

RESEARCH PAPER

Working with immigrant families raising a child with a disability: challenges and recommendations for healthcare and community service providers

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Purpose: Although providing culturally sensitive care is an important element of family-centered rehabilitation very little is known about providers' experiences working with immigrant families in pediatric settings. The purpose of this study is to develop a better understanding of the experiences of service providers working with immigrant families raising a child with a physical disability. **Method:** We draw on a qualitative approach involving in-depth interviews and focus groups with healthcare and community service providers ($n = 13$) in two multi-cultural Canadian cities. **Results:** The findings indicate that healthcare and community service providers encounter several challenges in providing care to immigrant families raising a child with a disability. Such challenges include the following: (1) lack of training in providing culturally sensitive care; (2) language and communication issues; (3) discrepancies in conceptualizations of disability between healthcare providers and immigrant parents; (4) building rapport; and (5) helping parents to advocate for themselves and their children. Service providers also have several recommendations for improving services to better meet the needs of immigrant families. **Conclusion:** Clinicians should be cognizant of how culture influences the care they provide to clients. More training opportunities are needed for enhancing culturally sensitive care.

Keywords: Immigrant, culturally sensitive care, children, healthcare providers

Introduction

There is a growing recognition that immigrants with disabilities need appropriate culturally sensitive rehabilitation services [1,2]. Immigrants are among the greatest in need for

Implications for Rehabilitation

- Pediatric rehabilitation providers working with immigrant families raising a child with a disability should engage in training and education around culturally sensitive care to better meet the needs of these clients.
- More time is needed when working with immigrant families to build trust and rapport.
- Clinicians need to be sensitive around gender issues and try to involve both parents in the decision making around the care for their child.
- Healthcare providers should help clients to become more aware of the resources available to them in the hospital and in the community.

rehabilitation care [3,4], yet they are often the least able to access and use culturally adapted services due to social, economic and political barriers [2,5]. Culturally sensitive care refers to health providers' understanding and appreciating clients' values, beliefs and goals, which are essential for planning and delivering effective healthcare [6–8]. This is closely aligned with family-centered care [9], a widely recognized best practice in pediatric rehabilitation [10–12].

Providing culturally sensitive care to immigrant families can be challenging because health beliefs, views of disability, perceived relevance of health services, and language of clients and their caregivers often differ from health providers [13–18]. Immigrants from an ethnic minority background often face a number of challenges to receiving effective healthcare [19,20] including language obstacles, discrimination, fear of Western medicine and lack of knowledge of healthcare services [21–23]. Such differences can create many challenges

for clinicians and families [24–26] affecting many aspects of healthcare delivery [15], adherence to treatments [27,28] and health outcomes [2].

It is particularly critical to provide culturally sensitive care to Canadian immigrants raising a child with a disability because Canada has the highest per capita immigration rate in the world [29]. Recent estimates suggest that 20% of Canada's population will be comprised of immigrants by 2017 [30,31]. In addition, over 83% of immigrants to Canada who arrived between 2001 and 2006 were born in regions other than Europe [30,31]. While such cultural and linguistic diversity creates several obstacles for immigrants and healthcare providers [32] research is only beginning to address this issue. Little is known about the experiences of pediatric rehabilitation clinicians providing culturally sensitive care to immigrant families. Given the rising number of immigrants to Canada [30,31] along with the increasing number of children with chronic healthcare needs [15,33], understanding this gap in knowledge is critical.

Culturally sensitive rehabilitation care

Cultural values (such as familialism, interdependence, gender roles and spirituality) and perceptions of disability often influence health behaviors and health outcomes [6,34], which can impact how health services are approached. Thus, providing culturally sensitive care is critical to promoting equitable health outcomes for members of ethnic minorities living with a disability [6,35,36]. Elements of providing culturally sensitive care include: understanding communication needs, cultural traditions, healthcare and education systems, investing adequate time in developing trusting relationships, and patient advocacy [37–39]. The family-centered behaviors considered to support culturally sensitive care include: enabling and partnership, respectful and supportive treatment, providing general information about disability and services, providing specific information about the child's progress, and providing coordinated and comprehensive care [40].

It is important to distinguish between culturally sensitive and culturally competent care. Providing culturally competent care involves delivering the highest quality care to clients regardless of race/ethnicity [41]. Cultural competence tends to operate at an individual level, referring to applying specific skills in the context of clinical encounters to meet the needs of diverse clients. Critiques of cultural competence models state that the notion of culture is often seen as static; is often conflated with race/ethnicity; does not acknowledge diversity within groups; and fails to recognize power imbalances [41]. For these reasons, we have chosen to use the term culturally sensitive care, which refers to health professionals' awareness of the influence of culture on clients' communication styles, beliefs about health and attitudes toward healthcare [42].

Although there is an increasing cultural diversity of clients who have differing beliefs, values, attitudes and behaviors [41], rehabilitation providers are often inadequately prepared to provide culturally sensitive care [16,27,43]. For example, Murden et al. [44] found that among occupational therapists, there was not enough exposure to cultural issues in both university-based education and fieldwork. Consequently, health service

providers often encounter challenges (e.g., cultural, societal and professional) in providing culturally sensitive care [45]. Lee et al. [46] found that although professionals felt that culturally appropriate services were important they reported several barriers that hindered their full implementation with clients.

Focusing on providing appropriate culturally sensitive care is important because members of ethnic minority groups are more likely than Caucasian clients to have poorer rehabilitation outcomes [3,47–49]. Similar evidence shows that being a member of an ethnic minority group often influences access to and type of rehabilitation services that are provided [49]. For example, research indicates that patients from an ethnic minority background who have limited English proficiency are often misdiagnosed and incorrectly treated within the healthcare system [16,47,50]. Other reasons for disparities in health outcomes may relate to discrepancies in understanding disability [18,51]. For instance, Yang et al. [51] found it was difficult for clinicians to promote independence in clients because families often viewed care giving as their duty. Thus, some clinicians questioned the applicability of client-centered care as patients took more passive roles in rehabilitation therapy [51]. Ultimately, it is up to health providers to inform clients and engage them in shared decision-making as much as possible in a respectful and supportive way so that parents can make choices about the roles they want to take [52]. Other researchers report that differences in rehabilitation services may also be a result of some members of ethnic minority groups being uncomfortable going to rehabilitation centers staffed mainly by Caucasian providers [18] or suspicious of them [53]. For instance, past research has shown how immigrants are distrustful of the medical community [22].

Most research on culturally sensitive care amongst people with disabilities has focused on *adults* with disabilities while less attention has been paid to *children* and their families. Culturally sensitive care in pediatric rehabilitation tends to focus on the impact of training programs on care [54,55] or the development of conceptual models of cultural competence [1,56]. Exploring culturally sensitive care in pediatric rehabilitation is salient because more than half a million Canadian children and youth under the age of 20 years have a disability [32]. Previous research often focuses on ethnic minority groups with little attention paid specifically to *immigrants*. It is critical to focus on immigrants with a disability because they can face the following disadvantages due to being an immigrant: acculturation, language obstacles, poverty, lack of health insurance and lack of knowledge of services/resources available to them [6,16,25,57].

Another gap in research is that the experiences of healthcare and community service providers working with immigrant families raising a child with a disability have rarely been explored [15,17,33,58–60], which is the focus of our study. More specifically, the purpose of this study is to develop a better understanding of healthcare and community service providers' experiences of working with immigrant families raising a child with a disability. Such knowledge can help clinicians to better respond to the needs of immigrants living with a disability and contribute to the development of more effective training programs in cultural sensitivity [35].

Method

Design

Our research question was: What perceived issues (barriers/facilitators) do rehabilitation service providers experience in providing care to immigrant parents raising a child with a disability, and what enablers/supports do they recommend?

This study used a descriptive, qualitative approach, which is relevant for understanding in-depth experiences. Focus groups and individual interviews were conducted with health service providers and community service organization representatives in two Canadian cities (Hamilton and Toronto). These sites were chosen because they serve multi-cultural immigrant groups. Ethical approval was obtained by a pediatric hospital and a university research ethics board (Toronto and Hamilton, Ontario).

Sampling and recruitment

A purposive sample was used to recruit healthcare and community service providers using the following inclusion criteria: (1) at least 2 years of experience working with children (aged newborn to 17 years old) with disabilities; and (2) at least 1 year of experience working with immigrant families. Healthcare and community service providers were recruited through an introductory e-mail and information package sent to key informants at both participating centers by the project coordinator. We aimed to recruit participants from a variety of backgrounds (e.g., social work, physical therapy, psychology, occupational therapy, speech language pathology, family medicine or developmental pediatrics) with experience in delivering pediatric rehabilitation or community services to immigrant families raising a child with a physical disability. A mix of interdisciplinary backgrounds was included to ensure a variety of health service delivery perspectives.

In total, we spoke with 13 healthcare/community service providers (refer to Table I), all of whom were females. The first focus group in Toronto included two social workers, two physiotherapists, and two occupational therapists with a wide range of experience of working with immigrant clients (refer to Table I). Three of the healthcare providers had received culturally sensitive training. The second focus group of

community service representatives included two social workers, one nurse, and a resource coordinator. The healthcare provider interview in Hamilton involved a physician who had been trained in culturally sensitive care with more than five years of experience working with immigrant clients. The community service representatives included a worker involved in recreation who had no training in culturally sensitive care but over 10 years of experience working with immigrant clients. The settlement worker in Toronto had more than 5 years of experience working with immigrant clients.

The adequacy of the sample size was determined when theoretical saturation was reached. This occurred when no new data emerged regarding a category; the categories were well developed, and the relationships among the categories were well established and validated [61].

Data gathering

Data were collected from June to July 2010. Each focus group and interview followed a semi-structured interview guide that included open-ended questions. Questions asked about barriers and facilitators to healthcare utilization, service issues, service integration issues, perceptions of the ways in which service organizations respond to the needs of immigrant populations and perceptions of culturally sensitive care. Two focus groups (one in Hamilton and one in Toronto) were held with healthcare professionals and community service representatives. Six healthcare providers from a pediatric rehabilitation hospital (Toronto) took part in the first focus group while four participants representing Toronto community-based organizations with experience in working with immigrants and people with disabilities in social services took part in a second focus group. Two community service providers and one healthcare provider were interviewed separately due to scheduling difficulties. The focus groups lasted between 75 and 92 min and the individual interviews lasted from 40 to 76 min.

Data analysis

All focus groups and interviews were audiotaped and professionally transcribed verbatim. The research assistant reviewed the transcripts to ensure that all identifying information

Table I. Overview of focus groups and interviews.

ID #	Interview/focus group	Background of participants	# of years experience	Culturally sensitive training
1	Healthcare provider focus group pediatric rehabilitation hospital	Social work	15+	Yes
		Physical therapy	1–5	No
		Occupational therapy	6–10	No
		Occupational therapy	1–5	Yes
		Physical therapy	15+	No
		Social work	15+	Yes
2	Healthcare provider interview (Children's hospital)	Medicine	6–10	Yes
3	Community service representative	Recreation	11–15	No
4	Community service representative interview	Settlement worker	6–10	Yes
5	Community service representatives	Nursing	15+	No
		Social work	6–10	Yes
		Resource/service	6–10	No
		Coordinator social work	6–10	Yes

was removed. Drawing on systematic procedures of inductive (open) coding within qualitative research, we sought an in-depth understanding of participants' experiences of providing care to immigrant families raising a child with a disability [61]. All members of the research team, which consisted of two scientists at a pediatric rehabilitation hospital (Psychology and Sociology), two professors (Pediatrics and Psychology) and a graduate student (Anthropology and Migration/Ethnic relations) read each of the transcripts. Three of the authors and a research assistant were involved in coding the data where each person read through the transcripts several times (independently) and noted emerging themes and patterns.

Our research questions served as a guide for the themes to emerge from the data. Themes were then compared and contrasted between members of the research team until consensus was reached. All codes were re-read and compared with each other in a constant comparison method. Then, codes were organized with regards to the structure and relationships between the codes [61]. Codes were examined, merged, relabeled or split as necessary. Then an advanced level of coding was used to reorganize data segments and assign those with similar meanings to a new category. Through this iterative process the key themes were identified. Direct quotes representative of each key theme and sub-theme from the interviews and focus groups were abstracted by and given a code. The whole context of the interview or focus group was considered when abstracting statements and labeling them with codes [62]. Code-recode and peer examination helped to ensure the trustworthiness of the findings. An audit trail of key decisions regarding data coding was carefully documented [61,62].

Results

Challenges in providing culturally sensitive services to youth with disabilities

The results showed that healthcare and community service providers faced several challenges in providing care to immigrant families raising a child with a disability. Such challenges included: (1) lack of training in providing culturally sensitive care; (2) language and communication issues; (3) discrepancies in conceptualizations of disability between healthcare providers and immigrant parents; (4) building rapport; and (5) helping families to advocate for their children. The healthcare and community service providers also had several recommendations for improving services to better meet the needs of immigrants raising a child with a physical disability.

Lack of training

Healthcare providers reported lacking training in culturally sensitive care in working with immigrant families. For example, one clinician said:

“This is where I think that the lack of training comes in because I've had situations where I am absolutely up against a wall” (Focus group #1, Hospital Physical Therapist).

She was referring to how to handle difficult situations such as differing views of disability and also the challenges involved with using an interpreter. Another clinician spoke to this issue:

There's no formal training for us to use interpreters. So it's something you've assumed that you'll figure out how to do and when I'm using the interpreter I'm always looking at the family member and talking to them. That's something after using an interpreter for 15, 20 years I learnt to do and certainly didn't do it the first two or three times I was doing it (Focus group #1, Hospital Social Worker).

Most often, healthcare providers said they learned how to be culturally sensitive on the job through “hands on” experience over time rather than through formal training. Many of the healthcare and community service providers mentioned there is a great need for more formal learning and training opportunities around providing culturally sensitive care to immigrant families.

Language and communication issues

As expected, language and communication issues were a key challenge for clinicians and community service workers providing care to immigrant families raising a child with a disability. One clinician described it best, “*Language is certainly a huge one which even with translators we don't necessarily overcome entirely*” (Interview #2, Hospital Physician). Lack of training in working with interpreters led to difficulties in providing effective care. For example,

A lot of [clients/parents] rely on family to do the interpretation, they do linguistic interpretation. And that, to me, is a dangerous thing because then you're relying on somebody who has a vested interest, one way or the other, to interpret for another person. Rather than having a neutral third party whose job is simply there to interpret the words and the meaning, you've got somebody involved who you don't know if they're telling you the right words or not, who knows? (Interview #4, Community-based Settlement Worker)

Other clinicians described their difficulties in working with interpreters:

When the interpreter comes in I find that my sessions are very concrete, very objective, very planned. It's difficult to build that rapport especially 'cause in our facility we take we ...most of the time professionally in my experience I've had to get a professional interpreter and I've always wondered how you communicate a rapport. How do you interpret rapport? (Focus group #1, Hospital Occupational Therapist)

Another key challenge, as described by healthcare providers, was around immigrant parents not being able to receive necessary resources. For instance, they stated that: “*The language stuff can affect their ability to access the resources that might help them*” (Focus group # 1, Hospital Social Worker). Other community service providers similarly commented,

It's a tremendous barrier [for immigrant families] to walk in here and see everything in English and we just don't do very much to

open ourselves up to being more welcoming. Not all of the information goes out in English but they are lucky if they can find someone to interpret it. (Focus group #1, Hospital Occupational Therapist)

Some healthcare providers mentioned that working with a professional interpreter also adds time to the clients' appointment and they do not always have time to get all of the details they need.

It takes a long time through a translator as well to kind of go through a full history if it's never been done, or that we don't have any records from. It takes quite a while and so we've learned to preface the discussion a little bit with how long we might spend together and why we're asking so many questions, to kind of complete a full history that we could then pass on to their new family physician or other healthcare providers that might need to see them so they don't need to do it repetitively (Interview #2, Community-based Settlement Worker).

Some healthcare providers discussed how rushed the interpreters' time was during appointments and the stress that it caused them in working with immigrant families.

With our clients when we are escorting them for the translation purposes, what happens is that the person providing the information for them, they are so much in a hurry to serve another patient that... sometimes I need to block [the interpreter's] way [to have more time] to ask a question on a client's behalf. So that happens (Focus group #5, Community-based Social Worker).

Indeed, language and communication difficulties between healthcare providers and immigrant families often created challenges in providing culturally sensitive care.

Discrepancies regarding understanding of disability

A third key challenge that healthcare and community service providers experienced in providing care to immigrant families resulted from differences in how disability is conceptualized and understood. For instance,

A lot of cultures don't recognize the concept of disability, right? Or there's a very distinctive negative connotation with that term. So that's often not the term used.... it's framed either as illness or deficit (Interview #4, Community-based Settlement Worker).

Another clinician raised a similar point,

The attitude that families have towards disability and what it means to them. How they perceive themselves as having a child with [a] disability and whether that means there's shame or guilt involved. It's something we're not just really good at tapping into and understanding (Focus group #1, Hospital Occupational Therapist).

Healthcare providers also mentioned that differences in how disability is viewed sometimes influenced whether their clients followed treatments and recommendations. One clinician describes such a situation:

Some recommendations you'll give a child for safety concerns or you provide a child with equipment so they're better supported so feeding could be more successful and more in a safe way and yet they still have a lot of [difficulty] culturally their food, they want

to be feeding that even though a different food is suggested (Focus group #1, Hospital Occupational Therapist).

Some healthcare and community service providers described how it takes a great deal of patience and understanding to relay differences in Canada's healthcare system compared to the model of care their clients are used to receiving.

Healthcare is very, very confusing to a lot of people, a lot of new immigrants. So when a new immigrant comes to Canada and their child has a physical disability like spina bifida or CP, they're dealing with a mixture of fear, grief, hope, happiness, and utter confusion. The healthcare system only makes utter confusion worse because where in a lot of cultures...you went to the medicine person who could help your family. There wasn't an elaborate you go to this person and have to tell your story; then you go to this person and have to tell your story... So one of the first things I do is sort of forewarn people: it's going to be a lot of paperwork (Interview #4, Community based Settlement Worker).

This example is linked to the family-centered care notion of the need for coordinated care. Indeed, multiple service providers, service delivery silos, lack of service integration even within organizations can create issues for all families, regardless of immigrant status.

A similar example was given by a healthcare provider who mentioned that some of her clients/parents were hoping to be cured of their disability upon arriving here.

The two children I have [in my care] with cerebral palsy and the one who arrived with uncorrected hydrocephalus at 18 months... fairly generally those parents really thought that their children are going to be cured upon arrival in Canada. And actually so did the family of a teenager with some global delays. When we start talking about it being a long term illness that we can support parts of it, but not able to cure it, likely, and that our process starts with investigating some reasons why and starting with some tests and some other visits with specialists and with allied health, and so I think the family becomes somewhat disillusioned or frustrated... you know, that wasn't what they thought would happen upon arrival (Interview #2, Hospital Physician).

Indeed, most of the clinicians and community service providers faced several challenges in delivering culturally sensitive care related to differences in how immigrant families understood disability, especially around notions of disability as something that can be fixed versus something that requires an environmental accommodation.

Building rapport

A fourth key challenge to providing care to immigrant families raising a child with a disability is building rapport and relationships. Most of the healthcare and community service providers highlighted that building trust and rapport were key aspects in working with immigrant families. For example, one clinician said: "*Another aspect is about trust in authority*" (Focus group #1, Hospital Social Worker). Other healthcare providers agreed: "*Sometimes I really have to build a trusting relationship with some of the clients. So that they respect my opinion*" (Focus group #1, Hospital Social Worker). Healthcare and community service providers mentioned that developing trust with immigrant clients, especially amongst refugees, was difficult. For instance,

There's a perception I have gleaned a little from families and a little in talking to other providers about families being hesitant to speak with someone who also sort of apparently works for the government...I ask them for OHIP card, that's a government document, in order to see them. Or that's sort of the process of seeing a physician. Then there's a little bit of skepticism depending on the culture and the country and infrastructure they arrive from of them telling me private information and wondering if some of that may get through and affect their claims hearing as a refugee or some other process (Interview #2, Hospital Physician).

Along with building rapport with clients, the service providers described how it took time to reduce some of these fears in their clients. Thus, another key challenge service providers encountered was lacking time to provide culturally sensitive care to immigrant families. Several clinicians described how it took a lot of time to build relationships with clients and yet this is often not reflected in the time allotted for the clients' appointment.

It's difficult because as a [health provider] I never have time to do that...I try to foster their independence but I don't have time to sit and talk about that kind of stuff...I have 45 minutes to do an assessment...or I have an hour to do a treatment. I mean if I spend half an hour talking and they want their kid to be physically treated. So it's a bit of a difficult situation (Focus group #1, Hospital Social Worker).

Service providers in Toronto suggested that newcomer families, who often come from resource poor countries, may feel they need to accept everything and not question health-care decisions because they are fortunate just to have health-care for their child. Meanwhile, most health service providers indicated that newcomer parents often viewed them as the "expert" and anticipated they would make all the decisions. This lack of involvement in decision-making posed challenges for clinicians because they typically try to maximize client engagement and shared decision-making.

I've heard a lot with new families... where 'you're the expert.' I would ask, 'how do you think your child looks right now in this position?' You're the expert. I'm not the expert when it comes to their child, right? They're the expert in my opinion, so I very much agree with that whole power and authority. I find that a struggle (Focus group #1, Hospital Occupational Therapist).

Indeed, clinicians found it challenging to involve clients in the decisions around their healthcare when they were used to a different model of care. Two clinicians describe their experience:

I'm giving you all the options, the goods and the bads and you're making a decision. I do it in a very supportive way but I don't think a lot of parents are ready and used to that. We can talk about the fact that we expect them to be consumers...I don't think many of our people are trained to be consumers and I think that new people are way at the other end of where they're completely expecting us to make their decisions for them (Focus group #1, Hospital Social Worker).

This is a reality that has to be respected; the idea of negotiating roles within a family-centered model.

The other issues of independence and our view of independence versus some other cultural views of independence. And how, you know,

we have an agenda. We may even push that agenda without understanding what the other side is looking for. I think we set ourselves apart in that way...Our goal may be to independently be feeding but maybe that's not an interest of the family per se. Maybe that's their pleasure to do (Focus group #1, Hospital Occupational Therapist).

This is another example of differences in family versus service provider goals that needs to be negotiated with each family.

Clinicians remarked, that compared to Canadian families, immigrant families with a disabled child tend to be less involved in the decisions around their care. For example,

Once you build that trust, they share a lot of what's going on with their families... and so again, it's like... the family as a unit, and not just one disabled child, that there's other children in the family. And so some of our families, I mean, they're blended families, but they might have 13 children. They're huge families and what kind of support do they need over and above the disabled child? Because I think if you're just treating the disabled child you're not treating the family, and I think that there's a lot more issues and stuff with that (Focus group #5, Community-based Nurse).

Community service providers in Toronto described a similar situation where immigrant children were often not involved in the decision around their care.

Canadian families, the children are much more involved. From what I've seen, many of the kids make their own decisions, when they get to a certain age range. I don't know if it's the same in the others because we don't get that sharing from them. When I'm at clinic and asking you know, how are you doing?, it's usually the child that's talking to me. But with the immigrant families, they don't even want to talk to me, so... I don't know what's going on with them or how I can help them...I'm not sure if the kids are even consulted about some of the things that are being suggested done for them. I think that's a communication barrier too, to accessing services (Focus group #5, Community-based Nurse).

In sum, building rapport and relationships with clients takes time and this often posed challenges for healthcare and service providers striving to deliver culturally sensitive care to immigrant families.

Gender

Gender was another key issue related to shared decision-making and authority that came up in each of the focus group interviews. Clinicians described gender-related challenges in providing care to immigrant families and indicated that it was sometimes challenging to tap into the caregiver most knowledgeable about the child (usually the mother) in situations where the mother had a language barrier resulting in the father having to be the spokesperson for the family. A clinician describes her experience:

It's a bit of a conundrum because often times in certain cultures the male is the head of the household. He's the one who's doing a lot of the talking and advocating. But the female [has] almost 100% responsibility for the kid. And so it creates this situation where the communication and the questioning happens with one family member but that's not the family member who's primarily responsible for the child...Even if there's an interpreter there, there's often, you know, a dominant person and it's often the male. So the mom does get left out and the information doesn't get transmitted to her even when there is an interpreter (Focus group #1, Hospital Social Worker).

Other clinicians and community service providers agreed that the gender of the parent communicating with the clinician often played a predominant role in relaying the information about the child. Specifically, there was often a disconnect between who is communicating to the clinician and who has the primary care giving responsibility for the child.

You can talk to Mom, but in actual fact, if Dad's there, Dad may be the decision-maker more so. So it depends on who the information is also delivered to. And I learned that the hard way once, so... the healthcare providers tend to go to the Mom, because the Mom is usually the one who's... the primary caregiver. But it's actually the Dad who's making all the decisions. I've seen in some cases too where the Mom doesn't even go into the appointment (Focus group #4, Community-based Settlement Worker).

Indeed, these gender and cultural issues where the male of the household is the key decision maker for the child's care can present challenges for service providers not only in receiving the appropriate information but also in developing a reciprocal relationship with the family. As one clinician said, "*We're all females so there's a gender issue that comes along too*" (Focus group #1). She was referring to the fact that there is often a perceived power difference. As a result, developing rapport and promoting independence among families were key challenges that clinicians experienced in providing care to immigrant families raising a child with a disability.

Helping immigrant parents to advocate for their children

A fifth key challenge encountered by many healthcare and community service providers was helping immigrant families to advocate for themselves to obtain supports and resources for their child. For example, one provider said:

"There's a certain number of families who are new and unfamiliar with the system and as a result they don't feel they can advocate as well as they might like to for their child" (Interview #3, Community-based Service Representative).

Many of the healthcare and community service providers working with immigrant families thought this lack of advocacy stemmed from immigrants not knowing what was available to them. One clinician describes her experience:

I find it a bit harder to partner on an equal level with the newer families to Canada because they don't know how to access what's available to them. They don't know what to ask for whereas families that were born and raised in Canada I find that they're able to advocate for what they want (Focus group #1, Hospital Physical Therapist).

This highlights that there needs to be an awareness of services, ability to partner and advocate for themselves.

Community service providers agreed that immigrant families encountered difficulties in connecting to resources that could help their disabled child. Several clinicians commented that immigrant clients were often very grateful for the services they received and felt it was inappropriate to ask about other resources or services that might be available to them.

What I've noticed quite significantly it's often people... when you've come from a refugee camp and are of generally very low

socio-economic status and very little ability to make your own choices in that environment, I tend to find those families very grateful to be in Canada and receiving some support (Interview #2, Hospital Physician).

This healthcare provider was describing how few resources and little healthcare is available to refugees when they arrive in Canada. Other community service providers reported similar behaviors:

Mostly [immigrant families] are so afraid to ask because they think this is a privilege; not a right. So that's why it's hard for them to differentiate between those two. But the Canadian raised or born... those are different. They know their rights and they know how to ask. They are confident. They are fluent in the language. So their case is totally different from those people. Just the level of sophistication (Focus group #5, Community-based Social Worker).

Thus, healthcare and service providers often found it challenging to help clients/parents to advocate for themselves.

Connections to resources: A key component of immigrant clients being able to advocate for themselves is having a good knowledge of available resources. Clinicians and community service providers said that this can be difficult if the appropriate referrals are not made. For instance,

If [clients] were floating around in the system before they got a referral or before they got connected. I mean, if they were lucky they get here and they had someone fabulous like you who lays it all out for them, but if they're out of the system then they don't have access to that 'cause they don't have someone to guide them through it (Focus group #1, Hospital Social Worker).

Others described how a client could easily miss out on other resources that are available to them if the right connections are not made within an agency.

Somebody who just came for a one-off clinic that wasn't associated with a team might not end up connecting with someone like one of the social workers who could set them off...Even if it was a clinic and the nurse identified an issue they might make the link at that point to someone, but if that didn't come up then the link may never get made (Focus group #1, Hospital Social Worker).

Some clinicians mentioned that they were often unaware of the resources available to immigrant families. For example, "*some of the health professionals don't know what the organizations are out there or what's available*" (Focus group #5, Community-based Social Worker). This makes it challenging to connect immigrant families to the appropriate resources. This lack of knowledge of external services requires service coordination. Although services are often fragmented along with a need for service coordinators to work with families to identify resources and supports these issues are common to all families. However, they may be more exacerbated for immigrant families. In sum, service providers described how it is often difficult to help immigrant families with a disabled child and that they often lacked awareness of the resources available to them.

Recommendations for practice

Healthcare and community service providers had several recommendations for improving culturally sensitive care to

immigrant families raising a child with a disability. First, they highlighted that more education and training is needed around how to provide culturally sensitive care. Second, immigrant families need more help in becoming aware of the resources that are available to them so they can advocate for themselves to access services. For example, one provider suggested:

I really think that they need more, not just brochures and stuff that will explain programs, but somebody that will help them to explain what the program is [e.g., service coordinator/system navigator] and... again with healthcare, that's a pretty huge area, and pretty intimidating (Focus group #3, Community-based Recreation Service Provider).

Along with awareness raising is a need for more effective teamwork and coordinated care to keep connected with other providers, especially in regard to certain immigrant clients who may need more assistance. For instance, one provider recommended:

Touching base with social workers is a really important issue and I think it depends on your team...Therapists are pretty sensitive and aware and they will often bring us issues...such and such is happening with a family, what do you think we should do? Or where should we go with this? Or let's put our heads together to problem solve (Focus group #1, Hospital Social Worker).

Others agreed that it is important to have a good team to provide effective care and services to immigrant clients.

Having a team that knows them well, like, we're privileged to work with settlement health workers that do a lot of the legwork. And get to know the families fairly well, kind of a drop-in basis often. You know, they come to see them when they're unwell and they can try and track down if they need to see us or not. So yeah, working with a team that kind of understands those issues is big (Interview #3, Community-based Recreation Service Provider).

Some providers also spoke about being knowledgeable about resources that are available in the community and providing that information to families.

I think knowing your own community and its supports very well. A lot of our Canadian families will investigate supports and kind of be their own child's advocate themselves, and navigate that system, often without me knowing as much about it. As the physician I don't know all the nitty gritty of their case manager and who calls who and... you know, how to get different supports in place as much. And for our newcomers, I and our settlement health workers tend to do a lot more of that, so I've learned the system well, probably, from doing this (Interview #1, Hospital Physician).

Some community service providers suggested that there needs to be stronger links between healthcare services and community services for immigrants. For example, "*I think as part of healthcare there needs to be more of a connection between healthcare services and settlement services*" (Interview #4, Community-based Settlement Worker).

A third key recommendation by healthcare and community service providers was to try and match clinicians with families from similar backgrounds (where feasible) and/or to hire more ethnically and/or linguistically diverse staff.

Furthermore, service providers in Toronto thought that newcomers could be linked with families in similar circumstances and who speak the same language to help orient them to the system.

Fourth, clinicians advocated that health providers try to work with the same or preferred interpreter for each visit. One clinician described her experience:

I find having a consistent translator with a family is very helpful, if possible. Our nurses are quite good at arranging that, especially if we ask for specific families that have longer term needs. I find just giving myself a lot of time, so not booking a traditional clinic, by any stretch, and then even warning my colleagues if I'm referring them onto some specialist of the same, that they will come with a translator and this is likely to take twice as long as your typical consult (Interview #3, Community-based Recreation Service Provider).

A fifth recommendation is that hospitals and rehabilitation services should collect relevant cultural background information from clients when they are registering so that the appropriate care can be provided. For instance,

If there's any sort of centralized system in people's charts or something because not everybody can spend time to really talk people through with their issues. Not everybody has the time to build the rapport but there are some positions that enable that a bit better (Interview #3, Community-based Recreation Service Provider).

Sixth, clinicians felt that more time is needed to work with immigrant families to build rapport and also to work with interpreters. Indeed, "*I think it's around taking that extra time to be able to allow the families to explain what they need or want*" (Focus group #3, Community-based Settlement Worker). It is very important to take the time to understand family situations, needs, concerns, worldviews, constraints and priorities, thus, providing services to meet their identified needs. Service providers in both Hamilton and Toronto believed that extra time needs to be taken with immigrant families to understand their family contexts and histories, including their experiences and perceptions of healthcare. A provider describes the importance of this:

To be culturally sensitive I think a lot of times when you meet with families, it's not what they initially say, and what they say when you've... had a conversation with them over a longer period of time. It's like maybe they'd be really positive when you first, you know, talk to them about healthcare, but as you speak to them and they share with you and feel comfortable and you build that trust then they're going to share with you more (Interview #3, Community-based Recreation Service Provider).

A seventh recommendation that service providers had to improving culturally sensitive care was that home visits and personalized support networks would help immigrant families to navigate the system. Several community representatives and service providers thought that home visits with new immigrant families helps build relationships and also introduces services available to them. A Hamilton community service representative was especially keen on the importance of home visits, believing home visiting to be a best practice when working with immigrant families.

Finally, clinicians and community service providers recommended that best practices around culturally sensitive care need to be shared between staff. For example, one clinician suggested:

I tend to have a lot more in-person discussions with my colleagues about these families, so... either sort of warning them that one of the kids I know well might be coming into hospital under them and we're kind of giving them a bit of an in-person brief, like an update. And provide, you know, making sure – as much as we do it for everybody, that all your notes are available so they don't have to start from scratch (Interview #2, Hospital Physician).

In summary, there are several key lessons that healthcare and community service organization representatives should consider when working with immigrant families who are raising a child with a disability.

Discussion

Our results show that health service providers faced several challenges in providing care to immigrant families raising a child with a disability. The findings also have several implications for pediatric rehabilitation clinicians to better respond to the needs of immigrants living with a disability and also to contribute to the development of more effective cultural competence training programs [35]. Clinicians reported lacking training in culturally sensitive care, which posed several barriers to offering effective care to immigrant families. This finding is consistent with past research showing that rehabilitation clinicians are often inadequately prepared to provide culturally sensitive care [16,43,54,63,64]. Indeed, clinicians need an increased awareness and knowledge of cultural beliefs and customs of their clients [16] through education and training. This could be in the form of formal university courses or continuing education programs. Such training is essential for health providers to be attentive and responsive to clients' cultural characteristics [65].

Furthermore, our findings indicated that healthcare providers encountered many challenges in providing care to immigrant families around language and communication, especially in dealing with translators. These findings are consistent with past research on ethnic minority groups who encounter language obstacles in accessing health services [21,23]. More time should be allotted when working with immigrant families, to build rapport and also to allow time for working with interpreters.

Healthcare providers in our study also reported several discrepancies around how disability is understood and responded to, especially with regard to viewing clinicians as experts and not realizing that they can be more involved in shared decision-making for their child's care. Indeed, culture influences how society understands and approaches disability [13,16,17,51]. Some researchers argue that there is a need for a fuller appreciation of the complex dynamic between our own cultural lenses and those of minority clients [66,67]. One way to achieve this is by hiring more ethnically and linguistically diverse staff, possibly matched with clients from similar backgrounds, especially in major cities where immigrants are most likely to settle.

Another aspect linked with our finding regarding challenges in providing culturally sensitive care was the role of gender. Clinicians in this study reported that among some immigrant families, the male head-of-household often did most of the talking and decision-making for the child's care even though the mother was often the person most knowledgeable about the child's condition. This was an important finding because recent evidence has highlighted that most culturally sensitive models lack an examination of power relationships [8].

Another key challenge to providing care to immigrant families raising a child with a disability was around building rapport and trust. Clinicians described that it took time and patience to develop these aspects as clients were often reluctant to trust them, particularly refugee clients. Other past research emphasizes the importance of creating a warm and accepting atmosphere and taking time to establish rapport and building relationships [16,68,69].

A final challenge in providing culturally sensitive care that clinicians reported was around helping immigrant families to advocate for themselves and to help them become aware of the resources that are available to them along with service coordination issues within their own organizations. Our results indicated that clients were often not aware of the services that they could benefit from. Health service providers said this often stemmed from appropriate referrals not being made, which is a finding that is consistent with previous research [65]. Our results are also similar to past research highlighting that rehabilitation clinicians can provide powerful advocacy for minority clients and their families by modeling culturally sensitive practice [16].

Health service providers should help clients to become aware of the resources that are available to them both within the hospital and in the community. This would require healthcare teams to work collaboratively and share information.

Conclusion

Providing culturally sensitive care is important because disability is often perceived differently based on cultural beliefs [16,35,70–72], which can influence health behaviors, health outcomes and impact how healthcare services are approached [2,6,64]. This study addressed several key gaps in the literature on culturally sensitive care by exploring the experiences of healthcare and community service providers' experiences of working with immigrant families with a disabled child. First, most research focuses on adults with little attention paid to children. Second, previous research focuses on ethnic minority groups with little attention paid specifically to immigrants. Focusing on newcomers is salient because they are often more disadvantaged in that they are affected by acculturation, language obstacles, poverty and lack of knowledge of services that are available to them [6,16,25].

The findings indicate that healthcare and community service providers encountered several challenges in providing care to immigrant families raising a child with a disability. Such challenges included: (1) lack of training in providing culturally sensitive care; (2) language and communication issues; (3) discrepancies in conceptualizations of disability

between healthcare providers and clients/parents; (4) building relationship; and (5) helping clients/parents to advocate for themselves.

Our findings have several links with family-centered service and relationship-based practice. First, there were parallels regarding coordinated and comprehensive care (e.g., system navigation, the need for one consistent interpreter and the issue of having to repeat one's story). Second, we found that there is a need to provide general information to families about resources and services available to them. Third, is the importance of relationship building and listening to clients to ascertain situations, needs and priorities. A fourth link of our findings to family-centered care was the true nature of partnership between healthcare providers and families and not leaving the responsibility on families to do everything and make all of the decisions, but supporting and enabling them in the decision-making around their child's care.

Future studies should be directed in several areas. First, more work needs to be done to explore differences in providing culturally sensitive care between various types of healthcare providers. Second, future research should examine cross-cultural differences in the needs of clients. Third, more research is needed to examine the promising practices of health and community service providers already serving the needs of immigrant families.

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