a set plan is developed for certain situations and for factors that are revealed as patterns in their clinical setting or with their particular clinical population. Participants recognize that certain situations are handled in standard ways. As one participant says, these situations become "the blacks and whites but shades of grey continue to provoke." (T2A, line 604). Also, participants offer that they are becoming less invested in one way or a right way of delivering service. In fact, participants think that unethical practice is evidenced when a clinician unduly exercises her authority as a health care provider to promote only one favoured treatment option. One participant sums up in this way:

> And you cannot if you are all powerful and only know one way, you cannot look at a situation ethically I don't think. (T2A, 951-952).

Participants regard all influences as important in contributing to the development of their notions of ethical practice. Each speaks knowledgeably about her own evolution toward better understandings of what is considered ethical practice as she experiences growth and change over the period of her career.

The ethical practice model

In order to provide the reader with an orientation to the ethical practice model that developed from participants' perspectives, a visual schema outlining the components of ethical practice and their relative relationships and influences is offered in Figure 1: the ethical practice model. Ethical practice in paediatric speech-language pathology consists of the following components: a) influences, b) characteristics of the ethical professional c) context for practice, and d) ethical action. The influences on the development of ethical practice over time were previously described. The remainder of this chapter will describe in detail the remaining components of the ethical practice model.

The clinical encounter

In laying out the model of ethical practice in paediatric speech-language pathology, I have chosen to present material in a framework that is familiar to clinicians and is drawn from the descriptions of clinical practice offered by study participants. Therefore, the sections that follow are structured around the activities that are central to clinical practice: assessment and treatment. The central event is the clinical

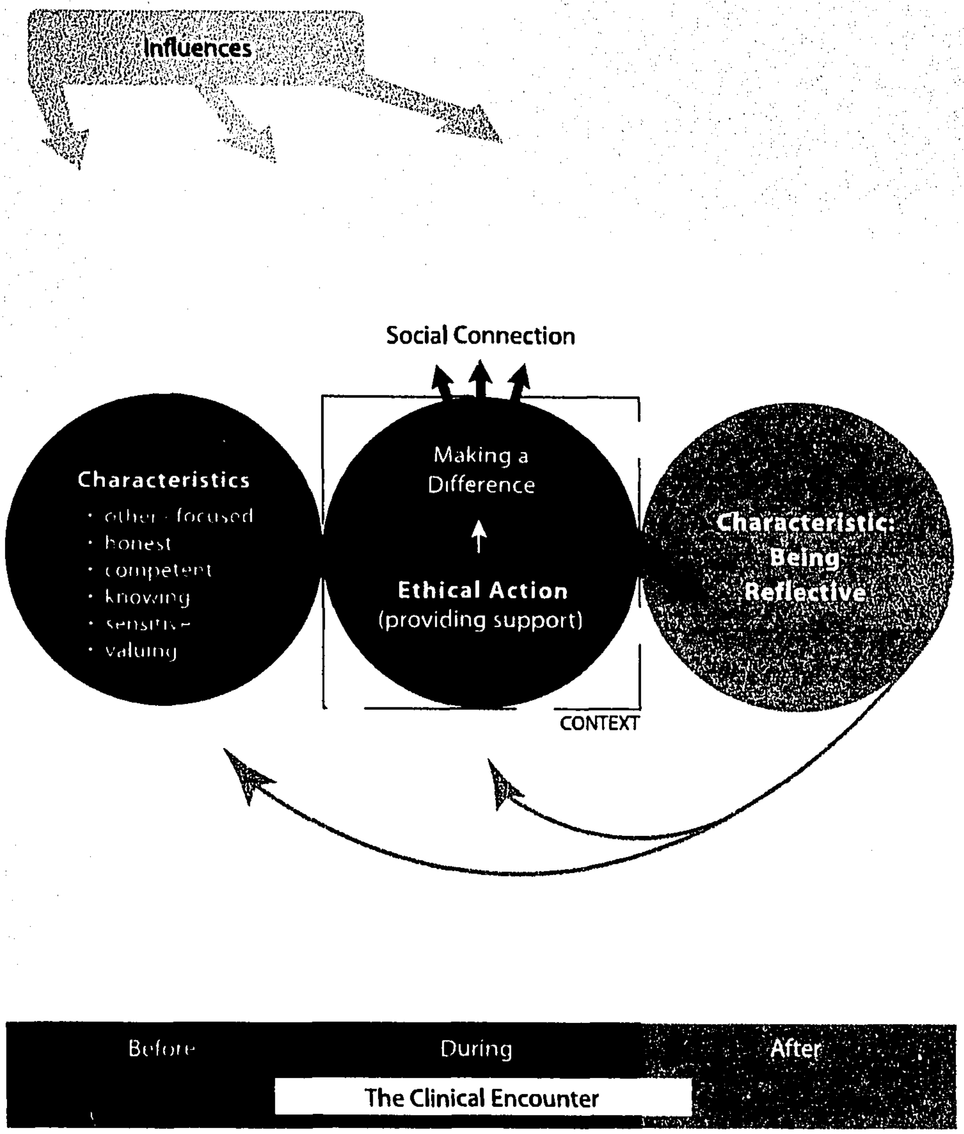

Figure 1: Ethical Practice Model

encounter. In the ethical practice model, the foundation for ethical practice begins in the time before the clinical encounter, continues to develop during the clinical encounter, and is continuously modified following the clinical encounter as the reflective clinician considers each encounter at its conclusion.

The ethical speech-language pathologist, participants state, brings certain characteristics to the encounter. Characteristics that are seen as essential to the ethical speech-language pathologist included being other-focused, honest, competent, knowing, sensitive as well as valuing others.

In the clinical encounter, the ethical speech-language pathologist engages in ethical actions which are aimed at achieving the core experience of *making a difference*. During the encounter, the ethical clinician aims to do her best. Following the clinical encounter, she reflects back on the encounter that just concluded and on the larger scope of her practice in general. In this way, participants identify the ethical speech-language pathologist as a clinician who is reflective.

The ethical practice model can be thought of as three interconnected pools with channels that pass from one major component to the next. Early and ongoing influences form a channel that enters into the development of characteristics attributed to the ethical professional in speech-language pathology and into the sphere of ethical action. Characteristics flow into the clinical encounter to mingle with ethical action in a context that is defined both externally by system, institutional, and practice constraints as well as internally by prior and ongoing individual experiences. Though constraints exist, some participants identify ways in which they are able to move beyond the constraints to seek creative solutions that maintain their focus on making a difference for the child and his family. Their contribution is represented by the broken line that defines the context of the clinical encounter indicating that the constraints are not always firm barriers. Finally, as the actual encounter closes with the completion of ethical action, the energies of the ethical clinician turn to reflecting. Reflecting, in turn, channels through to characteristics and action in an ongoing flow that is continuously changing with each clinical encounter over time. The pools that represent the components of ethical practice can widen and assume depth over time to represent the ongoing interaction between characteristics, action, and reflection, as depicted in Figure 2.

The clinical encounter contains a host of potentially challenging topics. The ethical speech-language pathologist must be prepared to navigate these challenges keeping the aim of *making a difference* at the forefront of her concern. In the sections that follow, I will outline those characteristics of the ethical speech-language pathologist that support ethical practice. Before detailing characteristics and ethical action, I will present the core category that frames the mission of ethical practice in paediatric speech-language pathology in order to set out the ethical aim of clinical interactions with families of children with communication disorders.

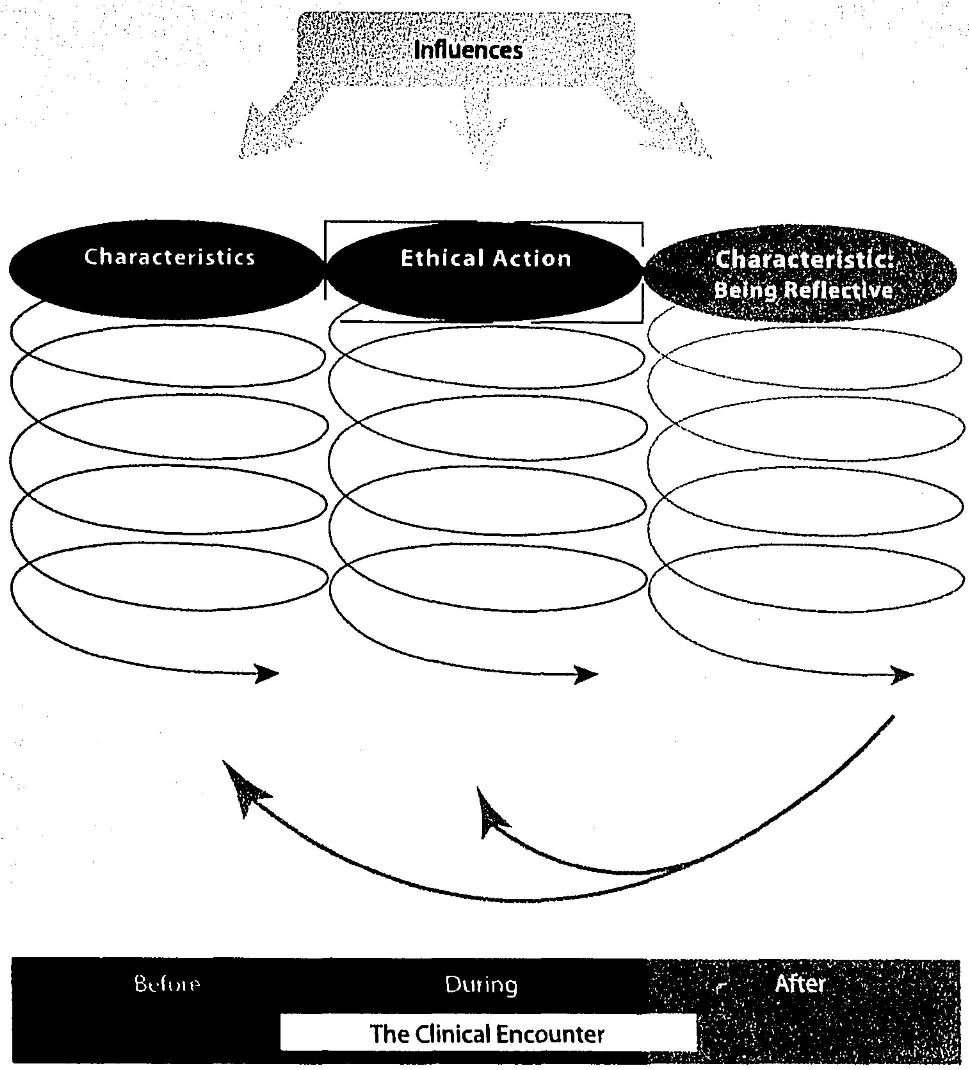

Figure 2 : Ethical Practice Expansion

The core category

The core category encompassing all components of ethical practice in speech-language pathology is that of *making a difference.* Though seen as the mission of speech-language pathology by participants in this study, this core category states a mission shared by other health care professionals. *Making a difference* in the lives of the people receiving health care services underscores the ethical principle of beneficence. Throughout this study, participants refer to *making a difference:*

> Researcher: What is it about what you are doing there [referring to parent group] that said to you *this* [italics added] represents ethical practice?
>
> Participant: I feel like it made a difference. (T1A, lines 385-387).

It is in the particular articulation of *making a difference* that ethical practice in this profession takes on its distinctive form. According to participants in this study, the focus of ethical practice is to encourage, through their efforts, the relationships fostered by communication that will ensure that the child is *part of* his world; a world that includes important others in his life. Therefore, the development and remediation of communication skills is not the end goal of ethical practice. Rather, ethical practice focuses on the formation of social relationships, mediated through communication, that ensure that the child is *part of* his world. In this way, ethical practice in paediatric speech-language pathology is aimed at *fostering social connection* with others. One participant illustrates this focus with a poignant example from her clinical practice with autistic children and their parents:

> I remember a parent saying to me and it happened pretty much on the video tape or it happened a couple of days prior where her kid is just starting to do joint attention where he would look at something and he would look at her, and he would look back. She said, "I feel like I never played with him before. I feel, when he looks at me, I can feel electricity going through my body. I feel like he is really there. He sees me. I am part of his world." And when parents told me that, I thought *it doesn't matter what else I do today I have made a difference* [italics added]. I have done something that has gotten [*sic*] this parent and this child to truly interact at least some times and on some plane, together. (T1A lines 445-459).

The ethical clinician attends to the child's milieu and then works toward developing the communication skills necessary to develop and sustain his *social connection* to others. Thinking broadly about the impact of communication on relationships with others, study participants are able to outline how the child's communication disorder interferes with his ability to *be part of* a world that includes important others. The child who possesses unique characteristics of speech, language, voice, resonance, or fluency will be noticed by others. Once a difference is signaled, reactions to the child may negatively affect his present and future interactions. As a result, the child experiences fewer opportunities to communicate, further compounding his isolation. In some cases, where his communication disorder is severe, others may make the child invisible by assuming his role in interactions. Over time, as the child grows, the effects of the communication disorder may be far reaching. This process is eloquently described by one participant in the following quotes:

> The thing though with these kids that I see, so they have these speech problems, and …people would hear them talk and think that they're mentally challenged. They will most likely …have difficulty finding …gainful employment…finding a spouse. …There's so many different levels of what I like to call social perception of speech…that marks a person to be thought of differently than what they actually are. (T8A, lines 430-438).

This participant further states:

> I can't tell you how many times I've seen people talk for the person sitting in the chair….they're completely out of the communicative loop because they're not given the tools that they need to be there. (T8A, lines 831).

Against this background, the speech-language pathologist develops her abilities to practice ethically to *make a difference* by assisting the child to remain *part of his world.* In all aspects of her practice, the ethical speech-language pathologist aims to preserve the relationships that both foster communication and are fostered by communication. She knows that the child with a communication disorder requires relationships with important others in order to fully develop his capacities to communicate well. These relationships are especially important where communicating with the child requires effort from others. For example, children with severe communication disorders must rely on the ability of others to accurately and sensitively interpret any behaviour that has the potential to convey communicative meaning. In the area of feeding, where the focus is not on communication skills per se, the ethical speech-language pathologist, participants note, would be sensitive to the need for the child to remain *part of his world* by participating in family meal routines.

The ethical speech-language pathologist knows that in order to *make a difference* for the child, she must engage his parents and sustain and support them. Her actions must preserve family integrity which is vital to the child's interest. One participant used the following analogy to illustrate:

> If you don't have a stable parent-child relationship and a stable family situation, that's where communication grows. So if you don't water the garden it doesn't grow. (T1A, lines 470-479).

To preserve family integrity requires the ability to respect the child's family and its decisions regarding how the child will be treated. The ethical speech-language pathologist also knows that a good relationship with the child and his parents develops from interactions with them that are honest and sensitive. By providing support to the child and his family in terms that are meaningful and useful to them, the ethical speech-language pathologist conveys her commitment to valuing children and families.

Characteristics

In the sections that follow, the characteristics that exemplify the ethical speech-language pathologist as well as the primary and secondary ethical actions will be presented. Before presenting the analysis, I offer the following narrative as it embodies expressions of overall ethical character and action evidenced in this study.

The narrative presents a challenging case that a participant offers as an example from her practice that she feels illustrates ethical practice in paediatric speech-language pathology. In this clinical encounter, the participant interacts with a native family as is common in her clinical setting. The child, in question, is disabled as a result of traumatic injuries for which the father had been found responsible.

In choosing this particular narrative, I wish to focus on the speech-language pathologist's response to a potentially challenging situation. Clinicians, particularly those who work in regional referral centres, frequently encounter children like the one in this narrative. Abuse of children crosses all social, economic, and cultural borders. In this regard, the family is not unique.

Other elements of this narrative deserve attention. In this narrative, the speech-language pathologist navigates the distance created by the social, cultural, and economic differences between the two parties. These differences offer potentially divergent perspectives and understandings of health issues such as developmental disability including the feeding concern that this child presented with. What is important in this narrative is how the speech-language pathologist mindfully brackets those elements of the family's history and identity in order to skillfully attend to the family in a way that places a positive focus on doing her best to make a difference for this father and son.

> Researcher: Think of a case you feel particularly good about because there is some thing that happened and you choose to do "x". And you did it because you thought it is ethical to do that.
>
> Participant: I'm just letting some things flood my mind for a minute. So I can think of specific examples of things that happened that I feel good about interacting with patients. They don't necessarily involve anything clinical.
>
> Researcher: That's okay.

Participant: I'm thinking of the time a man came in and brought his little guy in for an assessment. It is a little boy who is *very, very* [italics added] developmentally delayed. The Dad brought him in. They are a native family and at some point in time there is an investigation by the RCMP. The Dad had actually been responsible for the little guy's injuries. Anyway, so the Dad brought him in and he is [participant pauses] looking a little rough. He had long hair, isn't particularly clean looking. But he got there and he got there on time and he brought his little guy. Oh, actually, ... it is a speech and language review but the Dad's main concern is feeding. And I was filling in for someone.

So I started to do my assessment and this little kid, he is crying and miserable. He couldn't do anything. He isn't even going to score on the instruments that I had for him. And, frankly, I thought in that moment, that's really not what this Dad cares about. What is making this Dad's life hard right now is that the kid doesn't eat anything. I asked the Dad, because he is going to be there for a day, if he had brought anything for the little guy to eat. So he opened up his bag and he had. But it is, like, Kool-Aid and, I think, he had a can of canned milk or something and some dried cereal. And that is it because that is all the kid would take. And the kid is miserable and didn't eat anything anyway. I tried. I really feel like I hadn't answered this guy's question. It isn't my regular assignment. Somewhere in my mind I thought, yeah, yeah, this is a family that is questionable. They have completely different values than I have. But there is something about that Dad that just so impressed me that I feel he really did care for the little guy and he really is worried.

So I arranged for them to come back later that day or the next and I got some food from the supply room. I got some pudding and a couple of other things and worked with the little guy. And we did get him to eat a little bit. But he isn't fussy for the pudding. And so after I gave him a couple of bites, I gave it to the Dad. And I said, "I was going to throw it out. Do you want it?" And he just dived on it. I can't remember how he actually said it. Because I would have thrown it out. And it is something to the effect of I looked at him eating that pudding that his kid didn't eat and I said, "Yeah, it's really hard to throw things out, isn't it?" He kind of nodded and is ravenously eating this pudding. And I thought to myself, probably one of the reasons this little guy hasn't progressed to different foods is [that] they're poor, they have a big family and they don't have a lot of money to feed him. *So why would they* [italics added] try new foods when they are just going to have to probably throw it out anyway? And my stomach *just sunk* [italics added]. But anyway, I referred him to a feeding team and he came in and they worked with them a little bit.

I feel good about that because I feel like I had interacted with somebody really putting aside my beliefs, or not beliefs they're not my beliefs or putting aside the possibility that I would stereotype him like so many other people. And that I just worked with him in his role as a caring parent, no

> matter what else is going on. And I really feel like I could try to understand some of the things that are tough for him, that made it tough to parent. I feel good about that. (T1A, lines 254-332).

This participant, like others in this study, speaks of ethical practice in terms that refer to the central relationship between the speech-language pathologist and the parent(s) of the child with the communication disorder. Other relationships, particularly those with other professionals, are also explored with the participants. However, it is this relationship, the one between the speech-language pathologist and the family that is the hallmark of ethical practice in speech-language pathology and reflects the speech-language pathologist's concern for how she ought to treat those served.

Embedded in the narrative are characteristics offered as exemplifying the ethical speech-language pathologist engaged in service to the family. The speech-language pathologist is other-focused, valuing the child and parent, sensitive, knowing, and competent. The father is acknowledged and supported in his concerns. And the child's best interests are served. In the sections that follow, the relationship between the speech-language pathologist and the family that forms the sphere in which ethical practice unfolds is outlined. First, I will focus on the characteristics identified as elements of the ethical practice model. Figure 3 offers a closer view of these characteristics.

Characteristics of the ethical speech-language pathologist are revealed in two ways: in their response to my question, "Who is the ethical clinician?" and in their descriptions, examples, and stories about interactions with families. In order to

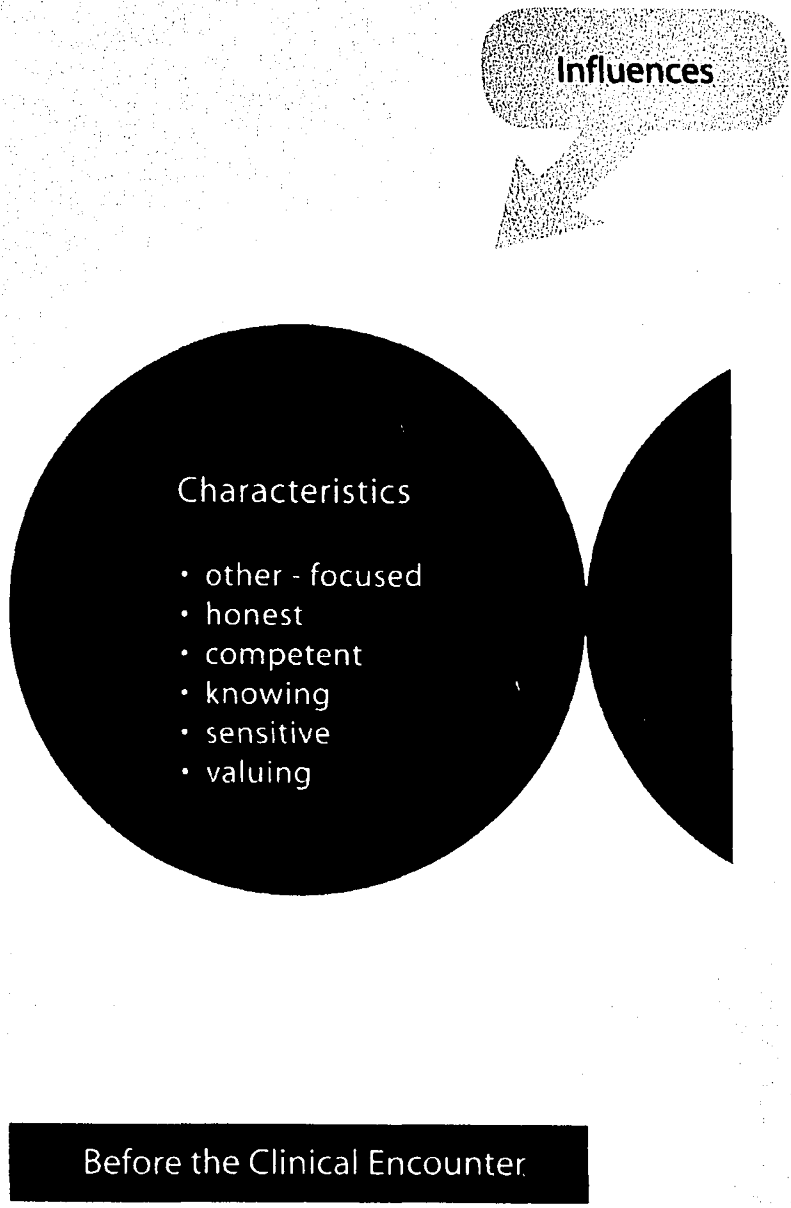

Figure 3 : Characteristics

achieve the mission of speech-language pathology, participants identify a set of characteristics that are essential to the ethical speech-language pathologist.

These characteristics are ones that the ethical speech-language pathologist brings to the clinical encounter and they embody prior experiences, values and education. They include being other-focused, honest, competent, knowing, and sensitive. Certain of these characteristics are highlighted at various stages as the ethical speech-language pathologist moves through the phases of the clinical encounter previously outlined. The following section focuses on each of these characteristics.

Other focus

An overall orientation to the other is a necessary pre-condition for ethical practice. In the preceding narrative, the ontological orientation to other is evidenced. The speech-language pathologist focuses on valuing another person despite differences in cultural or socioeconomic circumstances. The speech-language pathologist also engages in helping the family in the preceding example though the father's history could be seen as challenging. Her ability to do so highlights the importance of being able to set aside feelings and judgments that may undermine the success of the clinical encounter.

Throughout their descriptions of either the ethical clinician or ethical practice, participants emphasize a fundamental stance that calls upon the ethical clinician to place primacy on the concerns and priorities of the child and his parents.

> I can think of lots of families that come in from all socio-economic levels. .. I guess to think that because these kids don't talk [and] to believe that that's the parents' primary concern is really kind of narrow. And I guess that I don't think you can really show people much. You can't really expect them to make it their big concern if you can't identify with what their big concerns are. (T1A, lines 336-365).

Taking the position that the parents' concerns are primary means that the ethical clinician will put aside her agenda to attend to the concerns of those she serves. Like the speech-language pathologist in the opening narrative, the ethical speech-language pathologist will take the time to listen to the family's concerns and their stories to identify their most important issues. The ethical speech-language pathologist, in taking this orientation to others, will take an interest in their perspectives, concerns, and priorities. She will ensure that she "honours their stories" as they are told to her (T1A, line 563).

> And as much as you can to put your own values in the back seat and really try to focus on *where they are coming from* [italics added]. (T1A, lines 755-759).

Valuing others

In order to engage with others effectively and to address the other's concerns, the ethical speech-language pathologist must value the persons served. This orientation toward valuing those served is variously expressed in terms such as 'valued' and 'worthwhile' in statements such as, "I think just having the idea that the person ... is a worthwhile person " (T7A, lines 715). The ethical speech-language pathologist is described as a clinician who recognizes the child's value and acknowledges the child's value in relation to important others. She is seen by participants as aiming to preserve the child's value against others' negative valuations.

Participants talk about the child in ways that convey a sense of preserving the integrity of the child, placing his "child" status centrally and against all the other striking characteristics he might possess (e.g., language disorders, severe physical disabilities, autism, deafness). This commitment to valuing the child as a child first is reflected in the following quote:

> And one of the things that I always wanted to do is to make sure that the parents kept seeing their kids as kids [her voice conveying emotion] that are just as valuable and worthwhile as every other kid. No matter how weird they are, they are kids first. (T1A, line 432-437).

Where the child has severe disabilities, the ethical speech-language pathologist is in the position of seeking some characteristic that would allow the parent to sense that she recognizes their child's value. In such situations, participants note "how many things are we saying are wrong with their child?" (T3A, line 408) and would offer statements such as:

> "Did you see that smile? He smiled. Does he always smile that way? Look at her beautiful eyes?" You have to let them know what you think. It is their special child. (T3A, line 409-410).

This participant states that she wanted the parents to also see that their child had qualities other than those defined by disability. In highly medicalized settings, where often little is said that is not focused on the clinical problem at hand, this clinician's sensitivity served to counter a negative perspective and redirected attention to the child as a valued person. Even in less highly emotionally charged settings, participants convey their sense of valuing the child by expressing their concern that the child deserved to receive needed treatment services and that the child is worthy of every effort.

Participants are well aware of the challenge to their declaration when offering statements aimed at conveying the child's value. One participant articulated the challenge in this way:

> How to present information [while] keeping the child valued. Value that child, but just identify... what else needs to be done. And it can be tricky (T10A, lines 505-506).

Further she states:

> We're focusing on what's missing. We're not focusing on what's there. So, like, I mean, we're *pathologists* [italics added], so we're supposed to be concerned with the pathology. Well, can we get beyond that? Can we get beyond that? That's what I'd like to be able to do when I'm talking to parents. (T10A, lines 524-531).

Negative valuing of children with communication disorders has multiple sources. Parents, participants note, face comments from family, friends, the public, and institutions. At times, their child's health care and educational opportunities are limited by negative perceptions particularly if the child's severe disability involves not just communication but also cognition. One participant recalled:

> The doctor says your child is so retarded...that really this surgery is not going to be of any use to him at all. What they're saying is this child has no value so why would we do this surgery? (T2A, lines 637-641).

Participants note that the ethical speech-language pathologist must maintain her focus on valuing the child and supporting the parents in the face of these challenges. One participant described the challenge in this way:

> I feel like I'm bucking society in this situation. ...I guess I'm trying to offer a counterculture message because I frequently feel that they don't get it at all. (T10A, lines 655-660).

Participants are also prepared to challenge negative evaluations of the children served and to do so directly with others involved in the child's care. The ethical speech-language pathologist, participants offer, would state her commitment to other professionals involved in the care of her client. This participant illustrates in her example of speaking to her health care team by stating, "I don't believe this child is a retarded nothing. I believe this child has worth". (T2A, lines 1256-1257).

In other situations, the ethical speech-language pathologist's commitment to valuing the child may prompt her to challenge clinical decisions made by other professionals and to ask, by offering her observations of the child, what others considered in their decision:

> Why are you making this decision? What are you weighing? One of the kids that I went to see in the community, the surgeon had turned down [for] surgery. And I looked at this kid. The kid talks a little bit, is the highest functioning kid [in her group], eats a little bit, and her head is turned like this [participant demonstrates the child's head position] and she can't ever look at the speaker. So I went back to this surgeon and said, "You made a bad decision. This kid is functional. She can talk. She *loves* [italics added] interaction and communication. She *needs* [italics added] to be able to not have her head like this where she can't ever see." And so then they went back. (T2A, lines 676-689).

The commitment to valuing others is carried through encounters with families, colleagues, and other professionals involved in the care of the paediatric client.

In addition to valuing the child with a communication disorder, participants offer that the ethical clinician will assume that the parents are able to help their child, that they want the best for their child no matter how that might be expressed, and that nothing that they have done in their ignorance is intended to harm their child. In this way, the ethical speech-language pathologist values the child's parents as well. The ethical speech-language pathologist who demonstrates that she values the child and his parents gains a positive platform on which to build her relationship with the child's parents and engage those competencies and abilities that will serve important goals.

> We might not agree with the way that they're going about that but [we are] assuming that they want the best for their child. They don't want harm for their child….Their methods might not be what we would see as being the most helpful at that time. But I guess understanding where they are in their journey of …with acceptance. (T7A, lines 761-772).

Participants also recognize a professional responsibility for the relationship with the parents. As with the speech-language pathologist in the opening narrative, participants state that the ethical speech-language pathologist is one who brackets values and agenda that might interfere with a positive relationship.

> I would never put myself in the position of being the one who will make the big difference in the kid's life. It is the parent. And *I* [italics added] think that is a hugely undermining clinical activity, when you lead the parent to think that *you* [italics added] are going to fix their child or that if it isn't for *you* [italics added], that they would never learn this information. (T1A, lines 769-774).

Being honest

The participants emphasize that the ethical clinician is honest in all her dealings with the child's family. Participants speak of being honest in communicating findings, answering questions, including those about the child's future, in sharing information about resources and in discussing treatment plans and the child's progress. Participants emphasize the importance of sharing information honestly with parents so that they can work together for the child's benefit.

Participants also discuss challenges to being honest. They recognize that it is a challenge to be honest when you know how your words will impact others.

> I try to be as honest. Actually, that is something that I believe is ethical. I try to be as honest as I possibly can….It is hard to be honest in this field in a kind way because the questions that parents ask, the answers [*sic*] are somewhat devastating. My two year old with autism [or] say my five year old with severe autism and mental retardation, will he be okay by the time he is in high school? (T1A, lines 790-794).

Participants note that they are giving information that changes a family's perception of their child and changes their plans for the child. In being honest about the child's abilities, they risk anger and rejection from parents. Yet the ethical speech-language pathologist remains unwavering in her commitment to being honest. Participants think that in order for the child to be treated appropriately and to receive appropriate services, it is important for them to be honest when offering their assessment of the child's abilities, even when they encounter negative reactions.

Participants feel that being honest is a characteristic that could be assumed to be possessed by the ethical speech-language pathologist and to be central to interactions with others. Therefore, participants are not offering an expansion on what constitutes being honest in ethical practice beyond what is stated in the interview. Rather their concern shifts quickly to how to deliver on this commitment. Often the participants talk as if they are speaking with the parent, providing the text of how they would explain a diagnosis to a parent. Participants present practiced, considered responses to parents' important questions, as follows:

> I always ask what they think or I somehow frame it back. And again I try to answer with information based on what I know… [to] get them to sort of understand themselves what their child's rate of progress has been. And talk about what it is they need to be able to do next….I get asked a lot, "will he be able to go to a regular kindergarten?" I can usually say, "yes, they [*sic*] will be able to go to a regular kindergarten but in all likelihood your child is going to need some special help at least into the first few years of school and possibly after that. What do you think?" I always really try to find out what they are thinking. (T1A, lines 799-814).

At times, the very careful wording is aimed at allowing the parents to maintain their perspective while leaving open the opportunity to change their minds and not fear negative consequences for their child. Participants explained how they would say to the parent that:

> This is how we see your child's skills today. You know him better than we do, so you may have a different opinion. We suggest this [intervention] and you can try this [program] and if you change your mind, let us know and we can help you." (paraphrased and integrated T1A and T2A).

Though a commitment to being honest is evident as a characteristic of an ethical speech-language pathologist, it is, in the participants' views, intimately connected to the importance of another characteristic, that of being sensitive. This characteristic emphasis on *providing support* as the primary ethical action in clinical practice. Treatment therefore became only one of the ways in which ethical practice is enacted as support for the benefit of the child and his family. To illustrate this focus on *providing support*, one participant describes how providing treatment that is expected to make little or no difference in the child's communication status becomes an avenue to addressing the more crucial issue of assisting the family to adjust to the child's abilities:

> Even though in my head I know that this treatment isn't going to solve their speech problem, it's going to solve a completely different problem for that family which is a valid problem. And who else will take them to that point? This is their last hope. So if we don't do it there, they will search for [and] they will keep coming back to that. And how can they move on? So we are serving a purpose. Again it's more of a social purpose than a communicative purpose. But we are serving a purpose. (T8A, lines 771 -775).

From the participants' perspectives, *providing support*, as the primary ethical action, is aimed at preserving, strengthening, and facilitating the child's social relations within his family, and among important others in his wider community (e.g., peers and teachers at school, friends in the community). Responses other than direct treatment are deemed equally important to or more appropriate in the scheme of ethical practice than traditional notions of treatment intervention derived from a clinical practice framework. The core category *making a difference* whereby the child remains *part of his world* frames the ethical processes of *providing support.* Figure 4 offers a focused view of the clinical encounter in which ethical action occurs.

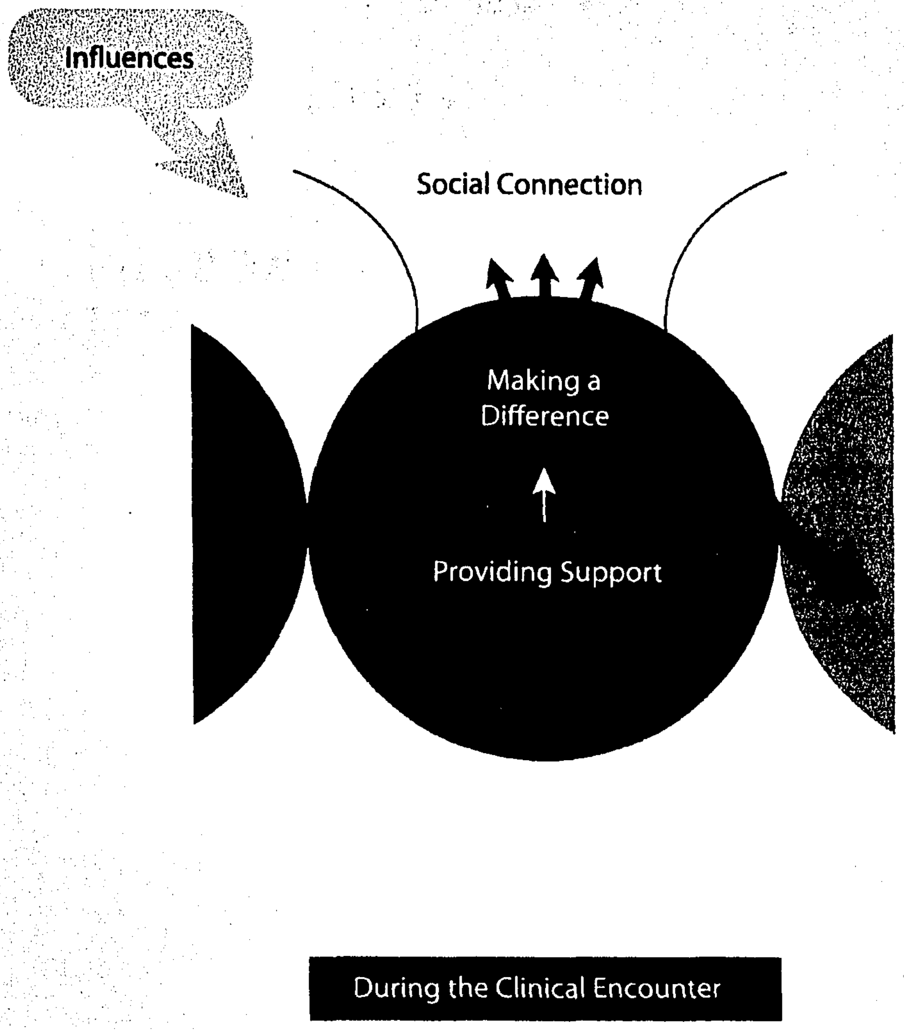

Figure 4 : Ethical Action

The actions that constitute *providing support* are multiple. Participants offer a wide range of activities that they engage in. Some actions meet basic needs in caring for vulnerable others. Such actions include creating a safe environment for the child away from the stresses associated with social circumstances. *Providing support* could also mean easing the parents' responsibilities by taking the lead for the child's intervention when the parent faces the challenges of illness, poverty, or abuse. Addressing immediate concerns, both formally, by engaging other professionals, and informally, by extending help in the moment, allows the ethical clinician the opportunity to *make a difference*. Participants offer:

> I think that when you work with an agency that serves the poor…, it really comes home to you every day. You know that, yeah, there's therapy and there's therapy. But you know what? Let the kid come in, feel safe, and play for an hour. Okay. That's it. And that's what makes a difference. (T10A, lines 585-589).
>
> Looking at different kind of ways to provide service to the family… so if the family seems to just have a lot going on and are unable to maybe follow up in the way we'd like them to, how else can that be done? Through an aide? Through the school? So looking at different resources that might be available. (T7A, lines 830-835).

Participants speak of the importance of providing support by fostering communities of parents with shared experiences. Participants emphasize the importance of listening to families and providing a place where parents can be with each other. One participant offers this example:

> These parents had never met anyone else in the same boat. And here they all are in the same room laughing about funny things their kids all did that are the

> same. And they are talking about their kids like they are kids. I loved that, you know. They aren't, they are in a group where their kids are truly peers. (T1A, lines 424-431).

Participants see that information sharing is an important form of support that contributes to the family's ability to assist their child in beneficial ways. Again, in the participants' view, it is important to be sensitive to the information needs of the particular family and not use scientific authority to present information. Instead, participants describe how they reframe scientific and clinical information to attend to the family's comfort level in terms of the complexity of information that they are seeking. They state:

> It's difficult. It's difficult because to say to a parent "well, research says this [and the] research says that". That frequently is not the best way to pass on information. So, I think the best is just to answer straight questions with real life examples. (T10A, lines 431-434).

> She really, really wants to spend a lot of time talking about what causes [communication disorder], and what's happening in the brain, and, she's studying in a medical profession and, I think, if... if this is ten years ago, even five years ago, I might try to re-direct her... [by saying to the parent] "well, this is what we need to do. We need to work on these skills... " And now... if she wants to spend half an hour and ask questions. And if ... her therapy is trying to understand [the communication disorder] more, then I'll provide [that].
>
> A theme that comes up regularly is hoping that ... maybe there is a medicine... there is some surgery.... The last time she was in I gave her all my articles that I have on... medication and said why don't you take a look at them. I told her one physician I knew in the States who is researching the area. And even though my inclination [is] that's way down the road.... we can't say.... here is this little area of the brain we're going to just [makes zapping noise]. But this is what she's interested in and so this is it. (T7A, lines 905-926).

By listening to parents, the speech-language pathologist develops a better understanding of their perspective and is in a position to deal sensitively when sharing information. At times, participants feel that ethical action in the form of support allows the parents to let go of perceived failures:

> ... if the family feels that they haven't done a good job and that's why their kid is going to have to have the tube, in the counseling around that why the kid's mouth is the way it is and it's got nothing to do with you as the mom, and you have proceeded longer than any one I know, and that many families would have given up before this. (T2A, lines 384-395).
>
> And when the child is still really young... they are thinking and kicking themselves that they didn't get in sooner when it is just [that] there really aren't a lot of agencies that can help... right now. And assuring them that what they have done is right. Because how many are just [saying] "oh, is he doing this because I thought of this when I was pregnant with him?" (T3A, lines 349-356).

Participants state that parents sometimes present misinformation to the clinician that interferes with their ability to make informed choices for their child. Participants emphasize the need to address misinformation in whatever form it arises in order to effectively support parents and children:

> [Teenagers who]...have either been hurt... in ...sporting or motor vehicle accidents and a lot of times they have not only this problem that we deal with...but they also have very severe dysarthria. And their breathing is all screwed up and, etcetera, etcetera. So, there [are] many things going on. And, a myth that I've been trying to debunk is, that if, and sometimes they're told this, that if they get this [names specific procedure], this is what they need, this is what's going to fix it for them....They come here with this idea that if they get this everything's going to be fine. (T8A, lines 604-617).

Another participant states:

> But sometimes a little knowledge is dangerous... And frequently, I would be talking to parents and they have a little knowledge, kind of pulled out, [participant pauses]... just from somewhere. Like, "oh, if my kid learns to sign he'll never learn to read. He'll never be a reader." Now, where did you get that? And, this is like a statement of fact. Now, where did [the parent] get that? I don't think it is off the Internet. But also, you can hear these things from other professionals who twist them around as well. You can read the tracts of Alexander Graham Bell or some statement from a parent that's [*sic*]come to the same conclusion and then that's the kind of shit that hits you at a vulnerable point and then she [the parent] hasn't got anything else to compare it to. (T10A, lines 405-423).

Providing support also includes acknowledging the family's efforts and, when the time is appropriate, celebrating their successes:

> I think you also want to give them some real acknowledgement for all the work that they have done to get the child to where he or she is at, too. I think [in] assessment, thanking the family and recognizing [that] to come here must have been such a daunting decision. To be put on the waiting list to say there is something wrong with my child; and to let them know they have done a *good* [italics added] job in coming here; and that they have done everything possible. (T3A, lines 341-349).

Participants pursue different avenues of *providing support* toward a variety of outcomes that are associated with *making a difference* for the children and their families. Again, their focus ultimately is on keeping the child *part of* his world. Family outcomes that they describe include: understanding the child's abilities and limitations, finding appropriate means for the child to communicate, accepting the child's limitations, and deciding for or against a course of action, and feeling able and empowered. One participant states, "Giving people, parents, or clients the confidence that they have the ability to make the changes. So, yes, I am making a difference." (T7A, lines 1382-1384).

For participants, ethical action involves *making a difference* even when it does not resolve the child's communication problem. Participants recognize that outcomes other than the clinically defined ones are often those which benefit the child and his family the most. In providing support, participants are open to the possibilities for outcomes that may not have been considered previously. In this way, ethical action aims to facilitate progress that reconciles the child's needs with those of his parents. A participant states:

> I guess I would be most committed to leaving a parent with something they could use that would be helpful to them. Not necessarily making their child any better but for them to leave feeling there is something they can do or there isn't anything they can do but now they understand why that is and so they feel comfortable... (T2A, lines 1136-1149).

In order to successfully provide support, participants note, they must maintain their focus on the family and the child, put aside any agenda that is counterproductive, and be knowledgeable, competent, and sensitive. Participants note that they are also flexible in order to support parents and their children "in ways they want". (T7A, line 939). For example, one participant states:

> What are the goals of the parents or the children and am I helping them to achieve those goals? I mean, for example, I have this one young man I work with who... [has] an extremely rapid rate. He has a very difficult time with self-monitoring. And I know that he can be fluent if I could just get him to do more prolongation and blending that's very hard for him to do... But for him what is most important is the three T's: Think what to say, take time to breathe, and

> talk…I see the potential for fluency but what is important to him?...So even though I say we could get him fluent but his goal is different. (T7A, lines 1405-1429).

Participants speak of exercising flexibility in thinking of a number of ways to make a difference that are respectful of family's wishes, though it sometimes occurs that the family's choice is not the speech-language pathologist's first choice. Therefore, in efforts to provide support, participants say that they sometimes encounter differences in how the family sees the child's difficulties and his potential, and what they see as appropriate intervention for their child. There may be differences in views on the diagnosis, the severity, and the prognosis as well as the proposed treatment plan.

In situations of disagreement or conflict, participants state that it is important to maintain their commitments: to be other focused, to value the child and his family, and to deal honestly and sensitively with differing viewpoints. These commitments sustain speech-language pathologists even though they may aspire to other goals. Participants emphasize the importance of keeping the parents engaged. They speak of the need to negotiate when possible and to remain engaged themselves in the process of arriving at common agreements with parents that benefit the child. They champion the child's interest by stating the speech-language pathology perspective. But participants note that they would not alienate the child's parents by forcing a particular intervention on them. Participants feel that the parents would distance themselves and their child if they feel misunderstood, undervalued, and disrespected.

Participants acknowledge that throughout the clinical encounter they are dealing with parents' hopes, dreams, and expectations. The challenges are to meet expectations where and when possible, to negotiate expectations when there are constraints, and to draw a line when called to stand firm, as when a proposed intervention clearly will not help the child in face of the parents' disappointment, anger, and despair. Participants note that the task of dealing with expectations necessarily brings them to supporting realistic expectations for the child. Participants use opportunities in the clinical encounter to educate parents about their child's abilities and challenges. Yet hope, participants offer, is a necessary component of intervention. Participants speak at length about hope as the following examples illustrate:

> I think [realistic expectations] would be the number one thing. There are families who ask for reviews three years down the road who are in because they believe in their hearts that their child is at a very different level. And you have to bring them back to what the realistic expectations are going to be. Maybe it has not been the most positive outcome for the family at first, but in terms of *the child* [italics added] and what too high expectations are, that would be very, very difficult. (T3A, lines 265-272).
>
> One of the kids is drinking all his Pediasure at three so he got his g-tube out but he isn't eating a regular diet at three…I expect he's going to have a good range. So I mean I try to ... 'cause otherwise, they're worrying ... They want the kid to go from where they are to completely normal in two months. And so, some of them start to cry when you talk about it in that way. I'm [saying], "I just don't want you to think that it's going to be that fast." (T2A, lines 453-481).
>
> I think …you can't destroy people's hope. You can't continue to live if you don't have some hope. So, focusing on small success, focusing on positive, [and] reinforcing the caregiver that they're doing a good job. (T7A, lines 1019-1025).
>
> I always really try to find out what they are thinking. It is not that I am chicken to say stuff. I just don't think it is helpful if you take away all their hope and give it nothing but grief to fill it up. (T1A, lines 813-817).

Providing support also involves respect for the family's decisions even when those decisions are controversial. Participants offer examples of the respect necessary when families made difficult and sometimes controversial choices. Respecting a parent's decision, participants note, may also involve a compromise of the speech-language pathologist's desired goals.

Some participants express ambivalence about situations in which other goals that would benefit the child are overlooked or put aside in favour of what they believe is adherence to the philosophy of family-centred practice. From their descriptions, the family-centred approach taken by many service agencies emerges as a consumer-driven approach to services for children. Participants note that service delivery models that claim to be family-centred are often infused with the potential for differences over intervention choices that are often resolved in favour of parent choice.

> And here's the numbers. ... This is where his development is on the development chart. And then I suggest that he would do better in focusing on visual communication. And the mom just pleads and says, "Can't we please try it again?" And I say, "Yep, I can." But I have told her...that the prognosis is not good, that he is not making progress and that it might be better for him, especially given his obvious intelligence, brightness, quickness of spirit, to move along. That's how I would put it....Well, she asks me. And we have a family-centred service. I mean, in this decade and maybe in the next decade, we are committed to working with our parents so..., I'm not in a position to say this is never going to [work]...and this is what I'm going to do. ...We do make recommendations but parents need to tell us what they want, too. (T10A, lines 356-377).

> So I mean, when is the parent right and when is the child right? And how cognitively impaired and ill and whatever does a child need to be before the rights of the parent supersede? (T2A, lines 326-328).

Conflicts also arise around decisions regarding distribution of limited therapy resources and appropriate levels of intervention. One participant describes how she explains the child's needs and the proposed intervention plan to the parent and then listens to the parent's point of view. However, should treatment not be indicated, her role is appropriately consultative only in light of the child's rate of progress. This is a common tension, particularly in the care of children with severe disabilities. The parent thinks it is unethical to deny her child treatment whereas the speech-language pathologist thinks it would be unethical to lead the parent to believe progress could be made with more hours of treatment. In these difficult circumstances, participants note how important it is to continue to engage with the parent, sometimes over an extended period of time, in order to help the parent develop an understanding of the child's limitations.

Participants also report that at times the parents' wishes are disregarded. When families move through different levels of the health care system or between the health care and education systems, they can experience conflicting levels of support for their plans for their child. Multiple interpretations of the family's wishes can arise. In some cases, the confusion can leave the family facing their worst choice. While family-centred intervention has its detractors, speech-language pathologists generally operate within its framework in organizations and agencies that have adopted this approach. Distress is experienced when the clinician sees the well considered decisions of parents overridden as the following participant noted:

> And that's how I look at this family who got the NG tube and didn't want it. This child looks beautiful all the time. Who are we to say? This is not a family that's abusing their child. This is a family that wants her to be the best she can be and this is how they believe they are going to make it. And after I gave them all of my information, who am I to say that they have made the wrong decision? (T2A, 1051-1060).

In the end, participants feel that ethical action focuses on providing support to the child and his parents that is respectful of the parents' choices within the scope of assisting the child to *be part of* his world. Only in instances where the child's physical health is in jeopardy, as with decisions in feeding and swallowing, do participants indicate that they must step in to claim a specific plan of action. However, in such instances, participants note that ethical action requires they remain attentive to the details of the family's context that may influence the decision-making. The following example illustrates this point:

> If there is a grandma that lives in that home that is from [names country] and is going to feed this kid no matter what anybody says and is the power figure in the home, we all have got to agree to that and we have to talk about this grandma and we have to say what are you willing to do differently? [The parents say], "Well, if we don't do what grandma wants she'll go back to [country] and we won't have any child care." [The speech-language pathologist responds], "Well, how much longer has she got? Only another two years? Oh, well, you know what? Maybe we should start working on this in two years." Like (sighs)... You don't say point blank, you have to start doing X, Y, and Z. There are no absolutes. (T2A, lines 931-944).

Participants also express frustration and regret surrounding situations where providing support is not realized. Lack of support for parents or for the child is noted following diagnosis as well as in planning and carrying out treatment. One participant comments, "When parents receive a diagnosis of autism, holy cow, do they ever need that emotional support. And it's just not there." (T4A, line 272). Further, another participant offers that situations where support is lacking are multiple:

> You look at something like the Latimer situation. Like, I've thought about that from an ethical point of view. Should this guy be in jail? I think it is too bad that he didn't feel that he had the support and that he had to kill her... I think the article that (name) and Dr. (name) wrote, I mean, we need to provide support to these families if they are going to live. (T2A, lines 1061-1070).
>
> I certainly get frustrated when kids come from a place where they're not going to get any support. Typically, those parents don't want the support and aren't seeking out the support and just think of you as a wasp in their hair that's just causing them more problems than not. (T2A, line 1027-1032).

Participants describe the ways in which they attempt to overcome lack of time and resources to ensure that support is available. Some actions taken by clinicians are directed in ways that could be interpreted as outside of conventional institutional solutions. However, from the participants' perspective, *providing support* is central to the work that they do with families of children with communication disorders. In pursuing support as ethical action, participants note that they will let the parents know where they can get support even if it is only minimal by their own standards and/or not in keeping with institutional rules:

> I know you won't get services for quite awhile, but why don't you try something like this and *call me* [italics added] and call me... That's not mandated. They have been discharged through those services. I maintain my own file. I guess I should put them through out-patient service, but these guys *need* [italics added] some kind of support until other things kick in. And the whole system sets you up so that at, boom, [funding] eligibility, we won't offer that kind of support. (T3A, lines 312-322).

> In our program, the mandate to enter is that you have to be [names criteria]. Now we have kids that come with a suspected hearing impairment, severe language delay, can't talk. We find out that they don't meet the criteria. Now, what do we do? Well, let's kick them out. That would be following the rules, right? And then, they have no place… to go besides [other program centre] and it's two months into the program that's already there. What is the best thing for this child? The best thing for this child is to stay in this group and get all this language stimulation, to come to speech with a speech pathologist for treatment every day. That's the best thing for this child. So, that, to me, is ethical practice. (T10A, lines 317-330).

In summary, ethical action aimed at providing support plays out in a range of options that participants feel are effective in achieving the overall purpose of fostering the child's ability to be part of his world. However, the complexity of individual situations means that the speech-language pathologist must judiciously balance a range of concerns that impact on the outcome sought. Ethical action, in order to be successful, requires that the speech-language pathologist attentively and sensitively engage with the family to realize the child's true potential.

Being reflective

For some participants, the conclusion of the clinical encounter is also the end of their contact with the parents and child. Generally, this would be the case when the encounter is a diagnostic one as in a clinic setting. For other participants, the clinical encounter is an event that is repeated as they progress with the family through a treatment program. For these participants, there are ongoing opportunities for providing support as the nature of the child's communication difficulty becomes more clearly defined, treatment progresses, or needs are altered in some way. Figure 5 presents the characteristic of being reflective during the period following the clinical encounter.

Doing one's best

For the participants, the conclusion of each clinical encounter prompts the ethical speech-language pathologist to ask, did I *do my best*? Being reflective involves a commitment to *doing one's best* expressed as a personal standard used to gauge the speech-language pathologist's efforts to make a difference for the child and his family. In assessing *doing my best*, the reflective clinician keeps in mind how she interacts with the family, whether or not she addresses their concerns, whether the information she provides is useful, and, where treatment is delivered, whether it is well planned and executed for the benefit of the child.

Participants feel that ethical practice involves offering the best of their knowledge, skills, and effort to affect positive outcomes for the family. *Doing my best* engages the characteristics described as constituent of the ethical speech-language pathologist. Therefore, *doing my best* means being other focused, honest, competent, knowing and sensitive. When circumstances are in the participants' view less than ideal, participants would still maintain a focus on excellence, as expressed in *doing my best*, in their work with families.

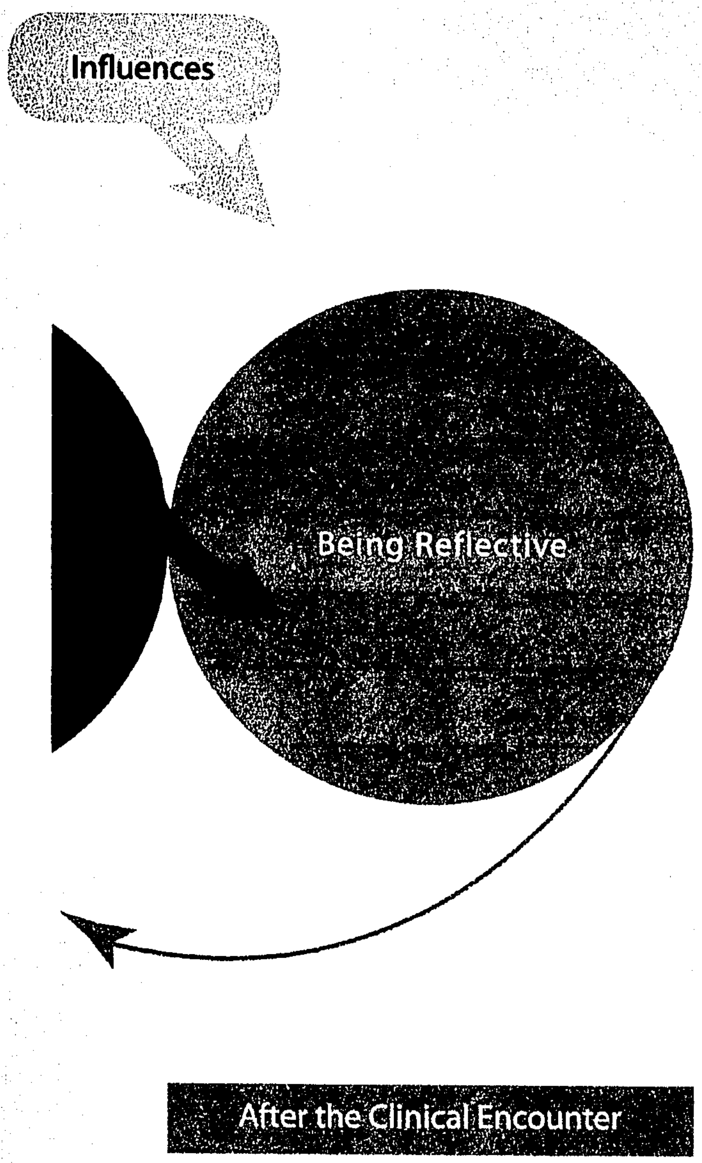

Figure 5 : Characteristic: Being Reflective

Doing my best also requires an understanding of the need for renewal and self care. Creating a balance described by one participant as "a fine line between wanting to do your best and burning yourself out" (T7A, line 882). She further states:

> Probably when I was a younger clinician wanting to do my best was really making sure I had my activities and I'd read everything. And now, wanting to do my best is I can probably improvise I think. When I feel like I've been successful, I feel like that child has some confidence. ((T7A, lines 887-889).

Participants comment that, though they may be pressed for time, being reflective- even briefly, helps them to be effective in subsequent encounters. Reflection, they offer, could be about the most recent encounter, other encounters, or the whole job. The ethical speech-language pathologist, they say, uses time alone or in dialogue with her clinical colleagues. One participant explains:

> At the end of the day... it is the team where we do the assessment together. [We ask ourselves], "So how do you think that went?" We are constantly evaluating what we could have done. (T3A, lines 448-450).

In this phase after the clinical encounter, participants express their worries, disappointments, and distress. Self-judgment and a sense of settling for less than desired outcome for each family are themes. Reflecting may be prompted by an encounter in which the parent appears unhappy or distressed or where the speech-language pathologist perceives that there are unmet needs or goals. In this way, reflecting is more encompassing than merely an assessment of the clinical aspects of the encounter. The ethical speech-language pathologist identifies those aspects of the encounter that she could modify toward achieving a better outcome for the child and family.

Reflecting is also seen as a source of learning about one's self as a professional or about others in their various roles in the clinical encounter. Participants are able to articulate the various roles and scripts that are developed over time and achieved as a result of reflecting on clinical encounters. In this way, being reflective about clinical encounters allowed the speech-language pathologist to develop a meta-knowledge referred to earlier as the characteristic of knowing.

The period following the encounter in which reflecting can occur also leads to planning for the future and for professional growth. This period of time offers a positive outlook on one's practice. Participants feel that being reflective provides the opportunity to ask questions that could advance practice. One participant offers encouragement to her colleagues as follows:

> ...if you see it working clinically get together those little research things that you might have going on and, and tell us about it. *Tell us about it* [italics added]...Our field will never advance if we don't start doing those things. (T8A, lines 1068-1075).

Summary

Ethical practice, according to participants, comprises characteristics of the speech-language pathologist as well as right actions. Participants offered a detailed understanding of how ethical practice is enacted which outlines the components constituting ethical practice in this area of health care. One participant sums up her view of ethical practice with the following words that reflect the major themes in this account of ethical practice in paediatric speech-language pathology:

> Have an open mind. Treat people with respect, families and colleagues. Assume everyone is doing their best with what they've been dealt. And then try to help them move forward in whatever your role is and help them have a better life because of something that you are able to contribute. (T2A, lines 1426-1430).

CHAPTER 5: DISCUSSION

This study developed an account of ethical practice in paediatric speech-language pathology from the perspective of practicing clinicians. Health care ethics is a field of inquiry that offers many understandings as the basis for ethical practice. While health care ethicists and their colleagues in the various health care disciplines debate and challenge the usefulness of any given theory at a practice level, participants in this study reflect understandings that are shared by other health care professionals who are concerned with practicing ethically. My task was to examine and describe the phenomenon of good practice that the participants offer as synonymous with ethical practice in paediatric speech-language pathology.

I will begin with a summary of the ethical practice model developed followed by a brief description of the current trend in ethics discussions in speech-language pathology. The results of this study will be highlighted in contrast to the prevailing professional discourse. In order to situate the results in the broader context of ethics in health care professions, literature from nursing will be introduced to situate the study findings in relation to the trends that are more broadly evident in contemporary discourses on ethics in health care professions. Study limitations will be outlined. Then implications for the practice of speech-language pathology will be discussed. Finally, future directions for research in ethical practice in the profession of speech-language pathology will be explored.

In order to assist in understanding study findings, the detailed discussion of findings that follows will employ, where appropriate, literature from the field of nursing. Though both medicine and nursing have attended to ethics and ethical practice in their respective fields with significant bodies of literature available in each, nursing is chosen for the purpose of comparison with speech-language pathology for the following reasons.

First, both nurses and speech-language pathologists occupy similar positions in the health care hierarchy in that they generally are employees of the system. As employees, nurses and speech-language pathologists will have duties both to their patients and to their employers. While clinical decision-making is generally less physician-directed in the case of speech-language pathologists, other decisions, such as administrative and budgetary decisions, are similarly not within the purview of either nurses or speech-language pathologists. Additionally, nurses and speech-language pathologists share similar varieties of practice contexts. Both nurses and speech-language pathologists practice in a variety of settings where they may be members of a team or function independently to deliver health care services. Finally, both professions are predominately female.

In comparing this study involving speech-language pathologists to the literature in nursing ethics, we find familiar themes emerge. Speech-language pathologists, like nurses, attend to context, focus on the relationship with the client and his family, recognize ethics as embedded in notions of good practice, and use everyday language to describe the ethical dimension of their clinical work. Speech-language pathologists and nurses know that their knowledge is more than the sum of the technical and skill sets they possess. Finally, nursing as a profession offers speech-language pathology an opportunity to consider how to engage with the various perspectives in the field of health care ethics as well as how to facilitate growth and change in ethical dimension of clinical practice.

Ethical practice in paediatric speech-language pathology

From their positions as clinicians in the field of communication disorders, participants are able to offer that ethical practice is concerned with making a difference that ensures that children with communication and related disorders remain *socially connected*. This clearly articulated core category encompasses the central and unique aim of this group of health care professionals.

Ethical practice, in the view of participants, takes place in the context of the speech-language pathologist's relationship with the child and his parents. Thus the clinical encounter becomes foremost in the minds of participants as the focus of relationship development for the overall aim of achieving *social connection.*

Further, to practice ethically, the speech-language pathologist must possess the characteristics of being other-focused, competent, knowing, honest, sensitive, and reflective. The ethical speech-language pathologist values the child and strives to do her best for the child and his family.

With the guidance provided by a clearly articulated core category, ethical action is centrally defined as providing support. Doing what is right involves a range of actions that are not just specific clinical activities. Before, during, and following the clinical encounter, the ethical clinician remains focused on rallying all resources to the aim of fostering *social connection* between the child and important others.

Facing constraints, the ethical speech-language pathologist remains committed to her goals while seeking creative solutions to challenging situations. A well articulated model of ethical practice for the field of paediatric speech-language pathology provides validation for practicing clinicians and a common source from which to expand dialogue on ethical practice.

Current framework for ethics in speech-language pathology

The ethical practice model presented can be set against the current discourse in the literature in speech-language pathology. As noted in the review of the literature, speech-language pathology has focused primarily on ethical decision-making models, using examples from clinical practice, to educate members. These decision-making models incorporate the bioethical principles outlined by Beauchamp and Childress (1994) to provide a process framework for dealing with difficult ethical situations.

In addition to educating professionals in communication disorders about ethical decision-making, professional associations in Canada and the United States provide guidance on interpreting the various provisions of the codes of ethics. The format of these publications, which appear in the professional associations' newsletters, is to present a situation that calls for an interpretation of one of the code's "Ethical Principles".

The available literature and publications of the professional association present a focus on the principle-centred approach. Whereas other health care professions, such as nursing, have been critical of this approach and have sought alternative approaches, speech-language pathology has not yet moved in that direction. Yet a careful read of Eadie and Charland (2005) reveals an awareness of some elements that are reflected in my study's model of ethical practice. They touch briefly on the notion of social connectedness in their statement regarding the clinical case example in their article by stating, "In the brief case study of Maria, we encountered the longing for human connection…" (Eadie and Charland, p.28). Further, they suggest that moral obligations are derived from the relationship between the clinician and the client. Unfortunately, the authors do not expand on these notions but instead quickly return to their exposition of the familiar four principles in relation to the various codes and regulations governing speech-language pathology practice.

The one exception to the predominance of the four-principle approach is a short article that I wrote for *Communiqué*, the publication of the Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA), in which I outlined the now familiar concerns about the principle driven approaches to ethical decision-making (Stewart, 2003).

The principle centred approach that dominates ethics discussion in speech-language pathology offers a framework and process for ethical decision-making. However, given its incompleteness and indeterminancy, this approach alone is unsatisfactory as it lacks the specific content that speech-language pathologists seek. In order to fully appreciate the ethical dimension of speech-language pathology, a more critical stance toward principlism and a widened view that includes contributions from other approaches to ethics in health care professions is necessary. Ethical practice, in the view of participants in this study, involves a more detailed engagement with the principles as well as with other perspectives in the field of health care ethics. In this way, the focus and content of the discourse on ethical practice is expanded with input from clinicians in the field.

Study participants offer an account of ethical practice that is more attuned to their understandings of the context of service delivery, to the centrality of the clinician's relationship with the child and his parents, and to the characteristics and influences that shape their notions of how they ought to treat persons served. From this we see that the emerging model of ethical practice in paediatric speech-language pathology contains elements of ethical perspectives that have influenced the overall understanding of ethics in health care practice.

Principlism

In the participants' expression of ethical practice, the underlying principles remain as guideposts attesting to the significant influence of Beauchamp and

Childress' contribution throughout the field of healthcare ethics. Participants offer details that demonstrate how these principles play out in the context of speech-language pathology practice. In this way, participants present a multilayered interpretation of the guiding principles that is embedded in what they feel is good clinical practice. Each of the principles is reflected in the accounts of ethical practice.

Beneficence

As with other health care professionals, speech-language pathologists are guided by beneficence. Participants describe how they direct their efforts to the promotion of a distinct version of the good. Their perspective reveals an elaboration of the stated purpose, or the good pursued, of speech-language pathology which is to alleviate human communication disorders. Participants emphasize that the overall aim in paediatric speech-language pathology is to maintain and promote the child's ability to be part of his social world through communication.

In considering the nature of human communication disorders, we find that while a host of disorders that speech-language pathologists treat are neurobiological in origin, the treatment focus is on the functional consequences that present as cognitive, social, and behavioural phenomena. Speech-language pathologists, participants state, employ their knowledge of human communication disorders and their technical expertise to eliminate or reduce the impact of a disorder's characteristics that mark the child as different from others, risking diminished social value, and reduced opportunities for social interaction in circumstances that may extend well into adult life. Participants are very clear on this. Throughout the range of human communication disorders from mild disorders of articulation and phonology to severe disorders including autism, participants voice their concern about the impact of the communication disorder on social connectedness.

The participants' commitment to a good that is defined in terms of pursuing social connectedness is perhaps most clearly stated in situations they describe in which conventional symbolic communication (i.e., verbal or sign language) is precluded by severe communication disability such as traumatic brain injury or severe autism. Even in the absence of the potential for conventional symbolic communication in such cases, participants state that they would direct their efforts to establishing a social connection with others through the use of intentional nonverbal behaviours that would support the child's ability to socially connect with others. In extreme cases, speech-language pathologists seek to develop unintentional behaviors that stand in for rudimentary communication as a means for the child so that his intimate relationship with his family could be established.

It is significant that study participants maintain their focus on fostering the child's ability to be part of his social world when the topic of their discussion is feeding and swallowing disorders. In feeding and swallowing, participants note that the ethical speech-language pathologist attends not only to the mechanics of how the child will receive his nutrition but also to the social communicative aspects of the family mealtime routine. This includes the impact of the child's feeding disorder on family gatherings and social events such as birthday parties and holidays, where sharing a meal with others forms bonds of community. The case of feeding and swallowing disorders is illustrative of the strength of the commitment participants feel to fostering communication for social connection. It emphasizes their worry about the consequences of failed efforts that results in social isolation for not only the child but his family as well.

Thus, speech-language pathologists in this study hold a social connectedness focus that means that their efforts to assist the child to make relationships with others employ communication skills as both the means to achieve the end and the end itself. This is also why the child's parents and significant others are integral to the speech-language pathologist's concern. Without responsive communication partners who receive the child's signals as they are intended, all social connectedness is lost. The ethical speech-language pathologist, as described by participants, is one who recognizes the need for engagement with the child's important partners. The commitment to fostering social connectedness as conveyed in the expressions of *being part of* also accounts for the commitment to pursuing the many avenues of support constituent of ethical action in speech-language pathology.

In defining good to be pursued in this distinct way, speech-language pathologists in this study make an important contribution to the profession's understanding of the larger scope of its mission. By acknowledging the enlarged focus of speech-language pathologists' efforts, as did these participants, all efforts that foster social connectedness will contribute to the child's well-being. In comparing this result with similar efforts to define the good elsewhere in health care professions, the uniqueness of each profession's mission in the larger scope of health care can be staked out. For example, nursing, the profession chosen for comparison, places care at the centre of its focus (Fry, 1989; Gadow, 1990; Noddings, 1984). Much has been written, researched, and debated about care as a guiding value in nursing. However, care, though contested, remains as a central tenet of nursing practice.

Nonmaleficence

Each health care profession needs to work out what harm means in the delivery of their particular health care service. With beneficence defined in terms of fostering social connectedness, it follows that harm in the practice of speech-language pathology is revealed when that connectedness is interfered with. While participants recognize the potential physical harms that can be incurred in particular areas of practice, notably in feeding and swallowing, they are also cognizant of harm that could be imparted if the clinician did not attend to the social connectedness between the child and important others in his life. In this way, participants are particularly worried about the harm they feel is caused when a clinician supports unrealistic expectations or pursues unrealistic goals that are detrimental to the child's communication growth and would ultimately interfere with his ability to connect with others. In defining harm in this way, participants are identifying one of the important tensions they face in clinical practice. Participants feel the strain between their version of doing good and avoiding harm for the child and the child's parents' version of these concepts.

Parental autonomy

The principle of respect for autonomy the foundation for the obligations of health care professionals to honour the decision-making capacity of competent adults in health care matters. Strictly speaking, this principle is not applicable to the clinical encounter in which speech-language pathologists find themselves working with families of young children. In paediatric speech-language pathology, as in other areas of paediatric health care, the child is not considered an autonomous agent. Therefore, the child's parents are accorded decision-making authority on their child's behalf. Participants see parents as natural decision makers for their children. Working within the framework of family-centred care, speech-language pathologists in this study recognize the need to respect parental decisions.

The ethical clinician, they note, would skillfully engage with the family in order to understand their perspective and to craft interventions for their child that respect the autonomy of the family as a whole. Speech-language pathologists are able to respect parental choices if they feel the choice contributes in some way to the child's progress. Given that there is usually a range of good options available for pursuing goals for the child, participants note respecting parental decisions is unproblematic when parent and child interests are congruent.

Participants become concerned about their ability to respect parental decisions when the parents' choice does not accord with the child's needs, abilities, or potential or when they feel parental choices are not informed. While participants are willing to assist parents by counseling and educating them about their child's communication disorder, they do not feel they can support unrealistic goals for the child over the long term.

Paediatric speech-language pathology is not different from other areas in paediatric health care in this regard. Public health nurses in a study by Oberle and Tenove (2000) similarly expressed their concern in dealing with children in families they served. In deliberating over the parent's decision, public health nurses feel challenged about interfering in family dynamics or imposing potential cultural biases. Speech-language pathologists also recognize this challenge as one of balancing the concerns of family members within the family context. Yet participants express ambivalence about a family-centred ideology, embraced in many service contexts, that seemingly promotes the parents' cherished goals despite what the clinician feels is indicated for the child. Participants are left questioning the role of expert knowledge and their ability to realize the aim of social connectedness for the child.

Participants are dissatisfied with this outcome but remained committed to upholding the parents' right to decide for their child. Thus, participants feel that they reach an impasse in their efforts to respect parental autonomy.

Participants also express distress over situations where other health care professionals do not respect parents' informed and often difficult, decisions. This is particularly true in extreme situations involving children with severe neurological disabilities.

Distributive Justice

Participants ably describe the constraints in publicly funded systems of health care and education, but feel that they are not able to address issues of priority setting, limitations, and fairness at the system level. The scope of speech and language services and distribution are decided at the systems level. Participants in this study are engaged in clinical service and therefore are not in positions that facilitate decision-making at the facility or system level. Therefore, it is not surprising that study participants speak of crafting solutions to the limits on their time and resources at a clinic level.

Where participants feel most particularly distressed is when they are called upon to defend decisions made by other health care professionals or by administration. Participants, as employees, feel that they have to defend these decisions to families while experiencing anguish over their inability to effect what they see as necessary change. As with other health care professionals, speech-language pathologists in this study experience the stress of meeting competing obligations to the public as custodians of speech and language services and as advocates for individual children and their families. Participants describe working within the limits imposed on their practice, as having their "hands tied". In this regard, nursing offers a framework for understanding these various challenges in terms of moral distress (Jameton, 1984; Rodney, 1988).

Summary

In summary, study participants are able to describe ethical practice in ways that reflect the underlying principles discussed. Their offerings provide some depth to how the principles are used as guides for ethical practice in speech-language pathology while also opening up the possibility of further examination of other influences from health care ethics.

Virtue ethics

As can be seen, the familiar ethical principles of health care practice provide only a partial account of what study participants included in their understanding of ethical practice in speech-language pathology. Participants see ethical practice as comprising not just right actions but also particular characteristics of the clinician including being other-focused, honest, competent, knowing, sensitive, and reflective. These characteristics, thought to be developed in the ethical clinician through experiences both personal and professional, are brought to the clinical encounter. By shifting from action to include characteristics as well, participants open up another aspect of ethical practice that has not yet received attention in speech-language pathology.

In focusing on the character traits of the ethical speech-language pathologist, participants in this study introduce the notion that the ethical speech-language pathologist be honest, competent, knowing, sensitive, and reflective, and that she would value the persons being served. The speech-language pathology participants in this study are not alone in the view that character traits of the health care professional have ethical importance. Perspectives from virtue ethics have entered the field of health care ethics where the character of the health care provider is seen as deserving of our attention (Pellegrino and Thomasma, 1993; Sellman, 2000).

Virtue ethics offers that a habit or disposition predisposes a person to act in a certain way. Virtues such as honesty are seen as tied to the aims of the practice community. Therefore, a strong understanding of purpose of a particular practice brings into view traits which are to be promoted. The promoted virtues guide members of a practice community to whom they should aspire to become.

The particular cluster of character traits identified as being associated with the ethical speech-language pathologist is not unique and other groupings can reasonably be expected to exemplify those health care providers who work specifically in paediatrics or in related areas in rehabilitation medicine involving children with disabilities. The character traits put forth by participants may represent only a partial list of traits that warrant further exploration. Virtue theory itself does not lay out which character traits are necessary for the health care provider to be termed a virtuous clinician. In fact, in the nursing literature there appear to be numerous candidates including competence, sensitivity, advocacy, and caring (Bishop and Scudder, 2001).

Perspectives from nursing

Principles and virtues provide useful theoretical guides to the underpinnings of the ethical practice model but do not fully capture its workings. By adding nursing perspectives, the components of the ethical practice model for paediatric speech-language pathology come into view.

Participants focus on other elements necessary for ethical practice as evidenced in the ethical practice model. Participants point to the importance of context and relationships as components of ethical practice. In order to understand these and other aspects of the ethical practice model, study findings will be more closely compared to the nursing literature in the following sections.

Everyday nature of ethical practice

Participants focus on the everyday nature of ethical practice. Principles assist in overtly deliberating dilemmas. But as participants point out, there are few occasions in their clinical practice in paediatric speech-language pathology where hard choices must be made. This leaves a vast terrain of everyday concerns that does not recognizably fall under the rubric of the familiar ethical decision-making frameworks. What I learned from participants is that most of their experience of ethical practice is in everyday clinical encounters. These participants see ethics not just in cases or episodes but in all aspects of practice; as a way of doing practice and as a way of being the sort of clinician who attends to each family. Their decision-making does not involve explicit reasoning. Rather, they act in ways that are consistent with the guiding principles and they do so in a spontaneous but reflective manner. The idea of the everyday nature of ethical practice is not new. Nursing has recognized in a variety of aspects of practice that ethics is in the everyday situations that nurses encounter (MacPhail, 1997; Oberle and Tenove, 2000).

Moral language

Just as ethical practice becomes intertwined with good practice in everyday clinical encounters, moral language, not surprisingly, is expressed in everyday language. Like their counterparts in nursing, speech-language pathology participants are able to provide ample descriptions of what they consider ethical practice using language familiar to them. The language of good practice is representative of the language of ethical practice. In fact, one participant stated how much easier she finds using everyday language to describe ethical practice than the language she had been exposed to in ethics education workshops. The implication for communicating with speech-language pathologists about ethical practice is that the connection between good and ethical practice will be more apparent to clinicians when everyday language is used. Speech-language pathologists and nurses appear to share many common approaches to thinking and speaking about ethical practice.

Focus on relationships

Study participants emphasize the centrality of their relationship with the child and his family to their definition of ethical practice. The core element in the participants' conception of ethical practice is the idea that relationships are integral to the central purpose of fostering human connectedness through communication. The clinical relationship marks the sphere of concern for enactment of ethical practice. In this regard, speech-language pathologists and nurses continue to intersect in aspects of their conceptions of ethical practice.

Nurses have recognized the relational nature of their practice (Bishop and Scudder, 2001). In their departure from a rationalistic perspective on health care ethics, proponents of nursing perspectives on ethics emphasize the critical importance the relational aspect of ethical practice (Fry, 1989; Gadow, 1990, 1999) Nursing theorists suggest that a moral attentiveness is developed that allows the clinician to deal with the unique characteristics of the persons involved and of the situation in which health care is to be delivered. In this regard, speech-language pathology participants understand that personal and contextual features potentially transform clinical situations. They are attentive to personal narratives in their moral considerations as they patiently sift through the details of families' stories to arrive at a deeper understanding of their concerns, priorities, and resources.

Participants acknowledge that the child and family are bound together by affection and responsibility. Throughout their descriptions of ethical practice, participants emphasize the myriad ways in which they seek to foster, nurture, and sustain the relationships between the child with a communication disorder and his family. More specifically, where the child is significantly disabled, participants understand that the relationship between parent and child is best seen as involving asymmetrical reciprocity (Young,1997) in which the parent will always carry an unequal responsibility for communication exchanges.

Further to the notion of the relational nature of clinical practice, Oberle and Tenove (2000) in their study of ethical issues in the public health setting, noted that public health nurses identified their clients' participation in health care as voluntary. The voluntary nature of the relationship, nurses noted, implied that the client could, at any time, discontinue or disengage. This observation by nurses holds importance for speech-language pathologists who also recognized the element of voluntary participation in the families served. As with nurses, speech-language pathologists, as noted, described the imperative to develop their relationship with the family in order to achieve the aim of making a difference.

However, speech-language pathologists have a slightly different focus than nurses regarding the creation and maintenance of the relationship with the parents and child. For speech-language pathologists, the relationship is also critical for the child's communication development. Facilitating positive change for the child often involves coaching the parent in adopting particular interaction styles. Given that certain interaction styles are known to enhance both the opportunities for communication and the actual development of speech and language skills, it is critical that the speech-language pathologist first attend to her relationship with the parents in order to establish a working relationship so that she can sensitively introduce changes to the parent-child interaction. Participants note that such sensitivity to the relationship is heightened when they are recommending changes to cultural or social interaction patterns.

Knowing

Participants separate competence from less formally defined ideas about knowing. Therefore, participants speak of "knowing" in the sense that the ethical speech-language pathologist possesses a type of informal knowledge characterized by a meta-knowledge about the clinical encounter and the interaction between the clinician and the family. Participants note that general patterns repeatedly occur in clinical encounters.

Unlike nursing, speech-language pathology as a field of health care practice does not presently have a research base that provides insight into more philosophical notions of practice regarding competence and clinical knowledge. As a relatively newer health care profession, attention to such aspects of the profession itself has not been connected to examination of ethical concerns. Therefore, competence is understood generally in the way study participants reveal. However, a focus on skill sets, standards of practice, and guidelines does not capture the informal knowledge participants feel is part of ethical practice. Participants' version of "knowing" reflects knowing what is going on, what to do (including what not to do), when to proceed and when to pull back, and how to make a difference. Their version prompts consideration of broader aspects of clinical knowledge that speech-language pathologists have yet to investigate.

In contrast, many aspects of nursing practice have been extensively investigated (Benner, 1984; Bishop and Scudder, 2001). For example, the elements of knowing described by study participants approximate those proposed by Oberle and Allen (2001) who described the knowledge engaged by nurses exemplified by common terms such as "know how, know what, know why, and know who." Practical wisdom allows the nurse to move from the general to the specific when attending to the family's concern. Similarly, speech-language pathology participants describe the element of experience that guides determination of know how as noted in the nursing example. Additionally, Oberle and Allan offer the notion of practical wisdom derived from Aristotle and articulated by Lauder (cited in Oberle and Allen, 2001). In their interpretation, practical wisdom in nursing practice informs the actions taken. Speech-language pathologists similarly spoke of the content, form, and use of an action aimed at assisting the other to achieve his or her aims. Therefore, the idea of practical wisdom is a novel and worthwhile notion for speech-language pathologists to explore further as a component of ethical practice.

Context

In the model of ethical practice in speech-language pathology, ethical action is framed by the context in which the action is to occur. Attention to context is thought of by participants in a number of ways. First, context refers to the health care and education systems in which practice is carried out. In referring to context in this sense, speech-language pathologists express concerns about resource limitations impacting their ability to realize goals for the client family. The constraints imposed by policies and mandates leave many participants feeling that their "hands are tied". Other participants, recognizing the constraints, nonetheless seek creative solutions at the clinical level that bypass the constraints.

Speech-language pathologists voice concerns about system constraints that are echoed by nurses from a variety of settings (Austin, Bergum, Goldberg, 2003; MacPhail, 1997; Oberle and Tenove, 2000; Pauly, 2004). In this regard, nurses share with speech-language pathologists the concern about how to use their clinical time and resources to the betterment of those served. Like nurses, speech-language pathologists are worried about how limitations impact their ability to do their best to provide a level of service that reflects best practice. Speech-language pathologists are, at times, distressed by their inability to control caseloads in agencies that have restrictive policies regarding who will be served and how clinical resources will be distributed. As with nurses, speech-language pathologists recognize their limited ability to influence systems-level decisions despite attempts to inform authorities regarding outcomes and practice standards.

Another aspect of context brought forth by participants concerns the social, cultural, and economic influences on individual families. In this regard, ethical practice in speech-language pathology is attentive to the notion of relational autonomy offered by Sherwin (1998). In dealing with families from a variety of backgrounds, participants are aware of the complex interplay of these factors in shaping the lives of families served. Participants speak sensitively of adjusting their practice in consideration of these contexts. The ethical speech-language pathologist, participants note, adjusts the level and intensity of intervention to attend to the situation of the family in order to approximate a goodness of fit between characteristics of the family, the context, and the action. This attention to the complexity of the clinical encounter as well as the attention to broader influences on families is documented in the nursing literature as well. Nurses have recognized that dealing with complexity is endemic to clinical practice (Benner, 1984; Bishop and Scudder, 2001). Therefore, ethical practice in both speech-language pathology and nursing calls upon the clinician to be attentive and to sensitively seek interventions that engage with the complexity of clinical encounters.

Participants in this study also recognize that in the context of health care and education they hold positions of relative power over families seeking their service. They demonstrate an understanding of power in recognizing that they name the child's problem and define and deploy a response. Participants recognize how controversial topics such as poverty and able-ism affected families served and were against inappropriate use of knowledge and positions to exercise power over others. Again, parallels can be drawn to nursing where nurses have voiced their concerns about such issues (Varcoe, 2004).

Attention to context also brings forth sensitivity to meanings. Speech-language pathology participants note that their sensitivity attunes them to how people are embedded in a social milieu that has symbolic characteristics. The critical importance of attending to meanings is most particularly felt by participants working in the areas of feeding and swallowing and deafness, but is also mentioned by others more generally in thinking about the meaning of disability for families and communities. Nurses have similarly been documented to be attentive to the meanings that ill-health hold for persons in their care and to the implications such meanings have for choices and outcomes in health care (Oberle and Allen, 2001).

Overall, speech-language pathologists, like their counterparts in nursing, attend to the complexities of the contexts in which clinical practice occurs. Despite the challenge, they wish to preserve and engage the complexity that is inherent in health care encounters in ethical practice.

Summary

Study findings are able to demonstrate similarities between speech-language pathology and nursing. Nursing ethics is a vast field with well developed theories and conceptualizations of ethical practice. Nursing has benefited from sustained interest, both in theory development and empirical study, in the ethical dimension of clinical work.

From their initial dissatisfaction with principle centred approaches, nurses are able to demonstrate the inadequacies of rationalistic accounts of ethics in addressing the complex nature of health care practice. Their response to the shortfalls in the dominant approaches led them to develop several avenues of exploration including the development of specific nursing ethics theories that moved in the direction of "a humanistic philosophy of nursing" (Lamb, p.31) focusing on the nurse-patient relationship. As Storch (2004) notes, advances in the field of nursing ethics have led the field to distinguish itself as separate from bioethics and medical ethics though these previous influences are still evident.

Newer contributions to nursing ethics have adopted a postmodern perspective (Benner, 2000; Gadow, 1999) that explores meaning and enactment in ethical nursing practice. Narrative approaches have moved to the forefront (Skott, 2001; 2002). Taking the view that nursing is a socially mediated process, interest has also moved in the direction of addressing the sociocultural and political context of contemporary health care (Doane, 2002). Nursing theorists have also challenged notions of ethical practice that are derived from conceptions of nursing as a profession noting that such notions shift over time in response to changing social environments (Liaschenko and Peter, 2004). This brief overview highlights the vigorous and challenging nursing literature that awaits speech-language pathologists interested in exploring ethical practice.

Whereas nurses voiced their dissatisfaction with the dominant principle centred approach in health care ethics by pointing out how their work is relational and contextual, speech-language pathologists, to date, have not. However, my findings suggest that speech-language pathologists agree with nurses' concerns. Participants' voices speak to the lack of depth in current offerings in speech-language pathology and a call for a more fully engaged discussion about ethical practice. That the notions of ethical practice developed from the participants' perspective are not entirely captured by principlism suggests a willingness to consider a wider range of perspectives from health care ethics than currently reflected in literature in speech-language pathology. This readiness to expand their understanding of ethical practice is reflected in the elements of the ethical practice model developed from their perspectives.

Study limitations

The extended time line of the study is a concern. However, I took steps to ensure continuity in the pursuit of developing a grounded theory using the available resources. However, it remains possible that the level of abstraction sought is not evidenced in my final conceptualization of ethical practice due to the extended research period.

Missing from my initial frame and subsequent sampling are speech-language pathologists who held primarily administrative positions. There are few such administrators as often service delivery is organized more centrally with psychologists, teachers, or professional health care administrators in lead roles. However, where speech-language pathologists do hold administrative positions, the duties and responsibilities to the organization may hold the potential for differing views on certain aspects of ethical practice. For example, given the pressures of serving more children with fewer clinical resources, it may have been instructive to have heard from speech-language pathologists in administrative positions.

Similarly, speech-language pathologists who held positions in professional organizations or regulating bodies are not participants. In both volunteer and paid positions, such speech-language pathologists would have specific responsibilities and experience that may have enriched the ethical practice model.

Implications and future directions

This study offered a description of ethical practice in paediatric speech-language pathology from the point of view of clinicians in the field. As such it provides a descriptive base that serves further investigation of ethical practice. As a preliminary study in speech-language pathology, this study opens up several avenues for future investigation.

As outlined earlier, nursing has made unique contributions to our understanding of ethical health care practice. How did nursing achieve this? It would be tempting to attribute their success to their numbers. While it is true that there are significantly more nurses, nurse researchers took a key action that I propose contributed to the development of ethics as a topic of inquiry in nursing. Nursing turned to its members as a resource for their exploration of ethics. Nursing researchers listened to practicing nurses in order to establish an empirical base and promote the conceptualization that led to theories of nursing ethics. Nursing benefited immensely from the narratives brought forth by its members.

Speech-language pathology has the opportunity to do the same. My study demonstrates the willingness of speech-language pathologists to discuss ethics and ethical practice and to open up exploration of the ethical dimension of clinical work. Therefore, an untapped capacity exists in speech-language pathology. Largely, the interest in stories in speech-language pathology is reserved for a focus on the experience of persons served. For example, case studies and interview studies offer insights of persons with stuttering (St. Louis, 2001). Studies such as these have made important contributions to our understanding of human communication disorders. Yet their focus remains exclusively on the client or the client's family members. The experience of the speech-language pathologist working with patients with communication disorders remains invisible and therefore inaccessible to other speech-language pathologists.

The feedback from participants and audiences of speech-language pathologists attests to the keen interest in hearing colleagues' stories. Therefore, my research also served a more intimate purpose for speech-language pathologists in that for the first time they are provided with an opportunity to articulate their own vision for ethical practice. As I was able to take the results to professional meetings and conferences, I encountered other speech-language pathologists who expressed their gratitude for the opportunity to hear their colleagues and to find resonance with their own understanding of what it meant to practice ethically and to be an ethical speech-language pathologist. In a small profession such as speech-language pathology, the opportunity to connect and validate is especially important.

By opening up opportunities for speech-language pathologists to tell their stories, we can develop a better understanding of specific aspects of ethical practice in speech-language pathology that this study highlights. For example, following nursing, we can further explore notions about who the ethical speech-language pathologist is. Using nursing research on moral identity (Doane, 2002), we can develop a deeper understanding of the work of fostering connectedness in children (and adults) with communication disorders. Further, with ethical action defined as providing support, we can explore moral agency in speech-language pathology.

Given the importance of contextualization to the ethical practice model, we can draw from nursing in our effort to situate ourselves with our clients and their families in the broader landscape of health care. We can examine the forces that shape the moral climate in which we practice. We can begin on a small scale engaging our colleagues, health care teams, and families.

One of the challenges I faced in pursuing this research was the lack of previous empirical research on the topic in speech-language pathology that would allow the results to be compared and contested. Therefore, suitable comparisons were sought in nursing where research in ethical practice is more established. One of the benefits derived from this comparison to nursing is to link speech-language pathology to the broader discourse on ethics in health care. The positive comparisons evidenced made speech-language pathology less isolated and lent legitimacy to speech-language pathologists' ethical concerns. Future collaborative research might lead to better understandings of ethical practice across health care disciplines. Differences as well as similarities will serve to strengthen the discourse.

Though collaboration with nursing creates a bridge to the larger domain of health care ethics, speech-language pathology is more closely linked to its companion rehabilitation professions, physical therapy, occupational therapy, and audiology. These professions share many features including practice settings, populations served, and team approaches to intervention. I originally conceived this research project as an exploration of ethical practice in rehabilitation medicine more generally. However, the scope was necessarily and practically limited to the one profession. At its completion, my findings indicate that paediatric speech-language pathology has a specific and unifying focus on social connectedness. As a core category, social connectedness, as expressed by the notion of *being part of*, is equally important to speech-language pathologists who serve children and their families across health care, education, and other settings.

It remains to be determined if the focus on social connectedness is shared among the other rehabilitation professions or whether they, too, can define a singular focus to encompass their conception of ethical practice. Similar research would serve to address this question and others related to ethical practice in the rehabilitation disciplines where clinicians commonly work together on teams.

In writing about the development of nursing ethics, Sara Fry (1989) proposed that as a profession evolves, it redefines its focus so that ethics moves from a rule focus to an examination and serious inquiry into the nature of ethical practice. Nursing can trace its development from an early concern with ethical conduct and morality to later concerns about the ethical use of new technologies and the role of the nurse in relation to the patient and other health care professionals (Lamb, 2004; Marck, 2000b). The shifting focus has been the result of many internal and external influences. Recent developments in nursing ethics theory confirm the impact of such influences (Liaschenko and Peter, 2004). In reflecting on the development of ethics in nursing, I think that speech-language pathology could locate stages of growth and change made evident by tracing the development of professional ethics in speech-language pathology, a much younger profession that has its beginnings in the early part of the 20th century.

Having speculated on future research directions, we must also consider how to proceed to investigate these topics. My research demonstrates that empirical study of ethics in speech-language pathology is possible. Grounded theory proves useful for exploring the phenomenon of ethical practice in paediatric speech-language pathology. Qualitative methods are particularly useful for exploring the ethical dimension of clinical work in speech-language pathology since only a small pool of participants can move a project forward.

Periodically, qualitative research methods come to the attention of researchers in the field of communication disorders (Damico and Simmons-Mackie, 2003; DiLollo and Wolter, 2004; Hammer, 1998; Tetnowski and Franklin, 2003). Using qualitative methods from social sciences will allow future investigators to continue exploration of ethical practice in this area of health care practice.

Finally, as research often serves as an impetus for change, it is my hope that this study contributes to the advancement of my profession's understanding of its ethical foundations and commitments by providing tools, links to other areas within health care ethics, and a platform for an expansion of the scope of ethics discussion in my profession.

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APPENDIX A

Letter of HREB Approval

Health Research Ethics Board
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UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES,
CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP

HEALTH RESEARCH ETHICS APPROVAL

Date:	March 2001
Name(s) of Principal Investigator(s):	Ms. Eleanor Stewart Muirhead
Organization(s):	University of Alberta
Department:	Graduate Studies; Rehabilitation Medicine
Project Title:	Ethical Practice in Paediatric Speech-Language Pathology

The Health Research Ethics Board has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the patient information material and consent form.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval.

Prof. Ian Pimlott
Acting Chair of the Health Research Ethics Board (B: Health Research)

File number: B-130500-REM

University of Alberta
Capital Health
CARITAS HEALTH GROUP

APPENDIX B

Letter to Administration

Administrative Director
(Name of institution/agency)
Edmonton, AB
T5G 0B7

8 March 2001

Dear (Name):

Further to our telephone conversation yesterday, I have enclosed copies of my dissertation proposal entitled *Ethical practice in paediatric speech-language pathology*, the Health Ethics Review Board (HREB) Panel B approval application, and the administrative approval form for (institution/agency). My proposal has ethics approval from HREB.

The focus of my dissertation research is ethical practice in paediatric speech-language pathology. The research aims to develop an account of what constitutes ethical practice for clinicians working with children, from birth to 18 years, and their families. Should you decide that (name of institution/agency) can support this research after reviewing the enclosed materials, I will ask that you send a letter of support to (name), Administrative Assistant, HREB Panel B, 3-48 Corbett Hall, University of Alberta, Edmonton, AB, T6G 2G4.

I am seeking your permission as well as that of (name), Manager, to meet with speech-language pathologists with the intent of providing them with information about my dissertation research and inviting those interested to participate. As a speech-language pathologist, I recognize the demands on clinicians' time. My meeting time with them will not exceed 30 minutes. Any clinician who wishes to further discuss his/her participation in the study is free to contact me at the university. As I anticipate that the results of my study will be of interest to my colleagues in speech-language pathology, I would welcome the opportunity to return to (name of institution/agency) to share the results once the study is completed.

I trust that all is in order. However, should you have any questions or concerns once you have read the enclosed materials, please do not hesitate to contact me at 492-7499. I will contact you toward the last week of March regarding your input. Thank you for your time and consideration.

Sincerely,

Eleanor Stewart, CCC-SLP, S-LP(C)
Ph.D. Candidate
Faculty of Rehabilitation Medicine

APPENDIX C

Letter of information

LETTER OF INFORMATION

Project title: Ethical practice in paediatric speech-language pathology

Researcher: Eleanor Stewart, MA, Doctoral Candidate, Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, AB

Supervisors: Dr. Sharon Warren, Faculty of Rehabilitation Medicine (492-7856) and Dr. Glenn Griener, Department of Philosophy (492-8023), University of Alberta, Edmonton, AB.

The purpose of this study is to describe ethical practice in paediatric speech-language pathology.

My interview with you will be held at a time and place convenient to you. The interview will take from one to two hours of your time. No interview will last longer than two hours. You may be asked to be interviewed a second time also at your convenience. The second interview will also take from one to two hours of your time.

If you decide to be in this study, you may quit at any time by telling me or contacting my supervisors, Dr. Warren or Dr. Griener. If you decide not to be in this study, you do not have to tell me why you made this decision.

The interviews I have with you will be tape recorded and a written record of the tape will be made. I will use the written record to learn about and describe the ethical practice in paediatric speech-language pathology.

You will not benefit directly from being in this study. You may find some value in talking about your experiences as speech-language pathologist working in paediatric rehabilitation. If you agree to be in this study, you may feel some anxiety and distress from talking about your experiences. If this happens, you might want to talk about it with someone you know or you might seek a referral to a professional counsellor.

Your name, where you work, or any other information that might identify you will not be typed into the written record of the interviews with you. Your name, where you work, or any other information that might identify you will not be typed into the written record of the interviews with you. However, it is possible that you may be identifiable from quotations taken from your transcripts. The final report will be made available to you to permit you to review how your quotes are being presented and allow you to withdraw any quotes you wish.

All of the taped recordings and written records will be kept in a locked cabinet separate from the consent form. Only my supervisors and I will have access to these records. The tape recordings and written records will be kept for a minimum of five years. The information and findings of this study may be published and presented at conferences. Your name or any information that may identify you will not be used in connection with this study. All information will be held confidential unless professional codes of ethics or legislation require reporting.

The tapes and written transcripts may be used for a different study in the future provided I receive approval from the ethical review committee.

If you have any questions or concerns about this study at any time, you can contact my supervisors at the telephone numbers above. If you have any concerns about how this study is being conducted, you may contact Dr. Paul Hagler, Associate Dean of Graduate Studies and Research for the Faculty of Rehabilitation Medicine at 492-9674.

APPENDIX D

Consent Form

CONSENT TEMPLATE
(On Letterhead)

Part 1 (to be completed by the Principal Investigator):

Title of Project: Ethical practice in paediatric speech-language pathology

Principal Investigator(s): Eleanor Stewart Muirhead

Co-Investigator(s): Dr. Sharon Warren, Faculty of Rehabilitation Medicine, 492-7856
Dr. Glenn Griener, Department of Philosophy, 492-8023

Part 2 (to be completed by the research subject):

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your clinical practice.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No

This study was explained to me by: ______________________

I agree to take part in this study.

Signature of Research Participant ______________________ Date ______________ Witness

Printed Name ______________________ Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ______________________ Date ______________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT

APPENDIX E

Speech-Language-Hearing Association of Alberta Bulletin

What is ethical practice in paediatric speech-language pathology?*

Ethics in speech-language pathology is an under researched area of our practice. Yet, we know that clinicians think about ethics in their interactions with families, children, and other professionals.

This doctoral research project is aimed at developing an understanding of what we think is ethical in our everyday clinical practice. Using an interview format, I will explore this topic with speech-language pathologists who have paediatric caseloads. The research results may have implications for how we view our practice and for the standards that we hold as a self-regulating profession.

If you would like to learn more about this research or are interested in participating, please contact me at:

Eleanor Stewart, Ph.D. Candidate, CCC-SLP. S-LP (C)
Faculty of Rehabilitation Medicine
3-62 Corbett Hall
University of Alberta

* "Ethical practice in paediatric speech-language pathology" has been approved by the Health Research Ethics Review Board, Panel B, at the University of Alberta and received funding from the Social Sciences and Humanities Research Council of Canada.

APPENDIX F

Biographical information form

BIOGRAPHICAL DATA SHEET

Project title: Ethical practice in paediatric speech-language pathology

Code number: Date:

1. Age: a) 21-25 years b) 26-30 yrs. c) 31-35 yrs. d) 36-40 yrs. e) 41-45 yrs. f) 50+ yrs.

2. Employment setting:____

3. Years of clinical experience:_______________________________________

4. Years of clinical experience in paediatric rehabilitation:___________________________

5. Length of employment in this setting:_________________________________

6. Professional education:
    __ Bachelor degree
    __ Master's degree
    __ Other (specify) ____________________

7. Ethics education:
    __ coursework
    __ workshops or conference attendance
    __ self-education

8. Caseload type
    __ single population
(name)____
    __ varied population
(list)____

9. Religious affiliation (optional)____

10. Race/ethnicity
(optional)____