Research Article

Health promotion for immigrant mothers of children with developmental disabilities: Towards a transformative approach

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Abstract: Background: High societal expectations that involve idealized and labor-intensive mothering are a source of stress, anxiety, guilt and frustration for women. Immigrant mothers caring for children with developmental disabilities are disproportionately burdened with health inequities. Study goals: The overall goal of our study was to examine health promotion practices of immigrant mothers with children with developmental disabilities using the Health Promotion Activities Scale (HPAS). Methods: Twenty-eight mothers of children with developmental disabilities were interviewed using the HPAS. A grounded theory approach was utilized to analyze the qualitative data. Results: Immigrant mothers of children with developmental disabilities' engagement in health promoting activities is influenced by their role as primary caregivers, the gendered nature of mothering, non-Western views on health promotion, mothers' burden from inequities and structural barriers pertaining to funding, disability, and migration status. The responses on the HPAS also underscore motherhood as a social construct with embedded assumptions and social expectations related to role and responsibilities that requires them to be "good" mothers. Discussion and Conclusion: There is need to incorporate transformative health promotion approaches in research and practice that consider mothers' multicultural contexts. The intersections of motherhood, disability, gendered role expectations and migration need to be taken into account.

Keywords: Mothers, Mothering, Developmental Disabilities, Health Promotion, Immigrant Women, Transformative Approaches

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Introduction

Motherhood is a central aspect of mothers' identities, experiences, gendered roles and societal gendered expectations. Mothers talk about the joys and sometimes challenges of their important role. However, idealized motherhood in contemporary societies may have negative physical and mental health outcomes for women (Henderson et al., 2016). Mothers of children with developmental disabilities have been reported to face increased health risks compared to mothers without children with developmental disabilities. experience higher rates of poor physical and mental health. Statistics from the United States and Canada report higher levels of depressive symptoms, health issues and poorer access to health care for some caregivers of people with developmental disabilities compared to families of children without developmental disabilities (Heller et al., 2015; Statistics Canada, 2011). This is the result of the "profoundly gendered" caregiving demands on mothers of children with disabilities (Gee & Ford, 2011; Islam et al., 2014, Statistics Canada, 2013, 2011). Most day-to-day caregiving of children and young adults with developmental disabilities is carried out by women (Tabatabai, 2020). Mothers are expected to fulfil the role of the primary caregiver indefinitely (Brock, 2015), an expectation that can have important repercussions for the physical and mental health of mothers (Khanlou et al., 2017). Societal expectations are often higher for mothers caring for children with disabilities, because they are subjected to an observational gaze that judge and monitor them (Knight, 2012). Mothers of children with disabilities are more exposed than others to the gaze of institutions and health professionals that intensify and reaffirm social norms.

Gender, racial and ethnic differences in health are well documented (Calabrese et al., 2015; Gee & Ford, 2011; Hyman &Wray, 2013; Jennings et al., 2014; Khanlou et al., 2014; Mawani, 2014; Osypuk & Acevedo-Garcia, 2010). Racialization is a key element in producing inequities. Particularly, racialized mothers of children with developmental disabilities bear a disproportionate burden of stress, illness and health inequities, which are the result of multiple intersections related to gender,

disability, and migration status (Benbow et al., 2015; Bloome, 2014; Gee, 2016; Gee et al., 2012, Gee & Ford, 2011; Hankivsky et al. 2010; Harrell, et al. 2011; Heard-Garris et al., 2017; Mawani, 2014). Challenges faced by immigrant mothers caring for children with developmental disabilities may be further complicated due to stressors related to mothers' level of acculturation, as well as newcomer challenges such as learning to navigate complex educational, social and health sector systems (Brar, 2009; Khanlou, 2017; Ruiz-Casares, 2013).

Pederson, Greaves and Poole (2014) highlight the need to implement gender-transformative health promotion approaches which are key in any effort to advance the health of women. These approaches recognize gender as a social determinant of the health and critically examine how gender roles, norms, values, along with structural socioeconomic factors, disproportionally impact on physical and mental health of girls and women. Gendertransformative health promotion interventions should have twofold implications, improve the health of women and change gender norms that negatively impact women's health (Pederson et al., 2014). We recognize that gender-transformative health promotion is an important step towards equality, but a more specific framework tailored to the particular needs of racialized immigrant mothers of children with developmental disabilities is much needed.

This article builds on our context-specific model for the health promotion of immigrant mothers of children with developmental disabilities (Khanlou et al., 2017). The overall goal of our study was to examine health promotion practices of immigrant mothers of children with developmental disabilities using the Health Promoting Activities Scale (HPAS) (Bourek-Taylor, Law, Howie, & Pallant, 2013). In this article we report on qualitative and quantitative results of the HPAS. We analyze immigrant mothers' unique experiences to identify key components of a transformative health promotion for immigrant mothers caring for children with developmental disabilities. We hope to contribute to the discussion of gender-transformative approaches in health research that take into account multiple intersectionalities of gender, race, ethnicity, class,

disability, culture, and health access and use (Pederson et al.2015; Simonsen, et al. 2017).

Methods

Our mixed methods study was conducted between April and October 2015. We received approval from York University's ethics review board prior to data gathering. A total of 28 immigrant mothers of children with DDs living in the Greater Toronto Area participated in the study. Mothers' demographic information is displayed in Table 1. The interview guide consisted of qualitative and quantitative questions divided in three sections: demographic information (e.g. age, education, employment status), the Health Promoting Activities Scale (HPAS) and questions on challenges, barriers, and enabling factors to health promotion for mothers. In this paper we specifically discuss findings of the HPAS. For other findings of the same study on health promotion for immigrant mothers see Khanlou et al. (2017) where we discuss the socioeconomic challenges that mothers face related to financial, language, lack of social networks, lack of trust as a barrier to access services for their children, and stigma. We analyzed the meaning of health for mothers, and the health promotion strategies they said they practice promoting mothers' health and wellbeing.

The HPAS (Bourke-Taylor et al. 2012) was created in Australia for mothers of school-aged children with developmental disabilities, to explore mothers' participation in health promoting and recreational activities and to measure the frequency of such activities. It is an 8-items questionnaire that collects information on mothers' health promoting behaviours, particularly engagement in passive activities (such as healthy living, social enjoyment, and spiritual engagement) and active recreational pursuits either alone or with others (Bourke-Taylor et al. 2012). The HPAS asks mothers questions on: i) personal health care tasks such as planning and eating healthy and following an exercise program, ii) pursuit of physically activate recreation alone, iii) pursuit of physically activate recreation with others, iv) participation in rejuvenating spiritual time, v) participation in social activities with supportive people, vi) time out for selfcare, vii) physically inactive leisure pursuit alone, and viii) physically inactive

leisure pursuit with others. Frequency of activities were scored on a seven-point Likert scale, with the least score of 1 assigned to "never" and a maximum score of 7 assigned to "once or more every day". The HPAS uses quantitative methods to collect and analyze data. In our study we included open-ending questions (the qualitative component) to each HPAS item through which mothers could specify and explain the type of health promoting activities they pursued.

Analysis: We conducted a descriptive and code driven analysis. Quantitative data obtained from mothers' selfreported responses on the HPAS items were analyzed using descriptive statistics. Scores for responses (7-point Likert scale) on each HPAS item (8 items) were summed and summarized as frequency percentage of occurrence. Qualitative analysis was guided by Corbin and Strauss' (1990) grounded theory approach to ensure study rigor and trustworthiness. We applied inductive coding as well as the use of deductive analysis to compare with existing approaches and for positioning our findings in the extant literature (Mills, Bonner, & Francis, 2006). Interview coding was grounded in the mothers' narratives. Subcoding, coding, and cross analysis of initial interviews was conducted, then we did the sub-coding and coding of remainder of interviews, and finally we identified emergent themes. We applied additional steps to enhance trustworthiness of findings. Triangulation was ensured as three coders (co-authors Khanlou, Vazquez, Mutafa) reviewed transcripts and mutually decided on emerging subcodes and codes. The three initial coders also conducted debriefing meetings to discuss any changes to codes and to identify emergent larger themes from the analysis. Furthermore, a member checking mechanism was implemented with members of the project's Advisory Committee.

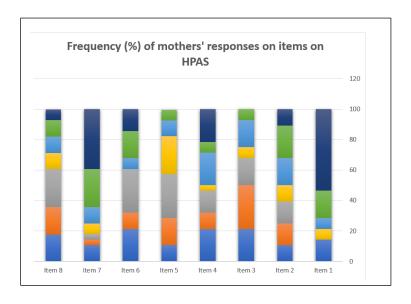
Results

The quantitative responses to the HPAS questions are presented in figure 1.

Table 1. Characteristics of Study Participants

Demographics of Mothers	Mothers N=28
Age in Years	
Mean	42.2 years
Range	35 – 55 years
Marital Status	
Currently married	21 (75%)
Divorce, common law	7 (25%)
Years lived in Canada	
Mean	14.5 years
Range	3-30 years
Region of Origin	
Asia	16
Europe	7
Latin America and the Caribbean	5
Number of Children per mother	
Mean	1.8
Range	1-3
Years lived in Canada	
Mean	14.5 years
Range (years)	3 – 30 years

Figure 1: The quantitative responses to the Health Promoting Activities Scale



HPAS it	HPAS items on graph		
Item	Question		
1	Personal health care tasks such as planning and eating healthy and following an exercise program		
2	Pursuit of physically activate recreation alone		
3	Pursuit of physically activate recreation with others		
4	Participation in rejuvenating spiritual time		
5	Participation in social activities with supportive people		
6	Time out for selfcare		
7	Physically inactive leisure pursuit alone		
8	Physically inactive leisure pursuit with others		

In Figure 2 we summarize relevant qualitative narratives that point out the factors influencing on the mothers' responses to some of the HPAS questions. These themes emerged from 4 items from the HPAS (1,2,3,5 and 6) which were the more relevant to our analysis.

Figure 2: Qualitative Narratives

Activities/tasks	HPAS item #	Factors influencing on HPAS
Planning Health Care Tasks	1	✓ Unpredictable nature of the mothers' everyday life;
		✓ Tasks driven for the sake of their children rather than for mothers
		✓ Financial barriers and economic constraints
Physically Active	2, 3,5	
Recreational Activities		✓ Individual activities vs group/family activities
Time for Selfcare	6	✓ Gendered and multitask nature of care
		✓ Financial constraints

Planning Health Care Tasks

When mothers were asked if they purposefully planned health care tasks, such as preparing and eating healthy food and drinks, following an exercise program, or participating in other tasks for their own health, more than 50% of mothers reported engaging at least once (or more times) in health related tasks every day, 17.9% reported doing this 2-3 times a week, 7.1% did this once a week, and 7% stated they did this 2-3 times a month. One participant said:

I think that would be almost every day when I plan the meal. Like every day I put a dinner or lunch I intentionally... I don't measure but a certain proportion of protein, certain proportion of vegetables and fruits. So that's on the daily basis. So, it's a habit now. So, whenever I make a meal, I make sure it's balanced (P15).

On analysis of the qualitative responses, we identified the following three themes that inform mothers' responses to the HPAS.

The Unpredictable Nature of Mothering a Child with Developmental Disabilities

Mothers interpreted the term "planning" as a systematic and organized activity. Participating mothers explained they had busy lives. They had to multitask to be able to meet the needs of their families while fulfilling the duty of a caregiver for their own parents, in laws, husbands, and children (with and without developmental disabilities). Although mothers frequently planned healthy meals, and activities, they often just did them without much planning, as planning these tasks was difficult. Their everyday schedule could not be completely planned. For example, mothers explained (several times) that they may suddenly receive a phone call from school asking them to pick up their child with DDs. This illustrates the unpredictable nature of mothering a child with DDs. The word "planning" was key in determining the responses we received.

I'm not very conscious about this. I'm like a lot of people who are thinking about it like they go to stores and say oh this is healthy I'll buy this. I'm not consciously thinking about those... but I do you know

when I'm cooking or just you know for the day for everybody you know I have to especially my son my husband they kind of need energy they need wheat. So, we say okay... you have to include this not just vegetables... (P8).

Gendered Nature of Mothering

The mothers' key rational to justify the relevance of cooking healthy foods was related to the health and wellbeing of their children. For example, one mother was concerned about her daughters' weight, and stressed that parents need to be more responsible in providing a healthy balanced meal to their child with DD.

Just recently I was out there biking with my children. And then uh...I start eating like salad with more veggie but not because of me, because of my daughter. She's 12 years old... So, I just happen to see on the TV when they say like, "60% of children now are overweight" and because of the parents. So, it's a wakeup call for me (P4).

Mothers explained that after a long exhausting day of caregiving, maintaining physical activity routine was not viable. The mothers who were able to have some physical activity did so with their children.

I do sometimes dance at home... not too much because the physical work cleaning ahh cooking was pretty kind of exhausting like sometimes... that's a lot of physical and work and shopping. Umm, umm on weekend...umm my son because he needs outdoors so we usually take him out on long walks. Umm, yeah, those things are already pretty...physically exhausting for me (P8).

I mean bringing him to the park you know, I try to walk around when he is playing or things like that because I know he loves being outdoors, so I do that as often as possible, so that's my time out as too. It's not as physical as I would like it to be but... (P23).

Financial Barriers, and Economic Constraints of Disability and Migration Status

The mothers' inability to actively plan healthy meals and/or exercise routine was related to financial barriers, and economic constraints. A good socioeconomic status

or being a full-time caregiver was as enabling factors which allowed her to plan healthy meals in advance.

Yes. I am a neurotic that way. I do my menu for two weeks ahead. Literally a menu, I practice lunch and dinner. I've always been that way, but when it comes to these guys, eating healthy is a big thing for me. So I literally sit down, make a menu for the next couple of weeks, lunch and dinner, um including all the veggies and fruits and try to get all the carbs and fiber and all that in there. And go shopping accordingly for the two week period. People think I'm crazy, my husband thinks I'm nuts but it works for me and if I'm organized enough, I have three kids I don't have time to go shopping every other day you know? And the fact that I don't have to go to work right now it helps me to prepare stuff and get things done, and get it cooked every day, not every day but every other day I cook for sure (P7).

Mothers recognized that finances influenced their ability to plan healthy eating and to promote their health and wellbeing.

I would say when I do grocery shopping, I plan carefully, try to avoid those um kinds of unhealthy foods... I try to buy organic... financially though is another zone, because organic food are very expensive (P13).

... but I am not taking any leisure programs just for myself. I am not register just for myself. Maybe when [my children] be a little bit older and more independent when finally I be more stable ... I [will] have a little bit time for myself. Yeah. Maybe when I will try to manage the money better...maybe even from Special Services at Home but it's not like big big money that can cover my son and myself since they are not like huge amount. I just prefer to put everything on him and give him a chance to develop (P2).

Physically Active Recreational Activities

When mothers were asked how often they practiced physically active recreational activities alone, 21.4% responded they did it 2-3 times a week, 17.9% reported once a week, 14.3% said once a month, and 14.3% did it 1-3 times a year. Roughly 11% of mothers said they did this 2-3 times a month and the same percentage said they never did this task. Active recreational activities

mothers pursued as part of their daily physical activities were exercise (21.4%), walking (17.9%), shopping (14.3%), preparing meals (17.9%) and washing clothes (3.6%).

When mothers were asked how often they engaged in physical activities with others, 28.6% of mothers did this 1-3 times a year, 21.4% never did this task, 18% did this once a month, 17.8% did it once a week, and 7.1% did this 2-3 times a month. Seven percent of mothers pursued physical activities with others about 2-3 times per week. None of the mothers engaged in physical activity on a daily basis. Walking (35.7%) and preparing meals with family (14.3%) were among the most frequent activities mothers did with others.

Qualitative analysis of open-ended responses showed a distinct cultural or lifestyle difference between Western and non-Western society in the type of recreational activities mothers engaged. The concept of individualism is deeply rooted to wellbeing in Western societies. In this regard most of the mothers did not envision themselves doing recreational activities by themselves, such as walking alone, or going to the park alone. Western lifestyle emphasizes individuality and the capacity of being alone as something positive. Immigrant mothers from different cultures did not find pleasure in doing leisure activities alone nor did they see this type of activity as something positive. Due to the lack of social networks and close family in Canada, mothers expressed their need and wish to do activities collectively. Mothers also expressed they were not able to engage in this activity as they are the main caregivers for their children, and therefore had no time alone to themselves.

No, it's always around them (children/family (P9).

Alone? Right now, I am going with my son everywhere (P19).

In response to this question, some mothers expressed strong feelings of social isolation.

Yeah, because I don't usually have any people to go with me (P7).

...two weekends ago umm his dad took the boys out and I stayed alone and I noticed I don't have any friends you know I do have friends with kids...but I wanted a friend that didn't have kids you know what

I mean. Just to tell that friend hey lets go out for coffee and I don't. So that made me feel like wow you know like I have...lost a lot a lot of contacts (P9).

One mother expressed feelings of fear and insecurity walking alone by herself on the streets in her neighborhood in order to pursue an active life.

Not alone. Because I don't feel comfortable being alone. I happen to have a very small frame. And I was an easy target. It happened to me, so that's why I am very scared to be out there alone. Like you know...I walked there once, I walk on the street once just to like crossing to my building and then there's a pickup truck and the guy keep asking me to come up to the truck (P4).

One mother said she did not engage in healthy physical recreational activities such as walking, gardening, swimming, jogging or cycling, but she was involved in more organized activities She played on a team sport and had a gym membership. For another mother regular meet ups meetings with her motorcycle club buddies was an activity good for her wellbeing.

Okay so just to be clear, I don't do swimming or martial arts or I don't belong to a hiking club or anything like that... Oh I belong to a motorcycle club so we meet once a week and we meet in a pub. And we'll have a pop and we'll go for rides... Okay umm I was confused by the question when you say recreational pursuits I'm thinking I don't swim, I don't jog but yeah, I was confused by the question. So yes, actually more than once a week. I'd say umm...tonight I'm meeting friends, Wednesday I'm going to the theatre, so this week is busy right (P10).

Mothers were asked how they spent time (or engaged in social activities) with important and supportive people in their lives or if they had social activities. Most of the mothers (28.6%) engaged in social activities once a month, 25% did this activity 2-3 times a month, around 10% did it once a week, and 18% socialized 1-3 times a year. Ten percent of mothers reported never spending leisure time with people important to them.

..go out for a movie or something like that shopping for something with friends. But yeah...that's like once in a blue moon (P5).

Even though the question did not refer directly to the family unit, mothers reported that social activities were done with their children (28.6%) and extended family (32.1%). Only 21% of mothers had social activities with friends.

I spend all the time with my children. My son. All the time! Like my life is like all around him. And my daughter (P4).

Initially mothers were confused about the term "supportive people". They explained that the important people they socialized with or spent time with, did not necessarily support them in caring for their child with developmental disabilities. Mothers also shared the difficulties they faced in finding supportive friends or family members. They said it was difficult to find a friend who may be able to provide the required support that they need.

Time for Selfcare

Mothers were asked if had time out for themselves, to spend as they wished. Mothers consistently explained how difficult it was to have self-care time. The majority of the mothers reported this activity once a month (28.6%), 2-3 times per week (18%), 7 % had done it once a week, 10.7% had selfcare only once a year, and 21.4% never had this leisure activity. No mother reported having personal time every day.

The gendered and multitask nature of providing care impacted the amount of time mothers had for themselves.

I used to fulfil my daughter in-law's duty, and have kept her healthy

Thoughts about feeling guilty were also shared by the mothers.

Actually, my time is always dedicated to some work um I don't feel relaxed if I relax myself like I don't feel happy that if I'm sleeping or like listening to music... not doing any work so I'm very simple that I should be productive each time so it gives me pleasure too... I feel that um that just doing nothing is a wasting the time... because you feel guilty at times, it keeps me healthy (P1).

I'm starting to do it. Umm, in my mom's house that's where my mom come to support me. She's like "you have been like a mother hen always with her chicks never for her now you need to go out don't feel guilty that you're not taking the kids don't feel guilty about it (P9).

Financial constraints were a barrier to mothers wanting to do tasks/activities related to themselves such as having facials or going shopping. As one mother explained:

I would like to increase I guess that... I would love to be able to get you to know facials and stuff like that. Once again, is it a financial constraint? Because we try to use all the money that we have towards his [son] therapy (P22).

One of the mothers mentioned that in her own personal time she is searching for a job so she can have enough money to spend on her son:

Like sending the email... because right now I am just looking for job. I was, I wanted to have a part-time job whenever I have my own time, I can look for my client, right? So, it will be to spend money with my son. If I have extra money (P19).

Discussion: Gender, Disability, and Migration Status

Gender and migration status are intersecting factors influencing on the health and wellbeing of immigrant mothers. Our findings show that the gendered role in context, for example mothers performing this role in the context of a host or new country and environment, shape and limit their options and on the decisions, they take in regards to health tasks included in the HPAS.

A family-centered view of health was highlighted in the answers related to the question of planning health care tasks on the HPAS showed mothers' conflicting view on planning a healthy activity in the context multitasking and busy unpredictable lives of mothers. A healthy lifestyle for the sake of their children was the most common response of the majority of mothers. Drawing from their limited budgets mothers prioritized paying for services for their children with disabilities (e.g., enrolling them in recreational activities) over their own needs. In sum, "mothers' health was viewed as holistic and tied to family health" (Khanlou et al., 2017).

Non-Western views on health and collectivism was another topic that emerged from the findings. There may be cultural and lifestyle differences between Western and non-Western societies in relation to the practice of health promotion activities. Individualism characterized by valuing autonomy and placing one's personal goals above those of others, whereas collectivism champions the interests of one's in-groups (such as one's family or community) above those of oneself" (Lykes & Kemmelmeier, 2013, p. 3). Mothers did not perceive the HPAS question in regard to the activities done "alone" (e.g., walking in the park by themselves) as something appealing and promoting their health. Most mothers expressed a more collectivist view. Due to lack of social networks and close family in Canada, mothers expressed the desire to practice healthy activities in a group.

Furthermore, along with factors related to the immigration experience, the disability dimension in the mothers' lives limits the options of performing activities alone. Some of their children have complex caregiving needs which require all day care, some even require a 24/7 intensive care. And this is closely related to the criticism Manuel elaborates (2015)individualization, as a Western value by which individuals have the power to have and exercise freedom of choice. In her study with mothers of children with disabilities Manuel (2015) found that freedom of choice is contingent to the availability of social support mothers need from family, extended family and the community. Furthermore, individualism is also a key axis of predominant neoliberal approaches to promotion, that emphasizes lifestyle approaches to wellbeing (Ayo 2011, LeBesco 2011). Within these frameworks, healthy lifestyles are a matter and individual choice, overlooking structural socioeconomic constraints or cultural barriers that may determine people's health behaviors.

The responses on the HPAS also express motherhood as a social construct with embedded assumptions and social expectations related to role and responsibilities that requires them to be "good" mothers, to be dutiful and entirely dedicated to their children (Brock, 2015; Thurer, 1994). Intensive mothering is described in the literature as a category of motherhood that is child

centered and labor intensive, by which mothers "are expected to be self-consciously dedicated to their children" (Green, 2015, p. 198). Mothers are subjected to an observational gaze that judge and monitor them (Knight, 2012). Societal expectations are often higher for mothers caring for children with disabilities, and they are also more exposed than others to the gaze of institutions and health professionals that intensify and reaffirm social norms. Mothers of children with disabilities "are not only expected to be the primary caregivers, but they're also expected to fulfil this role indefinitely" (Brock, 2015, p. 274), an expectation that can have repercussions on the physical and mental health of mothers (Khanlou et al. 2017).

When mothers were asked about how they felt about spending their time as they wished, many expressed feelings of guilt to take time out for themselves. The literature refers to the experience of mother self-blame and feelings of guilt in their task to fully accomplished the assigned societal expected role of being a good mother (Courcy and des Rivières 2017). In our study, mothers indicated that their roles correspond to the culture from where they came from. As they explained, they have multiple roles to play, for example the role of a daughter, daughter in law, sibling, spouse, mother, teacher, and support worker for their child(ren) with developmental disabilities, and it is expected from them to fulfil each. As indicated by one mother, this may also impact the type of decisions mothers make in relation to health promoting tasks. Social expectations may also be closely related to the way mothers think of their own health and wellbeing. For example, one of the mothers thought that spending time relaxing, resting or sleeping was a waste, she said that being productive was a way for her to stay healthy. Perceptions about what constitutes a healthy lifestyle is therefore determined by what mothers individually identify as health promoting choices.

The mothers expressed feelings of *social isolation* while engaging in certain health related activities. The lack of extended family and social networks may be one of the biggest barriers to health promoting activities for mothers of children with developmental disabilities in Canada. Due to absence of help from family members, and lack of close friends, mothers lacked respite care.

Furthermore, *stigma* around the developmental disability of their children made them distance themselves from family and friends. Mothers often felt misunderstood and judged. The majority of mothers stated that lack of extended family in Canada, and the amount of time needed to take care for a child(ren) with developmental disabilities it was difficult to have supportive people around them.

Disability as a ubiquitous influence was also relevant in mothers' narratives. They for example highlighted the difficulty for friends or extended family to understand their children's behaviours and health conditions. Supportive friends or family was related to their child's disability. The degree of complexity and difficulty to take care of children with developmental disabilities, made it difficult for mothers to find supportive friends or family that not only understand the situation but who are also willing to help the mothers in a meaningful way. As stated before, health promotion strategies must consider the central role of disability in the mothers' lives. type of disability and the age of their child (ren)/youth determined caregiving intensity of responsibilities and the challenges mothers face.

Our previous research has shown that immigration increases the barriers mothers face to achieve better health and wellbeing status, and this relates to difficulties faced due to language, economic constraints, navigation of the service systems, a lack of social networks, and social isolation (Jennings et al. 2014, Khanlou et al. 2015). Immigrant families face additional burdens due to the lack of disability funding for their children with developmental disabilities. In the interviews mothers highlighted economic constraints interconnected with their immigration status. Family caregivers are forced into precarious positions and often work multiple jobs to meet minimum out-of-pocket expenses or leave their job altogether. This often puts the health and wellbeing of their family unit at risk as well. In our previous research mothers had explained that they need to leave their jobs because of highly demanding caregiving responsibilities of their children with developmental disabilities (Khanlou et al., 2018; Khanlou et al., 2016). Furthermore, the type of developmental disability along with physical disabilities and other health related conditions, add to the financial

stress of paying for special services for their children with developmental disabilities. Economic constraints were raised by mothers when asked about preparing healthy meals and about having a membership to a sport venue. The interconnection between disability-poverty is also highlighted in the Canadian literature. Reliable prevalence data for childhood disability in low-income families is currently unavailable; however, an estimated 30% of Canadian children and youth with disabilities live in poverty (Petrenchik, 2008).

In our study, mothers shared experiences of discrimination. After their interaction with service providers, they said they had feelings of being excluded, and of not deserving, because they felt that they might be using more resources than others from the government, due to the disability of their children. They said that being an immigrant they felt are not deserving these services:

Barriers, first when we came here... Or it's been my personality that I cannot express well. I told them [migration officials] even in my native language [that] I'm having hard time expressing myself so...that's the first thing. And the second thing is somehow you can still feel discrimination... especially when they are thinking that I have kids with special needs and why am I here in Canada? Actually, they are not questioning me, but you can feel it... if you're telling them that, "My son needs this", they are not going to provide and then you can feel that you are not... you are not worth to be here or whatever. Or you are draining their social services... (P11)

Research on mothers' experiences with the service sector shows racial discrimination from service providers against visible minorities, and the negative health and mental health impacts on this population (Edge & Newbold, 2013; Thomson et al., 2015).

Towards a transformative health promotion approach for immigrant mothers with children with developmental disabilities

It is critical to consider the intersecting factors of gender, disability, and migration status to better address racialized immigrant mothers' health promotion needs. Results show that immigrant mothers have a <u>family-centered view</u> that supports a more collectivist view of health promotion. The center is a collective entity, the

family, and the health and wellbeing of the family determines the mothers' health, and vice versa. Predominant Western health promotion approaches favour individualism, where the center is the individual (mother). Approaches that address the lives of the mothers as single individual leave aside important elements from the mothers' immediate network.

Recognizing the <u>gendered nature of caregiving</u>, along with the <u>disability</u> dimension is essential. Integrating mothers' multiple roles and identities will remove <u>ableist</u> assumptions that separate disability from mothers' everyday lives. An ableist view may separate the mother from the child with developmental disabilities, as if the impacts of the child's disability impact only one individual (the mother or the child) and not multiple individuals (i.e. the family unit). An ableist approach may also overlook the fact that a child's disability for some mothers may have a positive meaning that may promote mothers' health and wellbeing.

Mothers' <u>financial precarious situation</u> as part of their immigration status and also, as part of the disability of their children, needs to be recognized. This will allow us to de-emphasize lifestyles individualistic approaches to health promotion and to highlight the multiple structural conditions that influence mothers' health and wellbeing. Assumptions tied to socioeconomic status appear to be appropriate to middle-upper classes rather than to the conditions of immigrant individuals. In light of mothers' narratives about financial difficulties, we should be sensitive to racialized mothers' contexts.

In the context of multicultural societies such as the GTA in Canada, a transformative health promotion should be sensitive to non-Western cultures, lifestyles and views from diverse populations about what constitute wellbeing is important. Context-based health promotion strategies, that take into account racialized mothers' cultural norms and values, is an important step towards the promotion of their inclusion in health promotion strategies.

Impacts of the pandemic on racialized populations

Our study was conducted prior to the COVID-19 pandemic. However, it is necessary to recognize the differential impacts of the ongoing pandemic on mothers with children with developmental disabilities. Recent studies report that caregivers of children with Autism experience amplified challenges to support their children's needs due to the pandemic, and as a result they experience stress, which have long-term negative consequences for caregivers' mental health (Lee et al., 2021). In a study that assessed the mental health of parents of special needs children during the COVID-19 pandemic the researchers found that parenting distress was associated with having children with special needs (Chen, Chen, Li, & Ren, 2020).

Our studies have shown that the pandemic has gendered, migration, disability and racialization related impacts and implications for marginalized and vulnerable sectors of the population (Khanlou et al., 2020a). It has heightened gender inequalities in relation to employment, job security, working conditions, and income (Khanlou et al., 2021).

Migration status for example is a key social determinant of health. The pandemic has increased the marginalization and vulnerability of migrant women. Pathways of exclusion for example include the way women with precarious status are excluded from COVID-19 related government financial supports, access to assistance programs are dependent on the individuals' legal residency status (Rezaee, 2020). Lack of access to income supports, such as Canada Emergency Response Benefits and Canada Child Benefit leaves, impact already-vulnerable sectors of the population (Abji, Pintin-Perez, & Bhuyan, 2020). The pandemic has intensified pre-existing structural socioeconomic issues such as low pay, poor working conditions, lack of benefits (e.g., paid sick leave) and other protections for nonstatus women working on the front-line (Khanlou et al., 2021). Other factors contributing to the increased risks and vulnerabilities for immigrants are the stress associated with the migration process and resettlement, the lack of social networks, lack of supports, and overall economic insecurity (Khanlou et al., 2020b).

Conclusion

Mothers' narratives point for the need to implement a transformative health promotion for immigrant mothers of children with developmental disabilities in multicultural contexts. Research findings from the Health Promoting Activities Scale captures immigrant mothers' views on their own health and health promotion needs, including the complex realities of their lives at the intersection of gender, disability, and migration status. We emphasize the need to consider a transformative approach to go beyond lifestyle health promotion approaches and to recognize structural impacts pertaining to finances, disability and the gendered nature of mothering children with developmental disabilities.

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References

- Abji, S., Pintin-Perez, M., & Bhuyan, R. (2020). In Canada, non-status women are being left behind: Non-status women remain largely invisible in the COVID-19 public health response and emergency support programs. Open Democracy. Retrieved from: https://www.opendemocracy.net/en/pandemic-border/canada-non-status-women-are-being-left-behind/
- Ayo, N. (2011) Understanding health promotion in a neoliberal climate and making of health conscious citizens. Critical Public Health, 22,1, 99-105. Available at:
 - http://ezproxy.library.yorku.ca/login?url=http://www.tandfonline.com/doi/pdf/10.1080/09581596.2010.520692 [Accessed 4 May 2019]
- Baum, F. and Fisher, M. (2014) Why behavioural health promotion endures despite its failure to reduce health inequities, Sociology of Health & Illness, 36, 2, 213-25.
- Benbow, S., Forchuk, C., Gorlick, C., Berman, H. and Ward-Griffin, C. (2015). Social exclusion and health: The development of nursing knowledge, Clinical Journal of Nursing Research, 47, 3, 56-72.
- Bourque, F., van der Ven, E. and Malla, A. (2011). A metaanalysis of the risk for psychotic disorders among first- and second-generation immigrants, Psychological Medicine, 41, 5, 897-910.
- Bourke-Taylor, H., Pallant, J. F., Law, M. and Howie, L. (2013). Relationships between sleep disruptions, health and care responsibilities among mothers of school-aged children with disabilities, Journal of Paediatrics and Child Health, 49, 9, 775-82.
- Bourke-Taylor, H., Lalor, A., Farnworth, L. and Pallant, J. F. (2014). Further validation of the Health Promoting Activities Scale with mothers of typically developing children, Australian Occupational Therapy Journal, 61, 5, 308-15.

- Bourke-Taylor, H., Lalor, A., Farnworth, L., Pallant, J. F., Knightbridge, E. and McLelland, G. (2015). Investigation of the self-reported health and health-related behaviours of Victorian mothers of schoolaged children, Australian Journal of Primary Health, 21, 1, 66-73.
- Brar, S., Tang, S., Drummond, N., Palacios-Derflingher, L., Clark, V., John, M. and Ross, S., (2009). Perinatal care for South Asian immigrant women and women born in Canada: telephone survey of users, Journal of Obstetrics and Gynaecology Canada, 31, 8, 708-16.
- Brock, S. A. M. (2015). The individualization thesis and mothering children with disabilities, Journal of Family Studies, 21, 3, 261-81.
- Calabrese, S.K., Meyer, I.H., Overstreet, N.M., Haile, R. and Hansen, N.B. (2015). Exploring discrimination and mental health disparities faced by black sexual minority women using a Minority Stress Framework, Psychology Women Quarterly, 39, 3, 287-304.
- Castañeda, H., Holmes, S.M., Madrigal, D.S., Young, M.E.D., Beyeler, N. and Quesada, J., (2015). Immigration as a social determinant of health. Annual Review of Public Health, 36, pp.375-392.
- Chen, S.-Q., Chen, S.-D., Li, X.-K., & Ren, J. (2020). Mental Health of Parents of Special Needs Children in China during the COVID-19 Pandemic. International Journal of Environmental Research and Public Health, 17(24), 9519. MDPI AG. Retrieved from http://dx.doi.org/10.3390/ijerph17249519
- Courcy, I., & des Rivières, C. (2017). "From cause to cure": A qualitative study on contemporary forms of mother blaming experienced by mothers of young children with autism spectrum disorder, Journal of Family Social Work, 20, 3, 233-50.
- Duff, C., Puri, A.K. & Chow, C. (2011). Ethno-cultural differences in the use of alcohol and other drugs: Evidence from the Vancouver Youth Drug Reporting System. Journal of Ethnicity and Substance Abuse, 10: 2-23.

- Edge, S. and Newbold, B. (2013). Discrimination and the health of immigrants and refugees: Exploring Canada's evidence base and directions for future research in newcomer receiving countries. Journal of Immigrant and Minority Health, 15,1, 141–48. Available at: http://doi.org/10.1007/s10903-012-9640-4 [Accessed 4 May 2019].
- Ford, C.L. and Airhihenbuwa, C.O. (2010). Critical race theory, race equity, and public health: toward antiracism praxis, American Journal of Public Health, 100, S1, S30-S35.
- Gee, G. (2016). Racism as a social determinant of health inequities. Report presented to the Robert Wood Johnson Foundation: Leveraging the Social Determinants to build a culture of health. Available at:
 - http://healthequity.globalpolicysolutions.org/wp-content/uploads/2016/12/RacismasSDOH.pdf
 [Accessed 20 September, 2017]
- Gee, G.C. and Ford, C.L. (2011). Structural racism and health inequities: Old issues, new directions. Du Bois Revue, 8,1, 115-32.
- Hankivsky, O., Grace, D., Hunting, G., Giesbrecht, M., Fridkin, A., Rudrum, S., Ferlatte, O. and Clark, N. (2014). An intersectionality-based policy analysis framework: critical reflections on a methodology for advancing equity. International Journal for Equity in Health, 13,119.
- Hankivsky, O., Reid, C., Cormier, R., Varcoe, C., Clark, N., Benoit, C. and Brotman, S. (2010). Exploring the promises of intersectionality for advancing women's health research. International Journal for Equity in Health, 9,1, 5.
- Heller, T., Gibbons, H. M., and Fisher, D. (2015). Caregiving and family support interventions: Crossing networks of aging and developmental disabilities, Intellectual and developmental disabilities, 53, 5, 329-45.
- Henderson, A., Harmon, S., and Newman, H. (2016). The price mothers pay, even when they are not buying it:

- Mental health consequences of idealized motherhood. Sex Roles, 74,11-12, 512-26.
- Netto, G., Bhopal, R., Lederle, N., Khatoon, J. and Jackson, A. (2010). How can health promotion interventions be adapted for minority ethnic communities? Five principles for guiding the development of behavioural interventions. Health promotion international, 25, 2, 248-57.
- Golden, S. D., and Earp, J. A. L. (2012). Social ecological approaches to individuals and their contexts twenty years of health education & behavior health promotion interventions, Health Education & Behavior, 39,3, 364–72.
- Green, F.J. (2015). Re-conceptualizing motherhood: Reaching back to move forward, Journal of Family Studies, 21, 3, 196-207.
- Hyman, I. and Wray, R. (2013). Health Inequities and Racialized Groups A Review of the Evidence. Prepared in collaboration with Toronto Public Health.
- Islam, F., Khanlou, N. & Tamim, H. (2014). South Asian populations in Canada: migration and mental health, BMC Psychiatry, 14, 154.
- Jennings, J., Khanlou, N. and Su, C. (2014). Public health policy and social support for immigrant mothers raising disabled children in Canada, Disability and Society, 29,10, 1645-57.
- Khanlou N, Vazquez LM, Pashang S, Connolly JA, Ahmad F, & Ssawe A. (2021). 2020 Syndemic: Convergence of COVID-19, gender-based violence, and racism pandemics. Journal of Racial and Ethnic Disparities. DOI: 10.1007/s40615-021-01146-w https://link.springer.com/article/10.1007/s40615-021-01146-w
- Khanlou, N., Ssawe, A., Vazquez, LM., Pashang, S., Connolly, JA., Bohr, Y., Epstein, I., Zahraei, S., Ahmad, F., Mgwigwi, T., & Alamdar, N. (2020a). COVID-19 pandemic guidelines for mental health support of racialized women at risk of gender-based violence:

- Knowledge synthesis report. Funded by Canadian Institutes of Health Research (CIHR) Operating Grant: Knowledge Synthesis: COVID-19 in Mental Health & Substance Use. York University. https://nkhanlou.info.yorku.ca/files/2020/11/Khanlou COVID19-Pandemic-guidelines-for-mental-health-support-of-racialized-women-at-risk-of-GBV.Nov2020.pdf?x68747
- Khanlou N, Ssawe A, S Zahraei, Connolly JA, Pashang S,
 Bohr Y, & Vazquez LM. (2020b). Information Sheet
 16: Gender-Based Violence and the COVID-19
 Pandemic: Risk Factors and Systemic Challenges.
 Toronto, ON: York University.
 https://nkhanlou.info.yorku.ca/knowledge-transfer/publications
- Khanlou N, Jones G, & Yoshida K. (2018). Impact of gender and migration status on accessing direct/flexible/ self-directed social funding for developmental services in Ontario. Funded by Ministry of Community and Social Services (Developmental Services Research Grant).
- Khanlou N, Mustafa N, Vazquez LM, Davidson, & Yoshida K. (2017). Mothering children with developmental disabilities: A critical perspective on health promotion. Health Care for Women International (38)6, 613-634. Available url: http://dx.doi.org/10.1080/07399332.2017.1296841
- Khanlou N, Haque N, Davidson D, & Dastjerdi M. (2016).

 Voices of immigrant mothers of children with disabilities: Availability and use of social support.

 Toronto: York University.

 https://nkhanlou.info.yorku.ca/files/2014/12/Voices-of-Immigrant-Mothers-of-Children-with-Disabilities-Research-Report-Khanlou-et-al.2016.pdf
- Khanlou, N., Haque, N., Sheehan, S. and Jones, G. (2015). "It is an issue of not knowing where to go": service providers' perspectives on challenges in accessing social support and services by immigrant mothers of children with disabilities, Journal of Immigrant and Minority Health, 17, 6, 1840-7

- LeBesco, K. (2011). Neoliberalism, public health, and the moral perils of fatness, Critical Public Health, 21, 2, 153-64.
- Lee V, Albaum C, Tablon Modica P, Ahmad F, Gorter JW, Khanlou N, McMorris C, Lai J, Harrison C, Hedley T, Johnston P, Putterman C, Spoelstra M, & Weiss JA. (2021). The impact of COVID-19 on the mental health and wellbeing of caregivers of autistic children and youth: A scoping review. Autism Research. https://doi.org/10.1002/aur.2616
- Liu, J.J., Davidson, E., Bhopal, R.S., White, M., Johnson, M.R.D., Netto, G., Deverill, M. and Sheikh, A. (2012). Adapting health promotion interventions to meet the needs of ethnic minority groups: mixed-methods evidence synthesis, Health Technology Assessment (Winchester, England), 16, 44,1.
- Lynam, M.J. (2005). Health as a socially mediated process: theoretical and practice imperatives emerging from research on health inequalities, ANS Advanced Nursing Science, 28,1, 25-37.
- Manuel, S.A. (2015). The individualization thesis and mothering children with disabilities. Journal of Family Studies, 21, 3, 261–81.
- Mawani, F. N. (2014). Social determinants of refugee mental health. In: Simich L. and Andermann L. (eds). Refugee and Resilience (pp. 27-50). Springer, Dordrecht.
- Mays, V.M., Ponce, N.A., Washington, D.L. and Cochran, S.D. (2003). Classification of race and ethnicity: Implications for public health, Annual Review of Public Health, 24, 83-110.
- Meng, X. and D'Arcy, C. (2012). Common and unique risk factors and comorbidity for 12- month mood and anxiety disorders among Canadians, Canadian Journal of Psychiatry, 57, 8, 479-87.
- Osypuk, T.L. and Acevedo-Garcia, D. (2010). Beyond individual neighborhoods: A geography of opportunity perspective for understanding

- racial/ethnic health disparities, Health Place, 16, 6, 1113-23.
- Pederson, A., Greaves, L. and Poole, N. (2014). Gender-transformative health promotion for women: a framework for action, Health Promotion International, 30,1, 140-50.
- Petrenchik, T. M. (2008). Childhood disability in the context of poverty. Hamilton, ON: CanChild Centre for Childhood Disability Research.
- Priest, N., Perry, R., Ferdinand, A., Paradies, Y. and Kelaher, M. (2014). Experiences of racism, racial/ethnic attitudes, motivated fairness and mental health outcomes among primary and secondary school students, Journal of Youth and Adolescence, 43,10,1672-1687.
- Rezaee, JR. (2020 March 27). An Intersectional Approach to COVID 19 She-Covery. YWCA Toronto, A Turning Point for Women, United Way. Available from: https://www.ywcatoronto.org/takeaction/additional/intersectional
- Ruiz-Casares, M., Rousseau, C., Laurin-Lamothe, A., Rummens, J.A., Zelkowitz, P., Crépeau, F. and Steinmetz, N. (2013). Access to health care for undocumented migrant children and pregnant women: the paradox between values and attitudes of health care professionals, Maternal and Child Health Journal, 17, 2, 292-8.
- Sanou, D., O'Reilly, E., Ngnie-Teta, I., Batal, M., Mondain, N., Andrew, C., and Bourgeault, I. L. (2014). Acculturation and nutritional health of immigrants in Canada: a scoping review, Journal of Immigrant and Minority Health, 16,1, 24-34.
- Shirazi, M., Shirazi, A. and Bloom, J. (2015). Developing a culturally competent faith-based framework to promote breast cancer screening among Afghan immigrant women, Journal of Religion and Health, 54,1, 153-9.
- Statistics Canada (2013). 2011 National Household Survey. Catalogue no. 99-010-X2011029. Available at

- : http://www.statcan.gc.ca/pub/89-503-x/2015001/article/14315-eng.htm [Accessed 20 September 2017]
- Statistics Canada (2011). Visible Minority Women.

 Available at:

 file:///Users/mac/Desktop/WCH%2015%20OCT%20
 2017/Visible%20Minority%20Women.webarchive
 [Accessed 26 September 2017].
- Stokols, D. (1992). Establishing and maintaining healthy environments: Toward a social ecology of health promotion, American Psychologist, 47, 1, 6–22.
- Tabatabai, A. (2020). Mother of a person: neoliberalism and narratives of parenting children with disabilities.

 Disability & Society, 35(1), 111–131

 https://doi.org/10.1080/09687599.2019.1621739
- Thomson, M. S., Chaze, F., George, U. and Guruge, S. (2015). Improving immigrant populations' access to mental health services in Canada: a review of barriers and recommendations, Journal of Immigrant and Minority Health, 17, 6, 1895-905.

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