

## **Abstract**

**Aim and objectives.** To provide knowledge about how immigrant parents of children with complex health needs manage their family lives and how this affects their own health and quality of life.

**Background.** Caregivers of children with complex health needs have additional risk for general health problems and mental health problems and immigrant parents may be more vulnerable to mental distress and failing health and quality of life.

**Design.** This qualitative study used an exploratory design with individual and focus group interviews. Data collection and analysis followed phenomenological hermeneutic guidelines.

**Methods.** Individual and group interviews with 27 parents: 18 mothers and 9 fathers from Pakistan, Poland and Vietnam.

**Results.** Immigrant parents of children with complex health needs experience their own health and quality of life challenges. They described the burden of dealing with their child's needs and special care, which affects their sleep and physical and mental health. Single mothers are particularly vulnerable.

**Conclusion.** Parents reported positive and negative effects of their caregiving experience that may affect their health and quality of life. Mothers were the primary caregivers and reported more health problems than did fathers. The lack of respite care, social networks and support impacted maternal health. Immigrant parents struggle to access resources for their child with complex health needs.

**Relevance to clinical practice.** Hospital nurses, schools and community health care can play a valuable role in supporting the parents of children with complex health needs. It is important that parents are informed about their rights and receive a co-ordinator and interdisciplinary group to ensure that their needs are met with assistance and respite care. That maternal health

was worse in this sample implies that health-care professionals should pay more attention to reducing stress among these caregivers.

### **Summary box**

What does this paper contribute to the wider global clinical community?

- This paper provides a greater understanding of how immigrant parents of children with complex health needs manage and experience health and quality of life.
- Focus on aspects that promote and inhibit health and quality of life among immigrant parents such as lack of respite care, social support, language barriers and access to resources when they have children with complex health needs.

**Key words.** Immigrant parent, children with complex health needs, caregiving, quality of life, health

## **On duty all the time: Health and quality of life among immigrant parents caring for a child with complex health needs**

### **INTRODUCTION**

Having a child with complex health needs in the family requires the family to adapt comprehensively to these needs, including changes in time allocation, which may in turn have psychological and social consequences. Children with complex health needs are a diverse population that require higher levels of physiological, psychological, social and educational care and support (Carter, Cummings, & Cooper, 2007). This may impact health and quality of life (QOL) among their parents. Immigrant parents may be particularly vulnerable due to language problems and limited knowledge about the health-care system. Many of the challenges parents of children with complex health needs experience are universal, but immigrant parents face more challenges because they often lack social networks such as help from families and have limited knowledge about the health and welfare system and what benefits they are entitled to in the new society (Söderström 2014). In addition, immigrant parents may experience social isolation, lower employment and marginalization (Berg 2014). Minority parents of disabled children encounter different types of difficulties in meetings with health-care workers than majority parents of disabled children. These challenges include language difficulties, perceptions fixed in advance, and inflexible services (Berg 2014). If health-care workers are not aware of the specific cultural context in which the services are embedded, they will miss out on the significance of both their own and the service recipients' inherent perceptions and views (Söderström 2014). Fellin *et al.* (2013) found that immigrant parents raising a child with disabilities face several barriers to accessing and using health and social services because their language barriers can lead to lack of knowledge of supports and service.

QOL has been defined as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL, 1995, p. 1405). Previous studies assessing parents of children with major congenital anomalies (Poley, Brouwer, van Exel, & Tibboel, 2012) and congenital heart disease (Lawoko & Soares, 2003) found worse QOL compared to a community population. Tung *et al.* (2014) also found poorer QOL among caregivers of children with autism (Tung *et al.*, 2014). The overall aim of this study was to investigate health, social support and QOL among immigrant parents of children with complex health needs. We also examined the differences between the maternal and paternal caregiving burdens.

## **BACKGROUND**

Studies from Norway (Solberg *et al.* 2011, Skreden 2011; Wendelborg & Tøssebro, 2010) Sweden (Olsson & Hwang, 2006), Canada (Burton *et al.*, 2008) and the USA (Seltzer *et al.*, 2001) have focused on how caring for chronically ill and disabled children negatively affects parental health. Adverse health effects of caregiving burden are more prevalent among mothers than fathers (Burton *et al.*, 2008; Olsson & Hwhang, 2006). In their cross-sectional Norwegian study of parents with children with disabled children, Wendelborg and Tøssebro (2010) found adverse health effects only among mothers; fathers in that study did not differ from a comparison sample. Previous research has also shown that behaviour problems among children with congenital anomalies have a range of immediate and long-term consequences for the overall well-being of their mothers (Hauge *et al.*, 2013; Nes *et al.*, 2014). Mothers worldwide are the primary caregiver more often than fathers are, and are also more susceptible to strain, stress and depression and in greater need of social support (Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002; Tsai & Wang, 2009). However, gender equality

is very high in Norway and many fathers are involved in childcare. Nadim (2014) found that second-generation Pakistani women in Norway distanced themselves from the domestic roles their mothers once filled. They considered work to be a central ingredient of a meaningful life in Norwegian society and it defined who they are in relation to others, as women, mothers and caregivers (Nadim, 2014).

An interesting question, then, is how immigrant parents adapt and whether the consequences of their care burden are gendered. Caregivers of children with complex health needs have additional risk for general health problems (Brehaut et al., 2009) and mental health problems such as depression (Singer, 2006). Family function and social support positively affect caregiver QOL and female caregiver QOL has been reported to be lower than that of males (Khanna et al 2010). Social support is an important factor in reducing caregiver strain (Tsai et al 2008).

There are reasons to believe that parents of children with complex health needs who have migrated to Norway may be more vulnerable to physical and mental distress and failing health (Fladstad & Berg, 2008). Factors that contribute to increased mental distress may include limited language skills, lack of knowledge about the health-care system, limited social networks and fewer economic resources (Berg, 2014). Ways of understanding disabilities are also culturally specific and may contribute to social isolation and experienced guilt and shame (Sørheim, 2011).

We interviewed immigrant families from Poland, Pakistan and Vietnam. These groups represent different family structures and immigrated to Norway during different periods and for different reasons. Polish work migrants and their families are the largest group to have immigrated to Norway from a single country within a brief timeframe (Friberg & Eldring, 2011).

The study aim was to provide in-depth information about how immigrant parents of children with complex health needs manage their family lives and how having children with complex health needs affects the parent's health and QOL. Based on existing knowledge, we developed these research questions: What are the health and QOL experiences among immigrant parents from Pakistan, Poland and Vietnam having children with complex health needs? What factors contribute to health and QOL among these immigrant parents? Are there differences between maternal and paternal caregiving burden?

## **METHODS**

### **Design**

For this qualitative study, which was part of a larger quantitative project, we used an exploratory design with both individual and focus group interviews. Data collection and analyses followed Kvale's (2009) phenomenological hermeneutic guidelines for qualitative research.

### **Participants**

The sample was 27 parents (18 mothers and 9 fathers) from Pakistan (n=13), Poland (n=9) and Vietnam (n=5), each of whom was individually interviewed. The participants were recruited through nurses and social workers at two hospitals in Norway. We used interpreters for participants who lacked Norwegian language skills. To facilitate discussion of their experiences among these parents, we also conducted three focus group interviews: two with Pakistani parents (separated by gender) and one with Polish parents.

### **Data collection**

Individual interview and focus group data were collected during autumn 2013 and spring 2014. The interview scripts included open-ended questions covering aspects of having children with complex health needs that emphasized the parents' daily life experiences. The

three focus group interviews were conducted with the same sample who was interviewed individually. Each interview lasted 45 to 90 minutes. We used a language interpreter for nine of the individual interviews and one of the focus group interviews.

### **Ethical considerations**

The Norwegian Regional Committee of Ethics (REK) approved the study. Written informed consent was obtained from participants before they were interviewed. The moderator followed professional practices to ensure that no information in the study results could be used to identify individual study participants. The data were stored safely and securely, accessible only to the researchers, were anonymous and were deleted at the completion of the project.

The information provided to the parents described the study aims, data collection procedures and that participation was voluntary. The letter also assured participants that they could withdraw from the study at any time without any consequences. Participants were asked to maintain the confidentiality of the focus group discussions.

### **Data analysis**

According to Kvale (2009), the research interview is an attempt to understand the world from the subject's point of view. Our study was designed to understand the parents' experiences and to gain insight into their world. Interviewing is an appropriate method for exploring experiences, opinions, wishes and concerns because it allows participants to state their experiences in their own words. It is a way to achieve a deeper understanding of how people feel and think about a specific issue. In focus groups, participants share their experiences and views through discussion (Wilkinson, 2004). In our study, the focus groups were used to explore parents' daily life experiences of having children with complex health needs.

We combined the individual and focus group information for analyses. Analyses consisted of reading and re-reading the transcribed interviews to achieve an overall

understanding before dividing them into themes and sub-themes. Kvale (2009) suggests three levels of interpretation: self-understanding, critical understanding based on common sense and theoretical understanding. Self-understanding consists of what the informants said and their intended meaning. Each interview session was analyzed separately for content. Interpretation was a circular process that moved back and forth from parts of the text to the text as a whole and then back again (Kvale, 2009). For the second level, critical understanding, the researchers used common sense and a critical perspective to interpret and comment upon what the informants said in each interview. The interviews were then analyzed as a whole to find common patterns or differences among the groups. This interpretation provided a broader framework for understanding the informants. At the third level, theoretical understanding, a theoretical framework was used to interpret the text within QOL dimensions.

Findings from other studies were also used to broaden the resulting perspective. To validate the interpretations, four independent researchers read and interpreted the interviews and further discussed the interpretations until they reached a consensus.

## **RESULTS**

Tables 1 and 2 display the characteristics of parents and their child. The majority of the sample was first-generation immigrants except five parents from Pakistan and about half of the mothers from Pakistan grew up in Norway. Our individual and focus group interviews with these 27 parents helped us identify a range of themes. The main themes were: everyday life of having a child with complex health needs; health challenges among mothers and fathers; and the challenge of being an immigrant parent.

### **Everyday life of having a child with complex health needs**

Our sample represents different families of children with complex health-care needs. A common pattern of which these families spoke was that those families who had children with



serious health problems had the additional burden of dealing with their child's needs, which led to their daily lives needing to be well organized. The differences between the families included their organizational structures, role expectations (that may influence their own health), their immigration stories and how long they had lived in Norway. The parents spoke of the joys and sorrows of parenting. One mother said, *"He is so smart, very intelligent and very sweet...He is very positive, always smiling and laughs a lot. He is smarter than healthy children, except that he can't walk"*. This shows that the mother appreciates her child as he is and is aware of her child's resources.

The parents also spoke of great challenges of having a chronical ill child, *"My son cries a lot, so I am afraid the neighbours will think that I am hurting him. We must watch him all the time, so we have no leisure time for ourselves"*, which indicated a sense of social stigma and lack of leisure time. A single mother of a five-year-old child with a severe disease described her day, *"Changing diapers is quicker with a normal child but in my case it takes about half an hour just to put him down, arranging him, and take off the diaper. He is very stiff, so I must massage his muscles. Every day things take time, such as brushing his teeth"*. Attending to this child's care needs for all activities and feeding is a full-time occupation for his mother. Having a chronically ill child also influences siblings. Many parents mentioned that they did not have enough time to take care of their healthy children, *"Even though I'm sitting in the living room and she is somewhere else, I think about her all the time and not about the other kids"*.

Some of the parents reported that taking care of their ill child impacted their marital relationship. For example, these fathers often worked full-time or more to improve their family's financial situation and were thus tired when returning home, at which point the mother was also quite fatigued from a day of caring for their sick child. This contributed to arguments and problems within their relationship. One father said, *"I have a full-time job, but*

*on weekends or when I'm at home I am eager to help my wife. We share everything and we all collaborate. Still, my wife is the one who has the main responsibility at home".* Some participants had supportive husbands, while other were divorced single mothers. One such mother said, *"He would not accept that our boy was sick even though he knew he did not eat, he could not walk or talk to his father and did not have any words to express. So it was very difficult for me to live with him and we quarrel a lot about that".* Several single mothers reported that it was hard to be divorced and to bear the full and constant responsibility for their ill child. Some of the mother said they wanted to work, but could not manage to do so full-time.

### **Health challenges among mothers and fathers**

Pain, sleep disturbance and mental health problems such as depression were common among these mothers with children of severe health problem, who reported more health problems than did the fathers. One mother said that she had lost weight, felt tired constantly and had disturbed sleep because her child woke her up every night. She reported only sleeping three hours each night, *"You are on duty all the time, you must always watch what he is doing, so you get very tired".* Another mother reported that, *"I cannot give time to myself. Sometimes if my son is sick at the same time as I am, then I have to think of him first and give him what he need such as medication. I always prioritize the children's needs before my own. So my health is in a way destroyed because of him and I miss having more help from our municipal".* Sleep problems were often mentioned. One mother described that her son could lie awake at four o'clock in the morning; they slept in the same room and he would wake her to tell her about something that happened two years ago at school. A father said they could not afford to buy a larger apartment, so all their children slept in the same room, *"All four children have to sleep together, the child with complex health needs is very upset and everyone in the family is affected. She is rolling around and making noise at night. All our children are tired when they*

*wake up because of her”.*

Another problem that was mentioned by several mothers was pain. They spoke of pain in their muscles, head and shoulders. The single mothers of seriously ill children with significant care needs had a difficult time, *“I used to carry her around and she is heavier now so I have pain in my hands and back. But what shall I do? I have to help her, she is my only child”*. The situation was especially difficult for one single mother with two chronic ill children. She said, *“There are some days that I think I have had enough, I think I cannot manage this anymore, but not all days are that bad”*.

These parents also talked about their mental health challenges, including being worried about their child and feeling depressed. Some mothers felt depressed and had difficulty managing their lack of free time. Despite wanting to look after her daughter by herself, one mother explained that she had become ill herself and had high blood pressure and depression because of caring for her daughter. Another mother said she had to wear a “mask” and pretend everything was fine in order to manage her situation. She did not like that other people felt pity for her. One single mother said that she wanted to have an education but that she could not manage to combine her studies and caring for her son, who had a very complex illness. He could not speak, was confined to his bed and had to be fed through a stomach tube.

Most of the fathers reported being healthy, but also expressed worry about the health of both their wife and child. They thought the situation was especially hard for their wife because she was at home all the time and could not go to work. One father described that his wife was ill and had to use antidepressant medication to cope with her situation, *“What will happen if I also get sick? Who will take care of the children then?”*

### **Challenges of being an immigrant parent**

Having a child with complex health needs is challenging for parents; it is particularly so for many of the immigrant parents who lack knowledge about how to obtain help, about who

might help them and about their rights. Most of these families were satisfied with the help they received from hospitals but were less satisfied with their local municipal authorities. In Norway, all children with complex health needs are supposed to have an individual plan and a responsible care team and co-ordinator. This plan is meant to provide each child with follow-up care according to his or her needs and resources. Many parents did not receive enough information to understand what we meant when we asked them about this.

Some of the participants reported language problems, difficulty understanding and accessing information; this was especially true for newly arrived immigrants who could not speak any or who spoke only limited Norwegian. This created a significant challenge to their use of the Norwegian welfare system. They had insufficient knowledge about their rights and resources that are initiated when the child is diagnosed. This diagnosis process took a long time for many of these families; some parents said that they submitted multiple applications for assistance that were rejected by the municipal authorities. One single mother explained her struggle, *“Now finally after 4 to 5 years I received respite care for one of my sick children and it was a struggle with the municipal, they would not understand the case. They would not understand how I felt and how hard it was for me as a single mother with two sick children”*. The majority of the mothers were at home with the ill child while the father was at work. Living on one income made family life even more difficult.

## **DISCUSSION**

In this study, we examined health and QOL experiences among immigrant parents of children with complex health needs. We also investigated the factors that contribute to their health and QOL and whether there are gender differences in caregiving burden. Our main finding was that most of these parents have issues with their own health and QOL. They spoke of the burden of their child’s unique care needs and how these affect their own physical and mental

health. Mothers were the primary caregivers of these children and reported more of their own health problems, including headache, pain and depressive symptoms, compared to fathers. The single mothers were particularly vulnerable in that they bore full responsibility for their child. However, even in two-parent families, the father often had to work more than full-time. Our participating families often lacked respite care and a social network, which impacted the parents' health.

We will first discuss the factors that may contribute to parents' health and QOL. QOL is an individual's perception of their position in life in the context of the culture and value systems in which they live (WHOQOL, 1995). The parents in this study saw value in having a child with complex health needs and spoke of loving and appreciating their child. Having children with complex health needs can enrich caregivers' lives. In their literature review, Horlsey and Oliver (2013) found that positive impacts may buffer the effect of stress and enhance well-being for parents of children with intellectual disabilities. The existence of positive impact is without doubt helpful to parents caring for a child with an intellectual disability because well-being is increased. Positive perceptions about caring have been found to be one of the strongest predictors of well-being (Horlsey & Oliver (2013).

Our study indicates that the most important aspect of health promotion and QOL among these parents was social support, respite care and access to social networks and health services. Social support includes support from family, friends and neighbours. In line with previous research (Berg, 2014, Tsai & Wang 2010) we found that social support includes support from family, friends and neighbours and that social support was an important factor in reducing strain on parents (Tsai & Wang 2010).

These families also need more time with all their children. As in previous research (Croot, Grant, Mathers & Cooper, 2012) some of our participants reported that they received help from their family to look after their other children, but seldom or never received help

towards their child with complex health needs. Two mothers mentioned that they received emotional support through speaking with their own mother over the phone. This is consistent with a previous study showing that emotional and social support may help individuals cope in difficult situations (Croot, Grant, Mathers & Cooper, 2012) and reduce strain (Tsai & Wang 2008). The support they received from their families varied among our participants. Similarly, Berg (2014) reported that immigrant parents' contact with friends is a coping method (Croot, Grant, Mathers & Cooper, 2012).

In line with previous research (Carter et al., 2007), the parents in this study expressed needing the opportunity to share and receive support from others to avoid feeling isolated and overwhelmed. They spoke of challenges of having a child with complex health needs and receiving help. Access to the health-care and welfare systems was important toward handling their everyday lives. Respite care so they could have a break was an important factor in the promotion of these parents' health and QOL. In Norway, children are guaranteed access to childcare after their first birthday. With the exception of the parents of children with autism who felt they needed more support from their child's school, most of these parents reported being satisfied with their child's kindergarten and school. This study shows that the daily life of parents of children with complex health needs is challenging, because these children may get sick more easily and may require hospitalization.

The primary challenges to the parents' health and QOL was their lack of resources. The parents in this study spoke of the negative impact of pain and sleep problems on their QOL. In line with previous research (Lawoko & Soares, 2003) our participants reported their subjective experience of poor QOL. Consistent with other studies (Brehaut et al., 2009) we also found that these caregivers are vulnerable to health problems. Some of the participants reported that a lack of resources increased their stress and they spoke about being exhausted by the burden of caregiving, particularly when their child was too sick to go to childcare or to

school. Stress correlates negatively with QOL among caregivers of children with complex health needs (Lawoko & Soares, 2003).

Another worry for these parents was their limited time to care for their other children. Welsh *et al.* (2014) found that caregivers had an unmet need for respite care. When they received respite care, they were able to sleep and to do other things as well. Moreover, the siblings also benefitted from increased attention from their parents (Welsh *et al.* 2014). They also spoke about their mental health challenges, including worry and feeling depressed about the future for their child with complex health needs. The situation also impacted the marital relationship. These results support earlier findings whereby the parents of children with cerebral palsy had low levels of QOL and mental health and greater depressed mood than the general population (Guillamon *et al.* 2013). Khanna *et al.* (2011) found that lack of social support and burden were significant predictors of caregivers' mental health-related quality of life (HRQOL). Caregivers of children with autism had lower HRQOL scores than the general population. Lack of respite was considered as a threat to these parents' health and QOL. In line with previous research showing a lack of contact with family and social networks (Ryan *et al.* 2009), parents in this study spoke of social isolation and little leisure time and infrequent contact with friends and family.

A qualitative study found that immigrant parents are vulnerable to physical and mental distress and failing health (Fladstad & Berg, 2008). Contributing factors may be limited language skills, lack of knowledge about the health-care system, limited social networks and fewer economic resources (Berg 2014). In line with previous research (Greenwood *et al.* 2014), some of the immigrant parents in our study lacked knowledge about how to obtain help, who could help them and what their rights were in caring for their child. They wanted more help from the municipal authorities, and spoke of a lack of information about the welfare system, and their rights as parents of children with complex health needs. They also

described that their applications were declined, similar to previous reports (Kittelsaa and Tøssebro 2014). Fellin *et al.* (2013) found that immigrant parents lack access to a translator and some parents were declined services and were not aware of the funding available for service or equipment unless someone helped them with paperwork and to navigate the system.

Mothers reported greater health problems and stress compared to the fathers in our study. They had sleep disturbance, pain and some felt depressed. This is in line with previous research showing the same pattern of greater maternal exposure to health problems (Hauge *et al.*, 2013; Nes *et al.*, 2014). Previous research found that caregivers and mothers in particular are more exposed to stress than fathers (Helitzer *et al.*, 2002; Tsai & Wang, 2009). According to the stress model described by Lazarus and Folkman (Folkman 2011) problems arise from an imbalance between environmental demands and available resources. Guillamon *et al.* (2013) found that caregivers of children with complex health needs have lower QOL compared to the general population, and compared to fathers, mothers of children with autism have lower QOL and that there is a positive effect on social support (Guillamon *et al.*, 2013).

This body of work highlights the importance of early identification and intervention. Parents and the disability service system need to know how families of children with complex health needs compare to families of typically developing children (Nes *et al.* 2014). One difference may be that mothers who are at home all day with an ill child may become exhausted and fathers must work even more to ameliorate the family economic situation. Some mothers reported that they miss working, but that it was too difficult to find a part-time job because of their child. Despite this, they expressed wanting more contact with others and a desire to use their resources.

Consistent with previous research (Greenwood *et al.*, 2014), some of our participants had significant language barriers. For some it was difficult to understand information and they reported problems expressing their feeling in a foreign language. A previous study found that



parents of children with complex needs felt isolated and had to rely on their own strengths. They also reported that having a care co-ordinator was a fundamental need (Carter et al., 2005). Many among our samples lacked both co-ordinator and individual plan, which likely increased their own stress and health problems and possibly worsened the situation for the entire family.

### **Limitations**

Our sample was mostly mothers because they were easier to recruit than fathers.

Generalization is not the aim of qualitative research; however, these findings may provide insight into similar situations. The use of interpreters may introduce some limitations if the interpreter does not correctly interpret what the parents want to explain. These analyses and interpretations were guided by both a theoretical approach and our pre-understanding as research nurses, a sociologist and a social anthropologist. Malterud (2001) claimed that the theoretical framework can be equated with the reading glasses worn by the researcher when he or she asks questions about the data. Our previous understanding and interdisciplinary background also led us to create a safe atmosphere when meeting with the participants and helped us to ask relevant questions.

### **CONCLUSION**

The parents in our study reported challenges from their caregiver experiences that may influence their own health and QOL. Mothers were the primary caregivers among our families and reported greater health problems compared to fathers. A lack of respite care, social network and support impacted their health and QOL, especially when their child had severe health problems. Many of these immigrant parents struggle to access resources. Having a child with complex health-care needs has great impact for immigrant parent's health and QOL. The parents need interventions and preventive care to reduce the level of strain and

increase the level of support, and to access resources such as respite care from municipalities and policy makers.

## **RELEVANCE TO CLINICAL PRACTICE**

Nurses, physicians and social workers can play a valuable role in supporting parents of children with complex health needs. It is important that immigrant parents be informed of their rights and that they receive assistance from an assigned co-ordinator of an interdisciplinary care team. Health-care professionals should also pay attention to the mother's health status and reduce her stress when possible (Tsai et al 2008). Health-care professionals should support the caregivers and in particular the mothers with their burden, and make sure that the mothers receive relief from continuous caring. Ensuring equal access for minority families of children with complex health need to public health-care services involves applying culturally sensitive communication and providing flexible and tailored health-care services (Söderström 2014).

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## **Author contributions**

Study design: LGK, EF, HL and IB. Data collection and analysis: LGK, EF, HL, LH and RG.

Manuscript preparation: LGK, EF, HL, IB and LH.

## **Disclosure**

All authors meet the ICMJE criteria for authorship credit

([www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html)): 1) substantial contribution to conception and design of, or acquisition of data or analysis and interpretation of data, 2) drafting the article or critically revising it for important intellectual content and 3) final approval of the version to be published.

## References

- Berg, B. (2014). Double vulnerable - Minority families of children with disabilities. In: Tøssebro, J. & Wendelborg, C. (ed.) *Growing up with disabilities. Family life and transitions*. Oslo: Gyldendal Akademisk. (In Norwegian).
- Carter, B., Cummings, J., & Cooper, L. (2007). An exploration of best practice in multi-agency working and the experiences of families of children with complex health needs. What works well and what needs to be done to improve practice for the future? *Journal of Clinical Nursing*, **16**, 527-539.
- Croot, E., Grant, G., Mathers, N. & Cooper, C. (2012). Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child. *Disability & Rehabilitation*. **34**, 18.
- Fellin, M.M., King G., Esses V., Lindsay S. Klassen A., (2013). Barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability. *International Journal of Migration Health and Social care*, **9**, 135-145.
- Fladstad, T. & Berg, B. (2008). *Give me a chance! Minority families with disabilities children in Bydel Bjerke*. Trondheim: NTNU Social Science Research Ltd., Department of research on immigration and refugee studies (In Norwegian).
- Folkman, S. (2011). *The Oxford Handbook of Stress, Health, and Coping*. Oxford Library of Psychology. USA.
- Friberg, J. H. & Eldring, L. (2011). *Polonia in Oslo 2010. Mobility, work and livelihood mix Poles in the metropolitan area*, Oslo: Fafo-rapport 2011. (In Norwegian).
- Greenwood, N, Habibi R, Smith R. Manthorpe J, (2014). Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature. *Health and Social Care in the*

*Community*, **23**, 64-78.

- Guillamon, N., Nieto, R., Pousada, M., Redolar, D., Munoz, E., Hernandez, E., Gomez-Zuniga, B. (2013). Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. *Journal of Clinical Nursing*, **22**, 1579-1590.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, **107**, 116-127.
- Hauge, L. J., Kornstad, T., Nes, R. B., Kristensen, P., Irgens, L. M., Eskedal, L. T., Vollrath, M. E. (2013). The impact of a child's special health care needs on maternal work participation during early motherhood. *Paediatric and Perinatal Epidemiology*, **27**, 353-360.
- Helitzer, D. L., Cunningham-Sabo, L. D., VanLeit, B., & Crowe, T. K. (2002). Perceived changes in self-image and coping strategies of mothers of children with disabilities. *Occupational Therapy Journal of Research*, **22**, 25-33.
- Horlsey, S., & Oliver., C. (2013). Positive impact and its relationship to well-being in parents of children with intellectual disability: A literature review. *International Journal of Developmental Disabilities*. University of Birmingham.
- Khanna, R., Madhavan, S., Smith, M.J., Patrick, J.H., Tworek, C., Becker-Cottrill, B. (2011). Assessment of Health-Related Quality of Life among Primary Caregivers of Children with Autism Spectrum Disorders *Journal of Autism Development Disorder* **41**, 1214–1227.
- Kittelsaa, A. & Tøssebro, J., (2014) Parents experience with help support services. In: Tøssebro, J. & Wendelborg, C. (ed.). *Growing up with disabilities. Family life and transitions*. Oslo: Gyldendal Akademisk. (In Norwegian)
- Kvale, S. & Brinkmann, S. (2009). *Interviews. Learning the craft of qualitative research*

*interviewing*. Los Angeles: SAGE, 2nd ed.

- Lawoko, S., & Soares, J. J. (2003). Quality of life among parents of children with congenital heart disease, parents of children with other diseases and parents of healthy children. *Quality of Life Research*, **12**, 655-66.
- Malterud K.(2001) Qualitative research: standards, challenges, and guidelines. *Lancet*; **358**: 483–8.
- Nadim, M. (2014). Reinterpreting the relation between motherhood and paid work: Second-generation immigrant women in Norway. *The Sociological Review*, **62**, 494-511.
- Nes, R. B., Roysamb, E., Hauge, L. J., Kornstad, T., Landolt, M. A., Irgens, L. M., Vollrath, M. E. (2014). Adaptation to the birth of a child with a congenital anomaly: a prospective longitudinal study of maternal well-being and psychological distress. *Developmental Psychology*, **50**, 1827-1839.
- Olsson, M. B., & Hwang, C. P. (2006). Well-being, involvement in paid work and division of child-care in parents of children with intellectual disabilities in Sweden. *Journal of Intellectual Disability Research*, **59**, 963-969.
- Poley, M. J., Brouwer, W. B., van Exel, N. J., & Tibboel, D. (2012). Assessing health-related quality-of-life changes in informal caregivers: an evaluation in parents of children with major congenital anomalies. *Quality of Life Research*, **21**, 849-861.
- Ryan, L., Sales, R., Tilki, M. & Siara. B. (2009).Family Strategies and Transnational Migration: Recent Polish Migrants in London, *Journal of Ethnic and Migration Studies*, **35**, 61-77
- Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation*, **111**, 155–169.

- Skreden M. (2011). *Psychological distress in mothers and fathers – Long-term follow-up after birth of healthy children and children with malformations*. Ph.D. thesis, University of Oslo.
- Solberg, Ø., Dale, Grønning M.T., Holmstrøm, H., Eskedal, L., T., Landolt, M. A & Vollrath, M. E. (2011). Long-term symptoms of depression and anxiety in mothers of infants with congenital heart defects. *Journal of Pediatric Psychology*. **36**, 179- 187.
- Söderström S (2014). Lost in translation? Communication challenges in minority families' and healthcare workers' interactions. *Disability & Society*, 2014 **29**, 807–820.
- Sørheim, T.A. (2011). *Gender perspective in caring for disabled families with ethnic minority backgrounds*. I: Grimen, H. & Ingstad B. (ed.). *Cultural perspectives on health and disease*. Oslo: Universitetsforlaget. (In Norwegian).
- Tsai, S. M., & Wang, H. H. (2009). The relationship between caregiver's strain and social support among mothers with intellectually children with intellectually disabled children. *Journal of Clinical Nursing*, **18**, 539-548.
- Tung, L.-C., Huang, C.-Y., Tseng, M.-H., Yen, H.-C., Tsai, Y.-P., Lin, Y.-C., & Chen, K.-L. (2014). Correlates of health-related quality of life and the perception of its importance in caregivers of children with Autism. *Research in Autism Spectrum Disorders*, **8**, 1235-1242.
- Tøssebro, J., Paulsen, V. & Wendelborg, C. (2014) A normal family? - About relationships, family structure and strains. In: Tøssebro, J. & Wendelborg, C. (ed.). *Growing up with disabilities. Family life and transitions*. Oslo: Gyldendal Akademisk. (In Norwegian).
- The WHOQOL Group, 1995. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. *Social Science and Medicine* **10**, 1403-1409.

- Welsh, R. Dyer, S. Evans D, Fereday J. (2014) Identifying benefits and barriers to respite for carers of children with complex health needs: A qualitative study. *Contemporary Nurse* **48**, 98–108.
- Wendelborg, C. & Tøssebro, J. (2010). *Health status of parents of children with impaired disabilities. A comparing of data from HUNT 2 og Forløpsdatabasen FD-Trygd*. Rapport, NTNU Samfunnsforskning AS. (In Norwegian).
- Wilkinson D. (2004) *Focus Group Research. In Qualitative Research Theory, Method and Practice*. SAGE Publications, London.



**Table 1 Characteristics of parents**

	Pakistan	Poland	Vietnam
Families	10	6	5
Female	8	6	4
Male	5	3	1
Parent age			
20–30 years	2	2	0
30–40 years	6	3	2
40–50 years	3	3	2
50–60 years	1	0	1
Marital status			
Married	9	8	2
Single	4	1	2
First generation	9	9	5
Second generation	4	0	0

**Table 2 Characteristics of children**

	Pakistan	Poland	Vietnam
Girls	2	3	1
Boys	9	3	5
Children's age			
0–5 years	3	2	0
5–10 years	4	0	2
10–17 years	4	4	4
*Health conditions			
1. Heart problems	2	2	4
2. Physical disability	0	3	0
3. Developmentally delayed	0	3	1
4. Complex health problems	9	1	2

*\*Health conditions: Children are presented in the following categories based on parental descriptions; some children may belong in two categories:*

1. Children who have heart problems such as heart failure and/or have had heart surgery, some of whom may be still unstable. These children may have physical limitations in relation to physical performance, but their cognitive functioning is normal.
2. Physical disability associated with neurological problems, such as children with cerebral palsy. These children may require a high degree of parental assistance, but cognitive functioning may be normal.
3. Developmentally children with complex health needs with cognitive dysfunction, but who manage some activities independently.
4. Complex neurological problems such as children with autism, progressive illness, serious behavioural problems, significant psychosomatic problems that require continuous care/supervision for which parents cannot leave the child unsupervised.