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Factors Supporting Autonomy Development in Individuals with Spina Bifida: A Qualitative Study

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Abstract

Studies have shown that autonomy is a strong determinant of psychological well-being and social participation for individuals with disabilities. However, the factors influencing the development of autonomy in individuals with spina bifida have not yet been elucidated. This study aimed to explore the life experiences of adults with spina bifida that influence them in building their autonomy. In-depth, semi-structured interviews were conducted with nine people diagnosed with spina bifida using the phenomenological research method, which is a qualitative research approach. As a result of the interviews, it was concluded that assuming responsibility, self-confidence and close relationships contributed to the participants' autonomy development. It has also been found that female participants faced additional challenges related to their gender when developing their autonomy. We expect that this qualitative study will contribute to a better understanding of the factors supporting autonomy development in youth with spina bifida. In particular, families and professionals working in this field should focus on helping children and adolescents with spina bifida to assume more responsibility at an age-appropriate level and participate in activities to increase their self-confidence. Supportive services should be developed to ensure strong family and peer relationships.

Keywords: *Autonomy, spina bifida, qualitative, empowerment, well-being*

Öz

Çalışmalar, engelli bireylerin psikolojik iyi oluşu ve sosyal katılımı için özerkliğin önemli bir belirleyici olduğunu göstermektedir. Ancak, spina bifidalı bireylerde özerklik gelişimini etkileyen faktörler henüz tam olarak aydınlatılamamıştır. Bu çalışma, spina bifidalı yetişkinlerin özerkliklerini inşa etmelerinde etkili olan yaşam deneyimlerini incelemeyi amaçlamaktadır. Nitel bir araştırma yaklaşımı olan fenomenolojik araştırma yöntemi kullanılarak spina bifida tanısı almış dokuz katılımcı ile derinlemesine, yarı yapılandırılmış görüşmeler gerçekleştirilmiştir. Bulgular, sorumluluk alma, özgüven ve yakın ilişkilerin özerklik gelişimine katkıda bulunduğunu ortaya koymuştur. Ayrıca, kadın katılımcıların özerkliklerini geliştirirken cinsiyetlerine bağlı olarak ek zorluklarla karşılaştığı tespit edilmiştir. Bu çalışmanın, spina bifidalı gençlerde özerklik gelişimini destekleyen faktörlerin daha iyi anlaşılmasına katkı sağlamasını umuyoruz. Aileler ve profesyoneller, çocukların yaşlarına uygun sorumluluklar almasına ve özgüvenlerini artırıcı faaliyetlere katılmalarına odaklanmalıdır. Aynı zamanda, güçlü aile ve akran ilişkilerini destekleyecek hizmetlerin geliştirilmesi önerilmektedir.

Anahtar Kelimeler: *Özerklik, spina bifida, nitel araştırma, güçlendirme, iyi oluş*

Introduction

The autonomy of individuals with disabilities has been discussed in a wide range of disciplines, including philosophy, sociology, law, and psychology (Collins & O'Mahony, 2015). Researchers have discussed autonomy under various headings: making decisions independently of other people and situations, individualisation, having self-confidence when making decisions, meeting self-care needs, self-determination, independence, and having control and power over one's own life (Morsünbül, 2011; Oliver, 1989; Reindal, 1999; Rock, 1988; Wullink et al., 2009). The concept of autonomy within the medical field refers to the ability to make decisions independently of other people or a given situation and to govern oneself without external influence (Reindal, 1999). When researchers define autonomy in terms of disability, the ability to perform self-care activities is a key consideration (Oliver, 1989); however, people with disabilities may have different ideas about autonomy. For example, in a study conducted by Rock (1988), people with disabilities defined autonomy as the ability to maintain the control and power to make choices regarding the management of their lives. Importantly, as opposed to taking action alone and without support, autonomy is about getting help when it is needed (Reindal, 1999). In Crittenden (1990)'s model, which examines the concept of autonomy in individuals with disabilities, autonomy is defined as the capacity of individuals to take responsibility for their behaviour, make decisions about their own lives and maintain supportive social relationships.

Improving autonomy will support the right to independent living and psychological well-being of individuals with disabilities, improve their quality of life and participation in community life (Çoban, 2008; Krhutová, 2017; O'Shea & Salzer, 2020; Ünal & Gençöz, 2018). It also supports them to participate in business life and achieve economic independence (Chumo et al., 2023; Romeo & Yepes-Baldó, 2019). Through these developments, individuals with disabilities can realize their own potential in their personal lives and make a greater contribution to society.

As postulated by Bandura (1977), the theory of self-efficacy provides a powerful lens for understanding how individuals perceive their autonomy and the factors that support its development. It is an approach that describes individuals' beliefs about their ability to perform a particular task or situation successfully, and examines the effects of these beliefs on behavioral, cognitive, and emotional processes (Bandura, 1997). Self-efficacy beliefs and their effects on behaviors are based on four main sources. The first source is mastery experiences, whereby individuals who have succeeded in a task believe that they will succeed in similar tasks (Bandura, 2006). The second source, termed vicarious experiences, posits that individuals will enhance their belief in their own success when they observe the success of others with similar characteristics. Another factor is verbal persuasion, where encouraging or discouraging feedback provided by individuals' social environment can affect their self-efficacy (Bandura, 1997). The last source of shaping self-efficacy is physiological and emotional states. For example, stress, anxiety, and physical health problems can downgrade the self-efficacy of individuals, while positive emotions and good health contribute to their self-efficacy (Chao et al., 2013; Warner et al., 2014). Assessing autonomy within the framework of self-efficacy allows for consideration of both personal empowerment and external support systems.

Spina bifida can be defined as a complex neural tube defect caused by closure problems within the spine and spinal cord, diagnosed before or during birth (Antolovich & Wray, 2008). The condition most commonly affects the nervous system (brain and spinal cord), urinary tract (kidney and bladder), intestines, and muscular and skeletal systems (Cevher, 2007). Spina bifida can lead to many limitations at various levels of severity such as congenital malformations of the brain, hydrocephalus, Chiari II malformation, abnormal spinal curvatures or bumps, neurogenic bladder, or muscle weaknesses. The degree of movement difficulty varies depending on the location of the sac on the back (Karaçul, 2017). Individuals experiencing problems with the kidneys and bladder have difficulty holding urine in the bladder or emptying the bladder; therefore, they need to void urine during the day using the clean intermittent catheterisation (CIC) method (Cevher, 2007) and/or diapers. They also suffer from side problems such as infections, skin irritations and pressure sores in daily life (Beierwaltes et al., 2020; Forster et al., 2021).

Individuals with spina bifida not only require various assistive devices for mobility and regular CIC for urine monitoring but often also need support from family members and people or systems in social life (McDonnell & McCann, 2000; Tradewell et al., 2018). Needing another person's support for health management can limit activities that could be performed independently and may require a reliance on others to organize daily routines (Logan et al., 2020; Sawin et al., 2021). These situations may have a significant effect on the autonomy-related experiences of those individuals. According to our review of the literature, some studies, albeit not many, have been conducted on the autonomy of individuals with spina bifida during their childhood and adolescence and these studies focus on whether children with spina bifida have the same level of autonomy as their peers or on their medical autonomy (Friedman et al., 2009; Monsen, 1992; O’Hara & Holmbeck, 2013); however, no studies have examined the experiences of adults with spina bifida. It is crucial to discover the thoughts and experiences of people with spina bifida who have completed the transition to adulthood regarding autonomy in order to assess disease-specific needs. Autonomy enables individuals with spina bifida to develop self-management skills, increase social participation, and monitor their health conditions more effectively (Meulenkamp et al., 2019; Psihogios et al., 2015). Researching the autonomy of individuals with spina bifida is crucial for enhancing quality of life at the individual level and for developing more inclusive policies at the societal level. Therefore, the present study aimed to uncover the life experiences that have influenced the development of autonomy in adults with spina bifida.

Method

In this study, phenomenological research method, which is a qualitative approach that facilitates the investigation of participants' life experiences and how they interpret these experiences, was used (Patton, 2014). Phenomenological research focuses on uncovering the shared meanings of life experiences related to a particular phenomenon or concept, aiming to understand the essence of these experiences (Creswell, 2013). Accordingly, the phenomenological method provided an appropriate framework for understanding the life experiences that influence the autonomy of individuals with spina bifida and how they interpret these experiences. The study sought to identify common themes from these life experiences related to autonomy.

Participants

As Spina Bifida is a rare disease and affects individuals at different levels, purposive sampling method was preferred in this study. Purposive sampling is a method that allows researchers to select a sample that more closely aligns with their research aims and objectives. This approach helps to ensure the study is conducted rigorously and the data and results are reliable (Campbell et al., 2020). This study involves individuals with spina bifida who have reached adulthood because the experience of autonomy during adulthood provides a better framework for evaluation. Adults can provide extensive insights into this process, as they have completed the stages of childhood and adolescence, where autonomy begins to develop. For this reason, interviews were conducted with people over 25. The participants were reached through an organisation that supports people with spina bifida. A poster for the study and the link to the application form created via Google Forms were shared with the organisation. The association sent the poster to its members via email, and the poster was also shared on social media accounts to reach non-members. Following the announcements, individuals who were interested in participating completed the form or sent an email. Participants were contacted by the researchers to provide detailed information about the study and to assess whether they met the participation criteria. Two people were not included in the study because they did not meet the age criteria. Ultimately, nine adults with spina bifida were selected for the study. Table 1 provides demographic information regarding the participants.

Table 1. Participant Characteristics

Characteristics		**n (%)**
Gender	Female	5 (%55,5)
	Male	4 (%44,5)
Age	26-30	5 (%55,5)
	31-41	4 (%44,5)
Education level	Primary school/	1 (%11.1)
	Apprenticeship	1 (%11.1)
	High school	3 (%33,3)
	Associate degree	4 (%44,5)
	Bachelor's degree	
Working status	Working	7 (%77,7)
	Not Working	1 (%11.1)
	Retired	1 (%11.1)
Marital status	Single	6 (%66,6)
	Married	3 (%33,3)
Health supports	No need	2 (%22,2)
	Orthosis / Crutches	3 (%33,3)
	Orthosis / Crutches / Wheelchair when needed	3 (%33,3)
	Wheelchair	1 (%11.1)
Bladder control	Complete control	3 (%33,3)
	No control	5 (%55,5)
	Partial control	1 (%11.1)

Procedure

A semi-structured interview form was developed by researchers, both of whom are social workers with extensive experience working with people with disabilities, based on the literature. The following steps were followed in the preparation of the semi-structured interview form in order to ensure validity and reliability. Before the semi-structured form was finalised, experts who work with individuals with spina bifida were consulted. Thus, the interview questions were reviewed and validated through expert opinion to ensure content validity. To test the reliability and clarity of the interview questions, pilot interviews were conducted with two individuals with the condition who were not included in the sample and the form was finalised. The form included questions focusing on basic demographic information and life experiences related to autonomy. Selected interview questions can be found in Table 2.

Table 2. Selected semi-structured interview questions

1.	What does autonomy mean to you?
2.	Which experiences have contributed to your sense of autonomy?
3.	What circumstances do you believe support your autonomy?
4.	What areas do you feel you can act autonomously?

During the interviews, care was taken not to be directive; participants were encouraged to elaborate on their narratives to increase data depth.

Due to the pandemic and the fact that the participants live in different cities, the interviews were conducted by video call. Zoom was used for the interviews. After approval from the participants, the interviews were recorded and transcribed verbatim. The interviews were completed in a minimum of 60 and a maximum of 184 minutes (resulting in a mean of 106.4 minutes). At the end of the interview, each participant was given an opportunity to provide additional information or ask questions. No material incentives were offered for participating in this study.

Ethics

We obtained approval from the University's Non-Interventional Clinical Research Ethics Committee before conducting the study. Individuals with spina bifida who wanted to participate in the study were informed about the purpose, method and how the data obtained would be used. As the interviews were conducted through a video call platform, the participants gave an audio-recorded oral statement of informed consent. Participants in the study were given pseudonyms to hide their identities.

Reflexivity

During the process of this study, the researchers were also preparing a doctoral thesis on separation and individualisation in individuals with spina bifida; the qualitative research presented in this article forms a part of the doctoral thesis. During the structuring process of the research, interviews were conducted with spina bifida association managers and professionals working with individuals with spina bifida. In addition, the researchers have personal working experiences and academic backgrounds in the field of disability. These experiences have shaped the study's construction and execution.

Data Analysis

The analysis of the data was conducted using thematic analysis, a method that systematically identifies, analyzes, and interprets patterns, themes, and meanings within qualitative data (Braun & Clarke, 2006). This process was carried out following the steps proposed by Braun and Clarke. The interviews were audio recorded after permission was obtained from the participants. Then the interviews were transcribed verbatim, and the transcripts were read multiple times to check for spelling errors and familiarise researchers with the data. The transcripts were transferred to the MAXQDA 2022 Qualitative Data Analysis Program to facilitate the coding and analysis process. We coded the data based on how individuals with spina bifida define autonomy and how their life experiences affect autonomy. Each point expressed by the participants was combined under the codes created, which were then thematically analysed within the scope of the purpose of the study.

Findings

The analysis of the participants' responses to the semi-structured interviews resulted in the creation of three distinct categories: assuming responsibility, self-confidence, and close relationships.

Assuming Responsibility

The theme of assuming responsibility was addressed through the sub-themes of decision-making in health management, problem-solving, and supporting individuals with disabilities. Individuals assume responsibility for their own lives through the decisions they make. Participants who were encouraged to make their own decisions as children by their family and social environment, and whose decisions were supported, stated that they did not have difficulty making decisions or expressing their preferences.

She can't do it, she can't come. Nobody thought of it that way. I would be asked first. I would say that I could or could not come. So they always gave me that right. (Derya)

Participants assumed more responsibility as their social and physical opportunities increased. Due to this, they became more autonomous. Some of them stated that starting to use a wheelchair and doing CIC on their own enabled them to act according to their own wishes and meet their own needs independently of their relatives.

During my adolescence, I started to take care of my personal needs entirely. I even cooked at home because I started to use a wheelchair. (Ayla)

When I feel self-sufficient... My story of autonomy began when I started using a catheter myself. It is not easy to live as two people. (Derya)

When faced with a problem, the participants made an individual effort and tried different solutions, thus assuming responsibility for their problems. For example, one participant (Yağmur), who did not have a high school for the disabled in her region, continued her high school education through open education. In this process, she conducted active research, came across a disability association, and spent time there regularly. Ayla, on the other hand, felt lonely when her peers started to get engaged and gradually broke ties. She took steps to create a new environment. Another participant (Barış) developed various measures to cope with his urinary incontinence problem.

I was at home since there was no high school for me. Then I discovered the association. I started spending time there. (Yağmur)

One day, while listening to the radio, I called the radio station. I said "I want to work. I want to DJ on the *radio." They said, "Let's meet." I went and met them. I spent most of my time at the radio station after that. (Ayla)*

Because I was consuming a lot of liquid in the summer, I was having trouble. Later, to compensate, I always kept spare underwear. I always had my bag with me. Even now, I do. (Barış)

Furthermore, some participants assumed responsibility for supporting other disabled people. Besides raising awareness in society, they want to strengthen bonds between disabled individuals. For this purpose, they participated in non-governmental organisations and both took part in and assumed responsibility for the development of sports activities for disabled people. One of the participants involved in basketball felt responsible for supporting people with disabilities and encouraging them to participate, eagerly communicating with everyone within her reach.

I speak for people who cannot speak out. I express their wishes. I try to bring people with spina bifida together so we can get to know each other. It is easier to overcome difficulties with solidarity. (Eda)

As my teachers guided and encouraged me to be involved in this sport, I wanted to act like them and to be a guiding light for my disabled friends and I achieved. Thanks god. That's why I'm so happy... Everywhere I go, I strive to reach and contact people with disabilities. (Ayla)

Self-confidence

Self-confidence enabled the participants to exhibit behaviours that made them feel more autonomous; a belief that they could do something provided a sense of autonomy. Some discovered their capabilities through sport and their relationship with themselves has been positively affected by these discoveries. Three participants said sports increased their motivation in life and made them more self-confident.

Sports gave me self-confidence. When I started playing sports, my motivation increased. I realised that I am alive. I was only 12 years old when I started. I travelled to Austria alone at 14. I became aware of things I could do. (Emre)

I overcame teenage depression by playing sports… Everything starts with self-confidence and sports should be one of the steps to becoming confident. (Ayla)

I felt that my health problems decreased as I played sports. I gained self-confidence. Before joining a sports club, I had a little self-doubt, but then it disappeared. (Barış)

CIC use is quite common in people with spina bifida and parental support while performing CIC can create a sense of dependency. The participants stated that they felt more self-confident and psychologically comfortable when they were able to complete the process on their own.

I couldn't take my mother everywhere. So I said I'd do it, and one day I sat down and thought about how to do it. I mean, I designed it in my head, planned it, and did it. (Emre)

As a final point, some participants stated that they had been self-confident from an early age and that this had made life more liberating for them.

I was always a kid who tried to be everywhere. I like doing everything I'm told I can't do. It's a bit about my personality. You have to say, "I'm here, I want to be here." Then, your family or friends will see this desire in you and support you. (Derya)

I've always been a self-confident person since I was a child. (Kerem)

Close Relationships

The theme of close relationships has been examined through two subthemes: primary relationships (family) and secondary relationships, which include individuals from the social environment, such as peers, teachers, and relatives. A key factor highlighted by numerous participants was their families' attitudes. The supportive attitudes of their families encouraged them to participate more in life, express their wishes, and take action. For example, some families had prepared for the challenges their children may face at school:

My family told me, "If they tell you something, pay no mind, don't listen. We love you as you are. Some people are fat, some are skinny, some can run, and some cannot run." Perhaps that's why I was able to take a stand against people a little more. (Ayla)

My mother visited and talked to the students at my school before me. She gave them information about me. She was more excited and worried than me. (Derya)

Barış experienced contrasting attitudes from his parents. His mother supported his desire for independent actions, whereas his father argued that these wishes would not be possible. Barış regularly mentioned how important his mother's support was to him.

The first time I wanted to buy a car, my father said, "No, you can't drive, you just got your driver's license. You'll have an accident, you'll get into trouble." But my mother said, "My son can do it. His uncles are drivers. There are many drivers in his family. He can do it too." I received a lot of support from my mother. I have driven for 17 years, never had an accident. (Barış)

Participants also said that being supported by relatives, school, or work colleagues increased their capabilities. Structural facilities and emotional support encouraged a greater degree of engagement with social life.

I can do the impossible if given the opportunity. But opportunity must be given. Until now, my family and environment have always offered me the opportunity. (Emre)

I started working as a barber for my uncle's friend. Socialising with people was very useful for me. My master's attitude towards me was very positive: "Never think of yourself as different. Don't restrict yourself. In fact, restricting yourself harms yourself." With his support, I enrolled in school. (Barış)

Due to both the transitional and developmental nature of adolescence and the changes in their environment, many of the participants experienced difficulties. During this period, they benefited from the support provided by their peers; the friendships developed highlighted that others were experiencing similar issues.

Where I did sports, I used to have long chats with men with disabilities. When I realised that many people were going through similar problems, I thought I should have confidence. (Ayla)

I have never experienced peer bullying. At school, I always had friends who looked out for me more than me. (Derya)

Teachers' attitudes and inclusion methods play an important role, with experiences during physical education lessons frequently mentioned. Most of the participants either waited in the classroom or watched from a distance during physical education classes; they stated that these experiences were damaging and that they would have liked to take responsibility at a level that suited their capabilities. Only a few participants were included in the class in ways that suited them, allowing them to stay together with their friends and helping them realise what they were capable of.

He knew how to behave and how to guide people with disabilities because he was always in touch with them. He knew that I could also play a sport. While they were doing physical exams, I was doing theoretical exams on basketball. After I started playing wheelchair basketball, he made me shoot free throws for the exam. (Emre)

Roles and behaviours attributed to men and women by the social environment also influence autonomy. Female participants faced more restrictions due to their gender, with the gender roles attributed to them by the social environment they lived in narrowing their range of experiences. Sometimes these limitations were overcome and sometimes they could not escape the cycle.

If I wasn't a woman, I'd be different in terms of freedom. I would be more assertive with my family about what I want. (Selin)

At first, my mother was against me playing with men. In the city where I lived, there were no other female players, so I would be the only woman on the team. My mum asked me, "Why is there no other woman player? Will you be the only one?" I said, "It's because of people like you. As you are against it, so are others' families. They don't allow their daughters to play. That's why *there are no women players. Women are stuck at home." (Ayla)*

Discussion and Conclusion

Developing autonomy is critical for people with disabilities, especially in the transition from adolescence to adulthood (Crittenden, 1990). To support this transition, the variables affecting it need to be understood. Three categories have been identified as a result of the analysis of semi-structured interviews with adults with spina bifida to identify life experiences that affect autonomy: assuming responsibility, self-confidence, and close relationships.

People who can manage themselves and make their own decisions about their own lives are able to access the resources they need and display attitudes and behaviours enabling them to achieve their future goals (Teater, 2015). Psihogios and Holmbeck (2013) stated that adolescents and young adults with spina bifida need a transition period in which they gradually move away from parental care, assume responsibility, and move on to self-management. The transition period involves taking responsibility for the personal needs we can meet by ourselves, and then trying to solve the problems we encounter. As they transitioned from adolescence to adulthood the participants in the present study began to take on various responsibilities gradually, from personal care needs to the organisation of their social environment. When we look at Derya's experiences about taking responsibility, we can see the effect of mastery experience and verbal persuasion. Starting to use a catheter on her own made it easier for her to take responsibility in other areas. People around her did not think that she could not do it and supported her. Eda, Barış and Ayla realized their own capabilities and felt responsible. They strived to support other people with disabilities, encouraging them to play sports and partake in daily life, advanced education, and work.

Self-confidence has been discussed and defined in various contexts in the literature. Essentially, it refers to people’s belief in their own abilities (Bandura, 1977; Feltz, 1988). In this study, participants with spina bifida stated that sports contributed to their self-confidence to a high degree. Playing sports created a space in which the participants could see for themselves what they were capable of and improve themselves. Self-confidence enables individuals to have positive thoughts about themselves, to believe that they are self-sufficient, to realise that they are valuable, and to be at peace with themselves (Eldeleklioğlu, 2004). This makes it easier to feel and act autonomously. In addition to physical benefits, sport also provides spiritual benefits, offering the opportunity to socialise, have fun, feel a sense of freedom, and challenge stereotypes (Aitchison et al., 2022). This is evidenced in a study conducted by Ridosh et al. (2011) showing that wheelchair sports helped individuals with spina bifida gain independence. During our interviews, it was observed that the participants who practised sports became more enthusiastic when discussing their sporting activities. They provided more details and smiled more. Here, the effect of the mastery success experiences brought about by being involved in sports is clearly seen. Through sports, participants experienced a shift in their perspectives on life, gained positivity, and expanded their social circles, ultimately gaining self-confidence.

CIC is part of the daily lives of many individuals with spina bifida. Developing the ability to use CIC independently will improve their self-confidence and enable them to take part in social life more comfortably (Fischer et al., 2015; Sawin & Thompson, 2009). The participants’ views are consistent with the literature as this process facilitated self-confidence and enabled them to remain active on an independent basis. Additionally, Derya and Kerem stated that self-confidence is a part of their character. Aside from the innate aspect, character structure is shaped in early childhood and continues to develop throughout life (Berkowitz & Grych, 2000; Lerner & Schmid Callina, 2015; Peck et al., 1960). Positive caregiver relationships during early childhood help children develop a sense of trust (Ainsworth, 1978). Sensitive and consistent caregivers support the development of children's curiosity, self-confidence, and independence (Hong & Park, 2012). This situation plays an important role in shaping children's future social relationships and personality traits (Hong & Park, 2012; Martín Quintana et al., 2023).

The development of autonomy is related to the maintenance of a support network and the development of a reciprocal adult attachment, both of which are shaped by the family system (Crittenden, 1990). Families are an important source of strength for individuals with spina bifida in terms of understanding and coping with the situations they are faced with (Ridosh et al., 2011). Accordingly, their parents' attitudes during childhood were highlighted by many of the participants. They stated that the supportive and solution-oriented approaches established by their parents enabled them to approach life in the same way. Parents' permissiveness in allowing children with spina bifida to participate in social activities and encouraging age-appropriate behaviours has a positive influence on their self-esteem (Wolman & Basco, 1994). In contrast, an overprotective attitude reduces their sense of autonomy (Holmbeck et al., 2002). One of our participants, Barış, experienced both. The overprotective attitude of his father prevented him from taking action, while the supportive attitude of his mother motivated him to do so. Individuals' perception of their abilities is more decisive than the difficulties actually experienced (Bandura, 1977). When parents care about their children's ideas and encourage them, their children are able to express their wishes and decisions more easily, thus expanding their autonomy.

According to Lister (1997), autonomy can be achieved through the human relationships that nurture it and the social infrastructure that supports it. McAndrew (1979) also argues that the coping skills of adolescents with spina bifida are not the result of the severity of their disabilities but rather of the environmental support systems available to them throughout their lives. The self-efficacy theory also states that the supportive and encouraging behaviors of others play a significant role (Chao et al., 2013). In addition to their families, children with spina bifida have frequent contact with relatives, peers, and teachers and are influenced by their attitudes. They express themselves more freely when they feel supported by adults and understood by their peers. However, their participation in out-of-school activities with their peers is often limited (Blum et al., 1991; Roux et al., 2007). Adolescents with spina bifida have fewer positive contexts than their peers (Essner & Holmbeck, 2010); problems at school, negative perceptions of people with disabilities, and living in a small city can all negatively affect their self-esteem (Wolman & Basco, 1994). In this study, the participants showed more active participation when they were able to get help from their teachers and friends to solve problems encountered at school, and when arrangements were made in the lessons to support their unique requirements. Adolescents with spina bifida find it important for their peers with disabilities to understand their challenges, which strengthens their friendships (Roux et al., 2007). Since they shared common experiences, participants stated that communicating with friends with disabilities fulfilled their need to be understood; in addition, these friendships helped to establish community bonds.

Society's perspectives and expectations regarding men and women are often different. Men are more likely to be trusted and supported in terms of decision-making, spending time outside freely, and being able to do things; women are more likely to be expected to be more careful and to give more importance to family life. Furthermore, women encounter more obstacles in terms of achieving their goals (Eagly & Steffen, 1984; Eccles, 1987; Green et al., 1987; Parsons et al., 2017). One of our participants, Selin, said that if she were not a woman, she would feel more free and could express her demands more easily. Ayla, on the other hand, had to deal with her family's objections because she was the only female player on the team. Being women has limited women with spina bifida and created additional challenges as they attempt to develop autonomy.

There is a widespread belief that people with disabilities need protection and cannot manage their own lives (Aciem & Mazzotta, 2013). Despite an increase in social awareness of the capabilities of individuals with disabilities compared to previous eras, the continued stigmatization leads to individuals' withdrawal from social life. This withdrawal affects various aspects of life, including employment, education, and social interactions (Adefila et al., 2020). One of the structural barriers to autonomy is limited access to resources. A low socio-economic level increases the risk of encountering barriers that limit autonomy. This negatively affects the autonomy of people with disabilities by limiting adequate access to education and health services, which are among the most basic needs (Burchardt et al., 2015; Clemente et al., 2022). Limited access to physical infrastructure also negatively affects capabilities. It limits the freedom to act independently (Chou et al., 2024; Iezzoni et al., 2006). This situation negatively affects mastery experiences and causes emotional difficulties, leading to a decrease in self-efficacy. Inclusive and supportive policies are needed to reduce stigmatisation and increase access to resources.

A sense of autonomy contributes to children's well-being and reduces the feeling of having an illness (Deci & Ryan, 2008). Autonomy positively affects financial independence, employment, social relationships, housing, and inclusion in post-secondary education for people with disabilities (Shogren & Shaw, 2016). Because young people with spina bifida often lack independence in functions such as social participation, independent living, and employment compared to their peers, it is of great importance to help them achieve autonomy (Greenley et al., 2006). Providing them with support during childhood and adolescence to strengthen their autonomy will make their lives easier in adulthood. Within this context, while adolescents with spina bifida build their autonomy, people in their immediate circle should strive to assist them in establishing positive relationships with themselves, thus cultivating the ability to accept responsibility.

Despite the valuable insights gained from this study, several limitations must be acknowledged. First, the qualitative nature of the study inherently limits the generalizability of the findings. While in-depth interviews and detailed participant observations provided rich data, the results may not be applicable to all individuals with spina bifida, as the sample size was relatively small and geographically limited. Second, since the focus of the present study was on the factors that positively affected the construction of autonomy, we did not include factors that had a negative effect. To better understand the concept, it would be beneficial to define the negative factors that affect autonomy. Performing future studies by determining such negative factors and taking them into account will provide the opportunity to understand autonomy better.

In the empowerment approach, which is frequently used in the field of social work, it is believed that the person knows his or her problems best (Adams, 2017). Consequently, the person is analysed cognitively, interpersonally, and politically based on his or her own story, which enables the researcher to take action in conjunction with that person. In the present study, we analysed the issue based on the meaning provided by participants who experienced the consequences of spina bifida. Autonomy can be critical during adolescence and young adulthood as perspectives on life and life plans are developed during this stage of life. When researchers work on autonomy, it would be useful for them to pay particular attention to adolescents and young adults and to conduct intervention studies to encourage greater autonomy among these cohorts. It is important to raise their self-confidence and increase their areas of responsibility. Moreover, in order to maintain healthy close relationships, it is important to have support from family, teachers, and peers. Coming together through group work will highlight the therapeutic effect of understanding similar experiences, and this togetherness will contribute to the processes of producing solutions. In addition to individual efforts, the social environment and physical opportunities should be considered when exploring the development of autonomy. Social policy practices can be developed and implemented to increase individuals' macro-level resources and expand their access to these resources. In future studies, it would be useful to investigate the problems arising from the family, social, and physical environments that negatively affect the construction of autonomy in individuals with spina bifida.

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