PREFERENCES FOR DECISION-MAKING INVOLVEMENT AND INFORMATION NEEDS OF PARENTS SEEKING TREATMENT FOR THEIR CHILD'S ANXIETY

by

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A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfillment of the requirements of the degree of

DOCTOR OF PHILOSOPHY

Department of Psychology

University of Manitoba

Winnipeg

THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES

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Abstract

Decisions concerning health services are often important and the process of making these decisions can be challenging for families. As part of family-centred care in pediatric practice, understanding the types of information parents need or prefer is important in helping them make informed decisions. While there has been a modest amount of research on parental decision-making for pediatric medical problems such as cancer, very little research has focused on decision making for child mental-health problems. Anxiety problems are common in children and the choices concerning treatment are quite complex, ranging from psychological and pharmacological treatments to combined treatments. The purpose of this study was to understand parents' views about their decision-making involvement and information needs when considering a treatment decision for child anxiety. A two-phase, sequential mixed-methods research design was employed consisting of an initial qualitative phase, followed by a quantitative phase. In Study 1, 19 parents were interviewed about their process of decision making and their information needs concerning treatment for child anxiety. Four themes emerged: (a) decision-making about children's anxiety is not explicit, but parents have perceptions about the decision-making process, (b) parents see themselves as protectors, (c) information is key in decision making, and (d) parents have different perspectives on psychosocial versus medication treatments. These findings informed the development of a quantitative survey about parents' information needs. In Study 2, 93 parents completed this survey of information needs and preferences for decision-making involvement, amount, and sources of information. Results showed that parents have a strong preference for decision-making involvement, desire a broad range of information, want a substantial

amount of information, and seek various sources of information (e.g., written pamphlets, discussions with a provider). Exploratory findings showed that symptoms of child anxiety and parental efficacy were related to the amount of information parents preferred. The research has implications for the development of materials and decision aids to facilitate parents' informed decision-making. It is hoped that such information will assist service providers in communicating with parents and families more effectively, supporting informed decision-making, and strengthening family-centred care.

Acknowledgements

I would like to thank Dr. John Walker and Dr. Diane Hiebert-Murphy for their guidance and continued support during this project. My research study could not have been conceived without John's enthusiasm and would not have been completed without his tireless dedication and words of encouragement. The detailed, constructive feedback that I received from Diane was essential in developing and refining my research. Thank you both very much for your time and commitment during this entire process.

I would also like to thank my committee members, Drs. Rosemary Mills, Dickie Yu, and Barry Mallin for their helpful and insightful suggestions, which resulted in a more polished thesis.

Many thanks goes out to Penny Stewart who greatly helped in recruiting families for my research. Without her, the project may not have been possible. I would also like to acknowledge the Social Sciences and Humanities Research Council for their financial assistance in this research.

Dedication

This is dedicated to my parents and family whose support I am truly grateful for during my years of graduate school. My frequent visits home and long-distance telephone calls meant that you were always nearby.

To my dearest, Colin, who has been my "rock" since the beginning of all this. I could not have done this without your endless love, support, and constant encouragement. You have always been there for me as my partner and "lab mate", and my gratitude extends far beyond what I can express here in words. Psychology is about understanding human thought and behaviour – I feel extremely fortunate to have someone understand me as well as you do.

"Everything that is meant to happen, happens."
– American Beauty

"You may be capable of great things, but life consists of small things."
– Tao

"I hear and I forget. I see and I remember. I do and I understand."
~ Confucius

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Preferences for Decision-Making Involvement and Information Needs in Parents Seeking Treatment for their Child's Anxiety

Personal health is one of life's most significant assets. Decisions concerning health services are often important and the process of making these decisions can be challenging in many situations, whether it be decisions pertaining to life-threatening medical conditions or decisions related to the preferred treatment for a mental health problem. Anxiety disorders are the most common mental health problems among children and adolescents (Costello, Egger, & Angold, 2005; Steinhausen, Metzke, Meier, & Kannenberg, 1998). Parents seeking help for a child's anxiety may be faced with a variety of treatment alternatives in the realms of psychological treatment, pharmacological treatment, or combined treatment. Each of these broad treatments, in turn, has alternatives such as psychological treatment involving mainly the child or the parent, or medication treatment with different pharmacological agents. Specific treatments have different requirements (e.g., time involvement, cost, duration) and different levels of scientific support concerning their effectiveness, and may have different advantages and disadvantages. Often providers with different types and levels of training provide each of the alternatives. The type of treatment offered may also depend more on the characteristics of the health-service provider and the service setting rather than the preferences of the family. Recently, there has been an increasing expectation by families that the treatments offered will be supported by scientific evidence and that parents will be involved in making informed decisions concerning health care for their child (Jackson, Cheater, & Reid, 2008).

Health-Care Decision Making

Health-care decisions cover a substantial range of concerns including preventive assessments and interventions, care during important life transitions (birth control, pregnancy, and childbirth), medical and surgical interventions, and psychological interventions. There are also one-time decisions (e.g., irreversible surgical procedures) and decisions that are revisited over time (e.g., most mental health treatments). While there has been a modest amount of research on health-care decision making around concerns such as cancer assessment (e.g., Davison, Degner, & Morgan, 1995; Luker et al., 1995), cancer treatment (e.g., Degner et al., 1997; Hack, Degner, & Dyck, 1994; Wong et al., 2000), diagnostic testing (e.g., Davey et al., 2002), and invasive medical procedures (e.g., Mazur & Hickam, 1997), there has been very little research focused on decision making for common mental health problems such as anxiety and depression. This is particularly true for children's mental health services.

The study of decision making for child mental health problems is important for a number of reasons. First, parents have a role as guardians and decision-makers for their child. They act in the interest of their child and as such, the decisions they make have a direct impact on their child. Second, choices concerning treatment for anxiety can be quite complex as they can range from psychosocial approaches to medication treatment, to combined therapies. There is often a greater range of choices in making treatment decisions for mental health problems compared to other health problems (e.g., heart disease, cancer). This may be due to the presence of psychological approaches as well as pharmacological approaches to treating mental health issues. Given the choices, individuals and health-care providers may face challenges in reviewing treatment

information in a systematic way to assist with making an informed decision. In making a treatment decision for a mental health problem, parents' preferences and values can play a strong role. Finally, treatment decision-making for child mental health problems is important to examine as it is tied to the practice of family-centred care in pediatric care, as discussed below. For all of these aforementioned reasons, it is important to study the process and the types of information parents consider when evaluating different treatments for child mental health problems.

Models of decision making. In a previous era of paternalistic decision-making, decisions concerning health care would have been made by a health-care provider (often a primary care physician) and patients would have followed or not followed the advice. In the past couple of decades, however, there has been a shift towards partnership in decision making between clinicians and patients (Brock & Wartman, 1990; Eddy, 1990; Emanuel & Emanuel, 1992). The increasing attention on clinician-patient decision making has resulted in growth of research in the area.

A variety of models have been described (Charles, Gafni, & Whelan, 1999; Deber, 1994; Emanuel & Emanuel, 1992) to guide the study of decision making in health care. The most prominent models include the paternalistic model, the informed decision-making model, and the shared decision-making model. The models differ in terms of the way information is transferred between the individual and health-care provider, and the way decisions are considered and implemented.

In the paternalistic model, the individual assumes a passive role in the health-care decision-making process, as the health-care provider is seen as the *expert*. Information about health care and treatment is transferred from the health-care provider to the

individual (in one direction) so that the individual consents to the intervention that the health-care provider considers best (Charles et al., 1999; Emanuel & Emanuel, 1992). The health-care provider deliberates about the decision with or without input from other health-care professionals and decides about implementing treatment. In this model, it is assumed that the health-care provider knows what is in the individual's best interest and acts on his/her behalf. This traditional approach to medical or health-care decision making is now less accepted due to changes in attitude about the involvement of the person receiving health care.

At the other end of the spectrum is the informed decision-making model, which focuses on the person receiving health services (Emanuel & Emanuel, 1992). The health-care provider's role is limited to the provision of information needed for decision making. Transfer of health information occurs one-way from the health-care provider to the individual, who deliberates about the decision and decides on the intervention (Charles et al., 1999). Informed decision-making assumes that the individual's values or preferences are known and that he/she lacks factual information, which is provided by the health-care provider. Although the idea of information-sharing is implied in this model, the individual proceeds with decision making on his/her own.

The sharing or exchange of information between an individual and health-care provider is involved in the collaborative process known as shared decision-making (Brock & Wartman, 1990; Brody 1980, Charles et al., 1999; Emanuel & Emanuel, 1992). Shared decision-making falls between the poles of the paternalistic model and informed decision-making model, and was largely developed during the 1980s in reaction to the paternalistic model. Increased interest in shared decision-making in mental health has

been related to views of empowerment, autonomy, and quality of life which underlie the provision of health care (Patel, Bakken, & Rulan, 2008).

Charles, Gafni, and Whelan (1997) define shared decision-making as having four key characteristics: (a) a minimum of at least two participants – a health-care provider (e.g., physician) and a health-care user or consumer (e.g., patient); (b) both parties take steps to participate in the process of treatment decision-making; (c) both parties share information; and (d) both parties decide and agree on the treatment to implement. The shared decision-making process requires at least two participants, but may involve others such as family members and other health-care professionals. It is important that both parties participate in treatment decision-making through the exchange and discussion of information between clinicians and individuals. There also needs to be complementary role expectations and behaviour between the health-care provider and user regarding their participation in the process. Once this is established, information is shared between the two parties and a decision is agreed upon. An essential feature of shared decision-making is the two-way exchange of information about treatment and patient preferences (Charles et al., 1997, 1999).

Role preferences for decision-making involvement. The three models of decision making (i.e., paternal, shared, informed) overlap with Degner and Sloan's (1992) concept of role preferences for decision-making involvement. This refers to an individual's preferred involvement in making a decision, which can vary in different decision-making models (Elwyn & Edward, 2006). Three types of roles are defined on a continuum ranging from passive to collaborative to active (Degner & Sloan, 1992). A passive role involves the health-care provider making the decision alone (the paternalistic model). A

collaborative decision-making role involves sharing decision-making control with the health-care provider (the shared model). An active decision-making role involves the individual selecting his/her own treatment (the informed model). This categorization of decision-making involvement can be further divided into passive-collaborative and active-collaborative roles to permit a finer distinction of preferences for decision-making involvement.

Pierce and Hicks's (2001) decision-making framework. Pierce and Hicks (2001) proposed a decision-making framework to help understand patient decision making (see Figure 1). Decision processes are described as the interaction of patient characteristics (e.g., values, expectations, preferences) and contextual factors (e.g., patient-provider interactions) which are set in motion by features of the decision problem (e.g., alternatives/choices, complexity). The decision-making process is further influenced by illness (e.g., severity) and demographic (e.g., age, education) factors. This framework is valuable because it recognizes the complex interplay of personal, contextual, and external factors in the process of decision making. The three models of decision making (i.e., paternal, shared, informed) and Degner and Sloan's (1992) concept of role preferences for decision-making involvement fit well with Pierce and Hicks's framework.

Family-centred care. Shared decision-making is consistent with the philosophy of family-centred care (FCC), which is an "approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare patients, families, and providers" (The Institute for Family-Centred Care, 2007). It has been recommended in the practice of pediatric medicine (American

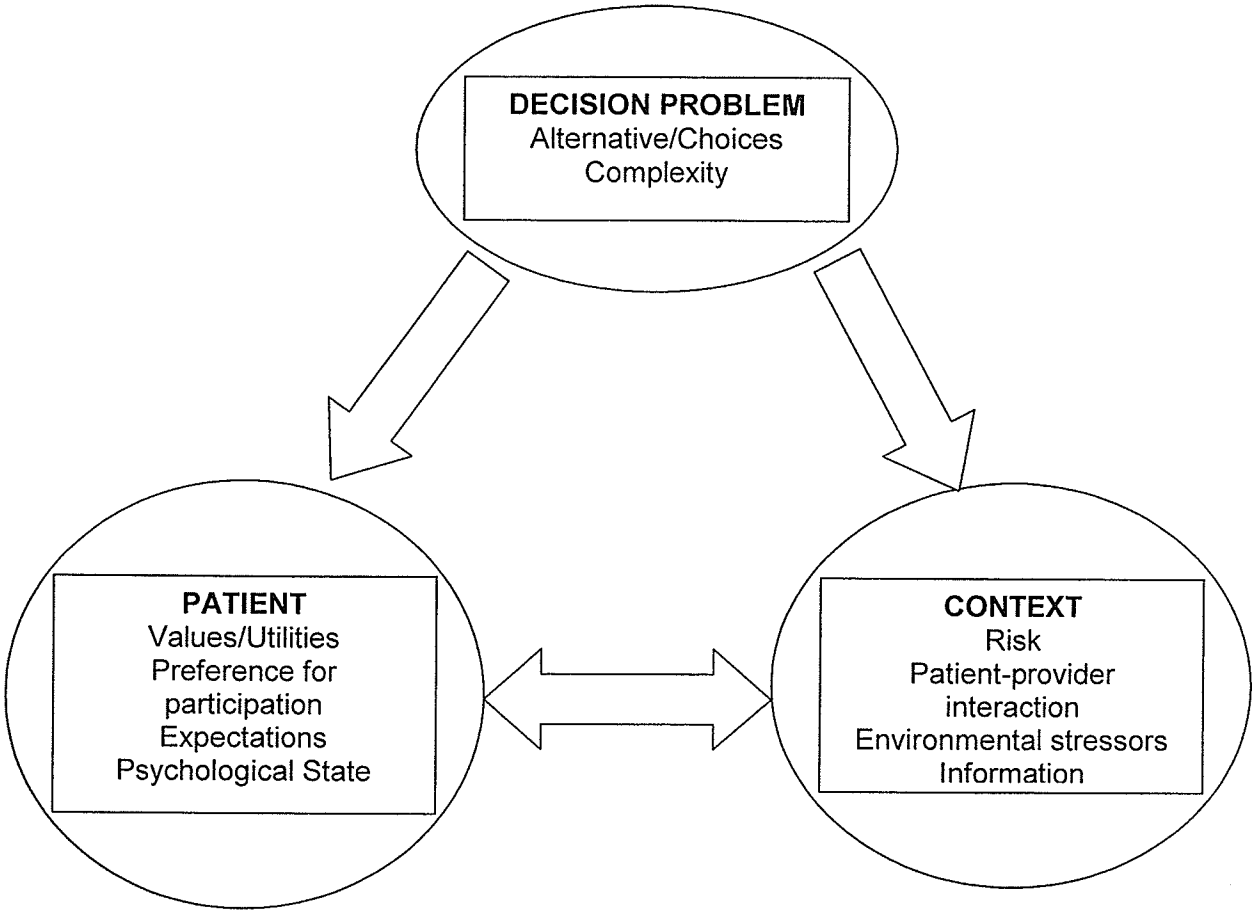

Figure 1. Pierce and Hicks' (2001) decision-making framework

Academy of Pediatrics Committee on Hospital Care, 2003). In general, FCC is based on the understanding that the "family is the child's primary source of strength and support, and that the child's and family's perspectives and information are important in clinical decision making" (American Academy of Pediatrics Committee on Hospital Care, 2003).

The FCC framework entails several components including (a) respect for the family as the constant presence in the child's life, (b) recognition of the family's cultural diversity, (c) recognition and respect for different methods of coping, (d) respect for the developmental, educational, emotional, environmental, and financial needs of the family, (e) family-to-family support and networking, and (f) access to flexible, accessible, and comprehensive health care delivery services and systems (Shelton & Smith-Stepanek, 1995). More specifically, FCC describes the need to facilitate parent-professional collaboration and to share complete, unbiased information with families on a continuous basis in an appropriate and caring manner (Franck & Callery, 2004; Hutchfield, 1999; Shelton, Jeppson, & Johnson, 1987). Furthermore, principles central to FCC such as dignity, respect, information sharing, participation, and collaboration (Institute for Family-Centred Care, 2007) reflect aspects of a collaborative, informed decision-making process.

Informed decision-making and informed consent. Informed decision-making should involve a process of informed consent. Informed consent entails an individual receiving and comprehending information concerning the decision, acting voluntarily, and providing autonomous authorization of a health-care service intervention (Beauchamp & Childress, 1994). Informed consent has been understood to occur when an

individual and health-care provider discuss a problem and choose an intervention together, a process that may happen once or over the course of several encounters that may be a routine part of assessment and treatment (Berg, Appelbaum, Lidz, & Parker, 2001; Lidz, Appelbaum, & Meisel, 1988).

There is a professional and legal obligation to inform individuals concerning health-care decisions, as described by professional codes of ethics. For example, one of nine Principles of Medical Ethics as stated by the American Medical Association states that "a physician shall...make relevant information available to patients, colleagues, and the public..." (American Medical Association, 2001). The Code of Ethics for the Canadian Medical Association (2004) contains similar guidelines on communication, decision making, and consent. It states that physicians should provide their patients with the information they need to make informed decisions about their medical care, make every reasonable effort to communicate with their patients in such a way that information exchanged is understood, answer patients' questions to the best of their ability, and respect the right of a competent patient to accept or reject any medical care recommended (Canadian Medical Association, 2004).

Psychological associations in Canada and the United States have similar ethical guidelines regarding informed consent and decision making. Informed consent is specifically highlighted in the Canadian Code of Ethics for psychologists (Canadian Psychological Association, 2000). Under the First Principle regarding respect for the dignity of persons:

I.16 Seek as full and active participation as possible from others in decisions that affect them, respecting them and integrating as much as possible their opinions and wishes,

I.17 Recognize that informed consent is the result of a process of reaching an agreement to work collaboratively, rather than of simply having a consent form signed,

I.18 Respect the expressed wishes of persons to involve others (e.g., family members, community members) in their decision-making regarding informed consent. This would include respect for written and clearly expressed unwritten advance directives, and

I.23 Provide, in obtaining informed consent, as much information as reasonable or prudent persons would want to know before making a decision or consenting to the activity. The psychologist would relay this information in language that the persons understand (including providing translation into another language, if necessary) and would take whatever reasonable steps are needed to ensure that the information was, in fact, understood. (pp. 10-11)

Overall, these guidelines emphasize that health-care providers such as physicians and psychologists have an obligation to engage in a collaborative process involving the provision and sharing of information with individuals, respecting their choices/concerns, and arriving at an agreement on a decision. Despite these guiding principles, the process of obtaining informed consent often does not go smoothly in the real world. The practice of informed decision-making as reflected in physicians' and surgeons' discussions of

basic (e.g., routine laboratory tests), immediate (e.g., medication use), and complex (e.g., cancer screening, surgery) decisions with patients has been found to be poor, which suggests inadequate provision of informed consent (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999). In order for individuals to make an informed decision, sufficient and relevant information about treatment is necessary. However, patients often want more information than they have been given (Coulter, Entwistle, & Gilbert, 1999). For example, information could be limited in the case of a new medical treatment for cancer, or scientific information about the range and effectiveness of different treatments for anxiety could be omitted. Without information or knowledge that is relevant, research-based, and useful, individuals are ill-equipped and are likely unable to make decisions in an informed manner. This is commonplace in mental health-care as patients have been found to receive insufficient information about their mental health condition and treatment options (Simon, Loh, Wills, & Härter, 2006) and feel uncertain about a decision when they are less informed (Stacey et al., 2008).

Information needs and preferences for decision-making involvement. Information needs are important to understand in studying the process of informed decision-making. While related, information needs are different from preferences for decision-making involvement in that individuals may want information but may not necessarily desire involvement or responsibility for making treatment decisions (Ende, Kazis, Ash, & Moskowitz, 1989; Sutherland, Llewellyn-Thomas, Lockwood, Trichler, & Till, 1989). Conversely, individuals may desire to be involved in making treatment decisions; however, they may have a limited awareness of the range of information and be poorly informed about information salient to the decision. In making decisions, it is important to

understand consumers' information needs because this can lead to the tailoring of information-giving by a health-care provider.

Research on Decision Making

Research on decision making has primarily examined two areas: preferences for decision-making involvement (e.g., Arora & McHorney, 2000; Beaver, Bogg, & Luker, 1999; Degner & Sloan, 1992; Hack, Degner, & Dyck, 1994) and information needs (e.g., Caress, Luker, Woodcock, & Beaver, 2002a; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Degner et al., 1997; Hack et al., 1994; Luker et al., 1995). Decision making for mental health problems is a relatively new area (Adams & Drake, 2006; Patel, Bakken, & Ruland, 2008; Simon, Wills, & Härter, 2009) and little is known about the decision-making process for mental health or health problems. Literature on adult patient research on the decision-making process and decision-making involvement for health and mental health problems will now be discussed.

The process of decision making. There is limited research on the *process* that individuals encounter in making health decisions. For example, Jones, Steeves, and Williams (2009) explored how and when men decided about prostate cancer screening and found that they (1) desired information on prostate cancer (e.g., risks, treatment, side effects), (2) considered the involvement of family and friends in the health decision, and (3) acknowledged the importance of trust in the health-care provider. Fraenkel and McGraw (2007) reported similar findings on patients' views of their decision-making involvement for osteoporosis. Patients described decision making as an ongoing process that occurs within a social context (i.e., involving family members), involves obtaining recommendations from the physician, occurs in response to their physician's

recommendations, and is influenced by their perceptions of their illness. O'Brien et al.'s (2008) qualitative study revealed that women with early-stage breast cancer sought information about treatment options and resources from informal and formal networks, preferred information prior to the specialist consultation, and considered different chemotherapy options both during and after the consultations. Women also valued the physician's recommendations and did not expect to be offered a role in the treatment decision-making process during the specialist consultation. In sum, these research studies provide a preliminary understanding of *how* patients make health care decisions. Exploration of the process of decision making for mental health problems is needed.

Patient preferences for decision-making involvement. Compared to the paucity of information about the decision-making process, there is considerable research on patient preferences for decision-making involvement. Research has generally shown conflicting results in patients' preferred roles (i.e., passive versus collaborative versus active) varying across studies, by individual, and by health problem. Despite this variability, however, a meta-analytic review on clinical decision-making has shown that a vast majority of patients and non-patients (58% - 93%) want to be informed about their diseases and varying proportions of respondents (15% - 42%) wish to be involved in the decision-making process (see Benbassat, Pilpel, & Tidhar, 1998)

Most research on decision making among breast and prostate cancer patients has shown preference for a shared/collaborative role (e.g., Degner et al., 1997; Hack et al., 1994; Wong et al., 2000). These studies used forced-choice items such as the Control Preferences Scale (CPS; Degner, Sloan, & Venkatesh, 1997) to measure an individual's preference for degree of involvement and reported that a majority of patients (44% to

60%) preferred an "active-collaborative" role in making a treatment decision with their physician. That is, patients expressed a preference for making the final decision after seriously considering the doctor's opinion.

While it appears that patients prefer being involved in decision making, most do not prefer the role of making a final decision on their own. In one study which found that prostate cancer patients preferred an active role in decision making (Davison et al., 2002), the authors noted that the patients' strong preference for complete responsibility for decision making might be explained by the younger and more educated individuals in the study. Preference for an active role in decision making has also been found among non-patients facing complex health care decisions such as surgery, pregnancy/childbirth, and medical treatment (O'Connor et al., 2003), with younger individuals preferring a more independent role. Non-patients presented with hypothetical cancer treatment alternatives have also been reported to prefer an active role (Degner & Sloan, 1992). It is noted, however, that this finding may be attributed to the absence of having a health condition so there is not the degree of threat which exists when the person has a serious health condition. In contrast to preference for a collaborative or active decision-making role, some studies have shown that cancer patients (Beaver et al., 1999; Davidson, Brundage, & Feldman-Stewart, 1999) and asthma patients (Caress et al., 2002a) prefer a "semi-passive" role whereby the physician makes the treatment decision after seriously considering their opinion.

Consistent with research on other health problems, persons with mental health problems also desire to be involved in their decision making. Research in this area has been limited, however. Recent investigations in shared decision-making regarding

treatment among patients with schizophrenia (e.g., Hamann et al., 2008; Mistler & Drake, 2008) and people with severe mental illness (Adams, Drake, & Wolford, 2007) indicate that patients prefer to participate in (shared) decisions about their care. A study on decision making and information seeking among community psychiatric patients and a mental health user group/forum also found that the majority of patients and users (70%) reported a moderate desire to be involved in decision making and wanted to share this role with the clinician (Hill & Laugharne, 2006).

Patient perspectives on shared decision-making for depression treatment were first examined in a study conducted by Simon et al. (2006). A convenience sample of 40 depressed patients participated in a semi-structured interview about treatment decision-making between doctors and patients. Questions focused on the sources of information available to patients, their first contact about health concerns, and topics/issues concerning treatment decision-making. Eighty-five percent of patients indicated that they had shared involvement with their physicians in decision making. Qualitative analyses revealed that depressed patients saw their general practitioners as their first contact and 65% of patients felt their general practitioners were an essential source of information about depression and treatment options. However, patients generally reported a basic lack of information about their illness and treatment options. Issues patients considered in treatment decision-making included the presence of a mental disorder, the necessity of treatment, social stigma concerns, and treatment type (i.e., pharmacotherapy versus psychotherapy).

Arora and McHorney (2000) examined depressed patients' preferences for decision-making involvement among their sample of patients with chronic illnesses (i.e.,

hypertension, diabetes, heart disease, and depression). The majority of patients preferred to leave the medical decisions to the physician (i.e., passive role), as measured by the one item used in the study. However, across health problems, patients with clinical depression were found to more likely prefer an active role than those with non-severe hypertension. Wills and colleagues have developed a program of research on decision aids concerning treatment of depression (see Wills & Holmes-Rovner, 2006). Their group is working on several sequentially-related projects to build an understanding of patient decision-making needs and preferences, which will contribute to the design and testing of a decision-aid intervention.

Benefits of patient participation in health-care decision making. Brody (1980) argues that increased participation in decision making by individuals will likely (a) enhance the quality of the health decisions being made given the inclusion of the consumer's opinions along with the health-care provider's rationale, (b) improve communication between patient and physician, and (c) increase compliance with therapeutic regimens as patient participation should lead to greater confidence in and commitment to these decisions.

Participation in decision making has generally been found to be related to positive health outcomes (see Guadagnoli & Ward, 1998). For example, allowing breast cancer patients choices about surgery has been found to be related to higher levels of life satisfaction at 3-months post-treatment compared to patients who were not given a role in making choices (Pozo et al., 1992). Improved psychological well-being has also been demonstrated when breast cancer patients were allowed to choose their surgical treatment (mastectomy or lumpectomy with radiation; Ashcroft, Leinster, & Slade, 1986). Cancer

patients who prefer to be actively involved in treatment decisions have been shown to be significantly more hopeful than those patients who do not want to participate (Cassileth et al., 1980).

While there is some evidence regarding the benefits of patient participation in decision making, some studies have reported negative outcomes and few or no effects. Early research demonstrated no improvements in psychological outcomes (e.g., depression, distress, anger) among women who had mastectomies who had a choice of surgery compared with those who did not (Levy, Herbermann, Lee, Lippmann, & d'Angelo, 1989; Morris & Royle, 1987). Cancer patients who preferred to participate in decision making were found to be slightly, but statistically significantly less satisfied with their care than those who wanted the physician to make decisions (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988).

Hamann, Leucht, and Kissling (2003) conducted a review on shared decision-making in mental health and identified four studies out of 193 that addressed elements of shared decision-making. Three of the studies (Bedi et al., 2000; King et al., 2000; Rokke, Tomhave, & Jocic, 1999) evaluated the effects of choosing between different treatments (i.e., psychotherapy or pharmacotherapy) on the health outcome of depressed and anxious patients. These studies showed no significant relation between patients' decisions about treatment and their depressive symptoms or satisfaction. Given the limited research on mental health decision-making, greater attention is needed to understand the impact of decision-making involvement on an individual's health.

An intervention study involving depressed patients who received education about depression and engaged in shared decision-making about the use of pharmacotherapy and

cognitive-behavioural strategies found that patients showed significantly greater self-efficacy in managing their depression (Ludman et al., 2003). They were also more likely to keep track of depressive symptoms, monitor early warning signs, and plan for coping with high risk situations compared with usual care control patients. Similarly, in their survey study, Loh, Leonhart, Wills, Simon and Härter (2007) reported that patient participation was positively correlated with treatment adherence and changes in patients' depressive symptoms. More importantly, they found that patient participation indirectly affected changes in depressive symptoms via treatment adherence. While more research is needed to examine the impact of individual (patient) involvement in health-care decision making, it is important to keep in mind that decision-making involvement is necessary for ethically and professionally appropriate service provision whether or not it influences later satisfaction and outcome.

Factors related to patient preferences for decision-making involvement. A variety of demographic and patient variables such as age, education, and gender are related to patients' preferences for decision-making involvement (e.g., Cassileth et al., 1980; Degner & Sloan, 1992; Ende et al., 1989; Stiggelbout & Kiebert, 1997; Vertinsky, Thompson, & Uyeno, 1974). Preference for participation has been shown to decline with age. For example, a greater proportion of older women (aged 65 – 83) with breast cancer have been reported to prefer a passive decision-making role compared to younger women (Bilodeau & Degner, 1996). In contrast, younger patients tend to express greater preference for decision-making involvement. Cassileth et al. (1980) reported that cancer patients who preferred to participate in treatment decisions were significantly younger. The pattern of older patients preferring less involvement in decision making has also

been demonstrated in other studies involving non-patients (Degner & Sloan, 1992) and chronically-ill patients (Arora & McHorney, 2000).

Education has also been identified as an influential factor on preferences for decision-making involvement. Cancer patients who prefer to participate in treatment decisions (i.e., prefer collaborative or active roles) have been found to be better educated (e.g., Cassileth et al., 1980; Janz et al., 2004). Arora and McHorney (2000) also found that college-educated patients with chronic disease were 3.5 times more likely to prefer active roles in their decisions about medical care than those with less than 12 years of education. Education may contribute to greater participation in decision making due to greater ease in understanding treatment and health information.

Gender has also been found to be an important factor. Degner and Sloan (1992) found that males with cancer of the reproductive system more often chose a passive role in decision making. Stiggelbout et al. (1997) found that more women (27%) than men (15%) who had cancer indicated a preference for active involvement in making decisions regarding their treatment. Similarly, Arora and McHorney (2000) reported that women with chronic health conditions were more likely to prefer an active role than men.

Another factor related to preference for decision-making involvement is the severity of the disease or health problem, although the results in this area are inconsistent. Benbassat et al.'s (1998) review of patient preferences for participation in clinical decision-making noted a few studies (e.g., Blanchard et al., 1988) which reported an association between passive role and severity of disease. A negative association between patient preference for decision-making involvement and health problem severity has also been reported in other health research (Arora & McHorney, 2000). Within mental health,

a lack of perception of depression severity has been found to delay patient engagement in treatment seeking and decision making (Simon et al., 2006).

A number of other factors have been acknowledged to influence preferences for decision-making involvement, including attitudes toward decision making and individuals' experiences with health-care professionals (see Say, Murtagh, & Thomson, 2006). For example, cancer patients who felt that they had a good relationship with staff members were found to participate more in decision making about treatment and care than those who perceived that the relationship was not good (Sainio & Lauri, 2003). Women's faith in the physician, among other personal factors, has been reported by breast cancer patients to influence their preference for an active or passive role in decision making (Hack et al., 1994). Given the interactive process in decision making, it is not surprising that the relationship between an individual and health-care provider could play an influential role in decision-making involvement.

Patient information needs. Patients and non-patients have indicated a strong desire to be fully informed about the benefits and risks of medical treatment (Stiggelbout & Kiebert, 1997). Several studies have found that patients desire information about their health condition (Deber, Kraetschemer, & Irvine, 1996; Hill & Laugharne, 2006), desire to ask questions and actively seek information about their medical problem (Sutherland et al., 1989), prefer detailed information (Cassileth et al., 1980), and often report a lack of information about their health concern and treatment options (Simon et al., 2006). In a recent review on the role and value of written information about medication, the findings revealed that patients value information in aiding decision making, see the importance of

information tailored to their condition, and desire sufficient detail in the information they receive (Grime, Blenkinsopp, Raynor, Pollock, & Knapp, 2007).

In terms of specific information needs, quantitative research has demonstrated that cancer patients wish to have information about treatment procedures, the likelihood of cure, stage of disease, treatment options, effects or side-effects of treatment, and effectiveness/success of treatment (Beaver et al., 1999; Bilodeau & Degner, 1996; Cassileth et al., 1980; Davison et al., 2002; Luker et al., 1995; Wong et al., 2000). Qualitative studies have also shown consistent information needs concerning side effects, different/new types of treatment, management of medication, and duration of treatment among breast cancer patients (Hack et al., 1994), asthma patients (Caress, Luker, Woodcock, & Beaver, 2002b), and patients with mixed medical conditions (Nair et al., 2002). Descriptive information about the medical condition (for example, causation/etiology) is judged to be important among patients with asthma (Caress et al., 2002b) and prostate cancer (Wong et al., 2000). Taken together, the findings suggest that patients generally want a wide variety of information about treatment (e.g., side-effects, options, effectiveness) when making decisions.

While attention has been focused on health problems, few studies have examined information needs for mental health problems. Pollock, Grime, Baker, and Mantala (2004) investigated the provision of medication information among psychiatric inpatients in a hospital and found that patients reportedly received inadequate provision of written and verbal information. This lack of information was recognized by professionals (i.e., psychiatrists, nurses, occupational therapists); however, there was strong ambivalence among some staff about the possible negative consequences of patients acquiring

information about their medicines. Patients wanted various types of information such as information about their diagnosis, name of the medication, dosage, side effects of treatment, long-term effects, and the consequences of not taking medication.

Garfield, Francis, and Smith (2004) interviewed patients who were beginning a course of medication for treatment of depression about their information needs. Patients were diagnosed with depression and had begun a new course of antidepressant medication in the three months preceding the study interview. Qualitative analyses found that information about adverse drug reactions was the most commonly reported unmet need. Patients indicated that they had not received information about the duration of treatment and issues regarding drug dependency and dosage. Both the type and timing of information were important to patients.

Information needs concerning treatment of anxiety has received little attention. Walker and colleagues (2000) investigated the types of information patients with anxiety found important in making treatment decisions. Patients indicated that information on psychological and pharmacological treatments, the patient's role in treatment, the effects of discontinuing treatment, and the effectiveness of different treatments as being highly important. Cost of treatment to the health-care system was rated as important but not as important as the other types of information. In terms of amount of information, the majority of patients were found to have received "none" or "little" information about most aspects of treatment when they received psychological or pharmacological treatment in the past. Furthermore, sources of information (i.e., information in a booklet, discussions with the health-care provider, discussion in a videotape) were all judged to be acceptable by the patients. Most indicated that when making decisions previously, they

received information in the form of discussions with the health-care provider. This finding is consistent with other research on mental health decision-making (Simon et al., 2006).

Factors related to patient information needs. Research has identified a number of factors (particularly age and education) related to information needs. Younger age has been associated with greater desire for information in a range of studies focused on cancer (e.g., Bilodeau & Degner, 1996; Cassileth et al., 1980; Luker et al., 1995). Higher educational levels have been found to be significantly associated with stronger desire for information (Cassileth et al., 1980; Ende et al., 1989). However, one study showed that highly educated women recently diagnosed with breast cancer or benign breast disease did not have different information needs when compared with those with lower levels of education (Luker et al., 1995). In terms of sources of information, a positive relationship has been found with higher levels of education related to greater patient preference for a medical journal as a source of obtaining cancer-related information (Bilodeau & Degner, 1996). Qualitative studies of breast cancer patients' preferences for information have found relationships with education and other factors such as personality, coping style, and illness severity (Hack et al., 1994). Furthermore, psychological factors (e.g., mood, anxiety) have been reported to influence information needs. For example, prostate cancer patients with high levels of anxiety and depression have been found to desire more information on coping and support (Wong et al., 2000).

The association between preference for decision-making involvement and information needs. Research has shown inconsistent results regarding the association between patients' preference for decision-making involvement and their information

needs. For example, Sutherland et al. (1989) reported a positive association in cancer patients' increased participation in decision-making and their high information-seeking. Hack et al. (1994) also demonstrated that breast cancer patients who preferred an active or collaborative decision-making role desired detailed information about their medical care (i.e., details about diagnosis, treatment alternatives, treatment procedure). Similarly, research with parents has shown that acquiring knowledge and experience about their child's health condition over time contributed to more active participation in parents' treatment decision making for their child's cancer (Pyke-Grimm, Stewart, Kelly, & Degner, 2006).

Some studies have shown a variable relationship between preferences for decision-making involvement and information needs. Among prostate cancer patients, Davison and colleagues (1995) found that men preferring a collaborative or passive-collaborative role in decision making wanted significantly more information about their prognosis, stage of disease, and treatment options than men with active or passive preferred roles. In contrast, men who preferred an active role desired less information on these three categories than men in the other preferred roles. A later study of prostate cancer patients showed contradictory results as patients' preferences for information were found to be similar regardless of the preferred decision-making role (Davison et al., 2002).

The majority of research on decision making has examined adult patients and studies in mental health have focused primarily on psychiatric problems and depression (Simon et al., 2009). Research on parental decision-making for child health and mental health problems will now be reviewed and discussed.

Research on Parent Decision-Making

Research on parent decision-making has primarily focused on pediatric medical problems such as cancer (Gagnon & Recklitis, 2003; Pyke-Grimm, Degner, Small, & Mueller, 1999; Ruccione, Kramer, Moore, & Perin, 1991), chronic illness (Angst & Deatrick, 1996), cardiac transplants (Higgins & Kayser-Jones, 1996), and critical illnesses (Abel-Boone, Dokecki, & Smith, 1989; Sharman, Meert, & Sarnaik, 2005). As in the patient literature on decision making, much of the research on parents has studied parents' preferences for decision-making involvement and their information needs.

Parent preferences for decision-making involvement. Parents want to be in control of the process of making a decision for their child (Jackson, Cheater et al., 2008). Regardless of the medical condition, research has shown that parents generally prefer a collaborative decision-making role and desire to be informed when making medical decisions for their child (e.g., Gagnon & Recklitis, 2003; Gore, Johnson, Caress, Woodcock, & Custovic, 2005). For example, Pyke-Grimm and colleagues (1999) conducted a survey examining preferences for participation in treatment decision-making and information needs among parents of children with cancer. Using the Control Preferences Scale for Pediatrics (CPS-P) that they developed, results showed that a majority of parents preferred a collaborative role in making a decision about their child's treatment at the time of and within one year of the child's cancer diagnosis. At both time points, parents indicated medium preference for a passive role (i.e., health provider assuming greater responsibility) and low preference for an active role (i.e., parent assuming complete responsibility).

Gagnon and Recklitis (2003) examined how parents' preference for decision-making involvement for their child's cancer care is related to their preferences for involvement in their own personal health care and their decision to use complementary therapies for their child. Consistent with Pyke-Grimm et al.'s (1999) findings, most parents (58.5%) reported a preference for a collaborative role in treatment decision-making, followed by preference for an active role (28%) as measured on the CPS-P. However, compared to parents in that study, a smaller proportion of parents preferred a passive role (13.6% vs. 29%). No significant relationship was found between parents' preference for decision-making involvement and their use of complementary therapies (i.e., external, biochemical, and mind-body treatments) for their child. Conversely, parents' preferences for involvement in their own personal health care were found to be related to the use of complementary therapies (i.e., external and mind-body treatments).

Despite the general finding that parents desire to be involved in making health decisions for their children, it should be recognized that parents' preferences for decision-making involvement may vary (Higgins, 2001). In addition, considering studies of *actual* decision-making by parents, decision making for child health problems has been found to be more paternalistic (practitioner-led or unilateral), with decisions being made based on the recommendations of the provider (Angst & Deatrick, 1996; Young, Moffett, Jackson, & McNulty, 2006). Parents have also reported having no discussion with health professionals about their role in decision making and little to no involvement in making a decision (Young et al., 2006).

Detailed study of the decision-making process suggests that parents and practitioners participate in different decision areas (Young et al., 2006). Typically,

parents have been found to be involved in decisions regarding the child's daily activities or functioning (e.g., contact with their doctor, child pain), while practitioners are focused on their responsibility for making decisions concerning the scientific or technical aspects of intervention. This difference in decision-making roles is consistent with parents' perceptions of their role as advocates for their children in seeking information about their child's diagnosis and medical care (Holm, Patterson, & Gurney, 2003). Parents may be able to better relate to and understand decisions concerning mental health problems (which may focus on the child's behaviour) compared with other health problems where the technical level of medical information may be quite difficult and complex. Also, they may have strong opinions and preferences for treatment for mental health problems. Given the life-threatening nature of some medical/health conditions (e.g., cancer) compared with mental health problems (e.g., anxiety), parents may feel incapable of making decisions for medical problems where there is typically less opportunity for negotiating the treatment that is chosen.

Parent information needs. Understanding parents' information needs or preferences is crucial in aiding their decision-making process. In Jackson and colleagues' (2008) systematic review of 149 studies on decision support needs of parents making child health decisions, it was concluded that parents desire information that is consistent, comprehensive, evidence-based, and tailored to their needs. Information was found to play a key role in making informed decisions.

Parents' information needs for children's health problems are diverse, ranging from information about the health condition (Pyke-Grimm et al., 1999) to information related to treatment (Gore et al., 2005). In general, parents of children with health

problems have been found to desire information related to conditions and symptoms, tests, treatments, management, and accessing services (Jackson, Baird, et al., 2008). Parents have also indicated a preference for information through discussions with the health-care provider and from written materials (Gore et al., 2005; Jackson, Baird, et al., 2008). When asked what they want from health professionals in qualitative studies, parents of children with chronic health problems report that they want to be given honest, accurate, and complete information, to have open communication regarding benefits, risks, and outcomes, to work with health-care providers who they can trust, and to be consulted in planning and decision making (Angst & Deatrick, 1996).

Examining parents' information needs during treatment decision-making, Pyke-Grimm et al. (1999) found that parents of children with cancer ranked treatments and tests, likelihood of cure from the disease, and care for the child as their top three preferred types of information. Information about the side effects of treatment and information about the emotional and physical impact of cancer on the child were considered a medium priority for parents. An association was found between parents' preferred decision-making roles and their information needs. Information about side effects of treatment was ranked as the most important need among parents who desired an active role and ranked the lowest in those who preferred a passive role. Furthermore, in terms of amount of information, the average parent wanted between "a little bit" and "a fair bit" of information about each content area.

While Pyke-Grimm and colleagues (1999) used quantitative methodology, Gore et al. (2005) utilized qualitative methods to identify core information needs among parents of infants with atopic dermatitis. They found an array of information needs

ranging from information about medication (i.e., side effects, new or different medication) and non-pharmacological measures, to information about dermatitis (i.e., causation, prevention, natural history), and other related types of information (i.e., exacerbating factors, role of diet). Interviews revealed that all parents expressed the need for detailed information about treatment availability, advantages, and disadvantages. Many specified the need for a skin care plan, which treatments to use, and how to use them. Additionally, parents generally felt that the information given by their doctors was insufficient in quantity, lacked detail, and was inconsistent.

Similar parent information needs about treatment have been reported for chronic conditions in children (e.g., asthma, cystic fibrosis, diabetes, epilepsy, leukemia; Hummelinck & Pollock, 2006). Parents' information needs were found to vary between parents and over time during the course of the child's condition. Consistent with other research (e.g., Pyke-Grimm et al., 1999), the most common information needs involved treatment (i.e., mechanism of drug action, potential side effects), diagnosis, and prognosis. Some parents reported wanting to know "everything" about the child's condition and treatment; however, most felt that professional communication and information provision were inadequate. Many parents also noted that they found it difficult to pinpoint and express what they need from professionals as they did not know what questions to ask or what information was available. Further, some parents reported wishing for more information to feel involved in managing the child's health condition and to be able to understand the decisions being made. These findings suggest that the provision of information may help facilitate parents' understanding of their child's health and treatment, which could enhance their involvement in decision making. Taken

together, research on parents' information needs highlights the inadequate provision of information to parents despite their high desire for information, particularly information regarding treatment.

Parent decision-making for child mental-health problems. Congruent with the limited research on decision making for mental health problems, there is paucity of research on parents' decision-making process, preferences for decision-making involvement, and information needs for child mental health problems. In a qualitative study by Taylor, Donoghue, and Houghton (2006), parents were interviewed to understand their process of making a decision about medication for children with Attention-Deficit/Hyperactivity Disorder (ADHD). The data revealed a theory ("doing right by my child") and identified three stages (i.e., grieving, cynicism, and proactive parenting) through which parents move in reaching a decision concerning medication treatment. Despite its exploration on parental decision-making, this study did not investigate *how* parents engage in the process of making a treatment decision and did not examine parent information needs. Exploration of the types of information parents seek or desire is an important part of understanding their decision-making process.

Parents' information needs for child anxiety has been examined in one study. Zacharias and Freeman (2007) surveyed parents from the community about the types of information they would find important if they were making treatment decisions concerning an anxious child. Forty-four mothers and 28 fathers recruited from the community, who were not necessarily parents of anxious children, completed the survey. Results indicated similarity of information needs and preferred sources of information between mothers and fathers. The highest information needs were information about the

parent's and child's roles in treatment, information about the various psychological treatments available, and common side effects of treatment. Parents indicated a preference for information in written form and in discussions with a health-care provider versus information provided by either a videotape or on a website.

With the exception of two studies (Taylor et al., 2006; Zacharias & Freeman, 2007), no research has examined parent preferences for decision-making involvement and their information needs regarding treatment for child mental health problems such as anxiety. It would be valuable to explore these questions in parents seeking help for children's mental health problems given parents' desire for information about their child's treatment (Angst & Deatrick, 1996; Gore et al., 2005).

Factors associated with parent decision-making. An association has been found between parent anxiety and education and decision making regarding child treatment (Ruccione et al., 1991). Parents with higher anxiety levels were more likely to believe that the explanation of treatment risks was not sufficiently clear before consenting to their child's treatment. Parents with higher education were more likely to report that they had received sufficient explanations of treatment risks. However, those with higher education more often reported that they were not given adequate time to consider the treatment options and to ask questions before consenting to treatment for their child.

Factors that impact the family or elicit an emotional response from the parent (e.g., the deteriorating condition of a child) have been shown to have a greater influence on parents' decision making for their child's transplant than a physician's endorsement of treatment (Higgins & Kayser-Jones, 1996). However, recommendations and information received from the health-care professionals (e.g., facts, explanations and opinions about

the patient's disease status, survival likelihood) were reported to be the most important factors that influenced the decision making of parents of pediatric cancer patients (Hinds et al., 1997). Feeling a sense of support from and trust in the staff was another common factor. In a later study by Hinds et al. (2000), these factors surrounding the family-physician relationship (i.e., being supported by staff, trusting staff) were also identified as being important in helping parents make decisions, as well as "getting information from the health-care team." Overall, communication and the exchange of information between families and health-care providers seem to be crucial in the decision-making process.

Several factors also have been found to be related to parents' information needs. Pyke-Grimm, Stewart, Kelly, and Degner (2006) examined factors that influence parents' role in treatment decision-making for their child's cancer. Qualitative interviews with 36 parents revealed several categories. The perceived parent-physician relationship was the most common factor described by 94% of parents as influencing their preferred treatment decision-making involvement. Knowledge was the second most common factor that parents identified to influence their preference for decision-making involvement. This specifically referred to physicians' knowledge in dealing with pediatric cancer and the process of parents gaining knowledge about their child's condition. Parents talked about learning and wanting to increase their knowledge about their child's cancer and treatment. Other factors that parents identified as being important in influencing their preference for decision making included their relationship with their child and their role as parents, the nature of their communication with their physician, trust in the physician, and the child's health condition (e.g., uncertainty of the situation). Beyond their "role as

parents" (i.e., sense of responsibility for their child), no parenting factors were examined in this study.

Pyke-Grimm and colleagues (2006) also reported several differences in the endorsement of factors influential in decision making based on parent treatment decision-making role preferences (i.e., active, collaborative, passive). Parents who preferred an active role in treatment decision-making were more likely to mention greater authority and greater perception of partnership or sharing with the physician compared with parents who preferred a passive role. On the other hand, parents preferring a passive role were more likely to report the importance of their own lack of knowledge, trust in the physician (to act in the child's interest), and the physician's knowledge and experience in influencing their decision making compared with parents preferring an active role.

Treatments for Child Anxiety

Deciding about treatments for child anxiety can be a complicated process for parents. Information on many aspects of treatment may be important to consider such as effectiveness, common side-effects, duration, and costs involved. Selection of an appropriate treatment is rarely a straightforward task. It is further complicated by the array of empirical evidence on interventions and the sometimes differing preferences for treatment between health-care providers and families. Hence, an important part of the provider's role is to discuss with the parent and child the pros and cons associated with each treatment approach.

Treatments for anxiety disorders generally involve pharmacological (medication) or psychological (e.g. cognitive-behavioural therapy) approaches. Research on pharmacological treatments supports the use and effectiveness of a variety of medications

in treating children with anxiety problems (see Walkup, Labellarte, & Ginsburg, 2002). The current medications of choice are the selective serotonin reuptake inhibitors (SSRIs; e.g., fluoxetine, fluvoxamine, sertraline) which have controlled clinical trials establishing their effectiveness in treating childhood anxiety (e.g., Birmaher et al., 1994; RUPP Anxiety Study Group, 2001; Walkup et al., 2008). There is, however, controversy (Licinio & Wong, 2005) and mixed reports surrounding the potential risk of antidepressant use in children and adolescents and increased suicidality (Hetrick, Merry, McKenzie, Sindahl, & Proctor, 2007; Kutcher & Gardner, 2008). Guidelines have typically recommended that medication be used in conjunction with psychosocial treatments for children and adolescents with anxiety disorders (Canadian Psychiatric Association, 2006).

Psychosocial interventions in the treatment of child anxiety have primarily consisted of various forms of cognitive-behavioural therapy (CBT; see King, Heyne & Ollendick, 2005; D'Eramo & Francis, 2004), which have been recommended as the first line of treatment for children with anxiety disorders (Stein & Seedat, 2004). Randomized controlled trials have documented the efficacy of individual, child-focused CBT in reducing anxiety (e.g., Kendall, 1994; Kendall et al., 1997). Family-based interventions and parental involvement in children's treatment have also been demonstrated to improve children's symptoms of anxiety (e.g., Barrett, Dadds, & Rapee, 1996; Mendlowitz et al., 1999). In some cases, combined treatments involving both the parent and child have shown greater improvement in children's emotional well-being compared to parent-only and child-only interventions (Mendlowitz et al., 1999). However, comparisons of parent-focused and child-focused interventions have yielded mixed results. While some studies

have reported marginal superiority of parental involvement in treatment compared with child-based treatment (Barrett, 1998; Spence, Donovan, & Brechman-Toussaint, 2000), other studies comparing family-based CBT and individual child-focused CBT have shown clear advantages for family-based treatment over child-focused treatment alone (Barrett et al., 1996). When comparing individual child CBT to medication (i.e., sertraline) and combination therapy (i.e., medication and CBT), results from a multi-site study recently reported superiority of combination therapy (80% of participants much improved) over CBT and medication treatments alone (60% much improved in each condition) at the end of twelve weeks of treatment (Walkup et al., 2008). No information is available of the relative effectiveness of the treatment options over the longer term and following the termination of psychosocial and medication treatments.

Research Overview

Given the various treatments available for child anxiety, making decisions concerning treatment for a child's anxiety can be quite complex for many parents. There are psychosocial and pharmacological approaches to choose from, and combined treatment may be recommended by some practitioners. Each of the major approaches, in turn, has different requirements (e.g., time involvement, cost, duration), different levels of scientific support concerning their effectiveness, and different advantages and disadvantages. It is challenging for parents and service providers to review this information in a systematic way to assist parents to come to a truly informed decision concerning services for their child.

Informed decision-making is consistent with the philosophy and practice of family-centred care. The present study was conceptually guided by Charles et al.'s (1999) decision making model, and Degner and Sloan's (1992) role preferences for decision-making involvement. The family-centred care framework (Shelton & Smith-Stepanek, 1995), which emphasizes the importance of the child's and family's perspective and the collaborative partnership between families and providers in decision making, also guided the present research.

Research Objective

To understand parents' preferences for decision-making involvement and their information needs in making decisions concerning the treatment of child anxiety.

Research Questions

Primary research questions.

1. The study sought to understand parents' preferences concerning decision-making involvement: What role do parents of children with anxiety desire in making treatment decisions? What child and parent factors are associated with parents' preferences for decision-making involvement?

2. The study sought to examine parents' information needs: What types of information, amount of information, and sources of information do parents prefer when making decisions about treatment for their child's anxiety?

Secondary research questions.

1. The study sought to understand the importance of different information needs: What types of information do parents find most and least important in making decisions concerning help for a child's anxiety problem?

2. The study sought to explore the association between parents' preferences for decision-making involvement and their preferred amounts of information.

3. Pierce and Hicks's (2001) decision-making framework was used as a basis for exploring various factors that may be associated with parental decision-making. Individual (i.e., parent) characteristics are recognized to play a role in decision making. As such, parent characteristics such as parenting efficacy, satisfaction, and stress were explored. The decision-making process is also influenced by severity of the problem and demographic (e.g., age, education) factors. Overall, the study sought to explore whether various child factors (i.e., age, symptom severity) and parent factors (i.e., age, education,

stress, efficacy, parenting satisfaction) are associated with parents' preferences for decision-making involvement.

4. Some research has shown support for the influence of several individual and sociodemographic factors (e.g., age, education) on individuals' information needs (Bilodeau & Degner, 1996; Luker et al., 1995). The study sought to explore whether various child factors (i.e., age, symptom severity) and parent factors (i.e., age, education, stress, efficacy, parenting satisfaction) vary with parents' preferred amounts of information for medication and psychosocial treatments.

Overview of the Research Design

This study employed a two-phase, sequential mixed-methods research design (Creswell, 2003). The initial phase consisted of qualitative interviews (Study 1) to obtain in-depth opinions of parents concerning these research questions. Findings from the qualitative interviews were then used to develop a quantitative survey of parents' information needs (Study 2).

Rationale for a Mixed-Methods Study

Given the scarcity of research in decision-making and parent information needs for child mental health problems (e.g., Taylor et al., 2006; Zacharias & Freeman, 2007), a mixed methods approach seemed most appropriate. No surveys or instruments were identified that assess parents' treatment information needs regarding children's mental health problems. Therefore, a qualitative phase was appropriate to gain an in-depth understanding of parent's views on these issues. Qualitative research is appropriate when researchers are "opening up" a new area of study (Fitzpatrick & Boulton, 1994) and seeking to understand and describe a phenomenon (Britten, Jones, Murphy, & Stacy, 1995). Qualitative methods have been used to explore patients' views on treatment decision-making (e.g., Markovic, Manderson, & Quinn, 2006; Sanders & Skevington, 2003) and have been employed to develop and evaluate clinical assessment instruments for families of children with adjustment issues (Gilgun, 2004). Qualitative studies by Gore et al. (2005), Hummelinck and Pollock (2006), and Jackson, Baird et al. (2008) provided parents with the opportunity to identify their information needs, discuss their preferences for being involved in decision making, and communicate their experiences with their child's illness. Furthermore, within the patient decision-making literature, two

notable studies (i.e., Hack et al., 1994; Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999) utilized qualitative-quantitative methodologies and indicated that the open-ended questions used in qualitative methods were complementary to the quantitative data gathered through survey items.

The qualitative findings in the present study were used to identify concepts that informed the development of items for a quantitative survey on parent information needs. This survey was used, in turn, to gather information from a wider group of parents concerning information needs and preferences. It was hoped that a mixed-methods approach would provide a comprehensive understanding of parents' preferences concerning decision-making involvement and the information needed for informed decision-making.

Study 1

Methods

Research setting. The research was based at St. Boniface General Hospital in Winnipeg, Manitoba, a teaching hospital of the Faculty of Medicine, University of Manitoba. The hospital is located close to the city's downtown area and is used by families with diverse socioeconomic backgrounds. Ethical approval for the study was obtained from the University Research Ethics Board and St. Boniface General Hospital Research Review Committee.

Recruitment. Participants were recruited from the waitlists of two services at St. Boniface General Hospital. One service, developed by the Child and Adolescent Mental Health Program, was the Anxiety Disorders Service for Children and Youth, which has staff from a variety of different health disciplines including nursing, occupational therapy, psychiatry, and social work and serves a large number of children and families in the Winnipeg Health Region and surrounding areas. This program offers a range of services to children and their families such as individual and group cognitive-behaviour therapy, medication treatment, and some family therapy. The other service was a teaching and research service of the Clinical Health Psychology Program that focuses on anxiety in children and adolescents (the Anxiety Disorders Program). This program focuses on psychosocial interventions with a particular emphasis on family-oriented cognitive-behaviour therapy with younger children and individual therapy with older children and adolescents. Parents interested in medication treatments are served through consultation with their primary care physician or a child psychiatrist. Parents on the waitlists of both

programs were chosen because they were seeking services for child anxiety and were close to the point of making treatment decisions for their child.

Parents were contacted initially by the program secretary through a letter and information sheet (see Appendix A) mailed to their home describing the study and inviting them to participate. The information sheet indicated that the family's decision to participate or not participate would not influence the services that would be offered to their family. One to two weeks later, a follow-up telephone call was made by a program staff member to inquire about the parent's interest in participation. Once parents expressed an interest in participating, they were contacted by the student researcher (L.M.) who provided further information about the nature of the study using a telephone script (see Appendix B). For those who agreed to participate, an appointment was scheduled to conduct face-to-face interviews at the hospital at a time convenient for the parent. We asked to interview the parent who spent the most time with the child. For two families, both parents asked to participate and were interviewed together. The interviews occurred between July 2007 and April 2008.

Forty-one parents ($n = 20$ parents of boys, $n = 21$ parents of girls) on the waitlists received letters in the mail regarding the study. Of these, 27 parents agreed to further contact by the student researcher about their interest in participating in the interview study. The student researcher (L.M.) asked several screening questions in her telephone contact to ensure appropriateness for study participation. Parents were eligible if their child experienced problems with anxiety and they were English-speaking. Parents were excluded from the study if their child's primary presenting problem was not anxiety (e.g.,

aggression) and if they did not understand or speak English as this was necessary in responding in the interview.

Recruitment began with a convenience sample and then moved to a more purposive sampling in order to maximize variability in the sample (Patton, 2002). During the later recruitment process, a greater emphasis was placed on contacting parents of boys as a high proportion of parents of female children participated in the early interviews. From the 27 parents who were contacted, a total of 19 parents participated in 17 interviews: 15 with one parent and two with both parents. Three parents indicated that they did not wish to participate, four families were not appropriate (i.e., one parent had difficulty with English, one child had a developmental disability, two children had anger/aggression problems), and three could not be contacted. Of the 19 parents who participated, 14 were awaiting services at the time of the interview, four had just begun treatment services for their child/family, and one had an initial assessment meeting. Prior to the start of the interview, the study's purpose was explained and written consent (see Appendix C) was obtained by the interviewer (L.M.). Recruitment for the interviews was sufficient at 19 parents because data saturation had been reached; that is, themes were recurring and no new information was emerging.

Research participants. The majority of the interviews ($n = 14$) were with the mother, two were with both parents, and one was with the father. The average age of mothers was 41.8 ($SD = 6.3$) years and fathers was 41.7 ($SD = 7.5$) years. The majority of parents ($n = 18$) reported their ethnic background as Caucasian. Most parents ($n = 14$) indicated being married, four parents were divorced, and one parent was a single parent. Parents had various levels of education, ranging from completion of high school ($n = 5$)

and business/technical college (n = 5), to completed university bachelors program or more advanced degrees (n = 9). All parents reported being employed and there was a range of occupations (e.g., retail, nurse, mental health worker, store clerk, teacher, pharmacist, social worker, business manager, architect). The average age of the child for whom services were being sought was 11.4 years (range 4 – 18 years, SD = 3.8). Eleven of the children were female and six were male. Using a general descriptive scale (i.e., mild, moderate, severe, very severe; see Appendix D) of anxiety symptoms, one parent reported that that his/her child experienced mild levels of anxiety, 10 parents reported that their children experienced moderate levels, and eight parents reported that their children had severe anxiety. The average duration of child anxiety symptoms was 52.6 months. Children were described by parents as experiencing various types of anxiety problems such as separation anxiety, social anxiety, sensitivities to transitions/changes, health anxiety, and specific fears (e.g., fear of gagging, fear of natural disasters). With respect to the child's previous treatment history, four children were reported to have received medication for their anxiety and six children/families received counselling. In terms of their own functioning, seven parents indicated experiencing problems with anxiety (5 moderate and 2 severe anxiety). Regarding their own treatment, some parents reported having used medication (n = 4) or receiving counselling (n = 4) for their anxiety. Seven parents further reported having a family member with anxiety.

Semi-structured interview. A semi-structured interview guide was used to explore parents' views about treatment decision-making. This approach allowed for an in-depth examination of specific areas of interest to the research while exploring other issues identified by the participants. Interviews lasted from 45 to 90 minutes and were all

conducted by the same person (L.M.) to ensure consistency. Interviews were audio-recorded and following each interview, field notes about the interview process (e.g., parent's understanding of the interview questions), flow, and context (e.g., room setting) were made by the interviewer (Patton, 2002). Quality assurance in the interview process was provided by means of regular meetings with the research team. During these meetings, aspects of the interview process (e.g., flow, content) were discussed to gauge the process of the interviews and minor revisions were made to the interview protocol to clarify the meaning of some questions and explore areas of interest in greater detail (e.g., awareness of decision making, expectations of the initial visit to a health-care professional). Preliminary themes emerging from the interviews were also discussed.

Qualitative interview protocol. Interview questions were derived from the literature on treatment decision-making and from the clinical experiences of the members of the research team. The semi-structured interview protocol (see Appendix E) covered two main content areas: (a) parents' roles in treatment decision-making, and (b) their information needs regarding decisions about treatments for child anxiety. The first part on decision making asked the parent(s) questions about her/his role in making treatment decisions, her/his preferences for decision-making involvement, facilitators and barriers to being involved in decision making, and reasons for his/her involvement. The second part on information needs was divided into three sections containing identical questions for each of the treatments: child-focused treatment, parent-focused treatment, and medication treatment. For each section, the parent(s) was asked questions about the types of information she/he would like or need in making a decision about the particular treatment, her/his views on the helpfulness/usefulness of the treatment, concerns/worries

about treatment, and likes and dislikes about the treatment. The last part of the interview protocol asked questions about sources in information-seeking, preference for amounts of information, and other aspects of treatment decision-making. Probe questions were incorporated in the interview protocol and were used, when appropriate, to prompt further discussion of a certain topic for greater detail or clarification.

Preferences for decision-making involvement. Following the qualitative interview, the Control Preferences Scale for Pediatrics (CPS-P; Pyke-Grimm et al., 1999; Appendix F) was completed by parents to assess their preferences for decision-making involvement. This measure was adapted from the Control Preferences Scale (CPS; Degner & Sloan, 1992; Degner, Sloan, & Venkatesh, 1997) used to measure the degree of control an adult wants to assume when decisions are being made about his or her medical treatment. Like the CPS, the CPS-P consists of a card sort procedure with five cards that contain written statements and illustrative drawings describing different roles in treatment decision-making. These roles range from active (i.e., A: "I prefer to make the final decision about which treatment my child will receive;" B: "I prefer to make the final decision about my child's treatment after seriously considering my child's doctor's opinion") to collaborative (i.e., C: "I prefer that my child's doctor and I share responsibility for deciding which treatment is best for my child") to passive (i.e., D: "I prefer that my child's doctor makes the final decision about which treatment will be used, but seriously considers my opinion;" and E: "I prefer to leave all decisions regarding my child's treatment to my child's doctor"). Rather than using the card sort procedure, for convenience of administration, parents were asked to select the statement from a list of these five statements that, in general, best represents their preferred role in making

treatment decisions. This approach of selecting a written statement to represent an individual's preferred role in decision making has been used previously with the CPS and CPS-P (Davidson et al., 1999; Gagnon & Recklitis, 2003; Gore et al., 2005; Pyke-Grimm et al., 1999). To increase the applicability of the items to a broader range of providers, the term "health-care provider" was substituted for "doctor". The alphabetical scale (A to E) was converted to a numerical scale (1 to 5) for ease of data handling. While the CPS-P has not been used as an interval scale, it has been used in previous research as a nominal measure to assess parents' preferences for decision-making involvement (e.g., Gagnon & Recklitis, 2003; Pyke-Grimm et al., 1999). The selection from five choices makes it easily understood.

Background questionnaire. After completing the CPS-P, parents were asked to provide background information such as their age, gender, race, education, child's age, and child's gender. Parents were also asked to describe the severity of their child's anxiety symptoms (ranging from mild to very severe) and the duration of their child's symptoms. Further questions asked about previous use of medication and counselling treatments for the child's anxiety problem and the parent(s)'s own treatment experience (see Appendix D).

Feedback form. Following the completion of the interview, CPS-P form, and background questionnaire, parents were given written feedback about the study's background, goals, and anticipated timeline of the final results (see Appendix G).

Data analysis. In the present study, data collection and analyses occurred simultaneously (Pope, Ziebland, & Mays, 2000), with initial findings shaping the subsequent data collection. At various points (e.g., after 3 interviews, 6 interviews, 10

interviews), the interviewer refined the questions in the interview protocol, with input from the research team, to pursue emerging avenues of inquiry in further detail. A few questions were also modified to clarify wording that was found to be unclear to parents. Emerging categories and themes during qualitative analysis were continually checked against the data. Data collection ceased when category saturation was reached, that is, when no new themes emerged.

Each interview was audio-recorded and transcribed by the interviewer (L.M.). Words spoken by each person (i.e., parent and interviewer) as well as comments reflecting non-verbal interactions (e.g., pauses, laughing) were included. The transcription was checked by the interviewer to ensure accuracy.

During the data analysis process, a journal was kept to record "analytical memos" (Strauss & Corbin, 1990), which are notes about questions or comments regarding identifying categories and themes. Notes about the coding process were also kept to document decisions that were made and the rationale for the changes during the analysis (e.g., revisions to a category in the thematic framework) to ensure consistency of coding and prevent any impulsive decisions. Furthermore, the journal record served to identify important issues during data analysis and aided in the process of "triangulating analysts" (Patton, 2002), whereby other research team members recorded their coding of the interviews in an attempt to provide evidence towards a unifying categorization scheme.

Data analysis utilized a "Framework" analytic approach (Ritchie & Spencer, 1994) that is not only inductive and "grounded" in the accounts/observations of people, but starts off deductively with pre-set objectives. The approach involves five interconnected stages (i.e., familiarization, identifying a thematic framework, indexing,

charting, mapping, and interpretation) and entails a systematic process of sifting and sorting material according to key issues and themes. In the present qualitative study, themes were guided by the research questions and emerged out of the data.

In the first stage, "familiarization" involved immersion in the data, listening to data, reading transcripts, and studying observational notes. Audio recordings and transcripts were reviewed several times by one member (L.M.) to become familiar with the depth and diversity of parents' understanding of decision making and the areas of information they described as being useful in their treatment decision-making. During several reviews of the transcripts, the researcher listed key ideas, made general notes on the general atmosphere of the interview, and began the process of conceptualizing themes/categories.

Once the material was reviewed, the researcher identified the key issues, concepts, and themes according to which the data were examined and referenced. This was carried out by drawing on questions derived from the objectives of the study, issues raised by the parent respondents themselves, and views or experiences that recurred in the data. During this second stage of "identifying a thematic framework," a detailed framework or index was constructed capturing the key issues and concepts, and codes were derived to label the data collected and used to code the data.

In the third stage, "indexing" involved applying the thematic framework or index systematically to all of the data in its textual form through the use of "codes" (see Appendix H) which link back to the index. Transcripts and the thematic index were entered into a code-and-retrieve computer program called Ethnograph (Qualis Research, Colorado Springs, CO). The program assisted with data analysis by allowing the

transcripts to be divided and attached with codes, and coded sections to be displayed and searched. This program was used to code all transcripts following the framework analytic approach (Ritchie & Spencer, 1994).

Coding of the transcripts was carried out by one member (L.M.), followed by a group discussion of the coding results, which showed high concordance regarding the main themes. The coded transcripts were then reviewed and compared by two research members (J.W. and D.H-M.) for accuracy and agreement on codes/categories and to search for missed concepts/themes. A review of the transcripts/data was performed during the qualitative analysis to ensure that the categories and codes reflected what the informants said and were accurately captured in the thematic framework. Confirming the definition of each code/category was an important procedure since it contributes to credibility and consistency (dependability) of the data. Reviewing the data also allowed for the completion of any notes regarding the framework and helped determine when to stop data collection. Discrepancies in coding (e.g., discussions concerning overlap between codes and the development of more refined codes) were discussed and resolved by discussion and group consensus.

During the fourth stage of "charting," the data was re-arranged according to the appropriate part of the thematic framework to create headings/groups and subheadings/subgroups which were drawn from the framework. Compared with the coding phase, "charting" was a broader, more conceptual level of analysis. Based on a thematic analysis, charts (i.e., groups) were devised for each key area or theme by recognizing patterns across codes. Part of the charting process involved a considerable amount of abstraction and synthesis as data were sifted and charted according to broad

core themes by locating recurrent patterns and associations across the data (code categories).

The four themes that emerged in the qualitative study subsequently arose during this "charting" stage. Some of the key issues to be charted were parents' view of the decision-making process and their information needs. For example, across code categories about 'unawareness of decision making' and 'unfamiliarity with treatment options' emerged the first theme: 'Decision making is not explicit.' Data related to parents such as their concerns about treatment, stigma about child mental health, and the child's best interest created the second theme: 'Parent as protector.' Another group of codes regarding information formed the third theme: 'Information is key in decision making.' Finally, code categories regarding psychological and medication treatments led to the development of the fourth theme: 'Different perspectives on medication as compared to psychosocial treatments.'

The last stage of analysis involved "mapping and interpretation." During this phase, key characteristics of the data were pulled together, mapped and interpreted as a whole. This was guided by the research questions and by the themes and associations that emerged from the data themselves. The process involved reviewing the charts (i.e., themes) and research notes, comparing and contrasting the perceptions, accounts, or experiences of the parent respondents, searching for patterns and connections, and using conceptual and intuitive ability to determine meaning. Interpretation of the data was mostly descriptive as the goal of the qualitative phase was to understand parents' decision-making process and identify the types of information that they describe as important in their treatment decision-making. During this "mapping and interpreting"

stage in the qualitative study, a coherent picture emerged regarding our understanding of parents' views on the decision-making process, their preferred decision-making role, their range of information needs, and their perspectives about different treatments.

Validity and reliability considerations. A number of techniques were employed to ensure validity and reliability of the study's findings, relating to the concepts of quality, rigor, and trustworthiness in qualitative research (Golafshani, 2003). Evidence of trustworthiness was addressed in the present study by examining *credibility* (truth value or internal validity), *dependability* (reliability or consistency), *confirmability* (neutrality or objectivity), and *transferability* (applicability or external validity) (Lincoln & Guba, 1985).

Credibility, which reflects the quality and rigor of a study, was established through the interviewer's notes concerning impressions of the interviews, elaborations of the coding framework, and documentation of data analysis procedures and decisions about category definitions. As part of "triangulation", which involves the use of different sources, methods, investigators, and theories in establishing credibility (Lincoln & Guba, 1985), multiple researchers were used to independently review the categories/themes and review the coding of transcripts. Codes and broader categories were continually checked and modified by members of the research team to ensure adequate "fit" with the data, while also accounting for negative cases (i.e., those which contradicted the main findings).

Dependability refers to the reliability of findings and was established in several ways. First, a standard interview protocol was utilized by the same interviewer (L.M.) for all interviews that were conducted. Data collection was monitored through team meetings

and modifications were made to the interview protocol over the course of the study to present the questions in clearer ways and explore some issues in more detail. Second, written definitions were created for each code in the coding framework and continually revised and refined through discussion. Third, two other members of the research team (D.H.-M., J.W.) each independently reviewed half of the interviews to ensure that all transcripts were reviewed and coded. Finally, the three members of the qualitative analysis team reviewed the coded data and themes emerging from the ongoing data analysis.

A record of notes and printouts of drafts of the coding framework documented the coding procedures and provided a record of the study's process, thus demonstrating *confirmability*, which is the degree of objectivity in research (Lincoln & Guba, 1985). Also, a journal of field notes containing the interviewer's observations and personal reactions during the interview provided a record of the interview process and any biases and personal experiences that may have affected the interpretation of the data. For example, the parents' experiences during the interview (e.g., level of understanding of the interview questions) and their perspectives on decision making (e.g., familiarity with treatments, experiences with accessing services for their child's anxiety problem) were considered when interpreting the emergent themes.

In terms of *transferability*, which pertains to the generalizability of a study, a detailed description of the sample (parents and children) was provided in the section on research participants above. By knowing the composition of the sample, we are better able to draw conclusions about the degree to which our findings can be generalized to a population of parents of anxious children.

To ensure that the derived themes accurately reflected participants' views, copies of a summary of the themes were sent (via email and three by letter mail) to all parent participants. Verification and feedback of the study results were elicited by asking participants to respond to four short questions, using a rating scale from 0 to 10 (see Appendix I). Feedback from 11 parents revealed that they rated the findings to be highly understandable ($M = 9.3$, $SD = .9$) and the conclusions reasonable ($M = 9.6$, $SD = .7$). There was also a high level of agreement with the results ($M = 9.4$, $SD = 1.0$). No respondents provided low ratings (i.e., less than 7 on a 10-point scale) on understandability, reasonableness, and agreement. Parents were also given the opportunity to provide written feedback. Of the 11 parents, eight wrote comments, most of which were reiterations of their agreement with the findings. For example, one parent stated:

> *"The findings above are very similar to how I feel about this issue."* (45-year-old mother of 14-year-old girl).

Similarly, another parent said:

> *"I strongly agree with the first bullet: "Most parents are unfamiliar with the range of treatments available for children's anxiety. As a result, they had not considered the decision-making process much before hand and were not really aware that there was a range of decisions to be considered," which is why the bullets following this are important. Thank you for the opportunity to participate."* (42-year-old mother of 15-year-old girl).

Another parent was less supportive, yet validating saying:

> *"I don't understand the purpose of the study – to me the answers fell into the*

> *realm of the "very obvious." However, I understand (intellectually, anyway) that so-called "obvious" impressions have to be studied because they can turn out to be wrong. I hope this study proves to be helpful."* (50-year-old mother of 9-year old girl).

There was also one parent who made a suggestion:

> *"A good idea would be more info available to parents about anxiety, what is it?, how does it display itself in kids? Maybe making the info available in the school system. If parents and teachers don't know what anxiety is or what is look like, they may think that their child is just misbehaving."* (44-year-old mother of 10 year-old girl).

Study 1 Results

Examination of the codes and categories resulted in the identification of four main themes: (1) decision making about children's anxiety is not explicit to parents, but they have perceptions about the decision-making process they prefer; (2) parents see themselves as protectors; (3) information is key in decision making; and (4) parents have different perspectives on medication compared with psychosocial treatments. Qualitative analyses also revealed themes about parents' decision-making process.

Decision Making About Children's Anxiety is Not Explicit, but Parents Have Opinions About the Decision-Making Process They Prefer

One main theme that emerged was that decision making about children's anxiety was not explicit to parents, although they had opinions about the process. In general, parents were unfamiliar with the range of treatment options, which seemed to contribute to their lack of awareness that there was a role for parents in decision making concerning

treatment for their child's anxiety. Because the process of making a decision for anxiety treatment may not be made explicit to parents (by health-care providers), they appeared to have some difficulty articulating their role in making a treatment decision. (One exception was a parent whose educational background and occupation was in the field of child mental health, which contributed to his awareness of decision making). A lack of information about the treatment options also led to parents' difficulty in expressing what they would expect or how they would engage in making a decision with the health-care provider. Typical views were expressed by two parents:

> *Again, not knowing what resources there really are, but in general decision making, I want to be involved.* (36-year-old mother of a 4 year-old child)

> *Um, ...I guess a bit of a problem I'm having here is that the decision was kind of made for me. So um, ...and I wasn't aware of the different types of treatment available so that's why I'm having a bit of trouble answering these questions [laughs] about how I make a decision.* (30-year-old mother of a 6-year-old child).

It was of interest that one parent also described the difference between decision making for mental health problems versus decision making for medical problems (e.g., cancer) where the health-care provider would likely play a greater role in decision making concerning medically complex treatments. Although this was a single case, it may suggest that for some parents, the nature of the problem (e.g., health versus mental health, and life-threatening versus non life-threatening) may affect their decision making.

Despite the limited preparation for involvement in decision making concerning children's anxiety, parents were able to speculate about the process and commented on broad aspects in making a treatment decision. Most parents responded to questions based on their views on the decision-making process they prefer, with the exception of a few

cases where parents recalled their actual experiences making a decision regarding treatment for their child.

One parent expressed her expectations about the decision-making process by saying:

> *I'd want to just probably have time to process it, little time to discuss with my husband and/or friends, or family, or whatever, and have time to ask questions. I wouldn't want a medical professional to think, you know, "You probably won't understand this so I just won't talk to you about it." I would, I would just want to know and maybe if I didn't understand, "Can you explain that in a different way that I could understand?" But I wouldn't want them assuming, "Well I'm a medical professional and you're just the parent," or "You wouldn't understand cuz you're not a medical professional." You know, I'd want some dialogue there.* (36-year-old mother of a 4-year-old girl)

In considering a decision-making process, parents commonly described a process that included a range of actions such as talking with their spouse and/or child about the decision being made, discussing or exchanging information about treatment choices with the health-care provider, evaluating the information that was provided (e.g., weighing pros and cons), and engaging in their own research about treatments (e.g. searching the Internet, talking to others).

Parents described the importance of obtaining information about treatment choices and evaluating information if they were making treatment decisions for their child.

> *You know, for me, I have to get the information and think about it for a bit. I don't think I can make a decision right then and there. So I would just like to be told, I'll listen, and then I have to go and digest it, and think about it. And maybe research it a little.* (45-year-old mother of a 14-year-old girl)

> *Well I guess our role would be to seek as much help and information as we can. Get a variety of the treatment options that are available, weigh out how we think those individual options would be applicable to [child's name] and which ones we think might be best.* (42-year-old father of a 9-year-old boy)

> *Probably sit down and just consider all the options, and weigh the pros and cons obviously like I think any good decisions are made that way, you know. [faint chuckle] (LM: Yeah, okay). I don't care whether they're business decisions or whatever, you just have to look at the...again, it's like if you're trying to decide which medication to use. "Well this one does this, and this one does that,...I mean there's a side effect with this one but this one isn't quite as good but it has..."You know what I mean? You're just going to have to make an informed... All we need to do is make an informed decision. That's it.* (34-year-old father of a 12-year-old boy).

In addition to their desire for information about treatment options, most parents indicated expecting or wanting the health-care provider to make suggestions in helping them make a decision. Some parents recognized their own lack of knowledge in the area and acknowledged that the professional would have the expertise to provide useful input.

> *Well I think ultimately because we're in a situation that we're kind of out of our depth, we will defer to the professional to a large extent. Now we're going to use some common sense, you know, if a professional says, "Well you've just got to beat him over the head three times a day," we're going to say, "No, I don't think so. What's the other option?" We're going to hopefully make some intelligent decision about it, but we will have to defer a lot to the professional decision, professional idea. We're out of our depth on a lot of this.* (49-year-old father of a 10-year-old boy).

Parents strongly stated they want to be involved in decisions concerning treatment for their child; none said they did not want to be involved in the decision making. When asked who would make the decision concerning treatment, parents commonly indicated that the parent, child/adolescent, and/or family (e.g., including siblings) would be involved in decision making. Sometimes the health-care provider was noted be involved in making the treatment decision along with the parent/family.

An overarching theme that emerged when parents were asked to envision their decision making was that they want the health-care professional to provide information about treatment options or make suggestions, with the final decision being made by the parent. This is illustrated by several parents in the following comments:

> *Ultimately I make the decision. I do take feedback – like I talk to his dad about it, although his dad and I don't have the same views, [chuckles] and his teachers. The counselors at the school and his teachers – they definitely have great input on, ...but I ultimately will make that decision from the information they give me.* (34-year-old mother of an 11-year-old boy)

> *No I would be the decision maker. I mean they're going to propose options...(LM: okay), but I and [child's name] will make the decision.* (42-year-old mother of a 15-year-old girl)

> *I see the professionals as presenting us with thorough researched options and us making the final decisions.* (42-year-old father of a 9-year-old boy)

> *So I'd like someone to tell me and then of course let me make the decision. But provide me with all the information they can and their opinion of what they would do if they were me. You know, "If I were in your shoes" so that I would feel comfortable that they're giving me an option that they would themselves do.* (45-year-old mother of a 14-year-old girl)

In a few cases, it seemed that parents' preferences or personal opinions about treatment would be a decisive factor in their decision making if they disagreed with the provider's suggestions or if it was not clear that one treatment was more effective than another.

> *I would say that my decision would be the best. Yeah, yeah. Of course with the practitioner, or therapist or whomever you want to call it, recommends him being on meds and it's like I say, "No, I want him to have counselling instead," then you know, I'm sure my decision would trump.* (42-year-old mother of a 13-year-old boy)

> *If I had a bunch of dissenting opinions that would just confuse the water because then we would be hard-pressed to make a decision, you know. Again, 50% say drug, "Yes, some medication would help," 50% say, "Nah, we won't go near there. We want to do this with family counselling and stuff," we'd be hard-pressed to make a decision. But then I would start to lean toward the family counselling more than the drug because I've made those, kind of those, earlier decisions on what processes I would accept. So if there was a....but if there was 80% saying, "You know what? Get him on some medication, we can take care of most of this right now," that to me is, you know, "Okay, fine, that's the route we should be going because the opinion is weighted that way."* (49-year-old father of a 10-year-old boy)

Factors influencing the decision-making process. Parents identified some factors that they thought influenced their decision-making process including (a) the age of the child, and (b) the type of treatment. Some parents of older children/adolescents described playing a supportive, peripheral decision-making role since the adolescent would be mainly involved in the decision.

> *Well I would be an active participant, but I think I would try and let [adolescent] lead the interview because it's her feelings and she knows what it is.* (42-year-old mother of a 15-year-old girl)

While parents viewed adolescents taking on greater decision-making involvement (due to their greater maturity and desire for independence), parents of younger children expressed the view that they were responsible for making the decision for their child because of the child's age.

> *She...yeah, I mean I would make that decision. I would definitely take what she has to say into consideration, but keeping in mind that she is only 6 years old. She can't make a decision like myself, as an adult, can.... I mean as far as treatment goes, um.... She's still young, too; she can't explain her feelings very well. She doesn't have the vocabulary so I think even though I'd listen to what she has to say, I would still make the decision, even if it was against what she wanted.* (30-year-old mother of a 6-year-old girl)

As illustrated by this comment, parents also seemed to recognize that there would be changes in their decision making as a child grows up:

> *I would like to be involved with all decision making. I mean as she grows older, I mean, that might change, right? She's going to start making decisions on her own and uh, certainly at this point in her life, I need to be there to make those decisions for her.* (39-year-old mother of a 10-year-old girl)

In considering the decision-making process, a few parents noted that making a treatment decision depended on the type of treatment (i.e., medication or counselling) that was being considered. They indicated that different treatments require different

considerations (e.g., type of information, amount of information) when making a decision.

> *Um, probably we would take the information. And, I mean it depends on what's proposed for treatment. We may be able to conclude it, you know, and agree on something in the office or we might say, "You know what, we're going to take this away and we'll call you back." Depending on our comfort level with what's proposed.* (42-year-old mother of a 15-year-old girl)

Some parents also reported the cost of treatment and time involved in treatment to influence their decision to choose a particular treatment or not.

Context of decision making. The context in which parents make decisions is important to consider, although this was not explored in great detail in relation to how it influences decision making. In the present study, some parents made or continue to make decisions around treatments for other problems (e.g., attention-deficit/hyperactivity disorder, depression, medical problems). Many parents also described having past and/or current experience with professionals (e.g., teachers, school counselors, pediatricians, general practitioners) in seeking help for their child.

Some parents, who were noted to have children with co-morbid problems or severe difficulty with anxiety, expressed feeling desperate for help and expressed a willingness to try any reasonable alternative, often deciding without knowing the treatment options. In a few cases, parents also described some of the challenges and frustrations they experienced in getting help (e.g., the child being on the clinic waitlist).

In addition to their frustration about difficulty accessing services, several parents noted the stress resulting from dealing with the child's anxiety and other disruptive behaviours (e.g., anger outbursts). For example, some parents expressed feelings of irritation or uncertainty about how to respond or deal with their child's anxious

behaviour. Others recognized the impact of the child's anxiety on their own behaviour. While a majority of parents commented on the strain on the relationship as a result of their child's anxiety, two parents reported that they felt the child's anxiety brought them closer to their child. When asked if the relationship with their child affected the decisions they would make about treatment, most parents indicated that it would not, stating that they wanted what was best for the child.

As part of the context of decision making, some parents indicated a need to be comfortable with the provider or treatment environment and raised concerns about trusting the provider. As reported by this parent:

> *I mean obviously, the obvious that you hope she wouldn't be with a person that would hurt her or abuse her, or you know. Like, you know, somebody that we can truly trust to not misuse that trust.* (36-year-old mother of a 4-year-old girl)

As part of helping them make a treatment decision, some parents also noted the importance of the provider's knowledge or confidence. In a few cases, positive and negative aspects of the parent-provider relationship such as communication and respect for the family's knowledge and opinions were described as important aspects of the process of making a decision and in receiving services.

Parents See Themselves as Protectors

A second prominent theme that emerged across interviews was parents' role as a protector for their child. This protective role was demonstrated in various ways ranging from parents' strong desire to participate in decisions concerning their child's treatment, to concerns about problems that could come up if there was a decision to undertake treatment. In addition, some parents expressed a concern about the stigma that could

come from being labelled as having an anxiety problem. In describing her child's problems with anxiety, one parent stated:

> *And particularly since I don't want it known, particularly in [child's] school, that she has difficulties of this sort. I don't think that's reasonable. Umm, ... word gets around and particularly now that she's approaching the teenage years, this could be very bad, uh, for her to be labelled as something odd. She is different and the kids know she's different, but I don't want her with a label stuck on her. That would be bad.* (50-year-old mother of a 9-year-old girl)

The stigma associated with receiving treatment for anxiety was another concern raised by a few parents. This concern that other people would know about the child receiving treatment may be a barrier in parents making a treatment decision. A few parents expressed a strong desire to protect their child's privacy:

> *I wouldn't want to run into her classmates somewhere or friends, or you know, I would want to keep it quiet for her - that would be really important to me too. So if she's comfortable to tell her friends, that's okay. But I don't want it; I would want her to be able to say what she wanted. To be in a place where it's very private for us, would be really important.* (45-year-old mother of a 14-year-old girl)

Parents reported various concerns about psychosocial and medication treatments, which seemed consistent with their role as protector of their child. These treatment concerns are discussed further below.

Related to parents' need to protect their child is their desire to help their child and to act in the best interest of their child when making a decision. Furthermore, when asked why it would be important to be involved in making decisions about their child's treatment, parents described their responsibility as caregivers and their understanding of their child as important reasons for being involved in making decisions about their child's treatment.

> *Um, well first of all, it would have to be the best interest of the child, I think it would have to be the number one concern. (*43-year-old mother of a 12-year-old boy)

> *I just feel, as her parent, I want to be involved. It's my responsibility to raise her to be a happy and well-adjusted and responsible adult. And so you know, anything that affects her certainly...just I do feel it's very, very important.* (36-year-old mother of a 4-year-old girl)

> *I mean obviously the professional is going to know what, hopefully the child is going to get the most benefit out of, but they've only met them once so they have to, you know, definitely talk to the parents to find out if something like that is going to work....cuz I think professionals have their expertise, but parents still have their expertise on their child.* (43-year-old mother of a 12-year-old boy)

Information is Key in Decision Making

A third theme that emerged was that information was a critical component of decision making. Parents generally were unfamiliar with treatments for child anxiety and recognized that information is necessary to make an informed treatment decision. The interviews revealed that parents have several types of information needs when making a decision about psychosocial or medication treatment for their child's anxiety problem.

Desire for information. Parents expressed a desire to be informed about treatment choices. They stated that information about treatment was valuable in equipping them with knowledge that facilitated their ability to make a decision. The variability of comments from parents is described below:

> *Knowing when, uh,...like right now, she's just coming in and talking to someone and knowing when some treatment options are coming, like for them to say to me, "We're looking at some options now – behavioural, perhaps some medications, perhaps some in-house training, whatever, letting me know that that decision is coming and that she may need some help or guidance in making that decision. That's all, just being informed.* (48-year-old mother of a 17-year-old girl)

> *I would say on a scale, it should be presented to the parents as this is all the information that we have, whether they choose to utilize that I think it needs to be still up to the parent. I think it's helpful to know.* (43-year-old mother of a 12-year-old boy)

> *What would make it easier? Um, ...what would make it the easiest would be having all the information so I know what I'm doing. That's the biggest thing for me. You know, this is all new and I want to make sure I'm making the right decision.* (45-year-old mother of a 14-year-old girl)

> *Um, just to give me some more information about different things available and different options. Explain different options available to me so I have all the information so I can make a decision.* (30-year-old mother of a 6-year-old girl)

> *I think the more information I have, knowledge is, you know it's everything. The more information you have that you can, um, you can make the right decisions.* (39-year-old mother of a 10-year-old girl)

What treatments are available? Some parents were able to make a general distinction between pharmacological treatment and counselling; however, it was apparent that they were not familiar with the types of medication used to treat child anxiety or the range of psychosocial interventions available (e.g., child- or parent-focused treatments). Those who showed some basic treatment knowledge seemed to draw from their personal experiences or reflect on information that is available in the media (e.g., weight gain as a side effect of certain medications).

Beyond psychosocial approaches (i.e., child-focused and parent-focused interventions) and pharmacological treatments, a few parents identified other treatment options when asked if there were programs or types of help they would consider for their child's anxiety. Parents mentioned an interest in whether there is a camp program for children with anxiety problems, school-based programs, and group treatment with peers. One parent also indicated the need for age-appropriate educational material about anxiety and treatment written for children.

Treatment familiarity affects information needs. Parents' lack of familiarity with treatments hindered their ability to specify the types of information they need in decision making. For example, as stated by this parent:

> *It's hard to know not knowing what some of the resources or some of the treatments might be but,...(LM: okay). Again, like a frank, honest conversation about what this might look like and maybe how if there's been some success, or what have some concerns been in the past?* (36-year-old mother of a 4-year-old girl)

Furthermore, lack of information about treatment options hindered the ability of some parents to answer questions regarding the helpfulness of a particular treatment.

Amount of information desired. When asked how much information they would prefer to have, nearly all parents indicated a preference for a lot of information about treatments.

> *As much as possible. I think whatever information there is should be given to every parent because you don't know. And I think every parent should educate themselves and learn about every type.* (30-year-old mother of a 6-year-old girl)

Although most parents wanted a lot of information, there were some exceptions and variability in what parents preferred, with some wanting more or less depending on the treatment, and others wanting a summary of information.

> *Well, medication I need to know a huge amount before I consent. [Slight pause] Just a huge. Umm....(slight pause) the other two [counselling approaches], rather less so. Sometimes it's rather difficult to explain just exactly what you're going to do, but it can also be outlined quite readily.* (50-year-old mother of a 9-year-old girl)

> *I think it probably sounds like I'd want a lot of information, but I also love the Coles notes [brief study guide] version [laughs]...for a quick review.* (36-year-old mother of a 4-year-old girl)

While the majority wanted a lot of information, some parents also noted the challenge of obtaining too much information as this might lead to conflicting information or complicate decision making.

> *Mmm, I would go not a lot because sometimes too much starts becoming conflicting and I think you can ask too many people. So somewhere in the middle where I had enough. It's hard to put a place on it, but enough that maybe a few articles supporting the same information along with what the health-care provider says so that it all looks like it's going the same way - and then that would be enough for me.* (45-year-old mother of a 14-year-old girl)

> *I would, I myself would lean towards lots. I would want lots of information (Wife: Yeah). The only problem I have is when I get lots of information, I'll get lots of conflicting information, which will then lead me back to what I said earlier. If I get 50% think this is the way and 50% say...that's not going to help. I'm going to be stuck. And then all of a sudden common sense comes into play. So there's a lot of different things that I want. I'd always want more information than less.* (49-year-old father of a 10-year-old boy)

> *I think the more information, the better. I think it could help parents decide. I mean there's, to a point, when there's too much information and then it just becomes confusing. [laughs]. But having I guess a little bit of each scenario on how things can go would be the best.* (34-year-old mother of an 11-year-old boy)

In a few cases, quality and relevance of information was described as more important in decision making than the quantity of information. As stated by this parent:

> *I don't think it's the quantity, it's the quality. So I would want as much as I need to make an informed decision. And I can't tell you quantity-wise what that would look like.* (42-year-old father of a 9-year-old boy)

Seeking treatment information from a variety of sources. In the interview, parents were asked to identify the sources they would seek in finding treatment information. The majority of parents would use a variety of sources such the health-care provider and other professionals, books/pamphlets, the Internet, and talking to friends and family. Media and support groups were occasionally noted by parents as sources of information. Given parents' lack of familiarity with treatments, it is not surprising that they may rely on

various formal sources (e.g., books, health-care professionals) and informal sources (e.g., other parents) for treatment information. Additionally, it appears that parents are not passive recipients of information as several expressed their opinions about the usefulness or lack of helpfulness with a particular source (e.g., provider, other individuals, Internet websites, and pamphlets). The variability of opinions about different sources of information is illustrated below:

> *Don't hand me a pamphlet, that's not going to cover everything. That's a general thing. [emphasized] Well that's a general thing! General thing is good...and you know, that's great, that's wonderful, but I need to know specifics.* (50-year-old mother of a 9-year-old girl)

> *He's [husband] talking to Dr. X. Well we did but I didn't find that very helpful either cuz um...2 years ago, we went a few times with her [Dr. X] and she didn't say anything in any of the sessions. She basically, you know, there were like 5 minutes of total conversation out of the hour. Her total number of words she'd say, it was basically us. I just found that very unsatisfactory...* (54-year-old mother of a 16-year-old girl)

> *And talking to family and friends I found in the case of medication it's not always a good idea because everybody has very strong opinions about it and you have to make your own decision as a parent.* (30-year-old mother of a 6-year-old girl)

> *I have looked things up on the Internet and I think there's a danger in doing that [slight chuckle] because you don't know. I'm not a professional, right, so I don't know exactly what <u>all</u> [underline added] her symptoms are and what would be the best scenario for her so, um. I think the Internet, ...I don't always think it's a good thing because you can get worse-case scenarios on there and I think that that just...it adds fear where there doesn't need to be fear you know and...(LM: you have to be careful). You do, yeah. And so it's great to kind of get some information, but would I do a lot of research that way? I don't think so.* (39-year-old mother of a 10-year-old girl)

> *I would be on the Internet, yeah. And I would... the sites, though, I would be very careful what sites I would be looking at. It would have to be a medical site, not just one that somebody put up, but a "Mayo clinic" type of thing...something reputable.* (45-year-old mother of a 14-year-old girl)

> *Internet probably. (Wife: Yeah, I mean really). It's the most accessible – you can get just about anything on the Internet. But you can get crap on the Internet, too, if it's not credible, right?* (34-year-old father of a 12-year-old boy)

Parent information needs - what do I need to know? Parents were asked to describe the types of information they would find important if they were making a decision about treatment for their child's anxiety. Information needs that emerged include information related to the health-care provider and basic information about anxiety. Several types of information needs were also identified when parents were asked to describe their information needs for psychosocial treatments (i.e., child-focused and parent-focused interventions) and medication treatment. In general, parents seemed to have some difficulty distinguishing specific information needs for the two psychosocial interventions, which may be likely due to the similarities between these approaches.

Consistent with their role as a protector of their child and concerns about trust, parents frequently expressed a desire to obtain information about the health-care provider, particularly information about his or her position, training, experience in providing care, and ability to relate to children. As reported by this parent:

> *Who's going to be helping? Who's this person? What's their background? What are their credentials? How much experience do they have? Have they worked with kids before? Do they have kids of their own? All that – I need to know all of that.* (39-year-old mother of an 8-year-old girl)

In a few cases, parents indicated interest in obtaining basic information about the nature of child anxiety (e.g., symptoms, etiology), and ways for them to cope with their child's anxiety. This included a desire for information from the provider about what parents need to do or how to respond to their child.

For both psychosocial and medication treatments, parents commonly wanted information about the content of treatment. This referred to information about what is involved in treatment, the approach that will be followed, the format of treatment,

questions the provider will ask, and the way (multiple) treatments will be coordinated. This was expressed in various ways by parents:

> *Um, I would be looking for, just you know, basic information on um, what types of [slight pause] what types of procedures, what kinds of things they will cover, what will be involved?*(44-year-old mother of an 18-year-old girl).

> *Well, I would like to know what the one-on-one whatever therapy would consist of. I would like to...be very aware of what, you know, methods are being used, what the philosophy behind the methods are.* (42-year-old father of a 9-year-old boy)

> *Yeah, ...like more of the details of the treatment like whether it's one-to-one counselling, once a week, once a month, three times a week, inpatient or group therapy, or kind of like, yeah a lot of the details.* (54-year-old mother of a 16-year-old girl)

Parents commonly wanted information about the treatment's length, effectiveness, and goal or outcome. They less frequently wanted information about the frequency of treatment, treatment setting, and scheduling of appointments. A few parents mentioned information about the time period required to see improvement in the problem, future applications of treatment, and the age-appropriateness of treatment. While most parents described certain types of information, some expressed needing to know many different types of information, as captured by this comment:

> *Um, ...the types of conversations that would be held. The duration, the place, the time, of course, who she will be seeing...I guess would be primary. Um, ...yeah, and what is the outcome? What are we supposed to realize from the provider's point of view?* (42-year-old mother of a 15-year-old girl)

Needing information about the various roles taken on by the parent, child, and the health-care provider in treatment was also identified by some parents.

> *I think it would be important for me to know exactly what my role will be [slightly emphasized] and where do I leave my role behind and let somebody take over? And where do I take over and let somebody else stay behind, kind of thing? So I think it would be important to have that defined – if there's a specific kind of treatment that needs to be done.* (39-year-old mother of a 10-year-old girl)

In considering the possibility of pharmacological treatment, parents indicated that they would want to have information about the short- and long-term effects and side effects of medication and other aspects of medication treatment:

> *I would just need to know like everything. [slight chuckle] Everything about the medication – side effects, how many kids are on it?, Who's on it?, Why? Um,...just as much information as humanly possible. How long? What's it going to do? How is it going to affect her?* (39-year-old mother of an 8-year-old girl)

> *I think for me, the information that I would want would be: how is it going to affect her moods?, is it going to bring her down?, is it going to keep her sort of in a zone, kind of thing? Um, is it going to increase weight gain, which a lot of antidepressants do? That's a concern.* (39-year-old mother of a 10-year-old girl)

Other information needs about medication that were less frequently commented on were information about dosage, dependency on medication, the effects of discontinuing medication, how the medication works, and how the doctor decides on which medication to prescribe.

> *Well, [sighs] I guess the information definitely: what kind of side effects that the medication would have, um, how, well how much she would have to, how they would go about deciding which medication for her and how much, and um. And I guess how long – like would she have to be on it forever or would she be able to eventually go off of it, or that kind of stuff?* (44-year-old mother of a 10-year-old girl)

Information that parents do not want to receive. Parents were also asked if there are any types of information they would not like to have in considering their decision. Despite the limited responses to this question, some parents indicated that they would not want information about treatments inappropriate for children of their child's age, information about medication, information that was anecdotal (i.e., not research-based), and information unrelated to their child's specific problem (e.g., getting information

about treatment for a child's fear of the dark when their own child experienced exam anxiety).

Parents Have Different Perspectives on Psychosocial and Medication Treatments

In order to explore in greater depth the kinds of information that would be helpful to parents, we asked about the benefits they might expect and the risks or worries they might see from each major form of treatment: child-focused and parent-focused psychosocial treatments, and medication treatments. From this inquiry, a fourth and final theme emerged which revealed that parents have different perspectives on psychosocial and medication treatments.

Many parents hoped to see a variety of benefits from psychosocial treatments, which can be categorized into child-related benefits and parent-related benefits. The most commonly reported child-related benefit involved the child gaining a sense of control or having the ability to manage his/her anxiety. Most parents also frequently described the child learning different skills or acquiring tools as a benefit of psychosocial interventions:

> *Well I think it would help her get some control over her fears at that particular instance. I think that it would give her some self-control that she could feel she's got a tool to manage some of that. So kind of learn its place...yeah, it's a like a tool.* (54-year-old mother of a 16-year-old girl)

> *It would give her the tools. I mean, certainly I'm not going to be around all the time so it's important she learns how to deal with it herself and that she doesn't rely on hospital staff or myself or other family members to...lift her up. I think she needs to learn to use those tools to do it herself.* (39-year-old mother of a 10-year-old girl)

Other benefits that were frequently noted included the child being able to function on a daily basis and having the opportunity for the child to express his/her feelings in therapy. As described by these parents:

> *Ah, only in the sense that if it could keep her um...in a place where it would make it easier for her to function. Um, you know, in being able to get treatment (LM: uh-huh), in being able to get counselling, um, or participate in whatever it is she needs to do.* (44-year-old mother of an 18-year-old girl)

> *Well I think there's I think at times if he becomes quite comfortable with the therapist, there might be things that he might share that he may not share with his mom or dad for certain reasons, whatever they may be. Um,...so I think it's valuable for him to be able to have an outlet to be able to talk about some of these things outside of the family.* (42-year-old father of a 9-year-old boy)

With respect to parent-related benefits, a majority of parents indicated a benefit that psychosocial treatments would help the parent assist the child with the therapy progress/sessions.

> *It might...umm...some simple information on how to deal with [child's name] when she's in the grip of her fear and how to deal with her, and how to help her with her lessons or whatever as she's going through the process. Now that's sort of assisting her outside; that would be of great help. Sort of, you know, reinforcing things at home for her.* (50 -year-old mother of a 9-year-old girl)

A handful of parents indicated that a benefit of psychosocial treatment was to help the parent relate to or understand the child's problem and support the child in treatment.

> *Oh because that way, we can relate to her when, if she comes to me to talk about what she's doing or experiencing or what she's trying to do. It's much easier if she knows that I understand. I know where she's coming from.* (48 year-old mother of a 17-year-old girl)

Other benefits that were less frequently noted include parents acquiring knowledge from the provider, parents gaining a sense of empowerment/control, the non-invasiveness related to psychosocial interventions, and the normalization of receiving treatment for an anxiety problem.

Some parents described concerns about psychosocial treatment such as the child's lack of response to treatment, negative experience from treatment, or the child's difficulty implementing treatment by herself (i.e., child-focused intervention).

> *Um, [pause]...I guess like anything else. Just...I would just hope that it would be helpful for [child's name] in the end and not do any more damage or be a scary or be too difficult an experience for her.* (36-year-old mother of a 4-year-old girl)

> *I guess, too, I don't know if she would quite carry out what it is that they're trying to get her to do. If it's just between her and them, then I don't know if she would maybe even get the full understanding of what it is they're, you know, discussing or whatever, so that too would be, I think one of the reasons why I wouldn't feel comfortable about just that approach.* (44-year-old mother of a 10-year-old girl)

Additional concerns that were less frequently reported by parents include the change required by parents in treatment, parents' exclusion from involvement in their child's treatment, treatment going "off-track" and negatively affecting the child, and concern over disclosing the family's private issues in public during the course of treatment. For example, as stated by this parent:

> *Well, in all honestly the thing is...the whole idea of psychiatry becomes like...There's people digging into your head, you know. What's going to be dug up? Again, an example, Dr. [name] said to me, he said...we were talking about my mom and he says, "You have a certain amount of rage over that." I'm there like, "What?" [laughs a little]. I didn't think so; I thought I dealt with my mother's past, but he said, "You have a certain amount of rage." And I thought, "Boy, you missed that one." ... Just the other nonsense that all of a sudden comes into action and it takes the focus off what we're trying to do, I think.* (49-year-old father of a 10-year-old boy)

A few parents did not prefer specific psychosocial approaches (i.e., child-directed therapy, parent/family-directed therapy), although this was rarely reported. This was usually related to having a preference for one form of intervention (e.g., individual child therapy) over another (e.g., parent-focused therapy).

When parents were asked in what ways medication would be helpful or useful for their child if they were considering this as a treatment option, the majority stated that they did not view medication favourably. Despite this strong sentiment, it seemed that some would consider it if the benefits outweighed the risks, and if other (non-pharmacological)

options had been tried. A few parents expressed a positive view of medication (e.g., medication used as a temporary tool) or recognized the usefulness of medication in extreme cases to help a severely anxious child. Some parents also indicated that medication might be beneficial in alleviating symptoms of anxiety or possibly correcting some kind of chemical imbalance. A few parents expressed the view that medication might allow more rapid progress in treatment.

Many parents expressed concerns about medication use in children and reluctance to consider this form of treatment for their child.

> *I just don't like, I've never liked, because I work in the health-care field, to alleviate symptoms of an illness to eventually cure it or treat it or control it, that's fine. But I have a problem with medications used for, um, particularly antidepressants and anti-anxieties cuz I always believe they stem from a root and sometimes I'm worried that we're not looking at the root. We're just looking at the symptoms.* (48-year-old mother of a 17-year-old girl)

> *I'd like to know why on earth they came up with the idea. Umm, I'd be very, very reluctant to consider medication. I don't think that's an appropriate thing for this case [pause]. She lives her daily life fine... you know. She doesn't need medication all the time for anything.* (50-year-old mother of a 9-year-old girl)

Some others seemed to have ambivalent opinions about medication – recognizing the risks while also accepting the potential, positive effects it might have:

> *Medications such as antidepressants are...it's nothing any parent wants to see their child on long-term; however, I think you come to accept that if it's necessary, then um, it's something you live with.* (44-year-old mother of an 18-year-old girl)

> *I'd always be concerned about taking any kind of medication because of other conditions that you could have or develop. And you don't really want to, if you can help it, you don't want to be on medication. But if it'll make you feel better, then you should be.* (45-year-old mother of a 14-year-old girl)

Consistent with their preference for non-pharmacological approaches and their desire for information about medication side effects, parents expressed concerns about

the side effects of medication treatments and possible negative effects for the child (such as changes in personality, weight gain, drug dependency, and risk of suicidal behaviour).

> *I wouldn't...you know she's a pretty high-spirited, high energy kid and I don't want a zombie walking around. Great, we don't have any anxiety attacks, but we also don't have [child], you know. I'm not up for that in any way.* (36-year-old mother of a 4-year-old girl)

> *Well I think with any medication, you know, the adverse effects. A lot of medications that if proven to be beneficial can also have most severe adverse psychological effects on people that causes deeper depression or suicidal tendencies, etc.* (42-year-old mother of a 15-year-old girl)

A few parents also expressed their concerns about their child disliking or being unable to ingest medication. In general, parents seemed to have more concerns about medication (e.g., safety) compared with therapy/counselling (e.g., child's lack of response to treatment), and viewed medication as a last resort. This seemed to be an important difference between pharmacological treatment and therapy approaches as expressed by this parent:

> *The worries? Well I would try to do it without medication cuz that's more of a worry than talking to somebody. But if the talking wasn't working and the therapy wasn't working, and the medication would help, then I would do that.* (45-year-old mother of a 14-year-old girl)

Parents' Preferences for Decision-making Involvement – Comparing Qualitative Findings With the Quantitative Scores

Following the interview, parents completed the Control Preferences Scale for Pediatrics (CPS-P; Pyke-Grimm et al., 1999) to assess their preferences for decision-making involvement. The mean score for this 5-point scale (described previously) was 2.11 (SD = .46). Fifteen of the 19 parents endorsed option 2 to "make the final decision concerning for their child's treatment after seriously considering their child's health-care provider's opinion." Three parents indicated that they would prefer "my child's health-

care provider and I share responsibility for deciding which treatment is best for my child," and one parent indicated that "I prefer to make the final decision about which treatment my child will receive." The mean rating was consistent with a prevalent theme from the qualitative findings: Parents desire information and treatment recommendations from the health-care provider while maintaining their role in making the final decision.

Study 1 Discussion

Findings from the interviews yielded rich information regarding parents' preference for decision-making involvement, how they would prefer to be involved in decision making, and the types of information they would like in making a treatment decision. Our study found that all parents preferred to be actively involved in decision making. Most parents preferred an "active-collaborative role"; that is, they prefer to make the final decision about their child's treatment after seriously considering the provider's opinion. They desired input from the health-care professional about what would be most helpful for their child, while maintaining control over decision making.

Our sample of parents was actively seeking mental health services and had previous interactions in health-care for other child-related problems (e.g., attention-deficit problems, medical illnesses), which may explain parents' strong preferences for decision-making involvement. It is likely that these parents are highly motivated and involved in their child's care, and thus, in decision making. Parents who are not seeking services for their child or those having difficulty accessing services may have different perspectives regarding their involvement in decision making. Additionally, our sample of parents had relatively high levels of education and came from various professional backgrounds such as nursing, mental health, teaching, social work, pharmacy, retail, and business

management. Preferences for decision-making involvement and views on decision making of parents with less education or coming from a situation of more limited resources may differ.

Parents viewed themselves as having an important role in making treatment decisions that were in the best interest of their child. They also viewed themselves as protectors of their children. Parents reported that they would typically weigh the pros and cons about a particular treatment, and ensure their treatment decision would benefit the child. This is consistent with other qualitative research which has shown that parents express a sense of responsibility for and expertise concerning their child (Pyke-Grimm et al., 2006), and indicate knowing what is best for their child (Hallstrom & Elander, 2004).

When we asked parents to consider their role in the process of making a decision, we found that most had not consciously thought about the process of making a decision about treatment. Although the process of making a treatment decision was not explicit, parents were able to express their opinions about how they could best be involved in decision making. With some prompting to think about the decision-making process, parents indicated that decision making would first begin with *gathering information*, including information about the treatment choices/options and the characteristics (e.g., side effects, effectiveness) of each of the treatment options. They would also *obtain the health-care provider's opinion* and seek recommendations as part of their information gathering. Parents would then *evaluate the information,* which could involve discussing it with the provider or family or seeking out more information through independent research (e.g., searching the Internet, talking to friends). From this, parents would *make a treatment decision* on their own or jointly with the provider in the context of what is in

the best interest of the child. Once a treatment is chosen, parents would continue to monitor the treatment's impact on the child. If the chosen treatment is not as effective as hoped, parents may engage in the decision-making process again in considering another type of treatment. Revisiting decisions about medication treatment for children have been shown to be common among parents (Brinkman et al., 2009).

Parents' description of a decision-making process corresponds with some research on parent decision-making for child health issues. Parents have been found to desire active participation, seek out information from multiple sources, weigh alternatives, and make the best decision for their personal life situation when considering a child's cardiac transplant (Higgins, 2001). Our findings are also consistent with a systematic review of parents' decision support needs which showed that parents desire time to process and discuss information and prefer control over the process of making a decision for their child's health (Jackson, Cheater et al., 2008). A similar decision-making process has been described in studies of women making decisions about treatment for breast cancer (O'Brien et al., 2008) and patients with osteoporosis (Fraenkel & McGraw, 2007). Previous studies have examined different aspects of decision making (e.g., parental beliefs in decision making, Sturm, Mays, & Zimet, 2005) and parents' experiences in decision making (Lan, Mu, & Hsieh, 2007) within the context of child health problems. The scarcity of research on parents' decision-making process suggests that future research needs to examine the process by which parents make a decision for various child mental-health and health problems.

Most parents in our study had limited familiarity about treatment choices and wished to have more information about treatment. The type of treatment was an

important aspect in decision making as some parents expressed a need for more information if they were making a decision concerning medication treatment as compared to a psychosocial treatment. Age of the child was considered to be another important factor in parents' decision-making as adolescents were noted to have greater input than children in decisions regarding their treatment. No literature has examined parental decision-making in relation to child age or treatment type. However, Brinkman and colleagues (2009) identified various factors (e.g., child functional impairment, positive relationship with the child's doctor, stigma, reluctance to use medication) that parents reported to influence their decision to initiate medication for their child with attention-deficit/hyperactivity disorder (ADHD). They also found that parents experience a variety of stressors (e.g., daily struggles in parenting, conflicts between parents about treatment) in helping their child. Parents in our study expressed these similar opinions about concerns over medication, stigma, and parenting challenges.

Our study found that parents wanted an array of information such as the range of treatment options, the content of treatment (e.g., procedures, approach), the effectiveness of treatment, the length of treatment, the side effects of treatment, the short- and long-term effects of treatment and the parent's, the child's, and the provider's role in treatment. Parents less commonly reported desiring information about more administrative aspects of treatment such as cost of treatment and scheduling appointments, although this could become more important when treatment is started.

Most parents wished to receive a lot of information, although some wanted less or more depending on the treatment under consideration (i.e., psychosocial compared to medication treatment). Quality of information was equally important to quantity. Parents

indicated the value of obtaining clear, relevant information regardless of the amount that might be provided. Parents also stated that they would obtain information from various sources such as the health-care provider/other professionals, pamphlets, the Internet, and friends/family. With respect to written information, we found that parents generally placed greater trust in information contained in pamphlets/booklets provided through a specialty clinic than information obtained from the Internet.

Different opinions about psychosocial and medication treatments for child anxiety were expressed by parents. A majority of parents raised strong concerns about the potential harm that they felt might come from the use of medication (e.g., weight gain, drug dependency). A few also recognized increased suicidal risk related to medication use. While some also reported a few concerns about psychosocial interventions (e.g., child's lack of response to treatment), parents expressed greater concerns about medication. Nevertheless, although parents in our study did not prefer medication to treat their child's anxiety, some would consider it as an option if other interventions (non-pharmacological) were not helpful and if the benefits outweighed the risks.

The qualitative findings that emerged should be understood within the study's context. Most of the parents were mothers who were the primary caretakers of the anxious child. Interviews were conducted with parents of anxious children and adolescents of various ages (e.g., between 4 and 18 years) with a range of anxiety problems (e.g., separation anxiety, social anxiety). The diversity in child age and child anxiety problem meant that the sample was fairly representative of parents who are making decisions for a range of children and adolescents with anxiety. Furthermore, the majority of the sample consisted of parents who were on the waitlist for clinical services

and were considering treatment for their child, while some had just begun treatment services. We feel confident that the findings about decision-making preferences and information needs are transferable (i.e., generalizable) to other parents in clinical settings who may be considering treatment for child anxiety.

In terms of cultural diversity, however, there was little variability in ethnic background among parents who were interviewed; all but one of the participants were Caucasian. Decision making research has shown that some cultural groups may be at risk for poor health and treatment outcomes (e.g., Hawley et al., 2008; Yearwood, 2007). Attitudes and customs of some cultural groups may also affect participation in decision making. Patients from some cultures (e.g., Latino) may be reluctant to ask questions of health-care providers because providers are seen as authority figures and repositories of specialized knowledge (Cortes, Mulvaney-Day, Fortuna, Reinfeld, & Alegria, 2008). The extent to which our results concerning parents' preferences for decision-making involvement and their information needs are transferable to other cultures and families with diverse backgrounds (e.g., ethnic minority group, socioeconomic status) need to be further explored. Issues about cultural variations in preferences for shared decision-making and on the use of decision aids have begun to gain recent attention (Charles, Gafni, Whelan, & O'Brien, 2006).

It is also important to acknowledge the possibility of gender differences in decision making. In our contacts with families for the qualitative interviews, we asked to speak to the parent who spent the most time with the child and in the vast majority of cases this was the mother. The views of parents who did not participate in this study are important to consider. Gender differences have been reported in decision making as

female patients have been found to have a greater preference for an active role (Arora & McHorney, 2000) and shared decision-making role (Salkeld, Solomon, Short, & Butow, 2004) when making medical decisions. There are also differences in the types of information preferred by men and women. Some research has found that men receive significantly more information and experience greater satisfaction with practitioners meeting their information needs compared with women (Stewart, Abbey, Shnek, Irvine, & Grace, 2004).

Study 2

Data from the qualitative interviews (Study 1) were used to develop the questions for a quantitative survey on parents' information needs for decision making regarding treatments for child anxiety. The goal of the survey was to understand the opinions of a wide range of parents with varying characteristics concerning their desire for decision-making involvement, views on the importance of different types of information about treatment, preference for the amount of information received, and preference for the source of information. This quantitative study also had an exploratory purpose. It sought to explore whether child factors such as child age, the severity of the child's anxiety problem, and parent characteristics such as parent age and education, parental stress, and parenting efficacy and satisfaction may be related to parents' preferences for decision-making involvement and their preferences for information.

Methods

Recruitment and Sample

Parents were recruited from four different settings. One source was the Anxiety Disorders Service for Children and Youth (herein referred to as the Anxiety Clinical Service) at St. Boniface General Hospital, which has multidisciplinary staff who provide clinical services to a large number of children and families in the Winnipeg Health Region and surrounding areas. Another recruitment source was the Anxiety Disorders Program (herein referred to as the Psychology Research/Teaching Service) at St. Boniface General Hospital, which is a teaching and research service focusing on psychosocial interventions for anxiety in children and adolescents. A third source of recruitment was large public information meetings for parents of anxious children

organized by the Anxiety Disorders Association of Manitoba (ADAM) and offered by staff from the Psychology Research/Teaching Service. The fourth recruitment setting was a seminar group, provided by staff of the Psychology Research/Teaching Service, which focused on teaching parenting strategies to parents of anxious children.

Parents of children seeking services from the Anxiety Clinical Service and Psychology Research/Teaching Service routinely receive a questionnaire package in the mail prior to their initial appointment as a part of the programs' assessment of needs. The programs ask that the clinical materials be completed by the parent who spends the most time with the child. The Study 2 survey (see Appendix J) was included in the package of clinical materials sent to families, along with an information sheet describing the research. Parents were informed that the survey is voluntary and that the decision to complete or not complete the form and the information they provide would not influence the services that they were offered. Both the clinical and research materials were returned by mail or at the child's first scheduled appointment in the respective program. The forms were returned to the program secretaries; the clinicians offering services were not aware of the parent's participation in the study. For those who participated, all parents provided written consent (see Appendix J) to complete the survey/questionnaire and for the use of some of the information provided in the clinical forms (e.g., permission to use information from the Spence Children's Anxiety Scale – Parent report in the Anxiety Clinical Service). Honoraria of $10 gift cards to Safeway were introduced midway through data collection to provide an incentive for participation and to recognize the parents' time in completing the survey.

From January to December 2008, a total of 149 survey packages were mailed out to families on the Anxiety Clinical Service waitlist. Sixty-six surveys were returned: 44 of them were complete (40 with honoraria, 4 without honoraria) and 22 were returned incomplete/blank. This resulted in a 29.5% response rate. Three sets of surveys were not included as the parents had completed the materials previously in one of the other recruitment settings - one parent from the public information night and two parents from the parenting seminar group. In the Psychology Research/Teaching Service, there was a 45% response rate as 9 surveys (7 without honoraria, 2 with honoraria) were completed out of approximately 20 surveys that were mailed out to families on the waitlist.

The public information meetings were advertised and held by the ADAM on two evenings in February and March 2008. The information sessions were attended by various individuals, including parents (some couples from two-parent families) with and without children, health-care providers, educators, and students who were interested in this issue and/or working with anxious children. At these information sessions, two members of the research team (L.M. and J.W.) distributed surveys to all attendees. At the start of the session, participants were informed about the study (e.g., purpose, time frame) and that participation in the survey was voluntary. At the end of 2-hour session, parents were reminded about the study and requested to complete and detach the enclosed contact slip if they were interested in participating in the survey. Across two information nights, 110 people attended the sessions and 35 parents left contact slips and took home the survey. In making follow-up calls, two were too busy and did not return their survey, four indicated that they were no longer interested in participating in the survey, and two

parents could not be reached by telephone. Hence, a total of 27 surveys of 35 were completed and returned, which resulted in a 77% response rate.

The parenting seminar group consisted of 2-hour sessions that occurred once a week for four consecutive weeks. Parents were looking to learn strategies for parenting their anxious child and self-referred from various communities in the city. The seminar series was publicized by the ADAM in the public information meetings it organized and through its newsletter and its website, as well as through the Psychology Research/Teaching Service at the Hospital.

During the parenting seminar group, surveys were distributed and introduced by the student researcher (L.M.) at the beginning of the third session. Parents were informed about the study and the honorarium for completion of the survey. At the end of the session, if parents were interested in participating they were asked to complete and detach the contact slip from the survey package so that follow-up contacts could be made. They were also told to return the completed surveys (if they wished to complete it) at the next session. Follow-up telephone calls were made two to three weeks following the end of the fourth (last) session. Twenty-two individuals were registered for the parenting seminar; however, one dropped out and two others did not have children and were attending to assist another parent. Thus, 19 parents attended the seminar and were eligible to participate. Among this sample, three parents had also attended one of the ADAM public information sessions. Responses from the survey they first completed and returned were accepted from these parents. There was an 81% response rate as 13 of the 16 surveys that were distributed and taken home were completed and returned.

The survey study consisted of a convenience sample that totaled 93 parents across all recruitment sources: 44 from the Anxiety Clinical Service; 27 from the ADAM public information nights; 13 from the parent seminar group, and 9 from the Psychology Research/Teaching Service. There were a total of 89 mothers and 4 fathers. The average age of parents was 39.7 years (SD = 6.1). Mothers and fathers had similar levels of education, approximately two years post-secondary on average. Parents reported on 48 girls and 45 boys. The ages of girls ranged from 3 to 23 years, with an average age of 10.8 years (SD = 4.3). Boys' ages ranged from 4 to 18 years, with an average age of 10.1 years (SD = 3.2). This was a reasonable clinical and community sample of parents who were concerned about their anxious child and likely considering a treatment decision.

Measures

Preference for decision-making involvement. As in Study 1, parents completed the Control Preferences Scale for Pediatrics (CPS-P; Pyke-Grimm et al., 1999) to assess preference for involvement in decision making for their child's treatment (see Appendix F).

Quantitative survey about treatment information needs. Specific items on treatment information needs were derived from the qualitative data and assessed parents' opinions concerning the importance of different types of information. Items are organized into four sections in considering different treatment approaches for child anxiety: (a) information relevant to both counselling and medication approaches, (b) information about child or parent counselling treatments, (c) information about medication treatment, and (d) information related to the service-delivery setting – such as times when appointments are scheduled and number of meetings for counselling and medication

treatments. Considering medication treatment, for example, "short- and long-term side effects of medication" was identified by parents in Study 1 as an important type of information to have when considering a medication decision. Hence, this translated into an item on the survey asking parents to consider the importance of information about: "The common short-term and long-term side effects of medication." Each item about treatment information was rated according to importance using a Likert-type scale from 0 (*not important at all*) to 8 (*very important*). The survey contained 37 items and one open-ended question which appeared at the end asking parents if there is any type of information about counselling or medication treatments for children's anxiety that would be important to them that is not mentioned. See Appendix J for a copy of the survey.

The survey was pilot tested in a sample of three parents from Study 1 and two clinical psychology graduate students. Piloting was done to ensure that the survey instructions were clear and understandable for each of the four sections, and that the items were clearly worded. Using a rating scale from 1 *(not at all clear and understandable)* to 10 *(very clear and understandable)*, all respondents rated the instructions to be very understandable, scoring between 9 and 10. They also found to wording of the items to be clear.

Preference for information amount and source of information. Following the information needs survey, parents were asked to indicate the amount of information they feel they need regarding medication treatment and psychosocial treatment. Parents indicated the amount of information they prefer on a scale representing page amounts from 0 (*0 pages*) to 5 (*10 pages or more*). This scale was created to provide concrete markers for amounts of information. Following this were questions asking parents about

their access to various sources of information at home (e.g., television, Internet). Then, using a Likert-type scale (0 = *not at all preferred* to 8 = *very much preferred*), parents responded to questions about their preference for receiving treatment information from different sources such as written information in brochures, Internet websites, video presentations, and discussions with health-care providers. See Appendix J for a copy of the items about preference for amount and source of information.

Ranking preference for source of information. After rating the importance of sources of information, parents were asked to rank order their preference for the different sources of information from most to least helpful. Additionally, an open-ended question was included asking parents whether there is any source of information they would find helpful that was not included in the ranking (see Appendix J).

Parenting Sense of Competence Scale (PSOC; Johnston & Mash, 1989). The PSOC is a 16-item self-report measure assessing parenting satisfaction and parenting efficacy. The Satisfaction subscale reflects parenting frustration, anxiety, and motivation, while the Efficacy subscale reflects competence, problem-solving ability, and capability in the parenting role. Items are rated on a 6-point scale (from *strongly agree* to *strongly disagree)* with nine items comprising the Satisfaction sub-scale and seven items comprising the Efficacy sub-subscale. An item from the Satisfaction sub-scale reads: "A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one." The Satisfaction sub-scale has demonstrated good internal consistency ($\alpha = .75$ in the initial sample [Johnston & Mash, 1989], and $\alpha = .80$ and $\alpha = .77$ in two subsequent samples [Ohan, Leung, & Johnston, 2000]). An item from the Efficacy sub-scale reads: "Being a parent is manageable and any problems are easily solved." Scores are calculated

by averaging responses with higher scores indicating greater satisfaction and efficacy. The Efficacy sub-scale has shown good internal consistency ($\alpha = .76$ in the initial sample [Johnston & Mash, 1989], $\alpha = .82$ and .88 [Lovejoy, Verda, & Hays, 1 997], and $\alpha = .80$ [Ohan, Leung, & Johnston, 2000] in subsequent samples). This sub-scale has been found to be weakly correlated with parents' general efficacy beliefs and adequately correlated with child behaviour problems (Lovejoy et al., 1997). The Satisfaction sub-scale has been shown to be correlated with measures of child behaviour, parent well-being, and parenting style (Rogers & Matthews, 2004). The PSOC has been used in studies on parent behaviour (Johnston, 1996) and intervention outcome studies of parents with children with attention-deficit/hyperactivity disorder (Anastopoulos, Shelton, DuPaul, & Guevremont, 1993) and parents of children with conduct problems (Sanders, Markie-Dadds, Tully, & Bor, 2000).

Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983). The PSS measures the degree to which situations in an individual's life are appraised as stressful. Items are designed to tap how unpredictable, uncontrollable, and overloaded individuals find their lives. The 14-item version of the scale was used in the study to assess the amount of stress in parents' lives. Individuals were asked to indicate how often they felt or thought a certain way using a 5-point rating scale from 0 (*never*) to 4 (*very often*). Scores are obtained by reversing the scores (e.g., 0 = 4, 1 = 3, 2 = 2, etc.,) on the seven positive items (Items 4, 5, 6, 7, 9, 10, and 13) and then summing across all 14 items. Higher scores indicate greater levels of stress. Factor analysis has shown that items on the PSS load on two factors: Positive and Negative (Cohen & Williamson, 1988). A sample positive item reads: "In the last month, how often have you felt that you were effectively

coping with important changes that were occurring in your life?" A sample negative item reads: "In the last month, how often have you felt nervous and stressed?" The PSS has shown good internal reliability ($\alpha = .84$ and .85 on two samples of college students, $\alpha = .86$ on a sample of individuals in a community smoking-cessation program; Cohen et al., 1983), adequate test-retest reliability ($r = .85$ for one college sample, $r = .55$ for individuals in the smoking program), and moderate correlations with life-event scores, depressive and physical symptomatology, social anxiety, and utilization of health services (Cohen et al., 1983; Cohen & Williamson, 1988).

Spence Children's Anxiety Scale – Parent Report (SCAS-P; Spence, 2000). The SCAS-P is a parent-report measure of child anxiety symptoms. It consists of 38 items tapping specific aspects of child anxiety and one open-ended, non-scored item. Parents are asked to respond to how often each item is seen in their child on a 4-point scale from 0 (*never*) to 3 (*always*). Confirmatory factor analysis provided support for six intercorrelated factors: separation anxiety, generalized anxiety, social phobia, panic/agoraphobia, obsessive-compulsive disorder, and fear of physical injuries. Internal consistencies for the subscales has been found to be satisfactory to excellent, with reliability co-efficients that were corrected for scale length, ranging from .83 to .92 for parents of clinically anxious children and from .80 to .90 for parents of non-anxious children (Nauta et al., 2004). The SCAS-P has also shown good convergent validity, both with another parent measure of child internalizing problems (Child Behaviour Checklist; Achenbach, 1991) and the child measure of anxiety symptoms (Spence Children's Anxiety Scale; Spence, 1998). The SCAS-P has also been found to significantly

differentiate between children with an anxiety disorder versus controls, and among the different anxiety disorders except Generalized Anxiety Disorder (Nauta et al., 2004).

Procedure

Parents completed the questionnaire package prior to their initial appointment for one of the clinical programs (i.e., Anxiety Clinical Service or Psychology Research/Teaching Service). For those who attended the ADAM information night or parenting seminar, study surveys were completed at a time and place convenient for the parent.

An information sheet describing the study and the consent form were included in the survey package. The "Parent Survey" package began with a cover sheet requesting background information (e.g., date, age, gender). This was followed by a question about preference for decision-making involvement (CPS-P), the quantitative survey about information needs in making treatment decisions, questions about preference for amount and sources of information, the ranking preference for source of information form, the Parenting Sense of Competence (PSOC) measure, and the Perceived Stress Scale (PSS). The measure of preferences for decision-making involvement preceded the information needs survey to prevent any possible prompting by questions on information needs on the opinions concerning preferences for decision-making involvement. The questionnaire took approximately 25 to 30 minutes to complete. Background information such as the parent's age and gender, and the child's age and gender were obtained from the cover sheet of the Parent Survey. Information about the child's anxiety was obtained from the Spence Children's Anxiety Scale – Parent report (SCAS-P), which was included at the end of the questionnaire package for parents recruited through the Psychology

Research/Teaching Service and public information nights, and routinely collected from families receiving services in the Anxiety Clinical Service program.

The Statistical Package for the Social Sciences (SPSS) Version 16.0 was used for the data analyses. Missing data (i.e., missing one or two items on a scale or missing responses on an entire measure) were handled by entering "99." Missing data for one or two items on the PSS, PSOC and Children's Anxiety Scale for five subjects were managed by calculating and substituting a mean score for the missing items. Mean scores for missing responses on the entire Spence Children's Anxiety Scale for four subjects were not calculated and thus, were not included in the data analyses. Computations and data analyses were performed on valid responses.

Study 2 Results

Multivariate analyses of variance and follow-up univariate analysis of variance (ANOVA) and post hoc comparisons were conducted to determine if there were any differences across the four recruitment groups (i.e., Anxiety Clinical Service, public information sessions, parenting seminar, and Psychology Research/Teaching Service) on several study (dependent) variables. As presented in Table 1, the largest proportion of parents came from the Anxiety Clinical Service and the smallest group was from the Psychology Research/Teaching Service. The Anxiety Clinical Service had data missing for father education ($n = 1$), information amount ($n = 1$), and the Spence Children's Anxiety Scale ($n = 4$). The Psychology Research/Teaching Service had data missing ($n = 1$) for information amount. As a result, these data were not included in the multivariate analysis of variance. Results found a non-significant multivariate F test, Wilks' $\Lambda = .58$

Table 1

Comparison of Parents From Various Recruitment Groups on Study Variables (N =86)

	Recruitment Group					
	Anxiety Clinical Service (n = 38)	Public Info. Sessions (n = 27)	Parenting Seminar (n = 13)	Psych. Research/ Teaching Service (n = 8)		
Parent or child characteristic	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)	*F*	*p*
Mother's education	14.0 (2.5)	15.5 (2.5)	15.9 (2.6)	15.4 (2.1)	2.86	.04*
Father's education	14.0 (3.2)	15.3 (2.5)	15.0 (1.8)	15.4 (2.9)	1.55	.21
Parent age	38.8 (6.1)	40.2 (6.7)	41.3 (5.8)	41.3 (4.4)	.75	.53
Child age	10.9 (3.4)	10.0 (4.4)	9.2 (4.1)	11.4 (3.3)	.84	.48
Parenting Sense of Competence – Efficacy	26.6 (5.7)	27.4 (5.0)	26.8 (6.6)	25.6 (5.9)	.23	.88
Parenting Sense of Competence – Satisfaction	38.2 (7.9)	37.3 (8.0)	36.6 (10.0)	39.4 (5.5)	.26	.85
Perceived Stress Scale	24.7 (7.3)	23.5 (7.9)	24.3 (10.8)	23.8 (7.1)	.12	.95
Spence Children's Anxiety Scale – Parent Version Total	39.9 (14.7)	34.1 (11.7)	24.5 (14.9)	32.9 (12.0)	4.35	.007**
Parent familiarity with treatments for child anxiety	4.0 (2.2)	4.5 (2.1)	3.8 (1.4)	4.5 (2.7)	0.55	.65

Preferences for decision-making involvement (CPS-P)	2.3 (0.6)	2.2 (0.5)	2.1 (0.8)	2.5 (0.8)	1.02	.39
Preferred amount of information about medication treatment	3.2 (1.5)	3.1 (1.6)	2.9 (1.6)	2.1 (1.3)	1.22	.31
Preferred amount of information about counselling treatment	3.7 (1.3)	3.8 (1.4)	3.3 (1.6)	3.3 (1.5)	.54	.66

Note. Parent familiarity with child anxiety treatments (0 = not familiar; 4 = moderately familiar; 8 = very familiar). Preference for decision-making involvement rated on a 5-point scale (1 = I prefer to make the final decision; 5 = I prefer to leave all decisions to my child's provider). Preferred amounts of information based on number of pages from 0 to 10 or more pages. Significant univariate *F*-tests were followed by comparisons among the groups using Dunnett's T3 test.

*$p < .05$, **$p < .01$

F (27, 223) = 1.18, $p > .10$; however, two significant univariate F tests were revealed by univariate ANOVAs on each dependent variable. Applying a Bonferroni correction to maintain family-wise error (alpha .05/12 variables = .004), post hoc comparisons using the Dunnett's T3 test (which assumes unequal variances) revealed that group differences in mother's levels of education and symptoms of child anxiety were not statistically significant ($p > .01$). Given these results, data from all recruitment sources were combined in subsequent analyses.

The Control Preferences Scale for Pediatrics (CPS-P) was used to assess parents' preferred level of involvement in making decisions concerning treatment for their child's anxiety. As shown in Table 2, the largest group of parents preferred to make the final decision after seriously considering the health care provider's opinion (69%).

In the survey, parents were first asked to rate their familiarity with treatments for child anxiety and 21.5% reported low familiarity, 49.5% reported moderate familiarity, and 29% reported high familiarity with treatments. Next, parents rated the importance of various types of information about treatments when making decisions concerning treatment for a child's anxiety. In order to summarize the responses, based on a review of the distribution of responses on the 9-point scale with the anchors 0 (not at all important), 4 (moderately important) and 8 (very important), we summarized the ratings as Low Importance = 0 to 2, Medium Importance = 3 to 5, and High Importance = 6 to 8. The majority of parents found every type of information to be highly important. In particular, information about the common short-term, long-term, and uncommon side effects, information about what happens when the child/adolescent stops taking medication, information about the specific types of treatment, and information about what treatment

Table 2

Parents' Preferences for Decision-making Involvement From the Control Preferences Scale for Pediatrics

Parental preference for decision-making involvement ($N = 93$)	Proportion of parents choosing each option %
1. I prefer to make the final decision about which treatment my child will receive.	6.5
2. I prefer to make the final decision of my child's treatment after seriously considering my child's health-care provider's opinion.	69
3. I prefer that my child's health-care provider and I share responsibility for deciding which treatment is best for my child.	21.5
4. I prefer that my child's health-care provider makes the final decision about which treatment will be used, but seriously considers my opinion.	3
5. I prefer to leave all decisions regarding my child's treatment to my child's health-care provider.	0

involves were found to be very high (i.e., rating above 7.80 out of 8) as shown by the mean ratings. However, mean rating scores and the proportion of parents rating information to be highly important indicated little variation in judgments of importance. Percent frequencies and mean ratings for the survey items are displayed in Tables 3 to 6.

In addition to rating the importance of different types of treatment information, a few parents ($n = 6$) responded to an open-ended question at the end of the survey items concerning other types of information that they thought was important in making treatment decisions. These parents indicated that it would also be important to receive information about the wait time to begin treatment ($n = 1$), the training of the person providing services ($n = 1$), the manner in which a resulting treatment report would be coordinated in the child's life and the school ($n = 2$), and the availability of parent and child therapies and the amount of consideration given to parental concerns and ideas ($n = 2$).

Following questions about information needs, parents responded to a question asking about the amount of information they would prefer regarding medication treatment and counselling treatments (i.e., therapy for the child or help for the parent). Table 7 indicates that the largest proportion of parents preferred 10 pages or more of information describing the treatment. The second largest group of parents indicated a preference for 4 pages of information concerning treatment.

To address the research question regarding the association between parents' preference for decision-making involvement and their preferred amounts of information, chi-square analyses were performed between CPS-P group (less vs. more active involvement) and preference for amount of information (moderate vs. high amount).

Table 3

Parent Ratings of Importance of Information About Treatments for Child Anxiety for Decision Making (N = 93)

Information Area and Survey Items	Rated as High Importance (%)	Mean rating	Standard Error	95% Confidence Interval
Information about different types of treatment available for children/adolescents with anxiety				
1. Information about the specific choices/types of treatments.	99	7.85	.05	7.75 – 7.95
2. Information about what treatment involves.	100	7.84	.04	7.75 – 7.93
3. Information about the parent's role in treatment.	99	7.75	.07	7.62 – 7.88
4. Information about the child's role in treatment.	97	7.73	.08	7.58 – 7.88
5. Information about the effectiveness of treatment.	98	7.75	.07	7.62 – 7.88
6. Information about how helpful treatment is for children and adolescents at different ages.	96	7.43	.11	7.21 – 7.65
7. Information about how treatment works.	96	7.57	.09	7.38 – 7.76
8. Information about the goal or outcome of treatment.	99	7.74	.06	7.62 – 7.86
9. Information about how long treatment takes to produce results.	90	7.25	.12	7.02 – 7.48
10. Information about how long treatment continues.	92.5	7.31	.12	7.08 – 7.55
11. Information about what happens when treatment the stops.	99	7.71	.06	7.59 – 7.83

12. Information about the common and uncommon side effects of treatment.	100	7.73	.06	7.61 – 7.86
13. Information about the advantages and disadvantages of each type of treatment.	99	7.66	.07	7.52 – 7.80

Note. Parents answered the question: "How important would it be for you to have information about [each item above]?" Responses were on a 9-point rating scale with the anchors 0 (not at all important), 4 (moderately important) and 8 (very important). Ratings were summarized as Low Importance = 0 to 2; Medium Importance = 3 to 5; High Importance = 6 to 8.

Table 4

Parent Ratings of Importance of Information About Counselling Treatments for Decision Making (N = 93)

Information Area and Survey Items	Rated as High Importance (%)	Mean rating	Standard Error	95% Confidence Interval
Information about child or parent counselling treatments				
14. Information about the format of treatment.	98	7.66	.08	7.50 – 7.82
15. Information about what the health-care provider would be doing in treatment.	97	7.52	.09	7.34 – 7.69
16. Information about what the child will be doing in treatment.	99	7.75	.06	7.64 – 7.87
17. Information about what the parent will be doing in treatment.	98	7.63	.08	7.48 – 7.79
18. Information about whether the skills learned from counselling treatment can be used in the future by the child or parent.	97	7.63	.09	7.46 – 7.81

Note. Parents answered the question: "How important would it be for you to have information about [each item above]?" Responses were on a 9-point rating scale with the anchors 0 (not at all important), 4 (moderately important) and 8 (very important). Ratings were summarized as Low Importance = 0 to 2; Medium Importance = 3 to 5; High Importance = 6 to 8.

Table 5

Parent Ratings of Importance of Information About Medication Treatments for Decision Making (N = 93)

Information Area and Survey Items	Rated as High Importance (%)	Mean rating	Standard Error	95% Confidence Interval
Information about medication treatments				
19. Information about what medications are used.	95	7.66	.10	7.46 – 7.85
20. Information about the advantages and disadvantages of one medication versus another.	97	7.75	.09	7.58 – 7.93
21. Information about how a doctor decides on which medication to recommend for a child/adolescent.	99	7.57	.09	7.39 – 7.75
22. Information about how long the medication has been used to treat anxiety in children/adolescents.	99	7.65	.09	7.47 – 7.82
23. Information about the amount of medication the child/adolescent takes and how often the child takes it.	94	7.49	.13	7.24 – 7.75
24. Information about the common short-term and long-term side effects of medication.	99	7.89	.04	7.81 – 7.98
25. Information about any uncommon, but serious side effects.	100	7.84	.05	7.74 – 7.94
26. Information about what usually happens when the child/adolescent stops taking medication.	100	7.89	.04	7.82 – 7.96

27. Information risk for dependency on medication.	99	7.80	.07	7.66 – 7.93
28. Information about areas in which there is limited knowledge about effects of medication for children/adolescents.	100	7.82	.05	7.72 – 7.92

Note. Parents answered the question: "How important would it be for you to have information about [each item above]?" Responses were on a 9-point rating scale with the anchors 0 (not at all important), 4 (moderately important) and 8 (very important). Ratings were summarized as Low Importance = 0 to 2; Medium Importance = 3 to 5; High Importance = 6 to 8.

Table 6

Parent Ratings of Importance of Information About Administrative Aspects of Treatment for Decision Making (N = 93)

Information Area and Survey Items	Rated as High Importance (%)	Mean rating	Standard Error	95% Confidence Interval
Information about other aspects of counselling and medication treatments that may depend on the program or service where treatment is provided				
29. Information about what is the training and profession of the person providing treatment.	96	7.43	.09	7.25 – 7.61
30. Information about the health-care provider's experience in treating anxiety.	98	7.62	.09	7.45 – 7.80
31. Information about when treatment would begin.	90	7.19	.12	6.96 – 7.43
32. Information about where treatment will take place.	68	6.35	.18	6.00 – 6.71
33. Information about how often the child or the parents come in for appointments.	74	6.55	.17	6.20 – 6.89
34. Information about when appointments are scheduled.	70	6.34	.20	5.95 – 6.74
35. Information about the cost of treatment.	71	6.10	.25	5.61 – 6.58
36. Information about which treatment option the health-care provider recommends.	99	7.69	.07	7.55 – 7.83
37. Information about how the parent will be informed about the child's treatment progress	92.5	7.39	.12	7.14 – 7.63

Note. Parents answered the question: "How important would it be for you to have information about [each item above]?" Responses were on a 9-point rating scale with the anchors 0 (not at all important), 4 (moderately important) and 8 (very important). Ratings were summarized as Low Importance = 0 to 2; Medium Importance = 3 to 5; High Importance = 6 to 8.

Table 7

Parents' Preferred Amount of Information Regarding Treatments for Child Anxiety (N = 93)

	Treatment type	
Information amount (pages)	Medication treatment (Proportion of parents - %)	Counselling treatment (Proportion of parents - %)
0	0	0
2	18	5
4	29	22
6	18	21
8	4	9
10 or more	32	43

Preference for amount of information was not significantly related to preference for decision-making involvement ($\chi^2 = 1.95, p > .10$).

Mean scores on the Parenting Sense of Competence (PSOC) subscales (Efficacy $M = 27.0$, $SD = 5.5$; Satisfaction $M = 37.8$, $SD = 8.0$) were found to be consistent with other community samples of mothers and fathers of school-aged children (Johnston & Mash, 1989). Thus, it appears that parents in our study felt competent and confident, and quite satisfied in their parenting role. Internal consistency (Cronbach's alpha) on the PSOC Efficacy and PSOC Satisfaction subscales were found to be .78 and .85, respectively. Cronbach alpha values at a minimum of .70 are considered to be acceptable (Nunnally, 1978).

The mean score on the Perceived Stress Scale (PSS) for this study ($M = 24.0$, $SD = 7.9$) was found to be comparable to community comparison studies. For example, Cohen et al. (1983) reported mean scores of 23.18 ($SD = 7.3$) and 23.67 ($SD = 7.8$) among their college student samples, and 25.00 ($SD = 8.0$) for smoking cessation sample. Our findings are also similar to those found among patients who were diagnosed with and reported experiencing constant symptoms of Crohn's disease ($M = 24.4$, $SD = 8.4$) and ulcerative colitis ($M = 23.0$, $SD = 7.7$), and those with less symptomatic Crohn's disease ($M = 20.2$, $SD = 7.9$) and ulcerative colitis ($M = 18.6$, $SD = 6.7$) (Graff et al., 2006). Thus, our sample of parents of anxious children appeared to experience moderate levels of stress. Cronbach's alpha for this measure was found to be .90 in our study.

Parents' ratings of their child's anxiety symptoms were measured on the Spence Total Anxiety Scale – Parent Report version. The total mean score ($M = 35.1$, $SD = 14.3$) and mean scores for the six subscales are consistent with ratings from parents of children

with anxiety disorders (Nauta et al., 2004). Internal consistency for the Total Anxiety scale was found to be good with a Cronbach's alpha of .89.

Responses on the CPS-P were categorized into a "more active" group (i.e., responses 1 and 2) and "less active" group (i.e., responses 3, 4, and 5) since the study was interested in group differences (responses "1 and 2" versus responses "3, 4, and 5"). Multiple analyses of variance were conducted to examine whether these two groups differed on various child factors (i.e., age, symptom severity) and parent factors (i.e., age, education, stress, efficacy, satisfaction). Given the exploratory nature of the hypotheses, several univariate ANOVAs were performed to explore specific relationships between each group (i.e., independent variable) and the dependent variables. Familywise Type I error was controlled by applying a Bonferroni adjustment (alpha .05/8 variables = .006) to the analyses. Results in Table 8 showed some differences between the two groups as revealed by *F* tests, although these differences were not found to be statistically significant. In light of these results, it should be noted that there was little variability in responses on the CPS-P (with the majority of parents falling in the "more active" group category), which could account for the possible statistical non-significance.

Multiple analyses of variance were also performed to examine whether differences in parents' preferred amounts of information concerning medication treatment and counselling treatment (i.e., "low/moderate" versus "high" information groups) vary with child and parent factors. Group differences were examined based on the distribution of parents' preferences for amounts of information (i.e., "4 pages" versus "10 pages and more"). To control for familywise Type I error, a Bonferroni adjustment was applied (alpha .05/9 variables = .006) to the analyses. As shown in Table 9, no significant

Table 8

Comparison of Parents' Preferences for Decision-Making Involvement on Study Variables (N =93)

	Preferences for decision-making involvement					
	More Active Involvement (n = 70)		Less Active Involvement (n = 23)			
Parent or child characteristic	*M*	*(SD)*	*M*	*(SD)*	*F*	*p*
Mother's education	14.9	(2.6)	14.1	(2.3)	1.62	.21
Father's education	14.6	(3.0)	14.6	(2.5)	.01	.93
Parent age	39.2	(5.8)	41.4	(7.0)	2.21	.14
Child age	10.0	(3.6)	11.8	(4.2)	3.77	.06
Parenting Sense of Competence – Efficacy	27.6	(5.5)	25.0	(5.1)	3.97	.05
Parenting Sense of Competence – Satisfaction	38.7	(8.1)	35.0	(7.1)	3.77	.06
Perceived Stress Scale	23.6	(8.3)	25.2	(6.7)	.69	.41
Spence Children's Anxiety Scale – Parent Version Total	34.3	(13.8)	37.6	(15.6)	.93	.34

Note. Groups of preferences for decision-making involvement based on categories: More Active = responses 1 and 2; Less Active = responses 3, 4, and 5.

Table 9

Comparison of Parents' Preferred Amounts of Information Concerning Medication Treatment on Study Variables (N =91)

	Amount of medication treatment information					
	Low/Moderate (0 – 4 pages) (*n* = 42)		High (6 – 10 pages) (*n* = 49)			
Parent or child characteristic	*M*	*(SD)*	*M*	*(SD)*	*F*	*p*
Mother's education	14.5	(2.6)	15.0	(2.5)	.93	.34
Father's education	14.9	(2.8)	14.3	(3.1)	.92	.34
Parent age	39.2	(5.5)	39.9	(6.6)	.32	.57
Child age	10.1	(3.8)	10.8	(3.8)	.87	.35
Parenting Sense of Competence – Efficacy	27.5	(5.7)	26.3	(5.3)	1.23	.27
Parenting Sense of Competence – Satisfaction	37.7	(8.1)	37.6	(7.9)	.01	.94
Perceived Stress Scale	23.8	(8.0)	24.5	(8.0)	.17	.69
Spence Children's Anxiety Scale – Parent Version Total	31.4	(13.1)	38.5	(14.7)	5.62	.02
Parent familiarity with treatments for child anxiety	3.9	(2.2)	4.3	(2.0)	.84	.36

Note. Categories of information amount based on number of pages: Low/Moderate = 0 to 4 pages; High = 6 to 10 or more pages.

Familiarity with child anxiety treatments rated on a 9-point scale (0 = not familiar; 4 = moderately familiar; 8 = very familiar)

differences in the amount of preferred medication information were found in relation to these parent and child characteristics. Similarly, no significant differences for parent and child characteristics were found in relation to preferences for amounts of counselling treatment information (see Table 10).

Parents' ratings of their preferences for receiving information from various sources are shown in Table 11. To determine whether there were any differences across the five sources, post hoc comparisons were also conducted through paired samples t-tests. A Bonferroni correction was applied in order to control for family-wise error (alpha .05/10 pairs = .005). The highest mean ratings were for information provided in written form and in discussion with a health-care provider. No significant difference was found between these two sources. Information provided from a website accessed from home was also highly rated, although it was less preferred than written information.

Parents were also asked to rank the sources of information (see Table 12). Valid data were provided by 43 participants in response to their ranking preferences; the remaining 50 responses were invalid due to problems in ranking responses (e.g., duplicate items ranked "first" or "second"). Similar to their rating preferences for sources of information, parents ranked written information as "most preferred," followed by information from a health-care provider. Information provided from a website accessed from home was ranked in the middle range (i.e., between first and fourth place) in seeking information. Information on an internet website accessed from the provider's office was found to be least preferred. Overall, across the two methods of inquiry about preferences for sources of information, parents indicated a strong preference for obtaining information in written form or through face-to-face discussions.

Table 10

Comparison of Parents' Preferred Amounts of Information Concerning Counselling Treatment on Study Variables (N =91)

	Amount of counselling treatment information					
	Low/Moderate (0 – 4 pages) (n = 25)		High (6 – 10 pages) (n = 66)			
Parent or child characteristic	*M*	*(SD)*	*M*	*(SD)*	*F*	*p*
Mother's education	15.0	(2.7)	14.7	(2.6)	.21	.65
Father's education	15.2	(2.7)	14.3	(3.0)	1.72	.19
Parent age	39.7	(5.6)	39.5	(6.3)	.02	.88
Child age	9.6	(3.6)	10.8	(3.8)	1.84	.18
Parenting Sense of Competence – Efficacy	29.0	(5.4)	26.0	(5.4)	5.47	.02
Parenting Sense of Competence – Satisfaction	38.2	(8.0)	37.5	(8.0)	.18	.68
Perceived Stress Scale	24.9	(8.1)	23.9	(7.9)	.29	.59
Spence Children's Anxiety Scale – Parent Version Total	30.7	(14.0)	36.8	(14.3)	3.1	.08
Parent familiarity with treatments for child anxiety	3.9	(2.4)	4.2	(2.0)	.32	.57

Note. Categories of information amount based on number of pages: Low/Moderate = 0 to 4 pages; High = 6 to 10 or more pages.

Familiarity with child anxiety treatments rated on a 9-point scale (0 = not familiar; 4 = moderately familiar; 8 = very familiar)

Table 11

Parents' Preferences for Sources of Information (N = 93)

Source of information	Rating preference: Low %	Medium %	High %	Mean rating	SD
1. Written information provided in an information sheet or booklet you could take.	1	20	79	6.7_{a}	1.5
2. Information provided in discussion with a health-care provider.	3	16	81	$6.6_{a, b}$	1.7
3. Information presented in a videotape or DVD which you could take.	27	30	43	4.6_{c}	2.7
4. Information on an internet website accessed at home.	6	28	66	5.9_{b}	2.1
5. Information on an internet website accessed and printed at the health-care provider's office.	30	34	36	4.1_{c}	2.8

Note. Parents were asked to indicate how they would prefer to receive information about various services. Responses were on a 9-point rating scale with the anchors 0 (not at all preferred), 4 (moderately preferred), and 8 (very much preferred). Ratings were summarized as Low Preference = 0 to 2; Medium Preference = 3 to 5; High Preference = 6 to 8. Higher mean scores indicate greater preference. Means with different letter subscripts indicate significant differences between sources.

Table 12

Ranking Preferences of Sources of Information ($n = 43$)

	Ranking preference						
	First	Second	Third	Fourth	Fifth	Prefer not to use	
Source of information	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)	Mean rank
1. Written information provided in an information sheet or booklet which you could take.	37 (16)	35 (15)	16 (7)	12 (5)	0	0	3.98
2. Information provided in discussion with health-care provider.	35 (15)	21 (9)	26 (11)	4.5 (2)	11.5 (5)	2 (1)	3.56
3. Information presented in videotape or DVD which you could take.	5 (2)	11.5 (5)	28 (12)	23 (10)	21 (9)	11.5 (5)	2.21
4. Information on a recommended internet website accessed at home.	21 (9)	26 (11)	21 (9)	23 (10)	7 (3)	2 (1)	3.23
5. Information on an internet website accessed at the health-care provider's office.	0	4.5 (2)	4.5 (2)	33 (14)	35 (15)	23 (10)	1.33

Note. Mean rank score is based on reversing the numerical ranks so 5 is most helpful/preferred and 1 least helpful/preferred. Higher mean rank indicates a more preferred source of information.

It should be noted that this ranking measure, which was developed for the purposes of the survey study, appeared to confuse parent respondents due to the format. Only about 46% of respondents answered the five items correctly by ranking their preferences from "most" (rank of 1) to "least" (rank of 5). Nevertheless, the findings were quite similar to parents' rating preferences.

After ranking their preferences for sources of information, some parents ($n = 11$) responded to an open-ended question about any additional source of information they would find helpful. Responses varied and included sources such as information from a phone line or helpline, information given at a local community location given by a health-care provider, and information from actual families who have experience with the treatment options or a parent support group. A few parents mentioned the need for a combination of discussion and follow-up (from the provider), information directly from a counselor, and recommended books to read.

Parents were asked about their access to different types of resources for information. Survey findings revealed that everyone had access to a DVD player (100%) and almost all had a television (97%) and computer with internet access (98%). While the majority had a computer with printer access (92%), fewer parents had videotape players (87%).

Study 2 Discussion

Findings from the quantitative survey confirmed and extended the results of Study 1 by examining the details of parents' information needs and their preferences for decision-making involvement. Parents wished to be highly involved in making decisions concerning their child's anxiety treatment. No parent desired to delegate the entire

decision making to the provider. Responses on the Control Preferences Scale for Pediatrics in both studies showed that 70% to 80% of parents preferred an "active-collaborative" decision-making role. The strong preference for decision-making involvement among parents of children with mental health problems is consistent with parental decision-making involvement for child health problems such as cancer (Pyke-Grimm et al., 1999) and dermatitis (Gore et al., 2005).

Parents' responses on the quantitative survey of information needs were consistent with the qualitative findings. In general, parents judged information on a wide range of treatment issues to be important when making a treatment decision. Parents rated very highly (i.e., over 7 on an 8-point scale) the need for general information related to treatment for child anxiety. This included information such as the availability of specific treatment options, the content of treatment (e.g., format, methods used), the effectiveness of treatment, common and uncommon side effects of treatment, and the effects of discontinuing treatment. These results correspond with a review study of parents' support needs for child health decisions, which concluded that parents have a strong need for information about all treatment options (Jackson, Cheater, et al., 2008). Our findings are also comparable to the treatment information needs reported by parents of pediatric oncology patients (Pyke-Grimm et al., 1999) and parents of children with rheumatic disease (Thon & Ullrich, 2009). In their study of treatment information preferences among a sample of community parents, who were not identified as having children with anxiety problems, Zacharias and Freeman (2007) found that parents strongly desired information about treatment options, side effects, and the parent and child roles in treatment. While this study involved parents responding to a hypothetical situation in

which they were considering help for a child with anxiety problems, the findings were consistent with our research, suggesting that basic information about treatment is highly desirable for parents.

There appear to be some subtle differences in parents' information needs for health problems compared to mental health problems. The subtle differences seem to lie in the focus on illness and prognosis for health problems. For example, parents of pediatric oncology patients have been shown to rank treatments and tests, and the likelihood of cure from cancer as their top information needs (Pyke-Grimm et al., 1999), which is not surprising given the gravity of cancer. Likewise, due to the nature of chronic illnesses and concerns surrounding prognosis, parents of chronically-ill children value obtaining information about the child's diagnosis, treatment, and expected outcomes of treatment (Hummelinck & Pollock, 2006). While parents of children with anxiety problems also desire information about treatment, there appears to be less emphasis on information concerning diagnosis and cure for mental health problems, as revealed in the qualitative interviews.

In addition to their desire for general treatment information, parents wanted a wide range of information related to psychosocial interventions (i.e., parent or child-focused) and medication treatment. Information about what the child and parent would do in treatment, the format of treatment, and the applicability of skills the child learns in the future were considered to be highly important. Similarly, parents noted the importance of obtaining information about the side effects of medication (i.e., short-term, long-term, uncommon), the effects of discontinuing medication, risk for dependency, and the advantages and disadvantages of one medication versus another. These findings

correspond with the needs of parents of chronically-ill children regarding information about medication management and potential complications/long-term side effects of medication (Hummelinck & Pollock, 2006). Parents of infants with atopic dermatitis have similarly reported a need for detailed information about medication treatment such as the medications available and their advantages and disadvantages (Gore et al., 2005).

Some types of information such as information about the scheduling of appointments, treatment setting, and cost of the treatment were rated slightly lower by parents (i.e., under 6.5 on an 8-point scale). Information about the logistics of treatment may be considered somewhat less important than information directly related to treatment. Interestingly, the lowest mean rating of 6.10 (although still moderately high) was for information about the cost of treatment. A possible explanation for this may be that the information was gathered in the context of a publicly funded service where parents would not pay for treatment visits to health-care providers and many parents would be covered by insurance for any medication treatment. In other situations where this is not the case, patients desire to know the cost of medication, particularly whether a medication is covered by their drug plan and whether there are more cost-effective alternative treatments available (Nair et al., 2002). Cost to the health-care system has been found to be even less relevant to parents in the community (Zacharias & Freeman, 2007) and adults with anxiety (Walker et al., 2000). Taken together, the results suggest that there may be greater preference for information that directly impacts individual well-being than information that may be less personally relevant (i.e., cost to the health-care system).

A significant proportion of parents indicated a preference for either moderate amounts of information (i.e., 4 pages) while another large proportion desired or a lot of information (i.e., 10 or more pages). As revealed in our qualitative findings, there appears to be a need for a balance between obtaining "too little" information, which may be inadequate in decision making, and obtaining "too much" information, which could be too technical, complicated, or overwhelming. It may be possible to accommodate individual preferences for amount of information by developing information that provides the key points and supplemental sections that provide additional information in areas that may be of interest to the parent. Furthermore, it may be important to consider other aspects of information other than page length such as the text size, presentation, and reading level, which could interact with an individual's literacy and comprehension of materials.

Information obtained through written materials (e.g., pamphlets), discussions with the health-care provider, and Internet websites were the three most highly-rated methods of seeking information by parents. In contrast, parents ranked information obtained on the Internet at a provider's office or information presented in a DVD as less-preferred choices. Parents' preferences for direct contact with providers and written materials are consistent with those found in our qualitative study.

Parents' preference for decision-making involvement was found to be unrelated to their preferred amounts of information. Although the majority of parents strongly preferred to be involved in treatment decision-making and desired moderate to high amounts of information, the limited variability in responses could have resulted in the lack of significant findings. Our results correspond to the mixed conclusions from

research in this area (e.g., Hack et al., 1994; Sutherland et al., 1989). Nevertheless, patients who feel they receive sufficient information tend to engage in greater participation in decision-making about treatment compared with those who receive insufficient amounts (Sainio & Lauri, 2003). Provision of information also enables patients to participate in decision making (Beaver et al., 2005). While patients may desire shared decision-making, some may feel that they should not be involved because they lack essential knowledge (Charles, Redko, Whelan, Gafni, & Reyno, 1998). Although information may be crucial in facilitating participation in decision making, individuals who desire information may not necessarily want to make the choice or take control in making the treatment decision. It has been suggested that some people may actively seek information to satisfy an aspect of "psychological autonomy," which is the capacity of a person to become informed so he/she may exercise the right to self-determination (Katz, 1984). Some persons may express their autonomy by choosing to participate or not participate in decision making (Kaplan, 1987).

Parents' preferred amounts of information for medication and psychosocial treatments were not shown to significantly vary with any child or parent factors. However, there was a tendency for parents desiring a lot of information about medication treatment to report greater symptoms of child anxiety compared to parents who prefer moderate-to-low amounts of information. It is possible that parents with highly anxious children may want to seek a substantial amount of information concerning treatment of their child's difficulties, or they may be more open to considering medication (given the severity of the anxiety problem). With the exception of one study on preferences for decision-making involvement and parental satisfaction for pediatric anaesthetic care

(Tait, Voepel-Lewis, Munro, & Malviya, 2001), the influence of parent or child characteristics on parental decision-making has not been explored in quantitative research.

Sample Issues and Generalizability

A number of issues should be considered in evaluating the results of this study. Our survey recruited parents from various sources, which yielded a reasonably large and diverse sample. As in Study 1, parents either had their child on hospital waiting referral lists for treatment services or were seeking information about child anxiety and parenting. The majority were recruited from a mental health program, which receives referrals for children and adolescents with significant mental health issues. Many parents were also recruited from public information sessions where they sought information about child anxiety. Thus, overall, parents were invested in seeking treatment services or treatment information for their child. Parents were also reasonably educated and generally reported that they were quite effective and satisfied in their parenting role. They experienced moderate levels of stress and their children were reported to be clinically anxious. Overall, the study findings appear representative of a broad range of reasonably educated parents of children and adolescents with significant anxiety problems. The information needs reported in the study appear to be generalizable to a population of middle-class parents considering treatment decisions for their child's anxiety.

It is important to note that our sample consisted of mature parents who had their children when they were relatively older and as such, may desire to obtain information that may be different from those desired by younger parents. Parental age has been shown to be associated with different parenting domains such as parenting practice (Bornstein,

Putnick, Suwalsky, & Gini, 2006) and parenting satisfaction (Ragozin, Basham, Crnic, Greenberg, & Robinson, 1982). Our results might have also differed among families in disadvantaged circumstances (e.g., trouble accessing services, greater stress, or lower socioeconomic status), parents with limited education, or parents with a child with anxiety who were not seeking help. Furthermore, our results might have differed among fathers given that the majority of our sample were mothers.

Our findings on parents' strong preference for decision-making involvement likely reflect true preferences among educated and invested parents. However, it is possible that social desirability could have played a role. Parents might have felt compelled to answer positively about their degree of desired decision-making involvement for fear of being cast in a negative way or judged to be less invested or responsible in their child's care. This remains speculative at this point as no research has examined the influence of social desirability on decision making.

Overall Discussion

Our research is the first to examine parents' decision-making and their information needs for the treatment of child anxiety. We aimed to address several research questions about parents' preferences for decision-making involvement, their role in decision making, and the types of information they find most important in making treatment decisions for child anxiety. Parents desire information, and time to process and discuss information when making decisions for their child's health, which is consistent with the research (Jackson, Cheater, et al., 2008). Our findings suggest that it would be important and worthwhile to involve parents in the decision-making process by explicitly communicating to parents that there is a decision to be made. The *process* of making a decision would be important to establish at the outset of an initial meeting. An open discussion is needed to determine the provider's and parents' role or involvement in decision making. Providing time to make a decision as well as information about the problem and treatment options would also be important.

While we know that parents prefer to be involved, parents may require encouragement to actively engage in decision making through discussing their preferences, asking questions, and seeking information. This two-way process of decision making between parents and providers is important in the practice of family-centred care (FCC), which involves facilitating collaboration between parents and professionals, and sharing complete, unbiased information with families on a continuous basis in an appropriate and caring manner (Franck & Callery, 2004; Hutchfield, 1999; Shelton et al., 1987). Our research suggests ways in which providers may communicate more effectively and efficiently with families who are seeking treatment for child anxiety by

attending to their needs and answering their questions. This shared interaction and exchange of information can promote a family-centred approach to service provision. Family-centred help-giving practice has been shown to be related to greater individual satisfaction with practitioners, stronger self-efficacy beliefs in individuals, greater perceived helpfulness of supports and resources, and greater positive effects on parenting and child behaviour (Dunst, Trivette, & Hamby, 2007).

Our understanding of parents' role in decision making and their description of the decision-making process is a new contribution in the field of parental decision-making for child mental health problems. Our research fits well with existing theoretical frameworks such as Charles et al.'s (1997) decision-making continuum model (i.e., paternalistic, shared, informed) and Pierce and Hicks's (2001) interactive decision-making framework (i.e., patient characteristics, contextual factors, decision problem). Parents' preference for active involvement in their child's treatment decision and their equal desire to receive input from the health-care provider closely reflects Charles et al.'s (1997) description of shared decision-making. Shared decision-making occurs when both parties are involved in decision making, share information about treatment, and come to a consensus about the treatment chosen (Charles et al., 1997). Corresponding to Pierce and Hicks's (2001) interactive framework, our findings reveal that decision making consists of interactions between individual differences (e.g., treatment preferences), aspects of the decision problem (e.g., treatment choices), and the context (e.g., relationship with the provider). In other words, beyond parents' preferences for involvement, factors such as parents' treatment preferences, the accessibility of treatment services, the range of

treatment options, and the interpersonal relationship with the provider appear to influence a treatment decision for children's anxiety.

Considering both the qualitative and quantitative studies, we found that parents in clinical and community settings strongly preferred to participate in decision making about treatment for their child's anxiety. This preference and desire for control in decision making are likely explained by parents' feelings of responsibility as guardians and their protective role in ensuring the health and well-being of their children. We found higher parental preferences for decision-making involvement for child mental health problems than those reported in studies on parent decision-making for child health problems (Gore et al., 2005; Pyke-Grimm et al., 1999). This difference may be attributed to the nature of the different types of problems (as noted by one parent in the qualitative study). Compared to the life-threatening potential of serious medical problems like cancer and their impact on a child's physical health, parents may view mental health problems such as anxiety to be less life-threatening, less medically complicated, and likely more familiar. Some of the psychosocial treatments for children's anxiety (such as problem solving, facing fears, realistically evaluating threat), for example, may be familiar and understandable to many parents. In contrast, the complex treatments associated with serious medical problems may leave parents feeling poorly equipped with the knowledge to assume a truly active role in decision making. As a result, they may feel that they have less input in making a decision, and feel more dependent on the provider to make a treatment decision.

Parents' preferences for decision-making involvement may differ from their actual participation when a decision is made. While our research focused on preferences,

it is important to recognize the distinction between *preferred* and *actual* decision-making. The actual decision-making process may deviate from parents' preferences or ideas as we found that parents often find that health-care providers do not make their role in decision making clear, and do not describe the possible treatment choices and the advantages and disadvantages associated with them. Future research is needed to compare parents' ideal or preferred decision-making with their actual decision-making in real-world health care settings. By understanding the actual decision-making process, we can address any discrepancies with parents' preferences for decision making, which would be helpful in improving services to children and families.

Our research suggests that some factors may affect parents' preferences for decision-making involvement (e.g., parental efficacy, child age). Type of treatment (i.e., medication compared to counselling) was also found to be important in considering what information to provide to parents. The qualitative study indicated that parents identified trust in the person providing service as being important in decision making. Providing clear information about treatment choices and about the qualifications of the clinician may support the parent's trust and comfort with decision making. Additionally, various factors such as the relationship with the provider, the stigma of having a mental health problem, differing opinions from other family members, and home stress were noted by parents to influence their decision making. Similar concerns have been reported by parents making decisions about ADHD medication for their child (Brinkman et al., 2009). Future studies could further explore these variables using qualitative methodology (e.g., interviews, focus groups) to gain a better understanding of their influence on parental decision making. Building on our quantitative findings, future research could test

additional hypotheses to examine whether other individual variables (e.g., parental stress, child symptomatology) are associated with parents' preferences for decision-making involvement.

Although parents strongly desire involvement in decision making and have a high need for information, the relationship between the two is unclear. Given the mixed evidence from patient research (Davison et al., 1995; Hack et al., 1994; Sutherland et al., 1989), it would be worthwhile to study whether provision of treatment information increases parents' decision-making involvement. Also, do some sources or forms of information (e.g., written versus verbal) contribute to decision-making participation better than others? Additionally, given the association between decision-making participation and positive health outcomes such as emotional well-being (Guadagnoli & Ward, 1998), it would be interesting to examine this in outcome studies. Do individuals who acquire information make informed decisions, which, in turn, result in greater satisfaction or treatment adherence? For individuals facing difficult treatment or screening decisions, decision aids have been shown to be better than usual care interventions in helping individuals acquire greater knowledge, but do not affect satisfaction with decision making, anxiety, and health outcomes (O'Connor et al., 2009).

Parents consider information a crucial factor in facilitating informed decision-making. However, they have difficulty pinpointing their information needs as they often do not know the right questions to ask or what information is available (Hummelinck & Pollock, 2006). Our survey on information needs may assist in developing information materials about child anxiety treatment for parents. The symptoms of child anxiety, the etiology of child anxiety, the types of treatment for child anxiety, pros and cons of each

type of treatment, the effectiveness of treatment, and the side effects of treatment are topics that decision aids need to address. Information about procedural aspects of treatment (e.g., cost and scheduling of appointments) may be less relevant to consider during decision making, but may become more pertinent once a treatment decision is made.

When given the choice, patients generally prefer more rather than less information and want detailed information when they receive written information (e.g., leaflets; Grime et al., 2007). Like patients, we found that parents of anxious children generally want considerable amounts of information about treatments for child anxiety, whether this is provided in brief pamphlets or lengthy booklets. Despite their desire for substantial information, parents tend to receive inadequate information when deciding treatment for their child (Gore et al., 2005; Hummelinck & Pollock, 2006). It would be important to not only provide parents with a quantity of information, but to also ensure that they receive quality, pertinent information to help them make informed treatment decisions. Our findings further suggest that clinicians should consider providing detailed information about medication and counselling treatments to parents and allot time to discuss and respond to parents' specific concerns when working with families with anxious children. Nevertheless, time constraint is often a barrier to implementing shared decision-making (Gravel, Légaré, & Graham, 2006) and may hinder health-care providers from providing parents with appropriate quantity and quality of information.

Various sources of information are sought when making a treatment decision. We found that parents tend to prefer seeking information through written or verbal means, which suggest that these may be good avenues to channel information. However, when

given a choice, we found that parents have slightly higher preferences for face-to-face interactions over other methods of seeking information since this provides opportunities to discuss information, ask questions, and converse with a health-care provider during the decision-making process. Some parents prefer information delivered on a verbal, one-on-one basis by a professional, supplemented by accessible, written materials that are condition-specific and age-appropriate to the child (Jackson, Baird, et al., 2008). This viewpoint is further shared by patients who have reported valuing spoken information from the professional more than written information because of the means by which information is tailored to the individual patients' needs (Grime et al., 2007). However, while medical providers (Pain, 1999; Thon & Ullrich, 2009) and other professionals (e.g., nurses and social workers, Ruccione et al., 1991) have been found to be important sources of information for parents, there are challenges such as access to health-care professionals or individual comfort in asking questions, which can make it difficult to receive spoken information.

Practically, given the time constraints associated with medical/health appointments, providing written information (as pamphlets or recommended websites) to parents could help support them by focusing on issues and generating questions to ask during consultations with a service provider. Written materials can be used by parents as well as service providers to assist in discussions. Written information may also assist parents by allowing greater time to review and process information before and after discussions with the provider. This may help parents retain the information and/or refer back to the materials when questions about various treatments arise. It would be difficult to communicate information orally and for parents to remember without the use of

written materials. Given the difficulties in recalling verbal information during doctor appointments (Garfield et al., 2004), repeated opportunities for providing and tailoring information during the initial stages of treatment are helpful. The use of written summaries and audio recordings has been shown to be valuable in improving patient recall of information during health professional consultations (Pitkethly, MacGillvrary, & Ryan, 2008; Watson & McKinstry, 2009). Other types of options to communicate information to populations who may be less educated or whose cultural norms may not be necessarily consistent with Western culture include videotapes/DVDs, television advertisements, materials written in a culture's native language, or cultural organizations. These methods may allow other diverse groups to better access and obtain health information.

The Internet was acknowledged by parents as an important source of information due to its availability, convenience, and usefulness. In this current age of computer technology and the plethora of information available, the Internet is an increasingly important source of information for parents (Thon & Ullrich, 2009). Despite these benefits, we found that parents viewed online information from unsolicited websites to be less trustworthy or credible than information in written pamphlets. One way to address parents' concerns is to provide evidence-based information from credible sources (e.g., scientific journals) when creating web-based materials. Online information with the possibility of linking to pages with more detail on selected topics from trustworthy websites (e.g., mental health associations and organizations, national research institutes) may be advantageous in providing information.

The diversity of needs expressed by parents reinforces the importance of tailoring information during clinical encounters. Materials can be formatted in several ways (e.g., print brochures, web-based information, information for families/consumers versus health providers) and information can be distributed through various channels such as publicly available websites, schools, counselors, health-service providers, and information provided by consumer associations. One of the advantages of written information and of websites is that information can be organized so that people can spend time considering the information that is most important to them. The information needs identified in our research can serve as broad topics or content areas (e.g., treatment choices, treatment side effects) for finding information. It would be important to organize and convey this information in an effective and concise way.

Some of the information parents want is reasonably accessible to specialized clinicians (i.e., specialty anxiety clinics), but may not be readily available to front line clinicians such as family doctors, pediatricians, school psychologists, and child specialists in psychology, psychiatry, social work, and occupational therapy. Very little information about treatments for child anxiety is easily available in forms that would be helpful to parents as well. It may be possible to answer some of these questions using knowledge synthesis (e.g., information about the effectiveness of medication and psychosocial treatments for child anxiety) that would systematically review the available evidence and summarize the information available at present. It may also be important to inform parents that we do not currently have information to answer some questions they might have (e.g., the long-term effects of medication on a child/adolescent). In such cases

where research on children/adolescents may be unavailable, information may have to be drawn from the adult literature.

Parents have a preference for non-pharmacological forms of treatment and prefer to see medication as "second-line" treatment if other forms of treatment are not effective. They also have strong concerns about the potential side effects or negative effects of medication treatments (e.g., issues of dependency on medication), which appear to motivate their desire for information about various aspects of medication treatments (e.g., short- and long-term side effects, effects of discontinuing medication). The literature on parents' concerns about medication use for children support our findings (dosReis et al. 2003). For example, concerns about drug addiction and medication side effects have been reported in the same way by parents of children with ADHD (Brinkman et al., 2009). Providing parents with accurate information may help them address their concerns and evaluate the pros and cons of medication treatments more effectively. Some parents who are very reluctant to consider medication treatments even when their child has had limited responses to other forms of treatment may be more willing to consider this option when they receive more complete information about medication (e.g., risk of suicidality with antidepressants) with a realistic assessment of benefits and risks.

Implications for Clinical Practice

By identifying the types of information that parents consider useful, we can develop decision aids to facilitate decision making, especially when parents face more than one treatment option. Decision aids serve as a form of educational intervention intended to provide information and promote *self-help* in the treatment decision-making process (Llewellyn-Thomas, 1995; O'Connor et al., 2009). They are designed to help

individuals make choices by providing information on the options (i.e., benefits, risks) and outcomes related to their health status and may include exercises to help people clarify their values so that they can make treatment choices that are consistent with their values (O'Connor & Edwards, 1999). Decision aids break down decision making into a number of specific and sequential steps and may be represented as interactive videos or pamphlets/booklets. Highly relevant and understandable decision aids can help communicate information from the health-care provider to parents and families. Exposure to decision aids has been shown to increase an individual's knowledge base and have no effect on anxiety (O'Connor et al., 2009). Future research could evaluate the usefulness of decision aids in assisting parents with decisions about treatment for child anxiety.

Our research has implications for training health-care providers in communicating with families in treatment decision-making. Health-care professionals should be prepared to review parents' preferences for decision-making and engage with parents in discussions about treatment (such as treatment options, and advantages and disadvantages of each treatment) as part of shared decision-making (Towle & Godolphin, 1999). Previous research, however, suggests that communication between doctors and patients tend to be poor, patient preferences or opinions about treatment are generally not elicited, and information about treatment (e.g., options, side effects, risks, benefits) is often not shared between parties during decision-making (Makoul, Arntson, & Schofield, 1995; Stevenson, Barry, Britten, Barber, & Bradley, 2000). Patients prefer that providers take their time in explaining treatment options in an open manner (Salkeld et al., 2004). In order to participate in shared decision-making, providers must have the interpersonal skills to establish a partnership in decision-making, communicate information clearly to

individuals, and engage in joint dialogue with them. Training in communication skills (e.g., asking questions, empathic responding) has been shown to increase physician skills in declaring agenda items, checking patient understanding, and inviting patient questions (Bylund et al., 2009). These areas may be particularly important to target in developing trust with the provider, which is important in decision making (Benin, Wisler-Scher, Colson, Shapiro, & Holmboe, 2006; Frantsve & Kerns, 2007).

Strengths and Limitations

There were a number of strengths of this research. First, the mixed-methods design employed in the current research was useful in providing comprehensive data by first exploring a new area of parents' decision-making process and information needs which led to the development of a quantitative survey to further examine parents' information needs. Qualitative interviews were essential in developing a rich understanding of parents' treatment decision-making (in their own words) and their views concerning the types of information they would find important in decision making. This is the first study to examine these issues among a sample of parents seeking treatment for child anxiety. The results helped us understand parents' views on the decision-making process and build on existing frameworks (e.g., Charles et al., 1997; family-centred care). Future studies could further explore aspects of this process (e.g., how do parents use information that they gather?) or explore the application of an existing model (i.e., Pierce & Hicks's [2001] interactive decision-making framework) that considers the interaction between decision problem, context, and individual characteristics.

Another strength was our quantitative survey, which was easily understood and highly applicable to the information needs of parents of anxious children. It allowed us to

formulate relevant questions related to parents' information needs. Hypotheses about the importance of different types of information (e.g., information related to treatment versus information related to the provider) can be developed and tested in future studies. Furthermore, research could examine whether additional parent characteristics (e.g., parental psychopathology) or child variables (e.g., symptom severity) influence parents' desire for information.

Despite the applicability of our survey questionnaire, a limitation was the ranking form that was used to examine parents' preferences for various sources of information (i.e., written, discussion, videotape/DVD, Internet). The measure, which was developed for the purposes of our survey, appeared to confuse parent respondents due to the ranking format. Only 46% of respondents answered the five items correctly by ranking their preferences from "most" (rank of 1) to "least" (rank of 5). It is possible that parents might have chosen to rank some information sources as ties because they felt that the sources were truly equal in importance. It is likely that if tied responses were included, the findings would further confirm the importance of information discussed with a provider and information presented in written form. Despite the small number of valid responses obtained in our study, results from the rating form on preferences for sources of information concurred with the ranking data.

Our research had fairly representative samples of parents who were making decisions or considering help for their child's anxiety problem. Parents were recruited from various sources such as hospital clinics and the larger community setting, which offered interventions for child anxiety. Nevertheless, the composition of educated, middle-class, and highly motivated parents may explain the strong preference for active-

collaborative decision-making found in our research. Future work on parental decision-making for child anxiety could be broadened to include parents from disadvantaged backgrounds (e.g., low education, difficulty accessing information in person or via the web) and different cultural or ethnic backgrounds (i.e., non-Caucasian). As the current results focused primarily on mothers, future research could examine the perspectives and opinions of fathers' decision-making as some gender differences have been found with females preferring greater decision-making involvement (Arora & McHorney, 2000). Furthermore, information needs of parents with anxious children suggest that there may be similarities and differences in the needs of parents of children with other health/medical conditions. Understanding parents' decision-making process and their information needs in different pediatric populations (e.g., ADHD, depression, chronic health problems, and developmental disabilities) is warranted. The qualitative methodology and the information needs survey used in the present study could be extended to these populations and prove to be very useful.

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Appendix A

UNIVERSITY OF MANITOBA

Hôpital général St-Boniface General Hospital

M5- Anxiety Disorders Program
Clinical Health Psychology
St. Boniface General Hospital
Winnipeg, MB R2H 2A6
Telephone: (204) 237-2335 FAX: (204) 237-6264

March xx, 2007

Client Address

Dear Ms./Mr. xxxx

Re: Participation in an interview as part of a research study

Your child is on our wait list for services at the Anxiety Disorders Program. We are contacting you because in addition to providing services to children and families, our program is also active in research. We are writing to see whether you would be interested in participating in a study by a student researcher from the University of Manitoba, Leanne Mak, M.A., and one of our staff members, John Walker, Ph.D. This study would involve coming to our office for an interview that would take approximately one hour. Only the parent participates in the interview, not the child. An information sheet about the study is attached.

You are free to participate or not participate in this study. This decision will not influence the services that you will receive at the Anxiety Disorders Program.

In the next week or so you will receive a call from me or one of the staff in our program to see if you are interested in participating in this study. If you would like to contact me first to let me know whether or not you are interested, I may be contacted by telephone or by email . Thank you for reviewing this material.

Sincerely yours,

Penny Stewart
Secretary to the Anxiety Disorders Program

UNIVERSITY OF MANITOBA

M5- Anxiety Disorders Program
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Hôpital général St-Boniface General Hospital

INFORMATION SHEET

Title of Research: A Qualitative Interview Concerning Parents' Preferences for Information Regarding Treatments for Child Anxiety – Pilot Study

Researchers: Ms. Leanne Mak, M.A., Clinical Doctoral student
Department of Psychology, University of Manitoba

Dr. John Walker, Ph.D., C. Psych, Research Advisor
St. Boniface General Hospital, Winnipeg, MB.

We are contacting families referred to the Anxiety Disorders Program to see whether they would be interested in participating in a study that is being conducted as part of a Ph.D. thesis in Clinical Psychology by Ms. Leanne Mak, under the supervision of Dr. John Walker at St. Boniface General Hospital.

The purpose of this study is to explore parents' views about the information they would like in making decisions concerning help for their children. We are also interested in parent's opinions about how they would like to be involved in decision making. This information will be used to develop a better understanding of parents' decision-making process and the type of information parents would like to have when they are making decisions. Our team plans to use these findings to help develop information for parents about treatment options available for children experiencing problems with anxiety.

You are free to participate or not participate in this study. This decision will not influence the services that you will receive at the Anxiety Disorders Program. Should you decide to participate in the study, you may stop participating at any time.

If you agree to participate, your consent will be obtained in writing. The study would involve engaging in a one-on-one interview with Leanne Mak, M.A. about your views and opinions about treatment decision-making. The interview (with the parent only, not the child) would be audio recorded and take approximately 1 hour to complete. The interviews would take place at St. Boniface General Hospital at a day or evening time that is convenient for the parent.

In the interview, we will also ask a few questions about you (such as your age and education) and your child (such as age and sex). Once you have completed the interview, written feedback will be provided to you. A summary of the results of the study will be provided to you, if you wish to receive them, once the results are compiled.

Appendix B

Telephone Script – Contacting Parents

(Have copies of recruitment letter and consent forms with you to refer to!)

Hello, my name is Leanne Mak and I am a PhD student in Clinical Psychology at the University of Manitoba, working with Dr. John Walker at St. Boniface General Hospital.

I understand that you received a letter from Penny, our secretary describing our study and indicating that I would call.

Is this a good time to talk? [IF NO] When is best time to call back?

[IF YES] Did you have a chance to read over the information about the study?

[IF YES] Were there any questions you had about the study after reading the material?

[ANSWER ANY QUESTIONS THAT COME UP AT THIS POINT.]

Would you like to hear more about the study?

The purpose of this study is to explore parents' views about the information they would like in making decisions concerning help for their children. We are also interested in parent's opinions about how they would like to be involved in decision making. This information will be used to develop a better understanding of parents' decision-making process and the type of information parents would like to have when they are making decisions. Our team plans to use these findings to help develop information for parents about treatment options available for children experiencing problems with anxiety.

The study involves a one hour interview with me about your opinions and your child's situation. The interview will be audio recorded so we can summarize the information later. The interviews would take place at St. Boniface General Hospital at a day or evening time that is convenient for you.

Do you have any questions?

Would you be interested in participating in the study?

[IF NO] Thank you for your time. Just to let you know, my study will continue over the summer so if you're still interested in participating at a later time, please feel free to call Penny back. If you like, I could also call you back in a couple of weeks.

[IF YES] Can I schedule a time for you to come in for the interview? What days and times work best for you?
Set date and time and give them Penny's telephone number (237-2335) if need to reach me. Also, give my email address if they want to contact me directly.

Appendix C

UNIVERSITY OF MANITOBA

Hôpital général St-Boniface General Hospital

M5- Anxiety Disorders Program
Clinical Health Psychology
St. Boniface General Hospital
Winnipeg, MB R2H 2A6
Telephone: (204) 237-2335 FAX: (204) 237-6264

Title of Research: A Qualitative Interview Concerning Parents' Preferences for Information Regarding Treatments for Child Anxiety – Pilot Study

Researchers: Ms. Leanne Mak, M.A., Clinical Doctoral student
Department of Psychology, University of Manitoba

Dr. John Walker, Ph.D., C.Psych., Research Advisor
St. Boniface General Hospital, Winnipeg, MB.

The present research study is being conducted as part of a Ph.D. thesis in Clinical Psychology by Ms. Leanne Mak, under the supervision of Dr. John Walker at St. Boniface General Hospital.

This consent form, a copy of which will be left for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the Study: The purpose of this study is to explore parents' views about the information they would like in making decisions concerning help for their children. We are also interested in parent's opinions about how they would like to be involved in decision making. This information will be used to develop a better understanding of parents' decision-making process and the type of information parents would like to have when they are making decisions. Our team plans to use these findings to help develop information for parents about treatment options available for children experiencing problems with anxiety.

Research Procedures: If you agree to participate, the study will involve meeting for a one-on-one interview with a student researcher about the topics described in the previous section. The interview will take approximately one hour to complete and we will use an audio recording device so that the interview can be typed into a file. We will also ask a few questions about you (such as your age and education) and your child (such as age and sex).

Potential Benefits of the Research: There are no benefits that would come to you for participating in this research study. We hope that a greater understanding of parents' views about their involvement in decision-making and the type of information parents

would like will help us to develop better information for parents and health care providers to use in decision making. This knowledge would be of benefit for other families and health-care providers.

Risks or Costs Associated with the Research: There are no risks that are associated with this study. If you agree to participate in this study, one hour of your time will be required to complete the interview.

Voluntary Participation: Participation in this study is voluntary and your decision to participate or not will not influence the services you may receive or are receiving at St. Boniface General Hospital. If we ask you to participate in future research we will inform you about how much time is required.

Freedom to Withdraw: Participation in this study is entirely voluntary. You are free not to answer any question without explanation. Should you decide that you do not wish to participate or that you wish to withdraw from the study at any time, this will not affect the treatment or services you will receive or are receiving at the Anxiety Disorders Program at St. Boniface General Hospital.

Confidentiality: Information from the interview will be recorded using an audio recording device. Information provided in the interview and the audio recording will be anonymous and identified only by a code number. Information will be stored on a computer and identified by this code number. Your name or other identifying information will not be associated with your responses in a computer research file and will be kept only on a list of participants and code numbers held by Leanne Mak and Dr. John Walker in a locked area. **The information will be held on a computer that is password protected and only the research team (Leanne Mak, Dr. Walker, and the project research assistants) will be able to access this information.**

Written information from the interview will be kept confidential and will be stored in a locked secure area. Access to the information will only be made available to members of the research team (Leanne Mak, Dr. Walker, and the project research assistants). The only external agencies that may have access to our research records are the University of Manitoba, Psychology/Sociology Research Ethics Board and the St. Boniface General Hospital which may review our records to ensure that we maintain their standards. The University of Manitoba and St. Boniface General Hospital may review information gathered during this study for quality assurance purposes.

The results of this study may be published or presented in public forums. However, your name will not be used. No information revealing any personal information such as your name, address or telephone number will leave the St. Boniface General Hospital. Medical records that contain your identity will be treated as confidential in accordance with The Personal Health Information Act of Manitoba.

Results will be reported for all study participants as a group, not for individuals. The study will conclude in September 2008. All audio recordings and the key linking your identifying information and your responses will be destroyed in September 2013. If you give permission, we may contact you to see if you are interested for future follow-up research related to this study.

Feedback About the Research: Feedback about the findings of the interviews will be provided to those parents who wish to receive this information by September 2008 at the latest.

Consent for Participation: Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Questions or Concerns: If you have any questions, please do not hesitate to call Dr. John Walker at 237-2055 or email Leanne Mak at ummakl@cc.umanitoba.ca.

This research has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122 or email margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent:

I have read this consent form. I have had the opportunity to discuss this study with one of the researchers. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity and my child's identity will be kept confidential, but that confidentiality is not guaranteed. I understand that my and my child's identity will be treated as confidential in accordance with The Personal Health Information Act of Manitoba. I understand that The University of Manitoba and St. Boniface General Hospital may review information gathered during this study for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

_____ _____

Signature of Participant Date (day/month/year)

_____

Printed Name of Participant

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

_____ _____

Signature of Person Obtaining Consent Date (day/month/year)

_____ _____

Printed Name of Person Obtaining Consent Role in the study

ALL SIGNATORIES MUST DATE THEIR OWN SIGNATURE

I agree to be contacted by telephone or via email for future follow-up in relation to this study.

Optional: I agree to be contacted for future follow-up in relation to this study.

Yes ___ No ___ Subject Initials _____ Telephone:_____

Email:_____

I wish to receive a summary of the results at the conclusion of the study as indicated below:

Email: Yes ___ No ___ Mail: Yes ___ No ___

Appendix D

BACKGROUND QUESTIONNAIRE

Gender: ☐ Male ☐ Female

Age: _____ (years)

Ethnic background: ☐Caucasian ☐African ☐Asian ☐Aboriginal
☐Other (please specify: _____)

Education: (please mark highest grade *completed*)

☐ Grade 12

☐ University undergraduate: Number of years _____

☐ University postgraduate: Number of years _____

☐ Business or technical college: Number of years _____

Marital status: ☐ Married/common-law

☐ Divorced/separated

☐ Single

Employment Status: ☐ Yes ☐ No

Gender of child most concerned about with anxiety problems: ☐ Male ☐ Female

Age of child most concerned about with anxiety problems: _____ (years)

Please describe the severity of your child's anxiety symptoms: (Please circle)

Mild----------Moderate----------Severe----------Very severe

How long has your child experienced these symptoms? _____ (number of months)

Has your child received medication for his/her anxiety: ☐ Yes ☐ No

- **If Yes, please indicate for how long:**

  ☐ less than 1 month

  ☐ 1 month to 1 year

  ☐ over 1 year

Has your child received counselling for his/her anxiety: ☐ Yes ☐ No

- **If Yes, please indicate for how long:** (number of sessions)

  ☐ 1 to 10 sessions

  ☐ 10 to 20 sessions

  ☐ over 20 sessions

Have you ever had problems with anxiety? ☐ Yes ☐ No

- **If Yes,** would you describe those problems as

  Mild----------Moderate----------Severe----------Very severe

Have you ever taken medication for Depression: ☐ Yes ☐ No

Anxiety: ☐ Yes ☐ No

Other mental health problem: ☐ Yes ☐ No

Have you ever been in counselling for Depression: ☐ Yes ☐ No

Anxiety: ☐ Yes ☐ No

Other mental health problem: ☐ Yes ☐ No

Do you have a family member (e.g. grandmother, father, sibling) who has anxiety problems? ☐ Yes ☐ No

Appendix E

QUALITATIVE INTERVIEW PROTOCOL

Start interview by saying:

"The purpose of this interview is to gather information from parents about their thoughts and opinions when making decisions about help for their child. Do you have any questions before we begin?"

"First, could you tell me a bit about the difficulties you have noticed for your child?"

"How would you describe your relationship with your child? Has your child's anxiety affected your relationship? How might your relationship with [insert child name] affect the decisions you might make about help for [insert child's name]?

"Next, I was wondering what you may have heard about the kinds of help that are available for children who are experiencing problems with _____ ?" (insert parent's description – e.g., shyness, anxiety).

Preamble:

"In this interview, I will be asking you some questions about decision-making and help for children. There are no right or wrong answers. I'm interested in your views as you think about your own child."

Questions re. Decision-Making Involvement:

1. In making decisions about help for children, there are many ways of being involved and different people who may be involved in the decision-making. In your situation, who do you think would be involved in making decisions about help for your child? Who is most involved in making decisions for your child?

1a) What do you expect when you come in for the first time to see the HCP about your child's anxiety?

1b) Are you aware that there's a decision to be made? Do you have any idea that there are treatment options?

2. How do you envision you and your family's role in the process of making a decision about treatment for your child?

Follow-up probes ☐(check if used):

a. What would you like to do/say/ask the HCP in making a decision?
b. What do you want the HCP to say/do in making a decision for your child?
c. Help me understand what your involvement looks like…what would you say/do/ask in making a decision?

d. What part would you take in making a decision about treatment?

3. How will your family make a decision about help for your child's anxiety? What role do you think your child will play in this decision?

4. Can you tell me why it would be important for you to be involved in making the decision?

5. What do you think might get in the way of making a decision about help for your child?

6. What do you think might make it easier in making a decision about help for your child?

7. So in coming to a final decision about treatment for your child, how do you see you and/or the health-care provider making a final decision about your child's treatment?

Follow-up probes ☐(check if used):

a. Who would you prefer to make that decision about treatment? [you, HCP, both]
b. What would need to happen in decision making? What would you say/do in making a decision? What would the HCP say/do in making a decision?

Questions re. Preference for Information about Treatment:

"There are several types of help for children's problems with _____ (anxiety, shyness). The three most common are: (1) help directly for the child, (2) help for the parent/family to deal with the child's problems, and (3) medication for the child to help with the problem. In this part of the interview, I will be asking you some questions for each of these types of help. There are no right or wrong answers; I'm just interested in hearing about your opinion."

"Let's start with help directly for the child. If you were considering this,

8. What types of information would be important to have in making your decision about this type of help for your child?

9. In what ways do you think this approach – so help for the child- would be helpful or useful for your child?

10. Would you have any concerns or worries about this form of help for your child?

11. Is there anything you think you would like about choosing this form of help?

12. Is there anything you think you might not like about choosing this form of help?

"Okay now, let's talk about help directly for the <u>parent or family</u>. If you were considering this,

8. What types of information would be important to have in making your decision about this type of help for your child?

9. In what ways do you think this approach – help for parents- would be helpful or useful for your child?

10. Would you have any concerns or worries about this form of help for your child?

11. Is there anything you think you would like about choosing this form of help?

12. Is there anything you think you might not like about choosing this form of help?

"Okay, let's talk about <u>medication for the child</u>. If you were considering this,

8. What types of information would be important to have in making your decision about this type of help for your child?

9. In what ways do you think this approach would be helpful or useful for your child?

10. Would you have any concerns or worries about this form of help for your child?

11. Is there anything you think you would like about choosing this form of help?

12. Is there anything you think you might not like about choosing this form of help?

[Questions 11 & 12 are global questions applied across all three types of help.]

"Parents find information about help in many ways. For example, through pamphlets, talking with other parents, family or friends, asking the doctor, or using the internet."

13. What are some of the ways you'd find information about each of these types of help?

14. In making decisions about help for your child's problem, some parents like to get a lot of information, some like to get a little, and some in between that. For you, how much information would you like to have about each of these types of help?

15. We've talked about various types of information that would be helpful for you in decision making. If you had the information you wanted, how do you think that would help you in decision making?

16. Is there anything you need to know about anxiety to help with your decision making?

17. Is there any information about help for children's anxiety that would not be helpful or that you would not want to receive?

18. What types of decisions regarding help for your child would you not want to be involved with?

19. In addition to the types of help we have talked about, are there other types of help that you might consider for your child's anxiety problem?

Appendix F

PREFERENCE FOR DECISION-MAKING INVOLVEMENT (CPS-P)

Instructions: Choose the statement that best describes your preferred role in decision-making. Please circle the letter that represents your answer.

A: I prefer to make the final decision about which treatment my child will receive.

B: I prefer to make the final decision of my child's treatment after seriously considering my child's health-care provider's opinion.

C: I prefer that my child's health-care provider and I share responsibility for deciding which treatment is best for my child.

D: I prefer that my child's health-care provider makes the final decision about which treatment will be used, but seriously considers my opinion.

E: I prefer to leave all decisions regarding my child's treatment to my child's health-care provider.

Appendix G

Qualitative Interview Pilot Study – Feedback

This is a preliminary study aimed at exploring parents' opinions and preferences for information regarding treatment for their anxious child. Using one-on-one interviews, we are interested in understanding the types of information parents seek when making decisions for their child's treatment. Types of information could range from knowing the benefits and risks of treatment, to the time and cost involved in treatment.

In this study, we are also interested in understanding parents' desire or preference in being involved in the decision-making process. Some parents want health-care providers to make the decision after considering their opinion, some parents want to make the choice themselves after considering the health-care provider's opinion, and some other parents want to share decision-making with the health-care provider.

The results of this study will be used in our work on developing educational material for parents in helping them make choices about the type of help they would like for children's problems with anxiety.

The results of the final project will be available beginning in September 2008. If you indicated that you would like information about the results of the study, we will send a summary of findings to you.

Questions or concerns about this study can be directed to Ms. Leanne Mak at ummakl@cc.umanitoba.ca or Dr. John Walker at 237-2055. If you have any complaints about this project, you many contact the above-named persons or the Human Ethics Secretariat at 474-7122 or via email to margaret_bowman@umanitoba.ca.

Thank you for participating in this study.

Appendix H

List of Codes for Qualitative Coding

- AMOUNTINFO
  - A LOT
  - MODERATE
- DMPROCESS
  - DECINVOLMT
    - CHDMGROWUP
    - CHINVOLVE
    - FAMINVOLVE
    - HCPINVOLVE
    - PARINVOLVE
  - DECMAKER
    - CHDECIDE
    - FAMDECIDE
    - PARDECIDE
    - PARHCPDEC
  - DMBEHACTS
    - DISCUSS
    - EVALUATE
    - FAMDISCUSS
    - HCPLISTENS
    - HCPRECOMM
    - INFORMHCP
    - OWNRES
    - TIME
  - HCPASSESS
  - HCPCOMFORT
  - MEET_TALK
  - NOEXPECT
  - PARDMNEEDS
    - DESIREINFO

        - WANTCHOICE
        - WANTEXPERT
        - WANTINVOLV
    - PARSUPPORT
- FACTORSDM
    - DEVELOPMT
    - DIFFOPIN
    - DM-FEAR
    - DM-HCP
    - DM-INDIVS
    - DM-INFO
    - DM-PARENT
    - DM-RELIG
    - DM-SPECIFS
    - DM-STIGMA
    - ENVIRON
    - FAMRELNP
    - HELPCHDEC
    - HOMELIFE
    - NEG-RELNP
    - NOTINFORM
    - PAREXPERT
    - POS-RELNP
    - RESPONSIB
- FAMILIARTX
    - DKNOW
    - EXAMPLE
    - OWNEXP
    - PREVKNOW
- INFONEEDS
    - EDUCATION
        - INFOANX

        - INFOCOPE
        - TX-CHOICES
    - HCPSPECIF
        - INTERPERS
        - POSITION
    - MEDSPECIF
        - DOSAGE
        - EFFECTDISC
        - MECHANISM
        - MEDAGE
        - MEDFORM
        - MEDPRESCRI
        - MEDPREVAL
        - MEDRELIANC
        - MEDTYPE
        - SIDEFFECTS
        - UNKNOWN
    - TXDESCRIPT
        - TX-ADVDISA
        - TX-AGEAPPR
        - TX-CONTENT
        - TX-EFFECTV
        - TX-FREQUEN
        - TX-FUTURE
        - TX-GOAL
        - TX-LENGTH
        - TX-OUTCOME
        - TX-RATION
        - TX-SCHEDUL
        - TX-SETTING
        - TX-SOCIAL
        - TX-START
        - TX-TIMERES

    - TXROLES
        - TX-CHROLE
        - TX-HCPROLE
        - TX-PAR_ROLE
- MEDVIEWS
    - MEDVIEW-N
    - MEDVIEW-P
- MISCELLAN
    - ADHD
    - ANXIETY-SX
    - DESPERATE
    - FRUSTRATED
    - HCPCONTACT
    - INFO_COMFY
    - PARANXIETY
    - PARENTING
    - PAREXPECTN
    - RESULTS
    - SCHOOL
    - TRUST
    - VIEWTREAT
- MOSTINVOLV
    - CHMOSTINV
    - MOMOSTINV
    - PARCHMOST
- MOTIV-DM
    - MOTIVHELP
    - MOTIVTX
- OTHERPROG
    - ALTER-PROG
    - CAMP_PROG
    - CHILDINFO

- PEERGROUP
- RESOURCES
- SCHOOLPROG

- PARCHRELNP
  - GOODRELNP
  - MIXEDRELNP
  - STRAINRELNP
- PARTXPREFS
  - NOTPREF-C
  - NOTPREF-M
  - NOTPREF-P
- SOURCINFO
  - BOOKS
  - INDIVS
  - INTERNET
  - MEDIA
  - PROFS
  - SUPPORTGPS
  - VIEWSOURCE
- TXBENEFITS
  - CHCONTROL
  - CHEXPRESS
  - CHFUNCTION
  - EXPERTISE
  - IMPROVEPAR
  - INCLUDEDTX
  - LESSRESP
  - MEDALLEV
  - NONINVASIV
  - NORMALIZE
  - PARASSIST
  - PAREMPOWER

- RELATE
- SKILLS
- SPEED

- TXCONCERNS
  - CHANGE
  - CHEFFECT
  - DEVCONCERN
  - EXCLUDEDTX
  - HCPISSUES
  - MEDCONCERN
  - MISTAKE
  - NOMONITOR
  - OFFTRACK
  - PARCONCERN
    - CHDISMED
    - LABEL
  - PAR_RESP
  - PRIVACY
  - SPECIFICS
- UNWANTINFO
  - IRRELEVANT
  - NOMEDINFO
  - NONRESEARC

Appendix I

PARENT INTERVIEW STUDY SUMMARY

Parent's Opinions Concerning Treatments for Children's Anxiety

---

Leanne Mak met with 17 parents for detailed interviews concerning decision making about treatments for children's anxiety. We explored how parents would like to be involved in decision making and what information they would like to have in making decisions. Please note that every parent did not mention every point. This is a summary of key findings from the interviews.

- Most parents are unfamiliar with the range of treatments available for children's anxiety. As a result they had not considered the decision making process much before hand and were not really aware that there was a range of decisions to be considered.

- All parents said they want to be involved in making a decision concerning treatment for their child.

- In making decisions, parents commonly preferred to discuss information about treatment choices with the health-care provider, evaluate the information provided (e.g., weighing the pros and cons), and talk with the other parents and/or family members. Many parents wanted time to consider the options before coming to a decision

- In making decisions, parents feel it is important to protect their children and do what's best for the child in the long run.

- Many parents indicated that having information is a key aspect in making a decision about treatment. Parents wanted information about what the treatment involves, how long treatment lasts, how effective treatment is, the goals/outcome of treatment, and scheduling of appointments.

- Parents desired information about the role of parents in treatment and about how they would be kept informed about progress in treatment.

- Information about the provider (e.g., training and experience) and a sense of trust in the provider was considered important.

- In order to make a treatment decision, parents said they need quite a bit of information and generally sought out various sources (e.g., the provider, pamphlets, internet).

- Parents indicated that they would have some specific concerns if they were considering medication treatment at some point. They would be interested in information about the side effects of medication and the long term effects.

- In coming to a final decision, most parents wanted to hear the health-care professional's recommendations about what would be most helpful for their child.

Please let us know your opinion about the summary by completing four short questions below. Just put your rating in the space after each question:

1. **How understandable was the summary of findings? Your rating: ____**

1----------2----------3----------4----------5----------6----------7----------8----------9----------10
Not at all understandable — Moderately understandable — Very understandable

2. **How much do you agree with the findings? (e.g., Do they ring true for you?) Your rating: ____**

1----------2----------3----------4----------5----------6----------7----------8----------9----------10
Strongly disagree — Mildly disagree — Strongly agree

3. **How reasonable are the conclusions of the findings? Your rating: ____**

1----------2----------3----------4----------5----------6----------7----------8----------9----------10
Not at all reasonable — Moderately reasonable — Very reasonable

4. **Please note any other comments/suggestions about the findings.**

_____
_____
_____
_____
_____

Thank you for taking the time to review our findings. Your feedback is greatly appreciated! ☺

Appendix J

PARENT SURVEY

We are conducting a Parent Survey asking opinions about the information parents would like in making treatment decisions for their child. It also asks about your experiences as a parent. We plan to use the information from this survey to help us prepare information materials to assist parents when they are making decisions about treatment of a child's anxiety.

The Parent Survey is optional for you to complete. Please read the information sheet and consent form that follow to see if you would like to participate.

If you decide that you would like to participate in the survey, please review and complete the consent form that follows. Then proceed to completing the Parent Survey. The consent form and completed Survey can then be placed in the attached envelope.

If you decide that you would not like to participate in the survey, please place the consent form and Survey (not completed) in the attached envelope.

Thank you for your consideration.

Appendix J

UNIVERSITY OF MANITOBA

Hôpital général St-Boniface General Hospital

St. Boniface General Hospital
Winnipeg, MB R2H 2A6
Telephone: (204) 237-2335 FAX: (204) 237-6264

INFORMATION SHEET

Title of Research: A Survey of Parents' Opinions about the Information Needed in Making Treatment Decisions about Children's Anxiety

Researchers: Leanne Mak, M.A., Clinical Doctoral student
Department of Psychology, University of Manitoba

John Walker, Ph.D., C.Psych, Research Advisor
St. Boniface General Hospital, Winnipeg, MB.

When we see parents and children in the Anxiety Disorders Service at St. Boniface General Hospital or parents in community seminars for parents of anxious children, we ask them to complete a history form and several questionnaires before they come for their first appointment, as part of service planning and evaluation. The cover sheet identifies these as the Part A questionnaires.

The information we gather for services is also useful for research purposes. It can only be used for research, however, with your permission. In this research study, we are asking whether you would complete a Parent Survey and also provide consent for the information you provide in the Part A questionnaires – the history form concerning the characteristics of the child and parent (such as the child and parent's age, gender, and education), the Spence Children's Anxiety Scale – Parent Report, and the questionnaire concerning attentional problems (the SNAP-IV) – to be used for research purposes. This information will be confidential as described in the consent form.

If you decide to participate in the research, the Parent Survey asks your opinions about the types of information parents need in making treatment decisions for their child. It also asks about your experiences as a parent (such as your confidence as a parent and the level of stress you experience). We plan to use the information from this survey to help us prepare information materials to assist parents when they are making decisions about treatment of a child's anxiety. The Parent Survey will take approximately 25 minutes to complete.

In Part B of this package (identified by a cover sheet) a copy of the consent form describing the study and the Parent Survey are attached. Please read over the consent form and decide whether you would like to participate in the research. If you have any questions about the research please contact Dr. John Walker by phone (237-2055) or email (jwalker@cc.umanitoba.ca) or Leanne Mak by phone or email).

Participation in this study is voluntary and your decision to participate or not will not influence the services you receive at St. Boniface General Hospital. The

consent form and the Parent Survey (completed or not completed) are to be returned in the sealed envelope so the clinician who sees you will not know whether or not you decided to participate in the survey.

If, after you have any questions answered, you decide that you would like to participate, sign the consent form to indicate that you consent to complete the Parent Survey and share the information you provide in the Part A questionnaires for research purposes. Then please complete the survey and put the survey and consent form in the envelope, seal it, and return it your other materials (Part A).

If you are not interested in participating you can leave the consent form unsigned and the survey blank, seal them in the envelope and return them with the other materials.

Appendix J

UNIVERSITY OF MANITOBA

Hôpital général St-Boniface General Hospital

St. Boniface General Hospital
Winnipeg, MB R2H 2A6
Telephone: (204) 237-2335 FAX: (204) 237-6264

Title of Research: A Survey of Parents' Opinions about the Information Needed in Making Treatment Decisions about Children's Anxiety

Researchers: Leanne Mak, M.A., Clinical Doctoral student
Department of Psychology, University of Manitoba

John R. Walker, Ph.D., C.Psych., Research Advisor
St. Boniface General Hospital, Winnipeg, MB.

The present research study is being conducted as part of a Ph.D. thesis in Clinical Psychology by Ms. Leanne Mak, under the supervision of Dr. John Walker at St. Boniface General Hospital.

This consent form, a copy of which will be left for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask any of the people associated with the study. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the Study:
The purpose of this study is to understand parents' views about how they would like to be involved in making decisions about the treatment their child receives and the information they would like to have in making these decisions. This information will be used to develop information materials for parents when making decisions about treatment for children experiencing problems with anxiety.

Study Procedures:
The staff of St. Boniface General Hospital routinely gathers information from parents and families for the purposes of service planning and evaluation. The information in the History Form and questionnaires (Part A) sent to parents before the first appointment is used to understand the characteristics, needs, and concerns of your child and family and to plan the services that we provide.

This information is also very useful in research to develop a broader understanding of the concerns of children and families. We are asking whether you would complete a Parent Survey (Part B) and also provide consent for the information provided in the History Form and the questionnaires from Part A to be used for research purposes. The Parent Survey asks your opinions about your involvement in decision making and your views about information needed in decision making. The Survey also asks about your experiences as a parent (such as your confidence as a parent and the level of stress you

experience). Information used from Part A includes the History Form concerning characteristics of the child and the parent (such as the child's and parent's age, gender, and education), the Spence Children's Anxiety Scale - Parent Report, and the questionnaire concerning attentional problems (the SNAP-IV). This information will be confidential as described below.

If you decide to participate in the Parent Survey, the information described above will be collected from the Parent Survey, the History Form, and the questionnaires you complete before the first appointment for the research file. Only the information provided by parents will be used and children are not asked to supply any information themselves.

Potential Benefits of the Research: There are no benefits that would come to you for sharing this information and completing the Parent Survey for research purposes. We hope that a greater understanding of the opinions of parents will help us to develop high quality information materials for parents. This in turn would be a benefit for other children and families.

Risks or Costs Associated with the Research: There is no risk or cost to you in sharing this information. For those parents who decide to participate, approximately 25 minutes of time is required to complete the Parent Survey.

Voluntary Participation: Participation in this study is voluntary and your decision to participate or not will not influence the services you may receive or will receive at St. Boniface General Hospital. Should you decide to participate, you will receive an honorarium of a $10.00 Safeway gift certificate in recognition of the time that it takes to complete the survey. The consent form and the Parent Survey (completed or not completed) will be returned in a sealed envelope so the clinician who sees you will not know whether or not you decided to participate in the survey.

If we obtain your permission to contact you about future research, we will inform you about what that research involves and how much time is required before we ask for your consent to participate.

Freedom to Withdraw: It is your choice whether or not to share this information for research purposes. Participation is voluntary and you may withdraw at any time at no penalty. If you decide to withdraw from participation in the research, the information in your research file will be destroyed.

Confidentiality: Your participation in this research is confidential. That means that we can not identify you or your family members as participating in this research unless required by law. The information that you give us as part of our service planning and evaluation is also covered by the Personal Health Information Act (PHIA), meaning that we can not share it with anyone who is not a member of the service or research teams.

For those families who choose to participate in the research, information gathered from the questionnaires for research purposes will be anonymous and identified only by a code number. Information will be stored on a computer and identified by this code number. Your name or other identifying information will not be associated with your responses in a computer research file and will be kept only on a list of participants and code numbers held by Leanne Mak and Dr. John Walker in a locked area. The information will be held on a computer that is password protected and only the research

team (Leanne Mak, Dr. Walker, and the project research assistants) will be able to access this information.

All records will be kept in a locked secure area and only members of the research team will have access to these records. The only external agencies that may have access to our research records are the University of Manitoba, Health Research Ethics Board and the St. Boniface General Hospital which may review our records to ensure that we maintain their standards. The University of Manitoba and St. Boniface General Hospital may review information gathered during this study for quality assurance purposes.

The results of this study may be published or presented in public forums. However, your name will not be used. No information revealing any personal information such as your name, address or telephone number will leave the St. Boniface General Hospital. Results will be reported for all study participants as a group, not for individuals. The study will conclude in September 2008 and the information in your research file will be destroyed in September 2013. If you give permission, we may contact you to see if you are interested for future follow-up research related to this study.

Feedback About the Research: Feedback about the findings will be available by September 2008 and provided to those parents who wish to receive this information.

Consent for Participation: Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Questions or Concerns: If you have any questions, please do not hesitate to call Dr. John Walker at 237-2055 or contact him by email (jwalker@cc.umanitoba.ca) or call Leanne Mak or by email

This research has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122 or email margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Statement of Consent:

I have read this consent form. I have had the opportunity to contact one of the researchers if I have any questions and to have my questions answered by them in language I understand. The risks and benefits of the Parent Survey have been explained to me in the form. I understand that a copy of this consent form will be mailed to me. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that my and my child's identity will be treated as confidential in accordance with The Personal Health Information Act of Manitoba. I understand that The University of Manitoba and St. Boniface General Hospital may review information gathered during this study for quality assurance purposes. By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I, _____, have read the above information and hereby consent to
(print name)
participate in this study.

_____ _____
Participant's Signature Date (day/month/year)

NOTE: If you provide consent, in addition to signing above, please initial the bottom right of each page (pages 1 to 4) to indicate that you have read it.

Permission for future contact: I agree to be contacted by a member of the research team by telephone or via email for future follow-up in relation to this study. If contacted, the nature of the research will be explained to me at that time and I will be free to either consent or decline to participate at that time.

Yes ___ No ___ Participant Initials _____ Telephone:_____
Email:_____

Summary of results: I wish to receive a summary of the results at the conclusion of the study as indicated below:

Email: Yes ___ No ___ Mail: Yes ___ No ___

Email address if you wish to have a summary by email: _____

Mailing address if you wish to receive a summary by mail:

_____

_____

[FOR OFFICE USE ONLY] ----------

_____ _____
Researcher and/or Delegate's Signature Date (day/month/year)

_____
Printed Name of Researcher and/or Delegate

Appendix J

PART B: PARENT SURVEY

A Survey of Parents' Opinions about the Information Needed in Making Treatment Decisions about Children's Anxiety

Today's Date: ____/_____/_____
(Day month year)

Parent's Initials:
of first & last name: ___ ___ Age: ____ Gender: Male / Female

Child's Initials:
of first & last name: ___ ____ Age: ____ Gender: Male / Female

The following information concerning the parent' education is very helpful also. Please fill in the number of years of education of each type completed by the mother and father. Thank you.

Parents' Educational Background

Completed years of education	Mother Number of years	Father Number of years
Grade School 1 - 12		
Technical, business, vocational program		
University program		

ID # _____ *(for office use)*

Appendix J

Information Needs Regarding Treatments for Children's Anxiety

When deciding about treatment for a child who is experiencing anxiety, parents often want information about the treatment options. There are several types of treatment for children's problems with anxiety. The three most common are: (1) counselling treatment provided directly to the child, (2) counselling treatment focused on helping the parents to assist their child, and (3) medication for the child to reduce the anxiety.

In responding to the following questions, please circle the number that best fits your rating from 0 to 8.

Different parents have seen or heard different amounts of information concerning treatments for children's anxiety. How familiar are you with the different treatments for children's anxiety?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not at all familiar — Moderately familiar — Very familiar

Instructions: Although we understand that you may have already made a decision about treatment for your child's anxiety or may not be currently making a treatment decision, we would like to understand your thoughts and opinions about what types of information are most important to parents when making decisions about treatment for anxiety.

Section 1: Information about the different types of treatment available for children or adolescents with anxiety

Thinking about both counselling and medication treatments, if you were making a decision about treatment for an anxious child, how important would it be for you to have information about:

1. The specific choices or types of treatments that are available.

0----------1----------2----------3----------4----------5----------6----------7----------8

Not important at all — Moderately important — Very important

2. What treatment involves (e.g., what methods will be used)?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

3. The parent's role in treatment.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

4. The child's role in treatment.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

5. The effectiveness or success of the treatment.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

6. How helpful is treatment for children and adolescents at different ages?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

7. How does the treatment work?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

8. What is the goal or outcome of treatment?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

9. How long does it take for the treatment to produce results?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not important at all — Moderately important — Very important

10. How long does the treatment continue?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not important at all — Moderately important — Very important

11. What happens when the treatment stops?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not important at all — Moderately important — Very important

12. What are the common and uncommon side effects of treatment?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not important at all — Moderately important — Very important

13. The advantages (pros) and disadvantages (cons) of each type of treatment.

0----------1----------2----------3----------4----------5----------6----------7----------8

Not important at all — Moderately important — Very important

Section 2: If you were considering child or parent counselling treatments at some point, even if you are not considering them now, how important would it be for you to have information about:

14. The format of the treatment (e.g., one-on-one counselling with the child/adolescent, group counselling for the child/adolescent, counselling for the parent on how to help the child/adolescent).

0----------1----------2----------3----------4----------5----------6----------7----------8

Not important at all — Moderately important — Very important

15. What the health-care provider will be doing in treatment.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

16. What the child will be doing in treatment.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

17. What the parent will be doing in treatment.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

18. Whether skills learned from counselling treatment can be used in the future by the child or parent.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

Section 3: If you were considering medication treatments at some point, even if you are not considering them now, how important would it be for you to have information about:

19. What medications are used to treat this type of anxiety?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

20. The advantages and disadvantages of one medication versus another medication.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

21. How a doctor decides on which medication to recommend for a child/adolescent.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

22. How long the medication has been used to treat anxiety in children/adolescents.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

23. The amount of the medication the child/adolescent takes and how often the child takes it.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

24. The <u>common</u> short-term and long-term side effects of the medication.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

25. Any <u>uncommon</u> but serious short-term and long-term side effects of the medication.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

26. What usually happens when the child/adolescent stops taking the medication? Are there any risks related to stopping the medication?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

27. Is there a risk for dependency on the medication?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

28. Areas in which there is limited knowledge about effects of the medication for children/adolescents.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

<u>Section 4:</u> The following questions are about aspects of counselling and medication treatments that may depend on the program or service where the treatment is provided and how that service is organized.

29. What is the training and profession of the person providing treatment (e.g., nurse, occupational therapist, pediatrician, psychiatrist, psychologist, social worker, school counselor)?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

30. The health-care provider's experience in treating anxiety problems.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

31. When treatment would begin.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

32. Where treatment will take place.

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

33. How often would the child or the parents come for appointments?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

34. When in the day would the appointments are scheduled (e.g., morning, afternoon, after school, evening)?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

35. The cost of treatment (if any).

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

36. Which treatment option does the health-care provider recommend for a particular child and why?

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

37. How the parent will be informed about the child's treatment progress (e.g., letter, feedback sessions).

0----------1----------2----------3----------4----------5----------6----------7----------8
Not important at all — Moderately important — Very important

Was there any type of information about counselling or medication treatments for children's anxiety that was not mentioned in the above questions that you think is important? If so, please describe:

_____

_____

_____

_____

Appendix J

PREFERENCE FOR AMOUNT AND SOURCE OF INFORMATION

Instructions: In making decisions concerning services for children and families, many people find it helpful to have information about the services available. This information may be provided in different ways (such as brochures, discussion with a service provider, Internet) and in different amounts of detail. Your opinions are very helpful in developing information for parents.

A. Please indicate the amount of information you would prefer regarding the following forms of treatment

1. Information about medication treatment

0----------1----------2----------3----------4----------5

0 pages or more (none)	2 pages	4 pages	6 pages	8 pages	10 pages

2. Information about psychological treatment (such as therapy for the child or help for the parents in helping the child to overcome anxiety)

0----------1----------2----------3----------4----------5

0 pages or more (none)	2 pages	4 pages	6 pages	8 pages	10 pages

B. Do you have access to the following sources of information at home? *(Please circle Yes or No)*

1. Television? Yes No

2. Videotape playback equipment? Yes No

3. DVD playback equipment? Yes No

4. Computer with Internet access? Yes No

5. Ability to print information from the Internet on your computer? Yes No

<u>Instructions</u>: Information about services can be provided in a number of ways. Please indicate how you would prefer to receive information about various services.

1. Information given in written form (in an information sheet or booklet which you could take with you)?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not at all preferred — Moderately preferred — Very much preferred

2. Information given by discussion with a health-care provider?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not at all preferred — Moderately preferred — Very much preferred

3. Information provided by a videotape or DVD (which you could take with you)?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not at all preferred — Moderately preferred — Very much preferred

4. Information on a recommended internet website which could be accessed from home where pages could be printed?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not at all preferred — Moderately preferred — Very much preferred

5. Information on a recommended internet website which could be accessed in the health-care provider's office and printed there?

0----------1----------2----------3----------4----------5----------6----------7----------8

Not at all preferred — Moderately preferred — Very much preferred

Appendix J

RANKING PREFERENCE FOR SOURCE OF INFORMATION

Instructions: Information about treatment may be provided in many ways. We are interested in your opinion about how helpful you would find information provided in various ways.

Please read this list describing the methods in which information could be provided.

Then, rank how helpful you think each method would be in your situation. Mark 1 beside the source of information that you think would be most helpful to you, 2 beside the source that would be next most helpful, and so on until you have ranked all five methods. Mark the preferred not next to any method that you would prefer not to use.

	RANK					
Method of providing information	1	2	3	4	5	Prefer not to use
Written information provided in an information sheet or booklet which you could take	O	O	O	O	O	O
Information presented in a videotape or DVD which you could take	O	O	O	O	O	O
Information on a recommended internet website accessed at home	O	O	O	O	O	O
Information on an internet website accessed and printed at the health-care provider's office	O	O	O	O	O	O
Information provided in discussion with a health-care provider	O	O	O	O	O	O

Is there any source of information that you would find helpful in obtaining information that was not mentioned above? If so, please describe:

_____

_____

_____

_____