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RESEARCH ARTICLE

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# Palestinian children's narratives about living with spina bifida: Stigma, vulnerability, and social exclusion

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## Abstract

**Background:** Living with spina bifida in Palestine is a critical issue that might influence various aspects of the individual's life. It is a challenge for children, their families, and health care providers because it requires lifelong treatment and follow-up of care provision. However, little focus has been placed on these children's perceptions about their daily life experiences with spina bifida.

**Purpose:** To illuminate the lived experience of children with spina bifida in the West Bank, Palestine.

**Methods:** A qualitative study was conducted using the phenomenological hermeneutical method to interpret the meaning of being a child with spina bifida in Palestine. Ten children with spina bifida, aged 7–18 years, were interviewed. The two local authors independently analyzed the Arabic transcriptions, whereas the two Swedish authors analyzed the transcriptions after translation to English. Finally, the four authors discussed their analysis and reached agreement about the themes.

**Results:** Studying the children's experience with spina bifida helped us highlight their feelings, needs, and challenges. The findings were formulated into one main theme, *Vulnerability and suffering due to social exclusion and stigma*, which was grounded in three themes: *Experiencing negative self-concept*, *Experiencing vulnerability*, and *Obtaining a sense of security*. These three themes were in turn derived from subthemes.

**Conclusion:** The Palestinian children in this study faced physical, emotional, and psychosocial challenges, which negatively influenced their health and development. They were vulnerable and stigmatized, and they lived with a negative self-concept. The findings could help health professionals, families, and caregivers to achieve a deeper understanding of what being a child with disabilities entails, and the findings may also serve as a platform for interventions that seek to promote these children's development and to enable them to experience childhood as a meaningful and positive process.

KEYWORDS

Arab Muslim, children narratives, Palestine, phenomenological hermeneutical, spina bifida, stigma

## 1 | INTRODUCTION

Spina bifida (SB) is the major congenital neural tube defect compatible with long-term survival (Copp et al., 2015). Children born with SB usually require neurosurgery soon after delivery, and they live with complex disabilities, including varying degrees of paralysis, bowel and bladder dysfunction, progressive hydrocephaly, and learning deficits (Ulus et al., 2012).

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Despite worldwide efforts to prevent SB through the introduction of folic acid programs, antenatal screening, and termination of pregnancy, the condition still affects 10–100 per 10,000 live births (Au, Ashley Koch, & Northrup, 2010). The most recent statistics in Palestine indicate that 7% of the population lives with some kind of disability; this is an alarmingly high figure. Children born with SB fall into the congenital and mobility-impaired category that accounts for 10% of all disabilities (Palestinian Central Bureau of Statistics & Ministry of Social Affairs, 2011).

Living with disability in Palestine, as in other developing countries, is a critical issue in that promotion and enforcement of human rights are often lacking. In these countries, the inadequate provision of services for empowering people with disabilities with low socioeconomic status might reinforce the negative social attitudes concerning disability (Lang, Kett, Groce, & Trani, 2011). In the Palestinian culture, a child's disability is connected with embarrassment and shame (Al-Aoufi, Al-Zyoud, & Shahminan, 2012), and many children are hidden from society or exposed to rejection, abuse, and humiliation (Burton, Sayrafi, & Srour, 2013). The stigma of disability can strongly affect the children and their family members in terms of their health, emotions, behavior, and social life (Saca-Hazboun & Glennon, 2011). Normal access to health services, social support, education, and work are often lost both for the children and for their families (Burton et al., 2013).

Further, the complicated sociopolitical situation in Palestine, involving constant stress, violence, poverty, movement restrictions, and constrained health resources, has a far-reaching impact on people's health (Giacaman et al., 2009). These circumstances might compound the effects of stigma and yield additional challenges for Palestinians living with disabilities.

In line with Sayrafi (2013), raising social awareness of disability in Palestine is important. This would facilitate health and social programs to protect the children's rights, and ensure their enjoyment of health, legislation, education, and economic empowerment. Therefore, understanding the lived experience of children with disability is urgently required, because childhood is a critical time for development, and the experiences in early years of life provide the foundation for the individual's development in all stages of life. Although research on the experiences of young people with SB has increased in recent years (Lindsay, Cruickshank, McPherson, & Maxwell, 2016), to the best of our knowledge there are no studies describing children's experiences of living with SB and disability within a conflict setting and conservative social structure, such as Palestine. The aim of this study was to illuminate the lived experience of children with SB in the West Bank, Palestine.

## 2 | METHODS

### 2.1 | Design

The study used a qualitative approach with individual interviews of 10 children in the age range 7–18 years. As the purpose of the study was to explore the lived experience of children with SB, a phenomenological hermeneutical method was chosen. This method is described by Lindseth and Norberg (2004), and is found to be suitable for understanding the meaning of lived experience.

**Key messages**

1. The present study focused on the effects of spina bifida on children's health and development.
2. Stigma linked to disability, and complex consequences of spina bifida have induced a negative self-concept and stressful feelings around being different, dependent, and discriminated.
3. The school community and negative peer interaction amplified the children's feelings of vulnerability and social exclusion.
4. The children were able to obtain a sense of security by emphasizing the role of the family as a supportive unit.

### 2.2 | Setting

Palestine has been under Israeli occupation since 1967. It has a population of 4.8 million living in the West Bank and Gaza, and 94% of the population are Muslims. Approximately 39% of the population are younger than 15 years old (Giacaman et al., 2009; Palestinian Central Bureau of Statistics, 2016). The political conflict, and the construction of the annexation wall by the occupying power is considered a serious threat that impacts health, economic status, environmental resources, and many other aspects of the Palestinian society. This situation creates great obstacles for the Palestinian authority to establish the basic infrastructure of the state (Abdallah & Swaileh, 2011).

The available scope of intervention for children with disabilities is predominated by medical and charity approaches. The national development plans have been committed to promoting the social rights of children with disabilities since the establishment of the Palestinian Authority in 1994. It emphasizes the principle of nondiscrimination and the provision of accessible services. However, there is still no actual implementation of the plans, and the transition to a rights-based approach is very slow.

### 2.3 | Participants

The participants were purposefully recruited according to the aim of the study. Inclusion criteria were being born with SB, having attended school, being 18 years of age or younger, and having communication abilities making it possible for them to contribute to the data. The nurses at the three main rehabilitation centers in the West Bank were asked to select children who were able to understand the questions and who could provide descriptions of their experience as children with SB.

## 2.4 | Data collection

The researcher contacted the parents of the selected children to ask for their consent, to check the child's readiness to participate, and to arrange for an interview with the child. The first author (MN) carried out the interviews at the children's homes. The children were interviewed privately, and they were encouraged to speak freely to promote narration. The interviews were audio-recorded, and each interview started with one broad question: Could you tell me about your experience with spina bifida? Then, follow-up questions were asked to confirm correct understanding. An interview guide was developed by the two researchers (MN, HW), who are pediatric nurses, both having clinical experience of children with chronic illness and disabilities. The interview guide is presented in Table 1.

The interviews were transcribed verbatim in Arabic and then translated into English by the first author (MN). The two local authors (MN, AI) validated the translation by comparing the Arabic and English texts and revising the English text where necessary to avoid any discrepancies. The translation was necessary to allow the Swedish authors (AA, HW) to be involved in the analysis.

## 2.5 | Data analysis

In the analysis, the phenomenological hermeneutical approach was followed. This method involves understanding and interpreting the meaning of a text through naive reading, structural analysis, and comprehensive understanding (Lindseth & Norberg, 2004). To make the meaning visible, it requires an interaction between the researcher and the text in a circular stepwise process, going back and forth between understanding, and interpreting to reach the comprehensive understanding of the phenomenon under study.

Initially, all authors read the whole text independently and repeatedly to obtain an immediate impression about the meaning of the text (naive understanding). Then, in the structural analysis, meaning units relevant to the aim were identified and excerpted from the text. These meaning units were condensed, critically reviewed, and compared for similarities and differences. In the final step, the meaning units were abstracted into subthemes and themes; an example is presented in Table 2.

The two local authors independently carried out the structural analysis of the Arabic transcripts, whereas the two Swedish authors analyzed the translated text independently. The structural analysis process continued by the four authors, moving between the original Arabic transcript, the English translated transcript, and the interpretations until they reached agreement.

**TABLE 1** Interview guide

| |
|---|
| Can you tell me about your daily life experience with SB? |
| Can you tell me about a typical day? What do you do every day? |
| Can you describe your experience with your family in the home environment? |
| Tell me about 1 day you spend with your friends. How you feel about it? |
| Tell me about 1 day you spend at school. What a school means to you? |
| Can you tell me about 1 day you spent in the hospital? |
| What about the equipment and devices that you often use? |

*Note*. SB: spina bifida.

**TABLE 2** Example of the structural analysis

| Meaning units | Subthemes | Theme |
|---|---|---|
| It is a misery, I am always nervous, I can't tolerate myself, I can't walk as other children. | Resentment against disability | Experiencing negative self-concept |
| I'm totally dependent, I can't manage my incontinence, my mother help me to deal with this, even at school, but when I'm older who will help me? | Powerlessness and dependency | Experiencing negative self-concept |
| I do not use a wheel chair, but I'm paralyzed, I cannot run like other children. I get angry when they laugh at me or make fun of me. Sometimes I cry, and sometimes I want to hit them with my crutches. | Struggle with being different. | Experiencing negative self-concept |

## 2.6 | Ethical considerations

The study was conducted according to the Declaration of Helsinki (World Medical Association, 2013). Local permission and ethical clearance were authorized from the Palestinian Health Authority and the Research Ethics Committee of Al-Quds University, Palestine. The children's parents were provided with written information about the study, and consent was obtained. The children were asked for their assent and reminded of their right to stop or withdraw from the study at any time. The interviewer (MN) is a pediatric nurse and experienced at interacting with children. After the interview, the interviewer made sure that the participants were not distressed, and assessed whether emotional support was needed.

# 3 | RESULTS

Ten children with SB, six boys and four girls, aged 7–18 years, were interviewed between February and May 2015, and the average duration of each interview was 35 min. The participants varied in their level of disability and were recruited from the north ($n$ = 3), the middle ($n$ = 3), and the south ($n$ = 4) of the West Bank. Table 3 presents the demographic characteristics of the participants.

The structural analysis revealed eight subthemes assembled into the three following themes: *Experiencing negative self-concept*, *Experiencing vulnerability*, and *Obtaining a sense of security*. Common meanings conveying the children's experiences are illustrated through the main theme, “*Vulnerability and suffering due to social exclusion and stigma*.” (Table 4). In the remainder of this section, the number after each quote refers to the child's age.

## 3.1 | Experiencing negative self-concept

The children described their physical appearance, personal attributes, and sense of self through a series of painful emotions. They

**TABLE 3** Demographics of the children with spina bifida (SB)

| Characteristics | *n* (unless otherwise stated) |
|---|---|
| Number of children | 10 |
| Age at time of interview (years) | |
| mean (min.–max.) | 12.1 (7–17) |
| Religion | |
| Muslim | 10 |
| Christian | 0 |
| Place of residency | |
| Urban | 3 |
| Rural | 4 |
| Refugee camp | 3 |
| Sex | |
| Male | 6 |
| Female | 4 |
| Level of disability | |
| Severe and paralyzed | 6 |
| Mild to moderate (can walk) | 4 |
| Incontinence | 10 |
| Intellectual problems | 0 |
| Hydrocephaly with V-B shunt | 8 |

*Note*. V-P: ventriculoperitoneal.

shared their reflections on their self-concept, which were primarily negative.

### 3.2 | Resentment against disability

The children highlighted their negative feelings towards their disabilities and the use of wheelchair or crutches. They expressed resentment about their distorted body. They also wondered why this was happening to them and not to their peers.

> *I hate the wheelchair … I hope to get rid of it … It annoys me. I cannot be like others … I often think 'Why me? Why am I not a normal child like others? (Boy, 14)*

Bladder dysfunction and occasional incontinence were perceived as major problems, which disrupted the children's lives. Some indicated that their lives were not worth living because of the exhausting difficulties in maintaining bladder control.

> *"Everything is difficult in my life. I feel tired of living with incontinence and diapers … I hate the catheterization … I wondered why children like me with Spina bifida should stay alive." (Girl, 12).*

### 3.3 | Powerlessness and dependency

The children were often incapable when it came to self-care activities. They were completely dependent on their mothers for their daily care needs and health remedies. Feeling dependent was one of the main difficulties reported by the adolescents, whereas it was not considered a problem for the younger children, aged between 7 and 9 years.

> *My family does everything for me. I don't have to do anything. I just play and study. (Girl, 7).*

The adolescents felt ashamed of still being dependent on their mothers for their daily care. Some adolescents reported the difficulties they faced in acquiring independency by managing the clean intermittent catheterization (CIC) and other health routines by themselves. These threats to self-management and independency intensified their emotional suffering and negatively affected their self-concept. They were more occupied with thoughts about the future than the younger children were, and they reported concerns about their education, future careers, work, and marriage.

> *Managing university studies alongside a serious health condition and restrictions in mobility can be a daily struggle. I will not be able to study at university, or to work and get married. I'm afraid of what will happen to me if my mother is no longer able to care for me … who will help me in this miserable life? (Boy, 14)*

### 3.4 | Struggle with being different

Struggling with being different and facing difficulties with promoting normality was apparent through the children's narratives. They did not want to attract attention to their use of diapers or CIC.

> *I pretend to use the bathroom while I am at school … So that other children think I'm normal and can use the bathroom as they do. (Boy, 10).*

The adolescents reported feeling sensitive about being different. They could not get along with their nondisabled peers or share their activities. They described how rejected they felt by their peers, who avoided communicating or playing with them. Some children expressed their desire to be transferred to a special disability school to feel normal or have friends.

> *The school took me out of my comfort zone … I became aware that I'm different from some children who stared at me and made fun of my shaky walk. (Girl, 12).*

**TABLE 4** Overview of the main theme, themes, and subthemes in children's descriptions of their experience of living with SB

| Main Theme | Vulnerability and suffering due to social exclusion and stigma | | |
|---|---|---|---|
| Themes | Experiencing negative self- concept | Experiencing vulnerability | Obtaining a sense of security |
| Subthemes | Resentment against disability<br>Powerlessness and dependency<br>Struggle with being different | Living with stigmatization<br>Living with limitations<br>Risk to body and self | Belonging within the family<br>Belonging with peers |

However, some younger children did not perceive themselves as being different from their peers or siblings.

> *My brothers are similar to me. The only difference is that they can walk. But I can crawl and control the wheelchair. (Boy, 9).*

The children revealed worries about being incompetent in academic achievements because of the frequent hospitalization and school absence that they often experienced. Feelings of anger were expressed for not being allowed to participate in school activities and social events arranged by their schools.

> *I was excluded from all the outings, such as field trips and physical education classes … I like to play football. But I couldn't participate in that … The teachers said 'It is difficult. You just sit there and watch the other children. (Boy, 14).*

## 3.5 | Experiencing vulnerability

The negative social attitudes and environmental barriers that the children faced, especially at school, influenced their vulnerability and suffering.

### 3.5.1 | Living with stigmatization

Negative attitudes and stigmatization were mainly experienced at school. The children described their peers' hurtful behavior, such as making jokes at their expense, and mocking their disability and incontinence. Some children were reluctant to return to school as a result of the negative attitudes of their peers. They felt ashamed of themselves and preferred to keep their interactions with peers to a minimum.

> *I hate school … I feel that many children give me looks and put me down … because they discovered my incontinence … They always make me feel afraid and ashamed … I usually like to stay alone. (Boy, 10).*

The children rarely left the house, in order to avoid the hurtful perceptions shown by their community. They felt annoyed with people who stared at them and expressed words of sympathy and sorrow, or pestered them with many questions.

> *I prefer to stay home … You know how people in our society deal with such cases … they look at me curiously … I do not like to hear words of sympathy … It's really hard … I'm a human. And I want people to respect me. (Boy, 16).*

### 3.5.2 | Living with limitations

The children claimed that access to buildings and streets is often impossible for them, because of the lack of disability-friendly environment and facilities. It was difficult for them to reach school on their own, or to go to places of recreation appropriate for their age, such as football matches and swimming pools. They always needed help from their parents, friends, or siblings.

> *I would like to join a public sports club. I love swimming and playing football with other children … I am very sad … It is difficult to reach these areas … I am not allowed to participate … I prefer to stay home. (Boy, 16).*

### 3.5.3 | Risk to body and self

The children's narratives revealed a significant physical and psychological risk related to their disabilities, and they frequently needed hospitalization. They described some dangerous events, which harmed their bodies and caused horrifying experiences for them and their families, such as burned legs, a chronically wounded foot, and complicated fractures.

> *Paralysis makes my situation tragic … I was just sitting near the heater. I did not notice that my legs were burnt until my mother entered the room and started shouting. (Boy, 14).*

The children reported feeling sad about their frequent need of a special therapy, device, or surgery. They gave examples of their family's struggles with the poor capabilities of the health care services in Palestine, the absence of advanced therapies, and the complicated process of logistical arrangements. If they were referred for advanced surgery in an Israeli hospital, they had to obtain a permit to cross a checkpoint at the annexation wall. They explained that getting the permit is often complex and arbitrary, therefore, the surgery they needed was postponed many times, and essential equipment and devices were not offered. Sometimes, they lost hope of any improvement, and two of the six interviewees who were completely mobility-impaired reported having seriously considered suicide in the past. However, they acknowledged their parents' efforts to help them relieve their distress and accept the difficult conditions they have passed through.

> *Three years ago, I felt depressed. I tried to end my life … Then my parents talked to me and helped me continue this miserable life. (Girl, 12).*

## 3.6 | Obtaining a sense of security

Certain sources of support that promote the children's feelings of security and belonging were recognized from their narratives.

### 3.6.1 | Belonging within the family

The children were able to feel secure, loved, and accepted at home. They gave examples about events with their families that excited them. Receiving support and encouragement from their family members helped them to think positively about themselves. Moreover, religious beliefs were frequently mentioned as sources of support and hope.

> *My mother taught me that I am a gift from God. She told me I will walk in heaven and will gain later whatever I have lost in this life. (Girl, 7).*

> *The religious beliefs I learned from my family and from my mum still help me. My parents took me to Saudi Arabia to request prayers … to protect me and my family. (Boy, 16)*

### 3.6.2 | Belonging with peers

Peer relations in the home environment emerged as a strengthening influence for the children. Playing with their close friends in the neighborhood, even if it was for a short while, made them happy and they saw these interactions as a kind of care, help, and support. They also felt happy to remain in contact with their peers through computer-mediated technologies although they were at home.

> *My friends, mainly cousins, are very helpful. I am happy to have them in my life … They often encourage me. I'm not allowed to stay out with them for a long period … but I'm lucky that I can keep contact with them through the computer. (Boy, 15).*

## 3.7 | Comprehensive understanding and discussion

Our study gives insights into Palestinian children's experiences with SB and explores their feelings, needs, and challenges, as well as the obstacles they face in exercising their rights. The main theme, Vulnerability and suffering due to social exclusion and stigma, indicates that the participants were extremely vulnerable, caught in a state of existential, physical, and psychosocial stress, and in need of a great deal of support. In this study, stigmatization, economic hardship, and further consequences resulting from the political instability in Palestine were identified as key stressors affecting the experience of our participants.

A marked impact of negative social attitudes and stigma on the children's psychosocial health was evident in our findings, as they felt discriminated in every aspect of their daily life. The greater obstacle they faced was the strained social interaction with their peers and other people in society. This was reflected by showing anxiety and fear about peer prejudice at school, and by rejecting people's sympathy and prying questions. These difficulties produced feelings including embarrassment, secrecy, shame, exclusion, and abandonment. Our results agree with previous evidence highlighting the broad spectrum and impact of disability in different contexts (Cocks, 2008; Connors & Stalker, 2007; Jahoda, Wilson, Stalker, & Cairney, 2010).

Inclusive education is broadly recognized as the ideal for most children with disabilities, because it protects the children's rights, fosters social cohesion, and reduces stigma (Haug, 2017). Since its establishment in 1997, the Ministry of Education in Palestine has adopted this as a philosophy for the provision of care for all children, including children with disabilities (Lifshitz, Glaubman, & Issawi, 2004). Nevertheless, we found that the reported stigma and exclusion that our participants experienced when attending regular schools is congruent with a recent report about children with disabilities in Palestine (UNICEF, 2016); this suggests that successful implementation of this philosophy has not yet been achieved. Because there are no special schools dedicated to satisfying the needs of children with complex disabilities in Palestine, substantial efforts by the Ministry of Education are required to ensure successful inclusive education, paying special attention to the need for more resources, materials, and specialized teachers in Palestine (UNICEF, 2016).

The influence of stigma upon our participants can be largely related to the conservative cultural attitudes in Palestine as well as in other Arab Muslim cultures. These cultural attitudes include internalized feelings of shame toward the birth of a child with disability. Some people believe that disability is God's will as punishment for a past sin committed by a family member, or they may believe it is a test from God (Hasnain, Shaikh, & Shanawani, 2008). These beliefs can magnify the risk of poor outcomes in children with SB and their family members. The family may be exposed to discrimination and a negative reputation that will influence their worries and increase their isolation from the society (Nahal, Wigert, Imam, & Axelsson, 2017).

The above-mentioned attitudes can also limit the families' ability to respond to the child's developmental needs or to access appropriate care and social support. Such beliefs can represent an important challenge for health care providers and stakeholders, especially related to the proposed provision of community-based rehabilitation programs in Palestine. These programs require shifting the care from a medical and charity approach to social inclusion and protection of the children's rights (Nasser, MacLachlan, & McVeigh, 2017). According to Ingal (2012), a lot of work has to be done to promote the scope of rehabilitation in Palestine. Alleviating the vulnerability concerns of children and their families about stigma is the most important.

Although children with disabilities in other Arab Muslim countries, as well as in developing and low-income countries, are suffering a similar impact linked to stigma and marginalization (Hasnain et al., 2008), the adversity faced by our participants can be more complicated. Children in this study might not have the same opportunities for habilitation, training, education, and counseling as children in other countries not having the same burden of the protracted political conflict overwhelming the infrastructure, straining the economy, the health care system, rehabilitation services, and service providers (Giacaman et al., 2009). In the present study, the participants did not directly address the political situation but they referred to its consequences. They described how their families were struggling with the devastated health care services in Palestine, the referral process to the Israeli hospitals, and the subsequent struggles of getting the permit to pass through checkpoints at the annexation wall. The incapability and dependency that were demonstrated by our participants in all aspects of their lives can be associated with the limited scope of rehabilitative services in Palestine; these services lack facilities, resources, and strategies of care (Ingal, 2012).

Text analysis revealed a substantial burden placed on the children's psychosocial health and development, represented by the theme *Experiencing negative self-concept*. The children in this study discussed the burdens of their physical appearance, incontinence, and mobility problems, as well as social prejudice, and restricted access to social activities. These consequences were strongly associated with lowering their self-concept, which is similar to previous reports by authors in a variety of other settings (Fischer, Church, Lyons, & McPherson, 2015; Shields, Taylor, & Dodd, 2008). Moreover, suicidal ideation was reported in our study by two out of six of the children living with paralysis, whereas children with satisfactory mobility did not report any self-harm or suicidal thoughts. Such findings are in line with previous studies (Appleton et al., 1997; Minchom et al., 1995), which have found an inverse association between the severity of the child's impairment and self-concept.

The stigma of incontinence was the major issue that emerged in this study. Our participants reported fears of being seen as different to their peers because they used CIC in school. This induced considerable health-risk behaviors, including the participant's attempts to hide and postpone the use of CIC, pretending to use the bathrooms as their healthy peers did, and preferring not to mix with others at school. These behaviors might indicate that our participants lack knowledge about CIC and its importance in preserving renal function. To train and encourage the children early in life how to manage the CIC on their own could promote their health and independence, and thereby enable them to feel comfortable, less stigmatized, and more dignified (Sawin & Thompson, 2009). Additionally, promoting the children's health and empowerment might be achieved by raising social awareness about the children's feelings toward the stigma of their incontinence, and by discussing these issues with the children and their families at young age (Fischer et al., 2015).

Our results illustrate the children's feelings of powerlessness and dependency. However, these feelings were perceived differently. Regardless of gender, younger children reported positive feelings about being dependent, whereas adolescents expressed their struggle to achieve autonomy. This difference can be linked to their stage of development. As with self-awareness and the acquisition of abstract thinking, the identification of various needs, including the importance of achieving independence in all aspects of life, generally increase with age.

Although it is clear that paralysis and poor motor skills will limit the children's ability to develop independence (Shields et al., 2008), it has been found that country of origin, society, and family structure are found to take priority over these issues (Varnum, Grossmann, Kitayama, & Nisbett, 2010). Studies of Arab and Muslim families indicate that parents are often overprotective of their children with disabilities and consider themselves responsible for continuity of care into adulthood. To some extent, this can overshadow the children's ability to develop independence and instead encourage complete reliance on the family (Hasnain et al., 2008).

Further, our findings highlighted the children's ability to obtain a sense of security and remain attached to their family, as represented by the theme *obtaining a sense of security*. The children in this study felt insecure in peer and social interactions. They resorted to the family and religion for protection and support. Their references to family, siblings, and peers in the neighborhood, in addition to their participation at the mosque and their faith in God, were all considered as important sources of support and security. These results could be related to the nature of Islam. As described previously, in the Arab Muslim culture, giving birth to a child with disability could be considered as a punishment from God. But at the same time, the principles and practical suggestions in caring for the disabled and those in need are provided by the Qur'an and the Hadith (Al-Aoufi et al., 2012). These indicate that caring for the disabled child is a responsibility and a religious duty of the family. To be faithful to the Qur'an, a Muslim should endure suffering with hope and patience, accept it as God's will, and submit to it as a test of faith. This is interesting, as religious beliefs and activities, as well as spirituality, might be regarded as a significant coping resource used by the children and their families.

## 4 | STRENGTH AND LIMITATIONS

One weakness of the present study is the relatively small number of children interviewed. However, in spite of the variation in age, sex, and place of residency, the children's narratives were similar, except that the older children were more troubled by their dependency than the younger ones, this can be considered a strength of the study, which indicates that the data collection was sufficiently extensive for a narrative analysis (Sandelowski, 1995). To enhance credibility, the analysis of data was systematically conducted and the different steps described by Lindseth and Norberg (2004) were followed.

The research collaboration made it necessary to work with multiple languages, which has been challenging. During the analysis, we have been aware of the risk of misunderstandings and the difficulties of capturing the children's experiences when translating to another language. To do justice to the children's narratives, the Arabic-speaking authors double-checked the interpretations made in English with the Arabic transcripts. Further, the authors discussed the themes and subthemes to gain mutual understanding and agreement. To enhance trustworthiness of the study, the analysis process has been described, an example was given, and the subthemes were confirmed with verbatim-translated citations from the interviews. We are aware that omitting children with cognitive limitations can be considered a limitation of the study. However, a qualitative study is dependent on the participants' ability to contribute to the data, and it would be difficult to interpret the narratives of these children.

## 5 | CONCLUSION

Children with SB experienced physical and psychosocial challenges related to stigma as well as to socioeconomic and political status in Palestine. These circumstances put our participants at risk in terms of vulnerability, behavioral problems, and feelings of shame, secrecy, and abandonment. Our findings could help stakeholders, health professionals, families, and caregivers to achieve a deeper understanding of the children's experiences from their own perspective, and to collaborate for the establishment of social services and family-centered policies to enable and empower these children and their families.

## CLINICAL RECOMMENDATIONS

- Based on the study findings, health care providers, educators, and family members dealing with children with spina bifida need to be aware of the stigma attached to disability and the consequences of this stigma on children's physical, emotional, and psychosocial health and wellbeing.
- Altering societal attitudes and beliefs about the child's disability is a first step towards counteracting the negative consequences associated with spina bifida in order to maximize the children's development, and to ensure their social integration.
- providing counseling intervention strategies to the children and their families is essential to improve adherence to the management of certain care needs particularly related to their incontinence.
- Particular attention should be devoted to the psychological health needs of children and their families, especially if the child has suicidal ideation.
- An approach based on the family as the unit of care is required to decrease the children's suffering and promote their development in the context of the family.
- In general, more emphasis needs to be directed toward emancipating and humanizing disabled children in the Palestinian context.

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### CONFLICTS OF INTERESTS

The authors declare no conflict of interest.

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