

Bridging the divide between families and health professionals' perspectives on family-centred care

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Abstract

Objectives To describe and discuss key findings from a recent research project that challenge an increasingly prevalent theme, apparent in both family-centred care research and practice, of conceptualizing family-centred care as shifting care, care management, and advocacy responsibilities to families. The purpose of the research, from which these findings emerged, was to develop a conceptualization of family-centred care grounded in the experiences of families and direct health-care providers.

Design Qualitative research methods, following the grounded theory tradition, were used to develop a conceptual framework that described the dimensions of the concept of family-centred care and their interrelationships, in the substantive area of children's developmental services. This article reports on and extends key findings from this grounded theory study, in light of current trends in the literature.

Setting and participants The substantive area that served as the setting for the research was developmental services at a children's hospital in Alberta, Canada. Data was collected through focus groups and individual interviews with 37 parents of children diagnosed with a developmental problem and 16 frontline health-care providers.

Findings Key findings from this research project do not support the current emphasis in family-centred care research and practice on conceptualizing family-centred care as the shifting of care, care management, and advocacy responsibilities to families. Rather, what emerged was that parents want to work truly collaboratively with health-care providers in making treatment decisions and on implementing a dynamic care plan that will work best for child and family.

Discussion and conclusions A definition of collaboration is provided, and the nature of collaborative relationships described. Contributing factors to the difficulty in establishing true collaborative relationships between families and health-care professionals, where the respective roles to be played by health-care professionals and families are jointly determined, are discussed. In light of these findings we strongly advocate for the re-examination of current family-centred care policy and practice.

Introduction and background

There is increasing talk of a paradigm shift in health-care to patient- or client-centred care where the focus is on people's experiences with illnesses and/or disability.¹⁻⁴ Comparatively speaking, this paradigm shift is further ahead in child health-care^{5, 6} where the term family-centred care is commonly used to describe this new way of providing care. Family-centred care can be literally defined as placing the needs of the child, in the context of their family and community, at the center of care and devising an individualized and dynamic model of care in collaboration with the child and family that will best meet these needs.⁵ The term family-centred care encompasses the concept of the client as the child patient and their family, rather than just the patient.^{5, 7-10} For the purposes of this article, whenever the term family is used we are operationally defining this as the child and their family. In this era of more children living with chronic and increasingly complex problems,¹¹ there has been increasing recognition that a system of care structured around a medical model that was developed to deal primarily with acute and infectious diseases is a poor fit for both child health-care providers and families. In response to these pressures, family-centred care is being increasingly viewed as best practice in child health-care settings.¹²⁻¹⁴

In North America, the concept of family-centred care emerged from a strong advocacy movement on the part of persons with disabilities in general, and parents of children with special health-care needs in particular.^{13, 15-17} This advocacy movement, with its early roots in the late 1960s and rapidly gaining strength by the mid-1980s, was particularly strong in the United States. Parallel movements were taking place in other industrialized countries, including Canada and the UK.^{12, 13, 18} In its early stages, this movement was predominantly led by parents of children with chronic illnesses and/or disabilities who were advocating, against the dominant expert model, for more involvement in their child's health and related care.¹³ The evolution of this movement is reflected in major

policy changes in how children with chronic illnesses and/or disabilities are treated in the health-care and related systems. One example is the change in visiting policies at children's hospitals over the past 40 years. In the 1950s and 1960s restrictive visiting policies were still the norm in most children's hospitals, with parents allowed in to see their children for a maximum of a couple of hours each day. Now, a majority of children's hospitals in North America have an open visiting policy for parents, allowing them to visit and stay with their child 24 h a day.¹⁹

The increasing interest in the concept of family-centred care, particularly over the past 20 years, is reflected in the health-care literature. Following are the six key elements of family-centred care described most frequently in the literature, up to and including 2000: (G. MacKean, W. Thurston, C. Scott, unpublished data).

- 1** Recognizing the family as central to and/or the constant in the child's life, and the child's primary source of strength and support;^{12, 20-23}
- 2** Acknowledging the uniqueness and diversity of children and families;^{7, 12, 20, 23, 24}
- 3** Acknowledging that parents bring expertise to both the individual care-giving level and the systems level;^{7, 9, 10, 12, 25, 26}
- 4** Recognizing that family-centred care is competency enhancing rather than weakness focused;^{7, 8, 10, 15, 27, 28}
- 5** Encouraging the development of true collaborative relationships between families and health-care providers,^{7, 10} and partnership;^{10, 12, 20, 24-26, 29, 30} and
- 6** Facilitating family-to-family support and networking, and providing services that provide emotional and financial support to meet the needs of families.^{15, 23, 31}

In the research and practice of family-centred care, there is an increasing emphasis on training parents of children with chronic illnesses and/or disabilities to assume more responsibility in their child's care, care management, and advocacy,^{26, 32-36} and comparatively less emphasis on other key elements of family-centred care (e.g. elements 2, 5, and 6 above). The increasing attention being paid to empowering parents to

assume more responsibility is resulting in a loss of focus on what many families, and some health-care providers, see as equally important elements of family-centred care, one of which is the development of true collaborative relationships between families and health-care providers. A contributing factor to this appears to be a lack of clarity about the concept of collaboration, a point that will be expanded on in this article.

There is a lack of shared understanding about the concept of family-centred care, not unlike the current status with respect to the concept of patient-centred care.^{4, 37} It was the overall lack of clarity in both literature and practice about the conceptualization and operationalization of family-centred care,^{7, 12, 14, 25, 38, 39} and the lack of a client or health-care system user perspective,⁵ that led to the research project being reported on here. The purpose of this research was to develop a conceptualization of family-centred care grounded in the experiences of families and direct health-care providers. The purpose of this article is to report on key findings from this research that challenge this increasingly prevalent theme of conceptualizing family-centred care as the shifting of responsibilities to families.

Methods

Qualitative research methods, following the grounded theory tradition,⁴⁰ were used to develop a substantive theory that explicated the dimensions of family-centred care and their interrelationships, as well as the relationship between the dimensions and outcomes. The substantive area that served as the setting for this research was developmental services at a children's hospital in Alberta, Canada.

Data collection

Data was collected in 1999, through focus groups and face-to-face semi-structured interviews, involving 37 parents of children diagnosed with a developmental problem and 16 frontline health-care providers working in developmental services

at the children's hospital. The majority of the data was collected through focus groups. Thirty-one parents (seven focus groups) and 15 health-care providers (five focus groups) participated in focus groups that ranged in size from three to seven participants. In addition, seven individual interviews were conducted, six with parents and one with a health-care provider. Questions were asked of both parents and health-care providers that allowed for the exploration of the following topics in some depth:

- 1 Families' good experiences with the health-care system, and contributing factors to these;
- 2 Families' bad experiences with the health-care system, and contributing factors to these;
- 3 Priority desired changes to the way that health services are provided to children and families; and
- 4 Information (scholarly, mass media) that has influenced participants' thinking about how health-care should be provided to children and families.

Study participants

Parent participants were recruited through developmental paediatricians affiliated with the children's hospital, the children's hospital's preschool treatment programme, and two community-based family support organizations. The study participants were selected using purposive sampling, specifically theoretical and maximum variation sampling.^{41, 42} In maximum variation sampling, study participants are selected to maximize variation on dimensions of interest.⁴¹ This supports the grounded theory tradition, where the importance of seeking multiple perspectives during the research inquiry is stressed.⁴² Theoretical sampling is a way of collecting data to generate theory whereby the analyst jointly collects and analyses the data, deciding what data to collect next in order to develop the theory or model.⁴⁰ In this research, some preliminary analysis of the data was carried out following each focus group or interview, and these findings used to guide subsequent sequencing and wording of questions and

sub-questions and the areas probed, as well as the selection of future participants.

Of the 37 parent participants, 19 were parents of children diagnosed with autism or somewhere on the autism spectrum, 12 participants were parents of children with Down syndrome, and six were parents of young children with a developmental delay who at some time in the past year had been involved with preschool treatment services' infant team. Of the 16 health-care provider participants, four were speech language pathologists, four were developmental paediatricians, and the remaining eight came from a variety of health disciplines (i.e. nursing, social work, occupational therapy, physical therapy, psychology). The majority of the parent and health-care provider participants were between the ages of 30 and 49. The majority of the parent participants (28; 76%) and all the health-care provider participants were female. Nine fathers did participate in focus groups and/or individual interviews. The children themselves did not directly participate in interviews, primarily because the majority of the children were not at a developmental stage that would have enabled them to provide meaningful input through an interview or focus group. Resource limitations prohibited data collection through observation. This is acknowledged as a limitation of this research.

Data management and analysis

The focus groups and interviews were audiotaped and transcribed verbatim, with both the signed and verbal consent of the participants. The data was imported into the QSR NUDIST software program to facilitate the data analysis.⁴³ Data analysis in grounded theory is interpretational and theory building. Constant comparative analysis was used to look for statements and indices of behaviour that occurred over time in a variety of contexts.⁴⁰ In this way the key concepts comprising family-centred care were generated. Once a preliminary conceptual framework was emerging from the data, a thorough review of the literature through the year 2000 was conducted to augment and help shape further theory development.

Trustworthiness

The rigor of a qualitative study can be assessed by examining trustworthiness.⁴⁴⁻⁴⁶ In this research, the following strategies were used to increase the trustworthiness of the research findings: reflexivity; triangulation of data collection methods and sources; member checking; and peer review.

Ethical considerations

Ethical approval for this research project was granted both by the Calgary Health Region's Child Health Research Committee and the University of Calgary's Conjoint Health Research Ethics Board. A variety of processes were used to address ethical concerns. All potential research participants were provided with information about the study and a copy of the interview questions. If they made the decision to participate in an interview or focus group, they were then asked to sign a consent form.

Findings

A conceptual framework that explicated the dimensions of the concept of family-centred care and their interrelationships in the substantive area of children's developmental services was developed as a result of this research. Three of these dimensions (i.e. relational competencies of health-care providers, expectations of families, priorities for health-care system change) are described and discussed here, to support our argument that the current emphasis in family-centred care research and practice on training parents to assume increasing responsibility for their child's care, care management, and advocacy may be misplaced. What emerged strongly through this research was that parents want to work collaboratively with health-care providers who care about their child on making decisions about, and then implementing, a dynamic care plan that will work best for their child and family. They desired more input into defining their respective roles. In particular, they wanted more help from health-care providers in: making decisions about what services would best meet

their child's needs; the ongoing management of their child's care; and advocating in their child's best interest. Quotes from the research participants are used to illustrate key points that emerged through this qualitative research project. These quotes contribute context and demonstrate how perspectives of participants were linked to analysis and interpretation.

Relational competencies of health-care providers

Both health-care provider and parent participants in this research described relational competencies of health-care providers as being an important contributing factor to families' experiences with the health-care system. Families did expect health-care providers to be technically competent; that is, they expected the health-care providers caring for their children to have good diagnostic and treatment skills as well as current, non-stereotypical knowledge about developmental problems. It was relational competency, however, that dominated parents' descriptions of their experiences with the health-care system.

The relational competencies described most frequently were: caring; communicating with parents; and interacting with children. Caring encompassed being compassionate, respectful, and providing care in a personalized way.

You can have someone who's educated; hell, I've got nine years of university behind me; and what does that mean? You need that...whatever that is, caring and humanity or compassion, along with competency. (parent)

Health-care providers with good communication skills were: open to discussion and negotiation; communicated in an honest and direct manner; listened; sought and valued parents' input; and were informative. Parents valued health-care providers who would not only openly share useful information with them and invite and listen to their perspective, but who would then continue to work collaboratively with them in developing a plan of care that would best meet the needs of their child and family.

Health-care providers also recognized the importance of both their technical and relational competencies, describing kinds of relational competencies similar to what parents had said.

I think, again, it's finding the time to really sit down with them and talk about, you know, what they already know about their child. Provide them with information options and help them narrow it down.... They are overwhelmed by the information. (provider)

There were also differences between health-care providers and parents' perspectives. Health-care providers spoke comparatively little about their interactions and relationships with the children.

Especially when they have very, very difficult children that aren't actually very likeable children some of them, you know.... But the parents really make up for that because they are such upbeat, great people, and they have 3 or 4 other wonderful kids. They are just doing so, you're just so amazed at their energy and uh, their ability to keep going to the next teacher, the next government person, the next whatever. (provider)

They also spoke more about their role as information-giver and comparatively less about their role as a caring person, collaborator, and helper.

We want to provide enough information for parents so that they feel empowered around making decisions for care for their child. (provider)

This second difference is expanded on under the next two dimensions, expectations of families and priorities for health-care system change.

Expectations of families

Health-care providers described the roles they saw parents playing in addressing the care needs of their children with developmental problems, and parents similarly described what they felt was expected of them by health-care providers. These expectations fell under four broad categories: providing specialized care and therapies for their child at home; obtaining needed information about their child's condition and/or about specialized services; finding appropriate

services for their child; and transmitting important medical information about their child to health-care providers.

Parent participants very much respected health-care providers' knowledge and wanted to work closely with health-care providers in making treatment decisions and implementing a dynamic care plan that would best meet the needs of their child and families. Parents strongly emphasized their desire to have more help from health-care providers in advocating for their child's best interest in a service system that they described as extremely complex and often fragmented. They felt that the health-care system did a reasonable job of diagnosing their child's problem, but then handed the job of finding appropriate services to meet their child's needs over to parents.

I feel like you guys have given me this devastating news that my child has a lifelong disability, and sent me afloat in an ocean and said, okay here it is, now go and do something about it.... (parent)

Other parents whose children had chronic physical medical problems, in addition to their developmental problems, described often feeling overwhelmed by the responsibility placed on them for transmitting highly technical medical information received from one specialist physician to another. They were worried that they would forget to share important information, putting their child at risk, and wanted some help to play this role.

Yup, it's basically incumbent on the parents. And they'll tell you that...like, right at the hospital. 'I don't have time to go through this [chart], give me the long and short of what she's got.' I think the two negative things I had were, [well] part of it was relying on the parent, ...I mean I can't tell a surgeon that [child] doesn't have the thing [certain vein coming off the heart] he needs, unless he shows me a diagram like they did the third time and say, 'This is what he's missing.' I didn't know that.... I want a card that I'm going to swipe. I've heard them talk about it.... If I'm not going to have anybody coordinating any of this crap for me, I want a disc. I want something so that I don't feel so responsible. (parent)

Although the parents who participated in this research wanted to be involved to some extent in

the development of a care plan for their child, working with their child at home and helping in their development, helping in the coordination of any medical care they required, and advocating for their needs, the role that they were able and wanted to play varied both between families and within the same family over time. Initially parents really wanted health-care providers to tell them what to do. They were reeling with a diagnosis and had no idea where to begin with respect to developing a care plan to address their child's special needs. Some health-care providers did recognize that the role parents were able to play would vary between families, and that working with families was truly a collaborative process.

...each parent...you know, and couple being so different in how much, and how little, and what kind of information and trying to be sensitive to that to engage them in the process. (provider)

This was uncommon, however. Many health-care providers expected parents to take the lead in designing and implementing their child's care plan, and saw their role as primarily being the information-provider and/or occasional supporter.

And they're telling you, when they're asking you for a letter they're not asking you for a 20-pager. It's not vague, I hate that. They say look, or they might even write it out in point form, you know and say this is what we need specifically to be said those ways, and this is how the wording has to be for this funding, or blah, blah, blah. Because you're not going to write it unless you believe it, if it's true; but it's such a relief as a professional to have it kind of organized for you. Instead of: 'could you write this letter, could you write that letter'. (provider)

Over time parents did come to realize they were their child's strongest advocate and how important it was that they fight for the services that their child required, but all parents found this to be a daunting task. They all wanted more help from the health-care system. Many parents began their story about their experiences with health-care and related systems on behalf of their child with, '*Our struggle began....*' A number of parents described struggling with

multiple roles: the responsibility of finding the best services and care for their child; working with and providing care for their child at home; looking after the needs of the rest of their family; and ensuring that enough income was coming into the household.

When it comes down to advocacy...you can only do that to a point, and I think that is something that hopefully will develop and be explored more in the future. But how much energy can you have left [to advocate] for your child when you are trying to care for this child? You run out of energy to be a wife and a mother and a person. Um, like, you can only do so much before you do run out of energy. I know I have. (parent)

A number of parents, all mothers, described feeling considerable pressure from health-care providers to quit work and stay at home with their child so that they could work with their child at home. They did not feel like they had a choice in the role that they were to play; rather they were expected to play the role defined for them by the health-care providers.

And, I also found a lot of judgmental behaviour towards working mothers, I mean mothers who work outside of the home; like in other words you should devote 24 hours a day to implementing the things we are teaching you [about working with your child at home].... (parent)

Finally, many parents expressed concern about the expectation being placed on parents to take the lead in designing and implementing their child's care plan. They felt that children who had parents who for various reasons may be unable to play this kind of a role would not get the treatment they required.

If you are a good advocate for your child, and we are all good advocates, let's face it, because that's why we're all here. We're doing great; our kids are doing great; we're getting the best of everything. And we are making sure they do, but we're such a small percentage.... (parent)

Priorities for health-care system change

The emphasis on wanting and needing some help and support and wanting to work collaboratively with health-care providers also came out

strongly in the context of priorities for health-care system change. Parents' highest priority for change was help with advocacy and care coordination, followed by coordination of services and transitions, and then information about services (i.e. consistent, accurate, central source) along with help accessing and interpreting the information. Health-care providers' highest priorities for change were: coordination within and between systems; increased resources (e.g. staff, time); and services that were truly driven by family needs. Both parents and health-care providers described a major priority for change as being the coordination of services within the health-care and related systems, so that it would be easier to negotiate.

...you know, you're emotive and attempting to advocate in a system that makes absolutely no sense. You know, even to me [because I work in the system], I just couldn't find a way to navigate through it, and found it very frustrating. (parent)

Many of the health-care providers also recognized that the system was not user-friendly.

But we really don't have a client, needs-based system here at all...the interactions that go on between individual patients and providers [may be positive], but the system that surrounds that very important dyad should become the fundamental basis of an integrated system of care for families. (provider)

A major difference between the perspectives of parents and health-care providers about the need for system change was the emphasis that parents put on wanting to work with health-care providers in coordinating the care and services their child required and in advocating for their child's needs. Parents again described feeling exhausted trying to do all of this on their own.

Everybody was telling us, get ready to fight for speech. We were at a point now, like when our whole family was just about crashed, we were going. (sigh), we gotta fight for something [else] now. Who's going to help me here? Like, whadya mean we gotta fight? (parent)

Health-care providers put a comparatively greater emphasis on teaching parents how to negotiate the system and how to be strong

advocates for their child, and on making the systems somewhat easier to negotiate. They very much appreciated parents who could take charge of their child's care and care management.

This was a very educated family, a very motivated family, and I think one of the things that was so positive was that even though they had absolutely no background, they were able to be engaged in a discussion around a pretty difficult medical area pretty quickly.... They were able to do a lot of the vetting and investigating of the different programs we discussed, some of the different options. They went out and met with some families, and they could carry a great deal of this themselves.... (provider)

Discussion

The findings of the research project reported here strongly support the importance of the relational component of family-centred care, specifically the development of a true collaborative relationship between families and health-care providers. Parents valued health-care providers with relational competencies who cared about them, understood that each child and family was unique, and who understood that the essence of a collaborative relationship involves the negotiation of the respective roles played by each partner in the relationship. In contrast, health-care providers valued parents who were able to take on a particular role, that of lead care plan designer and implementer and strong advocate for their child(ren) with developmental challenges.

Although a collaborative relationship or partnership between families and health-care providers is a central element in most conceptualizations of family-centred care, the findings of this research illustrate that when family-centred care is operationalized the collaborative processes often disappear. Specifically, the process of determining what role parents want to and are able to play in their child's care and care management is often not a collaborative one. Rather, the operational definition of a collaborative relationship, in the context of family-centred care, appears to be the devolution of

responsibility to parents. The role that each partner plays and the resulting outcomes of the partnership are not being jointly determined by the partners; yet it is this joint determination that is the defining characteristic of a collaborative relationship or partnership described in the literature on collaboration and partnership.^{47, 48}

The development of a true collaborative relationship between health-care providers and parents is characterized by trust and open communication, which in turn enables a negotiation of the roles that each partner is able to play at any particular point in time.^{49, 50} In a collaborative relationship, both the uniqueness of each child and family and the evolutionary nature of the health-care provider-family relationship are accommodated.

Since this research was conducted, there has been an increasing emphasis in research and practice on conceptualizing and operationalizing family-centred care as the training of parents, and related increasing discussion about families not wanting and/or not being ready for family-centred care.^{25, 32, 38} Family-centred care is beginning to sound like something that is being defined by experts and then carried out to families, which is ironic given that the concept of family-centred care emerged from a strong family advocacy movement.^{13, 14, 17} Leiter,³² in her recent research examining the dilemmas that result when mothers and professionals collaborate in providing care to young children with disabilities, did recognize that although parents did have a role to play in an early intervention programme, this role was defined and driven primarily by professionals. She raised the following question: *Does family centred care mean that the mothers take on therapy work [providing therapy for their children at home], or does it mean that the services that the program provides should be sensitive to individual families needs?* (p. 845).³² She found that the majority of health-care providers working with families operationalized family-centred care as the former, supporting the findings of the research reported here. Yet this operationalization of family-centred care did not meet the needs of

many families, neither in Leiter's³² research nor in the research reported here. Other emerging research is illustrating that parents of children with chronic health issues do not feel that they are working collaboratively with health-care providers, and they would like to; rather they feel that they are assuming all of the care management and much of the direct care responsibilities, with little ongoing support.⁵¹

Contributing factors to this difficulty in establishing true collaborative relationships between families and health-care professionals, and to this related trend to conceptualize family-centred care as the training of parents to take on more responsibility, include: the history of the family-centred care movement; the prevalence of business discourse; the medical model and professionalism; and traditional biomedical ethics.

History of family-centred care

As was described previously, the history of the family-centred care movement in North America was characterized by parents of young children with chronic illnesses and/or disabilities advocating for more say and involvement in their child's health-care and care management.¹³ This is because historically health-care providers discouraged any involvement of families, other than doing what they were told to do by health professionals. This history has contributed to the conceptualization of family-centred care as training parents to assume more responsibility for their child's care and care management, rather than the development of true collaborative relationships with health-care providers where respective roles are jointly determined.

Business discourse

Business discourse dominates North American society, and the health-care system is no exception. Terms such as efficiency, cost-effectiveness, and business plans are widely used; there is an increasing focus on doing more with fewer resources.⁵² Given this context, there may be pressure to conceive family-centred care as a way of shifting increasingly more care respon-

sibilities onto families so as to save money in the health-care system. There is increasing evidence that such downloading of responsibilities from formal systems to families results in a disproportionate burden on families and especially women.⁵²⁻⁵⁵

Medical model and professionalism

The traditional medical model is characterized largely by its orientation to disease and disability, rather than an orientation to people.⁵⁶⁻⁵⁸ Although traditionally associated with physicians, the assumptions underlying the medical model are shared by many health-care providers.^{56, 59} There are strong socially defined roles implicit in the medical model for both health-care professionals and families. It is a professional expert model, where the professional is assumed to have the knowledge to diagnose and treat the medically defined problem with no input from the child and family.⁵⁶ Authoritative relationships are inherent in Western models of professionalism, with 'authority being granted on the basis of claims to special knowledge and skills' (p. 241).⁵⁴ Professionalism, with its basis in the ownership of a certain body of knowledge, is an obstacle to developing services that envision a collaborative relationship between health-care providers and families. Rather than developing collaborative relationships characterized by open communication, trust, and negotiation, there is a tendency for health professionals as experts to define family-centred care and the roles that parents are expected to play. In practice then, although the role that parents are playing in the decision-making around and the implementation of their child's care and care management may be different than it was 30 years ago, what has not changed is that health professionals are still often unilaterally defining the role that parents are to play.

Traditional biomedical ethics

Traditional biomedical ethics, with its focus on autonomy and fairness, reflects an ethic of justice⁶⁰ and does not support the relational

component of health-care.^{60, 61} Frank⁶² describes patients as often wanting both more and less than autonomy; they want more in that they want truly informed choice, and they want less in that they do not want to make all of the decisions by themselves. Rather they want someone to guide them, but within a relationship of trust. The research findings reported here support this contention in the context of child health-care, where it is the parents who are generally making decisions on behalf of their children. The emphasis being placed on autonomy and self-determination, at the expense of recognizing the importance of relationships and working together, was reflected in parents' descriptions of how they felt abandoned by health professionals. The parents who participated in the research reported here did not want more autonomy, but rather wanted to be working with a trusted and knowledgeable professional who could help them sort through the complexities of the important decisions they had to make. Salmon and Hall,⁶³ writing about the sharing of responsibilities between doctors and patients, also question whether the transferring of responsibility from health professional to client is always in the client's best interest. They argue that the discourse of client control and empowerment can serve to free health-care providers from responsibility for problems for which they think that they can, or wish, to do little.

Conclusion

We have described some systemic contributing factors to the trends in family-centred care research and practice. Based on key findings from the research reported here, we argue for a re-examination of where we are going with respect to family-centred care, and advocate strongly for moving beyond conceptualizing and operationalizing family-centred care as the training of parents to assume more responsibility for their child's care and care management. The results of the research do not support the primary focus of family-centred care being to shift responsibility of caring for children with

illnesses and/or disabilities from the health-care system to families. Rather, they support the importance of the development of collaborative relationships between families and health-care providers, where the respective roles are jointly determined rather than dictated by health-care providers.

To advance family-centred care research and practice, collaborative processes at multiple levels involving children, families, front-line health-care providers, managers, and policy-makers is the way forward. This will require building on what is known about collaboration, effective client health-care provider relationships, individual change, organizational change, and public participation in policy and decision-making. Future research needs to be planned so as to begin to bridge the current disconnect between the perspectives of family-centred care 'experts' and families themselves.

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