

From Feeling Broken to Looking Beyond Broken: Palestinian Mothers' Experiences of Having a Child With Spina Bifida

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Abstract

Spina bifida (SB) is the second most common birth defect worldwide. Mothers of children with SB face extraordinary challenges due to the complicated conditions and disability of their children. Little is known about the impact of these challenges on the mothers' well-being, particularly in Middle Eastern culture, where chronic illness and disability are perceived as a stigma, and care of disabled children has traditionally been the responsibility of the mother. The aim of this study was to illuminate mothers' lived experience of having a child with SB in Palestine. Twenty Arab-Muslim mothers living in Palestine were purposefully recruited from several rehabilitation centers in Palestine and were interviewed in 2014. The transcribed interviews were analyzed according to phenomenological hermeneutics. The mothers' experiences were described in the main theme: From feeling broken to

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looking beyond broken. Four themes were interwoven: living with constant anxiety, living with uncertainty, living with a burden, and living with a difficult life situation. These findings highlight the burden and resilience of the Arab-Muslim Palestinian mothers while striving to maintain the well-being of the whole family as well as facilitating the child's welfare.

Keywords

mothers, spina bifida, phenomenological hermeneutics, Arab-Muslim mothers, qualitative, Palestine

Spina bifida (SB) is one of the most common congenital disorders worldwide (Copp et al., 2015) caused by failure of closure of the neural tube around the fourth week of gestation (Jenkinson et al., 2011). The incidence of SB with anencephaly varies worldwide, but it is assumed to be an average of one of 1,000 births (Copp et al., 2015). SB may occur at any level of the spine with various forms of severity (Copp et al., 2015).

Impact of SB on Families

Families of children with SB are often confronted with a series of stressors related to the disorder (Holmbeck & Devine, 2010). Research has emphasized divergent forms of burden and other predictors of these outcomes including marital quality, economic burden, and psychosocial maladjustment related to high levels of stress (Bannink, van Hove, & Irdro, 2016; Dodgson et al., 2000; Grosse, Flores, Ouyang, Robbins, & Tilford, 2009; Limiñana Gras, Corbalán Berná, & Sánchez López, 2009). Furthermore, it has been found that the burden of care falls particularly on the mother (Brekke, Früh, Kvarme, & Holmstrøm, 2017), and mothers report an increase in depression and anxiety (Civilibal, Suman, Elevli, & Duru, 2014).

Diagnosis of SB is generally made early in pregnancy through Alpha-fetoprotein (AFP) screening and fetal ultrasonography, which provides time for decision making and planning by families (Burke & Liptak, 2011). Children born with SB often live with neurological deficits and may suffer from altered motor and sensory functions, such as hydrocephaly, paralysis of the legs, bladder and bowel incontinence, and learning difficulties (Trudell & Odibo, 2014). The increasing survival of children with SB provides a global challenge to health care systems and family caregivers to meet their physical and psychosocial needs through childhood and adolescence (Sawyer & Macnee, 2010).

Diminished folate status is the best known factor influencing the risk of having a child with SB (Copp et al., 2015). Despite the focus of prevention programs on food fortification with folic acid and maternal supplements, these efforts at prevention have not seemed to slow the incidence of SB. Only an estimated 25% of preventable SB cases are addressed by current global fortification programs, meaning that a great deal of work still needs to be done to achieve global and total prevention (Youngblood et al., 2013). These data strongly suggest the importance of other determinants of SB that vary by geographic region including genetic and nongenetic factors such as consanguineous marriage, nutritional and environmental factors, gestational diabetes, lifestyle, obesity, and maternal age (Copp et al., 2015; Correa, 2008; Murshid, 2000; Wilcken et al., 2003). The genetic component has been estimated at 60% to 70% (Copp et al., 2015), which may have impact on cultures with consanguineous marriage.

Incidence of SB in Palestine

The context of this study was Palestine. The only data on incidence of SB in Palestine are from about 20 years ago, with an estimated incidence of 22.3/10,000 fetuses (Dudin, 1997). To prevent neural tube defects in Palestine, a mandatory program of flour fortification with folic acid was initiated in 1997 (Zimmerman, 2011). In 2010, United Nations Relief and Works Agency (UNRWA) introduced the program of daily folic acid supplement 1 month before pregnancy and during the first trimester (van den Berg et al., 2015). The impact of these programs has not yet been studied.

Beliefs of Palestinian Families About Chronic Illness and Disability

In the Arabic-Muslim culture, it is believed that sickness and suffering is a test of faith and not a punishment. This means that the Arab-Muslim family should have patience and endure the suffering as a sign of strong faith (Arabiat, Al Jabery, Abdelkader, & Mahadeen, 2013).

The social embarrassment of having a disabled child seems to have an important influence on how the family deals with the child. Chronic illness and disability are perceived as a stigma in traditional Arab-Muslim families, and seeking outside help from government services is considered unacceptable. Parents resort to hiding the disabled child from society to escape the associated humiliation and disgrace (Al-Aoufi, Al-Zyoud, & Shahminan, 2012; Hasnain, Shaikh, & Shanawani, 2008). Although the Qur'an and Sunnah

urges Muslims to treat disabled people equally, regardless of sex or disability, Muslim societies have made few efforts to improve the situation for disabled children on a national level. Thus, in most of the Arab-Muslim countries, as well as in Palestine, children with disabilities continue to be discriminated from receiving educational, vocational, social, and cultural opportunities (Crabtree, 2007; Hasnain et al., 2008).

The basic element of the society in the Middle East is the family. The hierarchical distinctions of Arab and Muslim families have some particular noteworthy features, in that the roles of men and women are complementary but polarized. Highest authority rests with the fathers, consigned by their role as breadwinner or provider. The mother is subordinate to him and is assigned the role of the housewife (Arabiati et al., 2013; Hasnain et al., 2008).

These clearly defined and accepted gender norms and roles particularly affect child rearing, and the responsibilities for caring for children with disabilities have traditionally fallen on the mother. Generally, mothers of disabled children have been held in low esteem and marginalized, and the challenges of caring for children with disability have scarcely been addressed (Ryan & Runswick-Cole, 2008).

Purpose of the Study

Most SB studies have been conducted in Western communities. To our knowledge, there are none from the Arab world and only a few from developing countries (Ong, Norshireen, & Chandran, 2011). It is important to note that results from a study performed in one context do not necessarily apply to families across different ethnicities and cultural backgrounds. No studies conducted in Palestine have been found, despite the reported high incidence rate of SB. This fact may be of special interest, as families in Palestine live under occupation and face continuous threats, which affect their life in all aspects: politics, social, economic, and health. The present study focuses on mothers' experiences of having a child with SB in Palestine. The aim of this study is to illuminate Arab-Muslim Palestinian mothers' lived experience of having a child with SB.

Method

Design

Phenomenological hermeneutics inspired by Ricoeur's (1976) interpretation theory and described by Lindseth and Norberg (2004) was chosen for this study. This is a qualitative approach developed to explore the phenomenon of

lived experience. Narrative interviews were used to gain knowledge about the mothers' personal experiences. The text of the interviews was then analyzed, interpreted, and described.

Setting

Palestine consists of two administratively segregated areas, the West Bank and the Gaza strip, with a population of approximately 2.58 million and 1.59 million, respectively (Palestinian Central Bureau of Statistics, 2012). Forty percent are women of reproductive age and children below the age of 15 years (Rahim et al., 2009). In Palestine, the family creates the dominant social institution, the social structure, and as in other Arabic societies, is influenced by the traditional cultural values and religious beliefs inherited by the family (Abudabbeh, 2005). Islam is the dominant religion (94%), 6% are Christian and there is a Jewish minority (Giacaman et al., 2009). The Israel–Palestine conflict that has been ongoing for more than 50 years has affected the health system and undermined an already fragile system of social and public health services (Mataria et al., 2009). The present study was conducted in the Palestinian West Bank and East Jerusalem.

Participants

Twenty mothers of children with SB were recruited purposefully with the aim to ensure a sample including mothers with different ages, education levels, and places of residence (different districts in the West Bank). Mothers were also selected to cover a wide range of SB forms and severity. Participants were contacted through the nurses in charge working in rehabilitation centers providing services for children with disability and special health care needs. The selected rehabilitation centers are considered the largest in Palestine in the various areas. Following their agreement to participate in the study, the mothers were interviewed by the first author (M.N.) at their convenience in their own homes.

Ethical Considerations

The study was performed within the parameters of the World Medical Association (2013) Declaration of Helsinki. The research body responsible for the study was the University of Gothenburg. Local approval and permission to conduct the study were obtained from the Research Ethical Review Committee at Al-Quds University, Palestine. Permission to carry out the study was gained from the Palestinian health authority. The mothers were

Table 1. Interview Guide.

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- Can you tell me about your experience: How it is to be a mother to a child with SB?
 - Can you describe your experience and your feelings the first time when you understood that you would have a baby with SB?
 - Can you describe your experience and expectations about your baby before delivery?
 - Tell me about your experience when your child was born with SB at the delivery time and after delivery.
 - Can you tell me about the reactions of people around you when they heard about it and when they saw the baby?
 - How does this, to have a child with SB, affect your family life?
 - How do you feel now with the number of years passed—what are your hopes?
 - Can you tell me about your experience with the child's treatment? How did it go? How do you feel about it?
 - Please tell me about your feelings after the number of the years passed with the child. How you experience the life and the future life?
-

Note. SB = spina bifida.

informed that participation was voluntary and all information would be treated confidentially. Their right to withdraw from the study at any time was emphasized, and they all signed consent and agreed to the audio recording of the interviews.

Data Collection

The interviews were conducted between March and September 2014. Data were collected through narrative interviews by (M.N.) at the mothers' homes. Interviews were audio recorded and lasted for 45 to 80 min ($M = 60$ min).

To promote narrative, the mothers were encouraged to speak freely about their experiences of having a child with SB and were asked broad open-ended questions. The opening question was, "Tell me about your experience of having a child with Spina bifida." Additional follow-up questions such as, "Can you tell me more about . . ." and "How did you feel when . . ." were posed to clarify statements and to confirm the interviewer's correct understanding. The interview guide is presented in Table 1.

The first author (M.N.), who is herself a Palestinian pediatric nurse, conducted all interviews in colloquial Arabic before transcribing them verbatim and matching the transcripts with the notes and memos she had taken during data collection. Subsequently, the text was translated and transcribed into English by the first author (M.N.) before being revised, discussed, and

Table 2. Examples of How the Subthemes and Themes Were Constructed From the Meaning Units in the Structural Analysis.

Meaning units	Subthemes	Theme
I prefer to stay home, because people outside will blame me. I don't even send him to school I'm afraid that the other children will never understand his conditions.	Experiencing social isolation	Living in a difficult situation
My family supported me, they accepted the child, and helped me through the critical situations.	Being in need of ongoing family and health care support	
This is from God. It is our destiny. God will reward us for having and caring for this child.	Finding spiritual consolation	

validated by the two local authors (M.N., A.I.) to be clearly understood by the two Swedish authors (A.A., H.W.). Double checking these transcripts was necessary to allow the coauthors to garner rich information on the topic.

Data Analysis

In the analysis, a phenomenological hermeneutic approach described by Lindseth and Norberg (2004) was used. Interpretation of the text constitutes a movement from understanding to explanation and integrates three phases: naïve reading, structural analysis, and comprehensive understanding.

Naïve understanding started by reading the entire text several times to obtain an immediate sense and broad picture of its contents. For transparency, the authors' preunderstanding was discussed openly before the structural analysis. In the structural analysis, each section was read carefully. Then, meaning units relevant to the aim were identified, abstracted, and critically reviewed in relation to the naïve understanding. Meanwhile, categories, patterns, and relations between meaning units emerged to form subthemes and to formulate the themes. Interpretation was carried out by the first author but discussed and validated by the coauthors. An example of theme, subthemes, and meaning unit is presented in Table 2.

In the final phase, the whole text was reread, and both the parts and the whole were discussed in a dialectic movement between understanding and explanation. The authors' preunderstanding, naïve reading, and structural

analysis were critically evaluated until the authors reached agreement about all the themes. The themes were then compared with the naïve understanding to formulate a critical in-depth interpretation, and to gain a comprehensive understanding of the phenomenon.

Findings

Description of the Participants

Demographic characteristics of the mothers who participated in this study and their child with SB are presented in Table 3.

Naïve Understanding

The naïve reading and understanding steps are important in phenomenological hermeneutic studies to gain an overall impression of the phenomena, which was obtained through careful reading of the whole text. Having a child with SB was understood as a hardship event that burdens the mother's life. Moreover, raising children with SB represents a journey into uncharted seas. When a mother faced the reality of having a child with disability and paralysis, she experienced a state of uncertainty and was overwhelmed with sadness, worries, and guilt. She would struggle to promote the child's health, despite the social and environmental pressures accompanied by limited knowledge about the child's conditions.

As a result, there appeared to be a long-lasting effect on the mother's psychosocial and physical health, which continued to burden many aspects of her life. However, many mothers found that a truthful faith in God and family support were the only consolation that helped endure the burden and live with hope for the future.

Structural Analysis

The structural analysis and interpretation was dominated by the main theme: "From feeling broken to looking beyond broken." Four interwoven themes were formulated in condensed descriptions to assemble the subthemes and to convey the meaning of the mothers' experiences: living with constant anxiety, living with uncertainty, living with a burden, and living with a difficult life situation (see Table 4). In the following text, the letter M and number after each quote refers to the mother interviewed.

Living with constant anxiety. Emotional impacts of having a child with SB were pervasive and emerged most frequently in this study. The experience of

Table 3. Demographics of the Mothers and Their Children With SB.

Characteristics	<i>n</i> (unless otherwise stated)
Mothers	20
Age at time of interview (years)	
Mean (min-max)	41.8 (29-62)
Religion	
Muslim	20
Christian	0
Place of residency	
Urban	5
Rural	7
Camp	8
Education	
University	7
School	7
Illiterate	6
Employed (mothers)	2
Consanguineous marriage	8
Children with SB	20
Age of children with SB (years)	
Mean (min-max)	11.1 (2-17)
Sex of children with SB	
Male	13
Female	7
Level of child disability	
Severe and paralyzed	11
Mild to moderate (can walk)	9
Intellectual problems	
Mild to moderate	5
Severe	0
Hydrocephaly with ventriculoperitoneal shunting	9
Number of children in the family	
Mean (min-max)	5.15 (3-10)
Age of children in the family (years)	
Mean (min-max)	15.56 (1-30)

Note. SB = spina bifida.

constant anxiety means that mothers experienced fear and worries and had a sense of blame and guilt about giving birth to a child with SB.

Feeling fears and worries. The mothers identified the period of diagnosis as their most fearful life event. It caused powerful reactions of crying,

Table 4. Overview of the Main Theme, Themes, and Subthemes in the Study of Palestinian Mothers' Lived Experience of Having a Child With SB.

From feeling broken to looking beyond broken			
Living with constant anxiety	Living with uncertainty	Living with a burden	Living with a difficult life situation
Feeling fears and worries	Uncertainty about the child's health	Constantly meeting challenges	Experiencing social isolation
Feeling blamed and guilty	Uncertainty about the child's future	Going it alone with the caregiver burden	Being in need of ongoing family and health care support Finding spiritual consolation

Note. SB = spina bifida.

screaming, loss of control, and shock. Giving birth to a child with SB destroyed the mothers' dream of having the ideal infant, launching them into a world of doubts and insecurity.

I felt lost; it was the most difficult time of my life . . . I went into shock. (M 1)

It is feelings of *marar* (bitterness) . . . (crying). (M 11)

Some mothers felt that health care providers were too direct and unempathetic when delivering the bad news, which provoked horrible fears, and intensified the mothers' worries.

During the ultrasound . . . the physician said: your child has a problem with her back, she will live with paralyses. He told me this, disregarding my feelings or my needs. I was pregnant in the eighth month, I could not handle being alone with the awful news. I was disappointed and destroyed . . . he Qatta Qalby (broke my heart) . . . (crying). (M 9)

Feeling blamed and guilty. Being blamed by relatives for giving birth to the abnormal child imposed feelings of guilt and abandonment. This caused the mother to isolate herself, to focus on caring for the child, and to avoid contact with family members. But eventually, when people realized and appreciated the mothers' struggle to care for the disabled baby, the mothers were shown sympathy by their family, friends, and neighbors, and given their help when needed.

(Initially) they (relatives) blamed me; they looked at me as if I had committed a crime . . . few days later my family offered their help . . . this supported me .

. . . I didn't hide him . . . I take him with me outside . . . I raised him as if he was a normal child, and his brothers helped me a lot. (M 5)

Mothers also experienced self-blame. They believed it was their fault that their children were born with a disability. They wondered if this was caused by inadequate intake of folic acid, not attending antenatal visits, or hereditary factors. Feelings of guilt and regret were also expressed by the mothers for previously wishing their child dead instead of being subjected to a life of pain and misery. The mother saw herself as bad for having these wishes.

I gave her a weak life, full of troubles. Once, she had some crises . . . , I thought a lot, who knows, if she dies, may be all our problems will be resolved *Samehni ya Allah* (God forgive me) . . . I felt guilty, but I loved her, I cared for her, I hope God will cure my child. (M 15)

The mothers' engagement in satisfying the needs of the disabled child, along with her usual daily responsibilities, resulted in a sense of guilt toward the other siblings and their own personal needs. Getting support from the family members and relatives helped the mothers to overcome feelings of guilt and to continue their lives with hope and resilience.

While it is hard, but it is my child, and it is my duty to keep him clean, healthy and happy . . . , I couldn't manage to do this alone. My mother lived near me, she helped me raise the other two children; I seldom had time to see to their needs. (M 12)

Living with uncertainty. The mothers lived with uncertainty regarding the child's health and future life. They described extreme concerns about the child's welfare. Their limited knowledge about SB kept them in a state of chaotic and gloomy thoughts.

Uncertainty about the child's health. Uncertainty about the diagnosis of the unborn child dominated the mothers' thoughts. They repeated the ultrasound several times to confirm the diagnosis, but received differing opinions. Each time, the results brought more worries and doubts about the child's health.

Physicians told me about the SB and large head . . . I was eight months pregnant . . . and I did not believe them . . . I heard various terrible comments about the repeated ultrasounds . . . he has no brain, he will die soon, and I was shocked. (M 17)

Some mothers received medical advice about terminating their pregnancies, but they did not accept this, and chose not to terminate the pregnancy

and to give birth to the baby. This was accompanied by faith and trust in God to give them a healthy baby. They preserved their religious beliefs concerning ending the life of a baby, which is forbidden (*Haram*) in Islam.

I couldn't kill my baby, it is not allowed in our religion. I would never forgive myself if I did it. Faith in *Allah* (God) helped me through; . . . we are in the hands of *Allah*, he is *Al-Shafi* (the healer). *Allah* can cure my child. (M 20)

Following the child's birth, the mothers received contradictory advice regarding the surgical treatments. It was difficult for them to understand the situation surrounding the immediate closure of SB and the shunt replacement.

They (the professionals) refused to perform the operation, and asked me to bring him back after two months, if he was still alive . . . without any explanations. (M 7)

Uncertainty about the child's future. The child's complicated conditions brought constant uncertainty about the future. Although they were told by physicians that their children would never walk, the mothers still wavered between hope and despair. They insisted on the need for curative surgeries or other devices to ease their child's future life and decrease suffering.

I am worried about his future . . . I will never stop seeking help to improve his health and help him manage his life easily. (M 10)

Mothers felt responsible for making their children feel accepted in the community. They were worried about how their children would feel when they got older and became aware of society's attitudes to them.

He is only seven years old . . . and the family is supportive . . . we all understand that he should not feel different from the other children in the house or in the surroundings and among relatives. But I'm worried about how he'll feel when he gets older. (M 17)

To control the child's bladder and bowel is a daily problem for the mothers to deal with. To increase the child's independence and avoid embarrassment, they wanted the child to do these measures by self.

They told me that he would learn to do it by himself. This is not true, he is 13 years old, and I still give him enemas and insert the catheter for him and this exhausts me. I need other measures to help solve my child's incontinence. (M 20)

The mothers articulated uncertainty about their children's welfare once they themselves were gone. The mothers did not expect healthy siblings or relatives to care for the affected child in the same way she did.

His father died five years ago. I'm worried about him if I die. I do not expect his sister or brother to care as I do. Who will be there for him to help with bathing, changing diapers, or anything else? (M 7)

Living with a burden. Mothers experienced numerous challenges and tried hard to endure the burden and preserve family cohesiveness. They felt alone with the overwhelming care demands of their child, even if they acknowledged the role of the extended family in providing support.

Constantly meeting challenges. Caring for the sick child was a natural extension of the mothering role. They learnt to deal with unexpected and considerable challenges. The advice, encouragement, and help given by the family maintained the mothers hope for a good life.

I have accepted it because I have already been given, I felt fatigued from suffering . . . , it is a big task, more than one ever expects. My mother in-law was angry for this to happen. However, she does love the child, and she supported my acceptance. She always asks me to be patient, and help me in the difficult situations. (M 6)

The economic burden was another important challenge. Burdensome responsibilities were considered essential to ease the child's life, for example, this sometimes necessitated moving the family to a ground floor, renovating the home, or changing residential area.

We cannot offer him everything. My parents helped me a lot. They brought him the electric wheelchair so he can move about without any problem. My parents-in-law gave us this ground floor apartment just for him. (M 5)

The mothers worked hard to make life as normal as possible for their child and family despite ever-present social and environmental barriers, such as access to suitable services, schooling, and transportation.

I want him to feel normal like his brothers. I treat them all the same and I want him to be independent . . . I sent him to school despite the difficulties. (M 20)

Going it alone with the caregiver burden. The mothers felt alone in satisfying the child's daily care demands, such as hygiene and schooling. The mothers

accepted that the father's main role was to meet the economic needs of the family, but they expected him to be there at some points, namely, when physical and psychosocial difficulties arose.

Caring for the disabled child was my responsibility and number one priority in my life. The help I got from the relatives and siblings was for other household needs. However, the father helps me in critical situations with my child. (M 9)

Having to live with heavy responsibilities increased the mothers' physical burden. They hardly allocated enough time for sleep and rest, and complained about headaches, back pain, and hypertension.

I lived with suffering all my life just to maintain the well-being of my child; I gave him the best care ever expected. (M 5)

Living with a difficult life situation. Having a lot of responsibilities and social pressures yielded a difficult life situation for the mothers, and they struggled to satisfy the social demands. In this difficult life situation, they often experienced social isolation and a need for emotional support. However, the received support from the family, together with the consolation found in spiritual and religious beliefs gave them the strength to make positive changes.

Experiencing social isolation. Social family life was found to be disrupted by the presence of the child with SB. The mothers suffered from people's reaction and curiosity, which made them avoid contact with the community. They preferred to stay home with the child to protect them both.

Our society is difficult . . . I prefer to stay home than to go out and see people. I do not want to hear their accusations. (M 19)

I hide her . . . I want to feel normal . . . no one realized it when she was a baby . . . I didn't tell them . . . but as she grew up . . . I couldn't keep it a secret any longer . . . I sent her to school. (M 8)

The mothers described environmental barriers that constrained the free movement of the disabled child, which further induced them to stay home. However, some mothers confronted these challenges and tried to keep in contact with their surroundings.

I don't like to go outside because I have to hold him and this is not easy . . . I cut down all our social contacts . . . but we recognized his needs . . . We visited

other countries to help him enjoy his life . . . I want him to drive a special car in the future. (M 14)

Being in need of ongoing family and health care support. The health care providers seldom recognize the mother's needs for emotional support at the time of diagnosis and crisis. These unexpected reactions of the health care providers made it more difficult for the mothers to understand what was going on.

I returned home, still in shock after the ultrasound . . . crying all the way . . . that nobody has supported me. I couldn't stop thinking my baby, what I should do. I felt that no one care and no one will help. (M 4)

A tiny seed of hope and acceptance was given to the mother when they sensed the husbands understanding of their fears and terrible thoughts.

My husband was supportive. He understood my innermost feelings, and he tried to console me. He knew that it is not my fault and this is from God . . . I will never forget his words when he said this is our son and we love him whatever he is. (M 20)

When the child turned out to be a survivor, the need for support increased, especially as the child got older. When help and support from health care professionals was received, it was highly valued by the mothers, positively affected their outlook, and increased their hope.

The physiotherapist helped me a lot. I will not lose hope, I want to see my child walking and playing in the future. (M 9)

The mothers viewed the compassion and emotional support they received from their families as essential in helping them to cope with mothering a chronically ill child. Receiving support from their husbands, family members, and neighbors majorly contributed to the mothers continuing their lives with resilience and hope.

After the birth, my husband supported me; he saw the baby, and explained to me everything about its conditions. My mother-in-law relieved my fears by her supporting words. (M 2)

Finding spiritual consolation. The mothers' faith in God and their religious beliefs supported them and provided strength and confidence. Being in communion with God helped them withstand the extreme changes to their family

life. In general, the mothers perceived the phenomenon of giving birth to a child with SB as special attention from God—an individual blessing—and that the cure would only come from God. They found consolation in the faith that their suffering would be rewarded in the end.

Faith in *Allah* helped me through, it is Allah's gift . . . This is our destiny; we pray that God will reward us. (M 1)

The mothers frequently mentioned the words *Al-Hamdu lillāh* (thank God). They had faith that God takes care of humans and that disease is mercy from God to expiate sins rather than a punishment. They also believed that being content with what they had in this life would provide a special source of support for them.

Comprehensive Understanding

Mothers of children with SB experienced a life world suddenly filled with struggles, worries, and powerlessness. Having a child with SB can be described as a serious and distressing situation, which seems to activate a new role of caring for the mothers. Their rosy dream of having a normal, perfect child was lost, and they faced the reality of caring for a child with complex conditions and paralysis.

These mothers' stories reflect how they met challenges in their life situation with a sense of broken feelings. They strove to promote their child's welfare despite uncertainty and helplessness but were overwhelmed by the unexpected social and environmental pressures with limited formal support, which thus disturbed their psychosocial life and basic capabilities. The mothers further felt the need for recognition and support by health care providers, particularly at times of crisis and stress. Not having these needs met led to feelings of loneliness and abandonment, and the mothers reported receiving less care and empathy than expected.

In this study, the mothers were able to secure their intrinsic resilient capabilities. In deciding to look beyond broken, they shifted from focusing on what they had lost to creating a new family life situation. Spiritual support, as well as encouragement from all members of the family, was seen as sources of this empowerment.

Discussion

The main theme of this study, "From feeling broken to looking beyond broken," describes how the psychosocial well-being of the mothers was

threatened by inner stress and hardiness, and how they tried to cope with this threat. These findings are related to the creation resource theory (Graungaard, Andersen, & Skov, 2011), a theory that enhances current understanding of coping. This theory attempts to explain why people frequently experience positive psychological states even in situations with severe prolonged stress. It explains the coping potentials of parenting disabled children, and how they continually create and maintain their personal resources, through positive cognitive reappraisals of their circumstances. Thus, despite the great emotional turmoil the mothers passed through, they showed the ability to frame the stressful family life situation in a positive way. The main sources behind the mothers' empowerment and coping potentials were found to be intrapersonal capabilities, ongoing family support, and spiritual relations. These resources, together with cognitive reappraisals of their circumstances, enabled the mothers to see the beneficial aspects of their experiences, which further helped them to deal with the constant challenges of caring for both the child and the family.

The text analysis showed that the mothers lived under threat for a long time before taking steps to adapt to adversity. The most prominent hardship situations were experienced at the time of diagnosis and just after the child's birth, and the mothers gave in-depth description of the suffering that threatened their life world. Their expectations of having a healthy newborn had been dashed. They found themselves in uncertainty and constant anxiety from the critical health conditions of the child, the complicated care measures, and the ascendant social obstacles. In a previous study, parents of children with SB reported a high intensity of acute grief that was considered a barrier to understanding the child's diagnosis and care (Hobdell, 2004).

The lack of formal support and the complexities of the ongoing physical care of the child with SB had a true effect upon the mother's well-being. Mothers in this study were dissatisfied with the information they received from health care professionals. They found it to be inappropriate and contradictory, and they suffered from the health care professionals' negligence to acknowledge their needs. Professionals are and should be perceived as the key figures of information and support. Previous research has described different findings related to the importance of formal support. Unexpectedly, Vermaes, Janssens, Bosman, and Gerris (2005) found that dissatisfaction with formal support does not necessarily imply increased risk of psychological maladjustment. In contrast, Zipitis and Paschalides (2003) suggest that health care professional's attitudes toward giving adequate information and support is vital to ensure the mothers' well-being, to alleviate suffering, and enhance their adjustment to the chronic situations of the child with SB.

In the present study, the mothers felt insecure in all aspects of society. They were blamed because of the traditional culture of considering them, in some way, responsible for their child's abnormality. Palestinian society, as in many other Arab-Muslim societies, perceives disability as a stigma with feelings of shame and guilt (Crabtree, 2007; Hasnain et al., 2008), a finding which was supported in this study. These attributes or folk beliefs influenced the subjective well-being of the mothers and increased their fears of losing their reputation by giving birth to disabled children. The role of the father and family members in providing social and emotional support had a crucial effect in reducing these fears. The importance of social support as a moderating factor in reducing stress and improving the mother's well-being has been well documented in the literature (Macias, Clifford, Saylor, & Kreh, 2001; Vermaes et al., 2005).

The mothers in this study tended to accept the child's complex conditions, despite their initial reaction of rejecting the child's disability within the family setting. Bringing family members around to accepting the child was, therefore, an important challenge. As the family is considered the main source of security for the mothers in the Arab-Muslim society, it was necessary to gain the family's acceptance. Values of family cohesiveness were stronger than abandonment for these mothers. Furthermore, a mother's loyalty to her husband, children, and family is a prominent cultural theme in Arab-Muslim society, and being the sole family caregiver and showing bravery in tackling difficult situations may outweigh the needs of the mother herself (Abudabbeh, 2005). These issues were significant factors in restoring the family. Thus, despite family members' first reactions of anger and blame, they were considered an essential source of emotional, social, and economic support to the mothers. This implies that the family as an institution in Arab society could be considered both a burden and a resource for the mother.

Furthermore, the husbands' efforts in fostering the mothers' role of caring, by providing emotional and social support, was a promising finding in this study, which empowered the psychosocial aspects of the mothers. The emotional support helped to reveal the intrapersonal resource, which buffered the mothers' feelings of grief and enabled coping. According to the traditional codes of Arab-Muslim families, both men and women are expected to contribute to supporting the family unit. In a crisis, both are expected to view the good of the family above self-satisfaction (Abudabbeh, 2005). A variety of predictors of mothers' adjustment were identified in the literature and may depend on factors such as the quality of the marital relationship, family climate, and support from informal social networks (Vermaes et al., 2005).

In the midst of adversity, the mothers may have found meaning in life through spiritual consolation. The mothers possessed an awareness and

appreciation of something beyond human faith, belief in God or a “higher power” in control. This appraisal of finding a meaning in life through spirituality afforded the mothers a resource that assisted them in facing the difficulties in their lives. A tendency to be spiritual, to have compassion, and a more united family have been reported in previous studies on parents of children with chronic illness and disability (Donelan et al., 2002; Resch et al., 2010).

The ultimate hope for the mothers in this study was for the child with SB to have an accepted place within the immediate family and community rather than entertaining plans for their child to be launched into a wider society. To realize these hopes, the mothers tackled normalization issues, keeping alive the hope of a meaningful future. This reflects the mothers’ attempts to develop satisfaction with their child and to keep positive adaptation rather than simple denial of the disability. Monsen (1999) found that mothers of children with SB lived with hope. Seeing their children living independently and managing to care for themselves was the biggest issue emphasized by these mothers.

The unmet needs of children with SB were reported as a constant challenge, and the mothers faced social barriers in education and lack of transportation in the presence of economic burden. Education was unattainable, when the majority of schools in Palestine have not yet adapted their environment, curriculum, and teaching methods for children with disabilities. An uncertain developmental prognosis for these children added to the mothers’ concern, although they continued to hope their offspring would go on to marriage and employment in the future.

A review of the research literature revealed that having a child with SB may negatively affect the mothers’ role in the child-rearing domain. Mothers feel less satisfied and less competent than mothers of able-bodied children. They may live in constant worry about persisting in their struggle and not giving up, or they may vacillate between hope and resignation (Monsen, 1999; Ulus et al., 2012; Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008). In our study, women were more likely to feel anchored by their intrinsic resilience, as they focused on promoting their capabilities throughout various challenges in the child-rearing domain.

Overall, this study contributes to the empirical basis of the resource-creation theory of Graungaard et al. (2011) and added new information to the existing body of research on mothers’ challenges to sustain coping resources (i.e., marital, familial, spiritual, and intrapersonal) during periods of prolonged stress. It suggests that Palestinian mothers were able to maintain resilience and process this difficult life situation in response to the threats experienced by having a child with SB.

Strengths and Limitations of the Study

Trustworthiness in qualitative research includes four interrelated criteria: credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). In this study, credibility was supported by the rich data from the 20 in-depth interviews, and by detailed descriptions of the participants and the method used. In addition, the mother's narratives were the original source for interpretation, and this is illustrated by citations exemplifying the sub-themes and themes, which help to clarify the findings. Dependability is closely related to credibility and was strengthened by using the same interview guide for all the participants, including the same opening question and similar follow-up questions.

Confirmability was established through the collaborations and participation of the authors in the interpretive process from the naïve understanding through the structural analyses to comprehensive understanding. The research findings are best understood within pediatric and family nursing in the Palestinian health care context. Still the findings could be transferable to the context of mothers caring for a disabled child, especially in the context of Arabic societies.

One limitation was working with multiple languages in capturing, translating, analyzing, and communicating the research findings. To meet this challenge, the research team discussed the translated ideas and the analyzed text, and double-checking between languages was done in each process to gain understanding and agreement between the researchers.

Implications of the Findings for Practice and Research With Families

The findings of this study indicate that to decrease the burden on the mothers of children with SB, a "family as the unit of care" approach is needed, with particular attention to the needs of the mothers and the children with SB. A "family engaged" approach to care as recommended by the American Academy of Medicine (Frampton et al., 2017) offered by a multidisciplinary health care team would be ideal to promote physical, emotional, and psychosocial development in the context of the family. It is essential that this approach ensure that services are appropriate for the family's culture and traditions and support is provided to sustain the resources within the family unit.

There are additional measures needed that should be considered within the scope of health care for families experiencing SB such as financial support, community services, and environmental development to improve the mobility

of children with a diagnosis of SB. In Arab-Muslim society, information and education is needed to reduce stigmatization of disabled children and their families. Further studies are needed to explore the needs, concerns, and lived experiences of children with SB and their siblings in various cultural contexts as well as evaluate family nursing/family-focused interventions provided to these families.

Conclusion

Mothers' lived experiences of having a child with SB in Palestine can be described as a process of feeling broken to looking beyond broken. This study reveals a lack of counseling and support of the mothers and families at the period of diagnosis, resulting in despair when confronted with their child's disability. The lack of support created constant anxiety and uncertainty about their child's health and future. Arab-Muslim mothers lived with the burden of daily stressors and challenges to caring for their child, and experienced a difficult life situation with isolation and lack of formal support from health care and society and no expectation of future relief. The longing of these mothers was to have their disabled children accepted within the family and the local community.

Sources of comfort to endure the burden and look beyond broken in the experience of caring for children with SB included intrapersonal, familial, and other intimate and spiritual relations. These findings highlight the burden and resilience of Arab-Muslim mothers in striving to maintain their own and their family's well-being in a society where disability is perceived as a stigma and governmental services are lacking. These findings call for more coordinated health care interventions for family-focused care to families who are caring for children with SB.

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