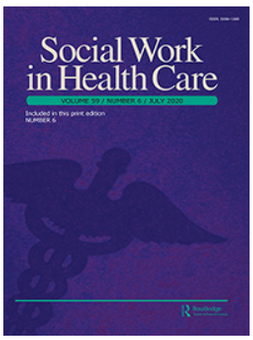

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Health challenges of mothers with special needs children in Pakistan and the importance of integrating health social workers

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ABSTRACT

There is concern that mothers of special needs children in developing countries like Pakistan are neglected populations facing hidden health challenges. The aim of this study was to investigate the kinds of health challenges mothers experience and to highlight the role of health social workers in supporting the needs of mothers. Twenty-one mothers were sampled across three cities and findings were analyzed through a thematic content analysis approach. Findings revealed that mothers faced significant and salient challenges under eight sub-categories of mental health and six sub-categories of physical health. We recommend that health social workers collaborate with healthcare practitioners to improve health services for mothers and also coordinate with other social workers, community members, and policymakers for improving both social and structural support for special needs families.

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Health social work; mental health; mother; physical health; special needs children

Introduction

As primary care-providers for special needs children (SNC), mothers spend an extraordinary amount of time, physical energy, and emotional labor in supporting their children's needs (Beaulaurier & Taylor, 2012; Brekke & Nadim, 2017; Resch et al., 2010), which has grave consequences on both their physical and mental health (Aghajani et al., 2018; Algood et al., 2013; Chavis, 2016; Shaykh, 2018). Deterioration in health and wellbeing of mothers has negative impacts on the quality of care provided to SNC, the future development and rehabilitation of SNC, relations with family members, and the ability to participate in income generation (Ahmed et al., 2016; Avis & Reardon, 2008). There is fear that sustained stress in mothers can lead to compounded problems of greater physical and mental health decline (Bourke-Taylor et al., 2012; Emerson, 2003). The theoretical foundation of this paper rests on the assumption that socio-structural support in the community influences health

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maintenance and health behavior (Gallant, 2013). Health theories have asserted that without adequate social support people facing stressful life circumstances can suffer from disease (Link & Phelan, 1995). Furthermore, negative social interaction, including having to face shaming and stigmatization, from both strong and weak social networks in the community, has adverse effects on both the physical and mental health of individuals (Cohen, 2004). Strong social networks include relations such as spouse, parents, in-laws, and immediate family members. Lack of support from these close relatives is known to lead to great psychological distress in new mothers who are attempting to cope with the disability diagnosis of their child (Ekas et al., 2010). Theorists have also discussed the role of information and communication in leading to health deterioration (Cassel, 1974). When people have less information networks and structural support in difficult life circumstances, they face greater stress and anxiety (Song et al., 2011).

Special needs people in Pakistan lie anywhere between 4% and 17% of the population (Mitra & Sambamoorthi, 2014; Moawad, 2012), which converts to approximately 8–36 million people. These figures might be even larger in countries like Pakistan as disability is not recorded systematically in healthcare settings (Eide & Loeb, 2005). Lack of state subsidization, tax exemptions, educational opportunities, and employment options makes the lives of families of SNC extremely complex and challenging (Singal et al., 2018). Regressive beliefs and religious interpretations have contributed to social exclusion of SNC in South Asian and Muslim countries (Al-Aoufi et al., 2012), making mothers exclusively responsible for the wellbeing and rehabilitation of child, and further complicating health challenges faced by mother for self and child (Ceylan & Aral, 2016). Further problems of a punitive and patriarchal culture, which oppresses women in all aspects of socio-biological eventualities, contribute to South Asian mothers facing consequential social stigma and cultural exclusion when they give birth to SNC (Katbamna et al., 2004) (Anwer et al., 2014; Gilligan, 2013). The lack of social support not only contributes to health challenges faced by mothers with SNC, but is evidenced to influence low life expectancy in child (Patja et al., 2000).

In the developed world health social workers have played a substantial role in supporting mothers of SNC through raising social support, providing therapeutic counseling, and mediating with policymakers (Gerten & Hensley, 2014; McWilliam, 2010; Reilly & Platz, 2004; Stainton et al., 2010). Health social workers have the advantage of direct access to clinical settings where they can help reduce the stress that mothers face by providing empathy when at first the disability is detected. Compared to healthcare practitioners, who have the responsibility of providing medical services, health social workers can understand the circumstances and emotions of mothers. This support is crucial for mothers who face considerable difficulties in healthcare settings with regard to (i) incomplete information about diagnosis and rehabilitation, (ii) inadequate

instructions for home care, additional needs, and follow-up plans, (iii) hope for the future development of child, and (iv) discrimination and prejudice against the child and mother (Avis & Reardon, 2008; Ngui & Flores, 2006).

In Pakistan, health social workers are regulated by the Pakistan Ministry of Health, Social Welfare and Social Education. There are 130 health social worker units in the country of which the dominant 100 are operational in the Punjab province. However, there has been no effort to integrate health social workers to deal with the needs of special needs families in the country (Malik & Sarfaraz, 2012; UNICEF, 2011). Currently, the health social workers in Pakistan are limited to distributing Zakat and Baitul-Maal (charity funds) to impoverished patients (Abdullah et al., 2014). Disability support groups like the National Disability and Development Forum (NDF), Network of Organizations Working with People with Disabilities Pakistan (NOWPDP), and the Association of Women for Awareness and Motivation (AWAM) have not submitted any concrete means of actualizing support for special needs mothers. In order to improve support for the health and wellbeing of vulnerable populations, like mothers of SNC, there needs to be an increase in recruitment, budget allocation, training, and capacity expansion of health social workers in the country.

Little research exists on the mental and physical health needs of mothers with SNC. It is important to first hear the voices of native women and understand the different experiences they encounter with regard to their health (Melvin & Uzoma, 2012). The aim of this study is to understand the types of health challenges that mothers of SNC face in Pakistan. Findings from this study will be relevant for societies with similar cultural beliefs and religious ideologies, like South Asia and other Muslim states. Similarly, this study will be of relevance to other developing nations that as yet are not comprehensively engaging health social workers for the support of special needs families.

Materials and methods

This paper is part of a wider study for special needs families in Pakistan. The findings presented in this article are the results of the qualitative data collection. Qualitative research affords the advantage of deciphering the lived experiences and subjective perceptions of the participants and shedding meaningful light on the study construct (Grinnell & Unrau, 2005; Padgett, 2016).

Ethics of research

Ethics approval for this research has been taken from the Ethics Review Board Committee of Forman Christian College – A Chartered University. Prospective participants were informed about the research through a cover letter. Both anonymity and confidentiality of mothers and families were

ensured. No names were taken of participants and effort was made to ensure that their identities would not be revealed.

Sample

For this study participants were defined as any mother who had at least one child with special needs. To measure region-specific experiences and values only mothers who had been living in Pakistan and from Pakistan origin were considered for the study. The number of students in the institutes ranged from 48 to 262. The disabilities included both intellectual and physical. There were two government institutes and two private institutes. Mothers were approached from these four special needs instituted located in Lahore, Multan, and Gujranwala. Mothers were asked if they wanted to participate in the research through the provision of a cover letter, explaining research objectives, during parent-teacher meetings. A total of 21 mothers agreed to be part of the study and meet for interviews. The response was very low due to the private nature of Pakistani society and the lack of comfort mothers felt in sharing personal experiences related to self and child (Edwards & Holland, 2013).

Instrument

A semi-structured and open-ended questionnaire was compiled through the help of a literature review (Davis et al., 2010; Durmaz et al., 2011; Inan Budak et al., 2018) and the experience of authors in working with SNC and their families (Attachment A). Five socio-demographic questions were asked from the mother, along with specific questions pertaining to the study construct of mental and physical health problems experienced by participant since the birth of their special needs child.

Data collection

The data collection period lasted five weeks from November to December 2018. Willing participants were interviews between 45 and 65 minutes in locations of their choice. Interviews were conducted in both English and Urdu, depending on the preferred choice of participants. Transcripts and notes were taken by the second author and her research assistants for all interviews.

Data analysis

The Urdu transcripts and notes were translated into English and then transcribed to Microsoft Word by the second author. The translation and Microsoft Word entries were double checked by first author for confirmation.

The interviews were next transferred to NVIVO software and categories and sub-categories of relevance were identified, under the two broad themes of mental and physical challenges. Thematic content analysis is an accepted qualitative method that helps to make sense of rich data and develop common themes of consequence (Elo & Kyngäs, 2008). The reliability of findings was confirmed through re-reading transcripts and manual coding by researchers. As advised by experts, member checks were also used to assure the reliability of findings (Barbour, 2001; Shenton, 2004). The first and second authors had meetings with two mothers of SNC who had not participated in the study and two medical practitioners who are working with special needs children and their families. The findings of the study, as presented in Table 1, were discussed. All four agreed with these categories and sub-categories of mental and physical health problems experienced by mothers with SNC in Pakistan.

Results

Mental health problems

Constant stress due to structural failure

All the participants mentioned that they faced considerable and persistent stress in their lives due to structural failure for support of special needs families. Structural failure was described as including lack of competent medical assistance, special needs institutes, and state subsidization. Mothers discussed how they had no support from the health sector, educational sector, and government for the support and development of their SNC. Having to solely be responsible for the health, educational, and financial needs of their child was a source of tremendous stress for the mothers. A divorced mother with a son suffering from Osteogenesis Imperfecta summarized:

Table 1. Categories and sub-categories of mental and physical health problems experienced by mothers with SNC in Pakistan.

Category	Sub-category
Mental Health	
	Constant stress due to structural failure
	Anxiety of social shaming and having to avoid public exposure
	Fear of public assault
	Morbid feelings and waiting for imminent death of child
	Accepting blame for child's condition and feelings of depression
	Apprehension about marriage of special needs children
	Mood swings and erratic outbursts
	Desperation to prove others wrong about value of child and defy fatalistic attitudes
Physical Health	
	Constant physical fatigue, migraines, and insomnia
	Muscle, bone and joint pains or bone deterioration
	Hypertension, high blood pressure, diabetes and nutritional issues
	Physical abuse and self-harm
	Health consequences of contraception and hysterectomy

> There are no capable health services for my son . . . no higher education opportunities . . . and no state subsidies to ease our financial troubles . . . how can I not be under constant stress when all the burden is mine alone to bear?

Anxiety of social shaming and having to avoid public exposure

Most participants described their persistent anxiety due to social shaming and having to hide from the public in order to avoid humiliation and social shaming. Not only was pity from society a source of stress and humiliation for the mothers, but it also prevented mothers from projecting normalcy in their lives. Participants emphasized that if they were not pitied so much and treated like a normal family, they would be able to be stronger and happier care providers for their SNC. A mother with a daughter suffering from complete paralysis described:

> The constant pity in society's eyes and the way that they talk implies that my daughter is a burden on me. The pity causes me great stress. I want to tell people that my daughter's health challenges would not be such a problem if there was more structural support. My daughter's mind is working . . . if society wants to help, instead of pity, they can pay for good tutors to teach her at home.

Participants also described how they would love to take their SNC out in public, to the market, the park, or to family functions. However, society made it difficult for them by ridiculing, shaming, and reacting with hostility to their SNC. Mothers described how it was simpler to pass life by hiding their SNC in order to avoid the anxiety of unaccepted events in public. A mother whose daughter had Down Syndrome stated:

> I avoid taking my daughter to the market because people stare at us and make us feel uncomfortable . . . some even look at us in disgust . . . I cannot take this.

Mothers mentioned that even when their SNC did not do anything overtly abnormal, relatives with knowledge of the disability attempted to make social engagement and public participation difficult for them. There was also another problem of the husband and other children in the family not wanting to experience the anxiety and embarrassment that the SNC attracted in public. A mother with a deaf child described:

> Relatives purposely mock and make fun of my deaf daughter . . . even when her speech is clear, relatives pretend not to understand what she is saying. This becomes a source of unease for my husband and other children and they are not willing to go to family functions with my special needs daughter.

Fear of public assault

Mothers described how they were in a perpetual state of fear with regard to leaving their SNC alone and risking different forms of violence against them at the hands of relatives, the public, or personnel at educational institutes.

The greater concern with SNC was that verbal abuse and sexual harassment might not be detected; and physical abuse would also be unreported due to communication problems. A mother shared that she had pulled her child with partial blindness out from another special needs institute due to physical abuse:

> My daughter was hit at the school by the school maid. She (my daughter) did not tell me anything at first, but I noticed the marks on her face. When I went to the school the next day to complain, they refused to acknowledge the incident and took no responsibility.

Mothers described some of the reasons for abuse and bullying against their child, including (i) when their clothes were not in order, (ii) if they were unable to answer questions, and (iii) if they did not behave as socially expected. A mother with a son suffering from a mental disorder stated:

> My son cannot answer questions when asked directly. When I am not there people slap him and hoot "mental mental". I fear leaving him alone as I may never know the extent of the abuse exercised against him.

Morbid feelings and waiting for imminent death of child

One of the most frequent questions that the participant mothers are asked by society is when the doctors have predicted the end of the life for their SNC. It was shared that sometimes mothers became so consumed by the belief that their child would die soon that they were unable to concentrate on the present or focus their energies on building a future for their child. A mother whose child has complete paralysis described:

> People regularly say that my son will not remain with us for long. This has been playing with my mind for years. I even dream of his death.

Mothers also described fears regarding their own death and the future of their child. They worried about who would care for their SNC when they died and also feared abuse against them. Participants stressed that they did not trust their family members for the care of their SNC in the event of their death. A mother in her sixty's with a mentally retarded son confessed:

> I often pray to God to take away my child before me. No one can look after him the way I do. It is better that I bury him before I die.

Accepting blame for child's condition and feelings of depression

All mothers described how they were forced by society to accept blame for the condition of their SNC. Mothers listed the different types of reasons that society employed to blame them, including: (i) paying for their sins or the sins of their parents, (ii) carelessness during pregnancy or before pregnancy, (iii) neglect after the birth of the child for special needs that developed or were

detected after birth. A mother described how society held her responsible for her son's mental disorder:

> My son developed a mental health condition after puberty. Everyone blames me for his condition, including my husband and family. They say it was either my neglect or my characterlessness that my child is now not mentally well. I am often told: "You should ask God for forgiveness to make your hardships easier!"

Mothers described how they had started to accept blame as they were too tired and emotionally drained to resist negative labels. Acceptance of blame and feelings of guilt led them to experience depression and dejection. Many believed that this depression, caused by guilt, kept them debilitated and not as physically and mentally active. A mother with a daughter who had Cerebral Palsy described:

> I feel guilty all the time. It must have been something that I did for which my child has to suffer. I just want to ask Allah to forgive me and create a miracle for my child.

Apprehension about marriage of special needs child

Some participants shared that their SNC could get married and have a chance for adult stabilization and conjugal care. However, family and relatives were not supportive of arranging suitable marriages for SNC, and instead kept mothers in a constant state of apprehension about the future of their child. One mother with a blind son described:

> I once mentioned that my son can get married and live a happy life . . . but I faced such ridicule and criticism from relatives, that I have never mentioned it again. How can I arrange his marriage without the support of others?

Mothers also discussed that there was great apprehension about the unknown even if families were able to arrange the marriage of their SNC in the future. The main apprehension was the risk of neglect and abuse in marriage, especially in the case of special needs daughters. A mother whose daughter was deaf stated:

> Maybe a boy will pretend to care for my child and get married to her. But this could also be pretence for dowry. I fear that she will be neglected or abused after marriage and I would not be there to protect her.

Mood swings and erratic outbursts

Many mothers mentioned that they suffered from mood swings and erratic outbursts. Not only was this behavior difficult for the husband and family of the mother to accept, but it was a source of confusion for the SNC, who could not understand the reasons for the mood shifts and outbursts. Participants mentioned that the mood swings rendered them incapable of consistently fulfilling roles for home care, child care, and work participation. Similarly,

outbursts in front of relatives and friends became a cause for furthering social disintegration. A mother with a daughter suffering from autism mentioned:

> A snide comment of a relative or the rude behaviour of healthcare staff can trigger me to lose it. People now know that I can be polite and patient one moment, but can also become rude and aggressive in the next! This emotional rollercoaster limits me from giving my best all the time.

Desperation to prove others wrong about value of child and defy fatalistic attitudes

Some mothers described how society was dominated by fatalistic and deterministic attitudes which put pressure on mothers to accept deformities and not try and change or improve conditions. Participants explained how they felt desperate to try and show the value of their child and defy fatalistic attitudes about their child's social and economic integration. Mothers felt that all their energies were being wasted on social acceptance, instead of focusing on the development and rehabilitation of their SNC. A mother whose son had Apert Syndrome described:

> I am sick of the Muslim tendency to relinquish control and leave all the planning to Allah. I want to spend my energy helping my child fit into this world that God has created for him. Instead, all my strength is taken trying to change the world and the people around him.

The need for society to praise and appreciate the SNC consumed many mothers. They acknowledged that this was wasted energy, but that the need for social acceptance had become a priority compared to investing time for training and development. A mother with a blind son stated:

> It is expected that I should spend all my time training my son to survive and cope within the four walls of our house … where he is expected to remain. I spend all day dressing him and making him presentable to please my in-laws and family. But this is a waste of time. Instead, I want to spend our time and energy helping my son to get training for a skill so he can be independent in the future.

Physical health problems

Constant physical fatigue, migraines and insomnia

Majority mothers described their constant physical fatigue, headaches, and sleeplessness since the birth of their SNC. This physical state was discussed to be a consequence of (i) the great physical challenge of caring for SNC, (ii) ensuring that society and its structures are not abusing the child through continuous physical presence with child, (iii) traveling or driving long distances for medical services or special educational facilities, and (iv) the lack of physical assistance for home and child care management. One mother described:

> I am constantly tired and have perpetual headaches. It becomes physically exhausting to do all that is needed … and to do it every day without a break!

There was concern expressed about the lack of concentration due to sleeplessness and the fear that this endless state of insomnia in mother's lives would cause further physical health problems. A mother mentioned her problems with insomnia and the resultant effect on her care quality for her SNC:

> I don't remember the last time I slept satisfactorily. Of course this affects my care for my child. I have tried medication, but even that does not help.

Muscle, bone and joint pains or bone deterioration

Mothers complained of sustained pain in the muscles, bones, and joints. There was also a complaint about bone deterioration, osteoporosis, and sciatica pain. Two mothers with slip disk stated that they had been recommended surgery, but they were surviving on pain medication, muscle relaxants, and epidurals as they did not have time for surgical procedures. Trained and paid nurses or care providers were too expensive for most participants to share their physical burden. For those mothers who were able to hire domestic assistance, the claim was that servants were inefficient and not trustworthy. A mother with a paralyzed child described her physical challenge:

> I have hired servants, but I cannot trust them with my daughter. I use the servants for the cooking and cleaning. The physical load of carrying my daughter for bathing, changing, and visiting the washroom, lies on me. My shoulders, neck and back hurt constantly. There have been weeks when I am unable to move without strong pain killers and muscle relaxants. I have heard one should not take these medicines for more than fifteen days as it is harmful for the kidneys.

Hypertension, high blood pressure, diabetes, and nutritional issues

Many mothers complained about having to take medicine for hypertension, high blood pressure, or diabetes since the birth of their child. It was believed that the stress and worry of assuming primary responsibility for the SNC, buffering the child from social stigma, and creating opportunities for the child in the absence of structural support, had played a toll on the physical health of mothers. Mothers were fearful that their cardiovascular and diabetic conditions would worsen; leaving their SNC more vulnerable in the world. Participants expressed that they had neither the time nor will to commit to physical exercise and improving diets to control heart and blood sugar problems, due to the belief that these problems were related to unavoidable stress. A mother suffering from high blood pressure and diabetes described:

> I forget to take my daily blood pressure medicine or monitor my insulin levels. The doctor says I must look after myself and change my diet. I don't think it would help though … it is all related to the worry in my life for my (special needs) child.

Mothers described how they perceived themselves to be either underweight or overweight, due to their bad eating habits. Participants from the lower socio-demographic background with financial constraints were giving themselves the least priority for nutritional intake. They discussed the rising cost of fruits and vegetables and the time it took to cook nutritious meals. Conversely, participants without financial problems were still not consuming a nutritious diet due to lack of time and energy. Instead, participants primarily consumed unhealthy traditional meals rich in oil and salts typical to Pakistani society or they consumed processed food. A mother described her weight problems:

> I know I am overweight by the difficulty I have in my breathing after climbing stairs. It is easier to make a Salan (oil based gravy with meat or vegetables) and Nan (bread made of processed flour and yeast) which can be eaten twice a day and even for breakfast. Both Salan and Nan as you know make one constipated and gain weight.

Physical abuse and self-harm

A few mothers bravely admitted that their frustration at life, social circumstances, and financial difficulties resulted in them becoming physically violent against their child and also themselves. As mothers spent the most time with their SNC, the brunt of their frustration came out on their child through physical violence, like slapping, jerking, or pinching. Mothers also opted for self-injury in order to emerge from their powerless state and also to demand that their family give them more assistance in child care. A mother described:

> Sometimes I get so depressed and stressed that I hit my SNC and also cut myself and make myself bleed. I want my family to wake up and see that I did not wish for a SNC. They (family) need to help me . . . otherwise one day I will not be there to manage all this.

The physical consequences of contraception and hysterectomy

Mothers described the dilemma of having to choose between contraception and hysterectomies for themselves and their special needs daughters. Participants wanted to prevent their own pregnancies due to fear of deformity in future children, and the lack of time and finances for more children. Participants with special needs daughters had the following to consider: (i) fear that daughter would be unable to understand or manage menstrual hygiene, and (ii) the more hidden fear of pregnancies resulting from rape of daughter, especially when mother was not alive to protect them. The known or experienced health side effects were shared of (i) hormonal contraception (hot flushes, mood swings, irregular menstrual bleeding, and abdominal pain) and (ii) hysterectomy (nausea, hormonal imbalances, cholesterol and heart problems, and bone deterioration). One mother who had chosen a hysterectomy for herself, and was considering it for her daughter stated:

> The ideal solution is to remove the reproductive organs of my crippled daughter. I will not always be here to protect her. I have had the same surgery and it has side effects, like hypertension, hot flushes, and weaker bones. However, not having it (hysterectomy) is a greater risk.

Discussion

Overall, our findings match international literature in that the governments of South Asian countries, and Pakistan are lagging far behind in sponsoring cultural acceptance and structural integration of SNC (Hari, 2016). We found that mothers face multiple forms of mental health challenges such as stress and anxiety due to social shaming and structural inadequacies. International research corroborates with our findings that mothers with SNC face compounding mental health challenges (Gomez & Gomez, 2013) and great stress due to socio-structural failure (Shin, 2002; Wang et al., 2017). Studies from South Asia also corroborate that mothers suffer from anxiety due to public shaming and humiliation when their SNC interacts in public (Karande et al., 2009; Lemacks et al., 2013). Traditional societies do not support the social integration and marriage of disabled people, leading to great worry for mothers with regard to the future of their SNC, especially after parents have died (Chen et al., 2002).

Another finding of our study is that mothers of SNC suffer from depression due to the acceptance of blame and guilt for the condition of their child. Despite the provision of rights for disabled people in Islamic theology, most Muslim societies perceive disability as a punishment from God and thus allocate great blame on mothers of SNC due to traditions and culture (Al-Aoufi et al., 2012). There is concern that guilt and depression can build over time in mothers, especially when they feel powerless in integrating SNC into society and are deprived of therapy and counseling (Broomhead, 2013). We also found that mothers fear to leave their child alone due to fears of physical abuse by strangers, relatives, and school employees. Other research substantiates that disabled children frequently suffer from physical abuse and maltreatment at the hands of others when their immediate family members are not present (Stalker & McArthur, 2012).

Our findings also disclose that mothers opt for hiding the SNC from the public in order to protect their families from social rejection. Other studies have found that the difficulty in "passing" and hiding disability is a source of perpetual anxiety for families (Linton, 2006). Lack of social integration may result in adverse consequences for the child such as isolation within the home or extreme neglect causing more permanent health problems (Rohwerder, 2018). Our results uncover that mothers suffer from mood swings, erratic behavior, and the desperation to prove society wrong about the value of their child. Mothers are desperate to change the fatalistic and deterministic attitudes that compel society to exclude

their child from possibilities of building a future and enabling integration. Other research also confirms that Muslim societies have fatalistic attitudes (Acevedo, 2008), which can prevent proactive involvement in health recovery and rehabilitation and lead to great frustration in mothers (Raman et al., 2010).

Physical health problems related to constant fatigue, migraines, and insomnia were discovered in our study. Other research confirms that mothers with SNC suffer from fatigue and sleeplessness causing poor functioning of care delivery for child and inability to concentrate generally (Gallagher et al., 2009) (Green, 2007). In fact, mothers who are evidenced to suffer from physical fatigue and migraines also show association with higher hospitalization rates for their SNC (Chambers & Chambers, 2015). Our study results also reveal that mothers are suffering from muscle and joint pains, bone deterioration, and degenerative spine conditions. International literature confirms that mothers with SNC do a lot more physical work with regard to long hours spent caring for the child, lifting the child, and pushing wheelchairs (Tong et al., 2003), leading to muscle and bone injuries and even permanent physical incapacitation (Datta et al., 2002).

Our findings indicate that mothers perceive their weight to be either in excess or under, due to inadequate nutrition. Other research confirms that mothers with SNC are unable to satisfy their own nutritional needs or that of their families due to lack of time, finances, and access to nutritional ingredients (Groce et al., 2014). Overall, international literature confirms that mothers of SNC tend to deprioritize a nutritious diet and physical exercise due to the immense burden of responsibilities that they must juggle alone (Emerson, 2003). Our findings further bring to light the greater risk to heart and organ damage in mothers who are suffering from heart disease and diabetes since the birth of their SNC. Other research confirms that when there are less psychosocial interventions for mothers with SNC and also there is a greater risk of high blood pressure and heart disease (Gallagher & Whiteley, 2012).

We also discovered the severity of hopelessness felt by some mothers who resort to using physical abuse against self and child to release their frustration and attract attention for social support. Previous research agrees that SNC are at risk of physical abuse from their mothers due to the despair of having to manage without assistance and support (Jarosz, 2008). Care providers are also known to inflict self-harm out of aggravation and stress in their lives (Gómez et al., 2015), and at times even contemplate suicide (Bumin et al., 2008). In Pakistan currently, there is no reporting cell or counseling cell for violence against SNC. With regard to mothers in our study who had used physical violence against their child, we were able to do the following: (i) share contact details for free counseling for such mothers, and (ii) shared their information with the Government of Punjab, Child Protection and Welfare Bureau. At the moment, however, the Child Protection and Welfare Bureau does not have a standardized or follow-up mechanism to deal with such mothers or families.

As researchers, we are trying to do more work in this area and have received funding for the development of digital literacy tools to prevent violence against SNC. The research will involve training of teachers and parents of SNC and a pre and posttest for perceptions of safety and protection.

Last, our findings highlight that mothers are trying to prevent the reproduction of both their daughters and themselves, despite the known health consequences of hormonal contraception use and hysterectomies. Medical research has also confirmed that early hysterectomies (Forsgren & Altman, 2013; Havryliuk & Kosylo, 2016; Lakshmi et al., 2016; Moorman et al., 2009) and contraception usage (Council & Population, 1989; Sabatini et al., 2011), can be associated with bone deterioration, hormonal imbalances, slowing of metabolic rate, cardiovascular disease, pelvic organ prolapse, urinary incontinence, bowel dysfunction, and weight gain. This study has limitations in that the sample is small and the results are based on subjective perceptions, thus not being generalizable to the wider population. However, the strengths of the study outweigh the limitations by identifying the health challenges faced by mothers with SNC and highlighting the role of health social workers in improving the support for the health needs of mothers.

Implications for health social work practice

The International Federation of Social Workers has acknowledged that social work practice must vary according to the needs of the community (Hare, 2004). The aim of this research has been to highlight the importance of integrating health social workers in the support of mothers of SNC. With foremost responsibility for child in medical care, mothers of SNC frequently visit and spend long hours in the clinical settings, allowing health social workers the opportunity to collect information about mother's health (Gerten & Hensley, 2014). In developing nations, including Pakistan, there is need for the health social workers to keep longitudinal records about the health condition of mothers with SNC (Reamer, 2005), including information about (i) family and community support, (ii) health risks and vulnerabilities, (iii) financial conditions of special needs families, (iv) the quality of education and employment opportunities, and (v) experiences of neglect, abuse, and violence.

Increased support for referrals to medical practitioners by health social workers has been shown to assist in lowering the physical and mental health problems faced by mothers with SNC (Schneiderman & Villagrana, 2010). We recommend that health social workers mediate the support of healthcare practitioners by expanding services for mental health therapy and regular physical health checkups. There is a significant opportunity for health social workers in screening and connecting with vulnerable mothers at healthcare settings when their children's special needs are diagnosed and in the early years when they are bringing their child for medical services (Kinrade et al., 2011). In

Pakistan where detection and early medical intervention are problematic, health social workers can assist in coordination for early detection of disability and also prevention in advance of disability by promoting acceptance, awareness, and psychophysical health of mother (Gehlert & Browne, 2011).

There is a considerable need for improving structural support and socio-economic integration for SNC, including three areas of healthcare assistance, educational opportunities, and state subsidization. Researchers from Pakistan have estimated that the integration of special needs people in the country can raise the GDP by more than 6% (British Council, 2014). Health social workers can assist in motivating policymakers to improve the educational and economic integration of SNC, and thus indirectly benefiting the physical and psychological health of mothers, who fear for their child's dignity and independence (Evenboer et al., 2018; Morris et al., 2018). Specific advocacy points that social workers may champion for special needs families, derived from our study findings, include (i) freely available mental health counseling services for feelings of stress, guilt, depression, and morbidity, (ii) freely available medical centers and medical camps for health awareness and medical checkups, (iii) subsidization, work benefits, and health insurance schemes for financial protection, and (iv) inclusive education and skill development for employability of SNC.

Overall, there is a need for the intensification in partnership between different social workers, including officers in health, child protection, school, and family, to comprehensively safeguard and further the cause of special needs families. Information from health social workers could benefit the direction of community social workers in networking with family members, community notables, and religious authorities to improve social support for marginalized communities (Stainton et al., 2010). In a closed society like Pakistan, the initiation of self-help groups in the community by social workers to promote social awareness and emotional stability through sharing of experiences would be advantageous to help alter community and family level norms (Bridge, 2005). From a multidisciplinary approach, social workers, lady healthcare workers, community workers, and congregational social workers must effectively coordinate to assert collective pressure in raising the social status for mothers of SNC, who are providing a tireless service for society and the economy by driving the adaptation of their children.

Conclusion

There is a dire need in Pakistan for special needs people to be supported with social acceptance, inclusive education, training and employability, and constitutional rights. Though mothers in Pakistan are expected to play a critical dual role in care provision and policy mobilization for the rehabilitation and development of SNC, their agency is weakened due to the substantial physical and mental health challenges that they may face. We need mothers to remain physically and

emotionally healthy so they can optimize their capacity and roles across different spheres of life. There is an important role that can be played by health social workers in supporting the sustained health and wellbeing of mothers with SNC. Support for mother's health would not just mean better care for the SNC, but also improved care and relations with other family members and macro-level gains in socio-economic development for the nation.

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Research interests

Women's Social Development through Microfinance; Women's Health, Gender-based Workplace Violence; Special Needs Children and their Families; and Informal Congregational Social Welfare

List of publications

1. Book – Women, Healthcare and Violence Recognizing the Risks faced by Female Healthcare Providers in the Islamic Republic of Pakistan, 2018 *Oxford University Press.*

Links for online order and reviews

https://oup.com.pk/academic-generalbooks/sociology-gender-studies/women-healthcare-and-violence-in-pakistan.html

2. Jafree, S. R., Zakar, R., Mustafa, M., & Fischer, F. (2018). Mothers employed in paid work and their predictors for home delivery in Pakistan. Springer, *BMC Pregnancy and Childbirth*, 18(1), 316; https://www.ncbi.nlm.nih.gov/pubmed/30075757

3. Jafree, S. R., Zakar, R., Zakar, M. Z., & Fischer, F. (2017). Assessing the patient safety culture and ward error reporting in public sector hospitals of Pakistan. Springer, *Safety in Health, 3*(1), 10; https://safetyinhealth.biomedcentral.com/articles/10.1186/s40886-017-0061-x

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