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Learning coping strategies in the narratives of young bloggers with SMA: The role of family, school, and community

***Keywords*:**
educational environment, school, family, disability, coping with illness

Abstract

Research objectives and problems: This study investigates how environmental contexts—family, school, and the social environment—shape the development of coping strategies among young bloggers living with SMA. The analysis focuses on turning points in their lives and the influence of significant others in learning to manage illness-related challenges.

Research methods: The study employs a qualitative methodology grounded in hermeneutic phenomenology. Proxemic analysis (Walulik 2022) served as the primary analytical tool. Blog content was supplemented with semi-structured interviews with the authors, providing a broader understanding of their lived experiences.

Process of argumentation: The article opens with an introduction outlining the conceptual motivations, research aims, and contextual background on SMA. It then describes the methodological framework, including the methods used, analytical techniques, characteristics of the research sample (five bloggers), and data sources (blog entries and interviews). A subsequent section discusses the main theories and key concepts, which is followed by an analysis of the empirical findings. The final section concludes with a summary and pedagogical implications.

Research findings and their impact on the development of educational sciences: The findings underscore the importance of the environmental context. Family members, teachers, peers, professionals, and clergy emerged as influential figures supporting the development of both task-oriented and meaning-oriented coping styles. The study

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also highlights the value of blogs as research material, as they offer authentic insights into the daily experiences of individuals with SMA. These findings may inform and enrich the training of future professionals.

Conclusions and/or recommendations: The study emphasizes the importance of developing coping competences among children and adolescents with disabilities while ensuring that parents do not fall into patterns of overprotection. Mechanisms such as modeling, resilience, and transgression play a key role in helping young people overcome their limitations.

Research objectives

In this article, I examine the impact of environmental context on how young bloggers with spinal muscular atrophy (SMA) learn to cope with their illness. The reflections presented here are drawn from my doctoral research on this process, published in my dissertation (2023). That work documented the stories of patients who, despite significant health challenges, have learned effective strategies for coping with life's demands. These individuals demonstrate notable resilience and seek to inspire others.

The impetus for this research came from observing the blogging activity of people living with SMA, particularly the narrative of my friend, Kamil Cierniak, a doctoral student and blogger whose work became an important reference point for this analysis. Kamil could move only three fingers on one hand. Despite significant functional disability, he remained active both academically and socially. His posts blended reflection and humor in a distinctive narrative style. His example and outlook inspired me to search for other narratives created by people in similar circumstances. The analyzed stories reveal mechanisms that build psychological resilience and illustrate how experiences of illness are presented in the public sphere.

Before presenting the study itself, a brief explanation of SMA is necessary. SMA is a rare genetic disease that affects the neurons responsible for muscle contraction and relaxation, resulting in varying degrees of symptoms (Saniewska & Saniewska 2019). The condition leads to the loss of motor function in different parts of the body, though the severity varies widely. Some patients require ventilatory support and cannot eat or speak independently. Others use wheelchairs but can still perform some self-care activities. Still others experience only mild muscle weakness.

For many years, SMA was considered incurable, until 2016, when a drug was introduced that halts the progression of the disease (Saniewska & Saniewska 2019). Unfortunately, the treatment does not reverse existing damage or restore full function. Approximately 1,000 patients with the condition have been registered in Poland, some of whom participate in the SMA patient association. Prognoses vary greatly, and there are no official statistics on long-term outcomes. Before turning to the interpretation of findings, a summary of results, and recommendations for pedagogical practice, I will briefly outline the theoretical background.

Research methods

This article presents the results of research that I conducted in 2022 and 2023 on the role of primary environments—family, school, and community—in shaping coping strategies among young bloggers living with SMA. The main aim of the study was to identify the role of the educational environment (family, school, and local or national institutions) in the process of learning new strategies for living with the illness. I sought answers to questions concerning:

- coping strategies modeled by significant others,
- turning points in the participants' lives that led to the development or modification of coping strategies, and
- the influence of other people—parents, significant others, mentors, and professionals (e.g., doctors and physiotherapists), as well as friends, co-workers, and teachers—in learning these strategies.

In my dissertation, I employed qualitative methods, drawing on the interpretive paradigm, which focuses on the search for meaning and the interpretation of statements in a broad context. The analysis combined

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phenomenological-hermeneutic and biographical approaches, treating blog posts as first-person narratives. I used Marek Walulik's proxemic analysis technique (Walulik 2022), which distinguishes five stable categories that reflect the context of human life particularly well: place, time, actors, values, and expectations.

Semi-structured interviews served as a complementary technique, enabling structured organization of information, analysis of key moments, and examination of the influence of significant individuals. Although the questions were prepared in advance, the conversations remained flexible and unfolded naturally. For ethical reasons, informed consent was obtained both before and after each interview to ensure that participants fully understood the purpose of the study and felt comfortable throughout the process.

The research materials were blogs, supplemented by additional sources: pre-existing materials (press articles, interviews with the authors) and materials generated for the study (interviews conducted by me with the bloggers). Although blogs are still used relatively rarely as research data, they offer valuable insights into individuals' experiences and interpretations of life events. They are distinctive sources and should be treated as such. Their structure—often reverse chronological and interconnected through hyperlinks—allows readers to engage with the authors' present experiences and then explore their past. In many ways, blogs resemble diaries: first-person narratives about one's life and the surrounding world. They are virtual and interactive, but they may also function as forms of self-presentation or, as some scholars describe them, online self-creation.

The study focused on five purposively selected blog authors, all living with SMA. The group included several well-known figures—a wheelchair-using model and foundation president, a lifestyle and fashion blogger, and a writer and journalist—as well as less widely recognized individuals, such as a social activist residing in a care facility and a late friend, a doctoral student with journalistic experience. The shared inclusion criteria were active blogging for at least one year, a confirmed SMA diagnosis, and being in early adulthood (Erikson, 2021). Three participants agreed to be interviewed; one had passed away and another declined to participate.

During the dissertation evaluation, it was noted that the sample does not fully represent the SMA population. While this limitation is acknowledged, the sample does accurately reflect the population of SMA *bloggers*. The study therefore centers on individuals whose coping strategies are more task-oriented and outward-directed. People with more avoidant or emotionally destructive coping tendencies appear to be underrepresented in the blogging community. Only one participant described negative experiences related to parental attitudes, which she perceived as a source of later difficulties.

Although some depressive passages appeared in the narratives, they constituted only a small fraction of the entries. For example: "It was a difficult year. All the plans fell through. Everything is not as I would like it to be. I started to think about what I'm grateful for this year and, all in all, despite everything, there's still a bit to be thankful for." Such entries, even when describing hardship, also reveal strategies of positive reappraisal and meaning-making. They cannot be categorized as escapism. It is also important to note that the Internet is a form of self-expression, and authors may not always wish to disclose their vulnerabilities. The assisted-living system for people with disabilities in Poland generally does not allow for full independence, and not all individuals with disabilities lead highly active or eventful lives. In my dissertation, however, I aimed to present examples of active coping in the face of difficulties, such as stereotypes, architectural barriers, and insufficient systemic support.

Process of argumentation

In the theoretical section of my dissertation, I examined in detail several coping strategies: task-oriented, avoidance-oriented, and emotion-oriented coping (Lazarus & Folkman, 1984), as well as meaning-oriented coping (Park & Folkman, 1997). I sought to identify the context in which these strategies are learned—specifically, the role of primary educational

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environments such as the family (significant others), school, religious communities, and the local environment.

The theoretical layer of analysis built upon several concepts, including Tomaszewski's Theory of Difficult Situations (1975) and Park and Folkman's Model of Meaning-Making (1997). I also referenced Erikson's Theory of Psychosocial Development (2011) and Jarvis's work on Lifelong Learning and Existential Learning (1987). In addition, the dissertation incorporated the human ecosystem model, known as the *Mandala of Health*.

As a researcher, I approach health from a holistic perspective, conceptualizing it as a state of physical, psychological, and spiritual well-being arising from multiple factors, rather than the absence of observable disease symptoms. Similarly, I view illness as a subjective experience: a disruption of well-being in various spheres that impedes everyday functioning. In my approach to disability, I include the principles of inclusion, normalization, and social integration, understood as processes aimed at combating discrimination, promoting self-determination, and ensuring that marginalized groups can fully participate in and co-create social and cultural life.

I understand the environment as a set of life conditions that influence human development and upbringing. Following Kowalski (in Dykcik, 2001), I adopt a three-part division of the environment:

1. natural environment (immediate surroundings—family, neighborhood, friends, peer groups);
2. institutions of formal education (e.g., preschools and schools, educational centers);
3. institutions of informal or non-formal socialization (e.g., workplaces, healthcare institutions, the military, foundations, associations, religious organizations).

A key concept related to the environment—and one I refer to frequently—is "situation." I understand this as an individual's life situation: a set of circumstances connected to a particular person, shaped by their unique life experience, at a specific place and time. I assume that situations influence behavior to some extent, but do not fully determine it. Here, the concept of *transgression* is especially meaningful to me—understood as the act of transcending one's limitations and engaging in the humanistic process of "becoming," the development of one's individual potentials. In Tomaszewski's (1975) view, behavior is not simply a response to stimuli or the result of fixed individual predispositions, but emerges from an individual's interaction with others in a specific context. Situations can be classified as *ordinary*, which do not require changes in coping strategies, or *difficult*, which require adaptation either to the task or to the demands of the environment.

I assume that life difficulties do not prevent individuals from developing. The phenomenon of resilience—an individual's capacity to withstand adverse life conditions—demonstrates this clearly. However, the presence of difficulties does not always allow for the full development of a person's potential. In the literature, illness is often conceptualized as a difficult situation. Yet it is worth noting that patients themselves sometimes describe their experiences simply as "the only life they know"—that is, as ordinary life situations, especially when the illness has been present since childhood.

Findings

I will now present the findings of the study. In my dissertation, I analyzed each case individually and then conducted a horizontal comparison, identifying shared and divergent categories. During my interviews with bloggers, I was struck by the strength of their will to live and their inclination to transcend personal limitations. They primarily seek "ordinary treatment" and equal access to everyday conveniences. The respondents were oriented toward self-development and relied on many constructive coping strategies: mostly task-oriented, but also meaning-oriented. Despite significant differences in personality, they shared a tendency to use escapist strategies only rarely; they neither withdrew nor gave up easily and generally exhibited optimistic attitudes.

Without question, these people possess significant personal resources: intelligence, a strong sense of agency, a sense of humor, determination, and well-developed intrinsic motivation. In this study, however, the factors shaping these traits are of particular interest. While intelligence and temperament have genetic components, it is life context, unique experiences and interactions with others, especially significant others, that determine a person's character and outlook on life. Based on my interpretations, I identified the fundamental importance of environmental context in the process of learning coping strategies. Participants emphasized the influence of family and early school experiences—particularly the attitudes of teachers and peers toward their disabilities. They also pointed to religious communities as important formative environments in their lives. Some highlighted the role of patient-oriented communities, such as the SMA Foundation. Finally, the online blogging community itself emerged as an environment in which participants learned coping strategies.

What emerged clearly from my research was the importance of modeling, that is, learning from the behaviors and attitudes of significant others, in the development of coping strategies. Children often mirror the behaviors of their parents. The role of parents—especially those raising children with disabilities—is to create the right conditions for development: to meet their children's needs while also supporting independence, showing encouragement without slipping into overprotection. As Radziewicz-Winnicki observes, the family plays a crucial role in shaping a child's personality during the early stages of life, whereas school, as an educational institution, becomes most influential during adolescence. This pattern was also evident in my findings.

Regarding behavioral models for coping strategies, four bloggers described their parents as teaching them not to give up but to face difficulties directly. One blogger quoted her mother: "I am proud that your dad and I raised you to be a happy, joyful, and ambitious woman, despite your physical limitations." In another post, I read, "Even when we didn't always feel up for it, we were all very determined. And it worked." The participants emphasized that their parents tried not to create a "glass bubble" around them, which is more commonly referred to in English as "helicopter parenting." As Agatha wrote in one entry: "My parents expected me to overcome my own difficulties, to smile at people. I know that this helps everyone, not just me." This is an example of parental influence on the development of coping strategies, such as optimism and positive reappraisal.

One respondent noted: "My mother is with me 99% of the time, 24 hours a day." This illustrates how much influence a parent can have. Other participants no longer lived with their parents and were not dependent on them in adulthood, yet still emphasized how deeply their parents' attitudes toward illness had shaped their own.

Bloggers usually described school as a difficult but valuable experience. One interviewee told me:

> There was a period in my life when I think I saw more of my deficiencies. That I couldn't dance at school parties like my friends, that I couldn't go out on my own, that someone always had to be with me. That I needed someone's help. That I couldn't use the restroom by myself. I think that during that adolescent period, I noticed my limitations more.

In school, they had to face the fear of being different, curious stares, and exclusion from certain activities. For every blogger in the study, entering school marked a turning point in their narratives. Another participant recalled:

> I don't think I ever really had that moment of asking, "why me?" I think I accepted it from the beginning. Maybe also because my parents sent me to school with non-disabled kids, and those kids always played with me—they never excluded me. I think that also mattered.

School was often the place where they first encountered major practical barriers: inaccessible bathrooms, inadequate ramps, and the absence of elevators. One blogger's words had a powerful impact on me:

> When I was seven, I was sent to school. A school attended by non-disabled kids. Was the school accessible? No, it wasn't. Even getting to the first floor required climbing stairs. But that didn't change my parents' or the school administration's decision. And I am very grateful to them for that.

This illustrates that, from an adult perspective, exposure to adverse events and critical life junctures does not necessarily lead to trauma; individual coping strategies and resilience mechanisms can mediate how such experiences are processed.

Another important factor seems to be the level of collaboration between these primary environments. Gaś (2016) writes about the risks associated with a lack of coordination between family and school:

> It is important for parents and teachers to speak with one voice on important issues. When the values that they communicate conflict, a rift can form within the child, resulting in the development of double standards of behavior and only superficial internalization of the prevailing norms.

The living environment of a child with a disability can also be understood as an institutional one. Kamil joked: "I've got no shortage of muscles, muscle atrophy, scoliosis, dealings with ZUS (Social Security Association), and category E." In his narratives, ZUS is personified and treated as one of the actors in the text. This represents a humorous coping strategy for managing bureaucratic challenges. At the same time, these entries address serious issues, such as systemic inefficiencies and the lack of clear regulations.

A key institution for the SMA community in Poland, frequently mentioned by the bloggers, is the SMA Foundation. Kamil wrote about the organization: "I generally felt like I was among my own. I have met many open-minded and ambitious people who, despite their illness, are doing something with their lives to the best of their ability." He described a meeting organized by the foundation as a major turning point that changed his attitude toward his illness and himself.

The foundation was established in 2013 by parents of children with SMA. Its main goals include gathering and disseminating comprehensive knowledge about SMA, maintaining patient statistics and a national registry, and supporting families of those affected. It collaborates with international research initiatives and is a member of the European Organization for Rare Diseases (EURORDIS), a pan-European scientific research network. The community brings together a large portion of SMA patients in Poland, organizes conferences for families and specialists, and runs various educational and social campaigns. It plays a vital role in shaping the lived environment of patients.

Another environment, specifically, a network of institutions, that has a significant impact on patients' lives is the healthcare system. People with SMA must make frequent hospital visits, including lumbar punctures required for administering the medication that slows disease progression, as well as regular monitoring during treatment. Their interactions with the medical community also influence their perception of the disease and their attitudes toward their own bodies.

In one of the blog narratives, the author wrote, "Doctors made various diagnoses, including some that completely baffled my parents. They were told I would die during puberty, that I would stop breathing." One participant described on her blog the inappropriate behavior of a gynecologist who refused to examine her and spoke about her in the third person, addressing only her mother, despite the fact that she was already an adult woman at the time.

During an interview, another blogger recounted an incident involving a nurse's inappropriate conduct in a hospital. She had been a teenager at the time. She described the experience as follows:

> There was this spiteful woman on the ward, and in her anger, she started whispering to me that she wasn't surprised that my parents had left me there, that they couldn't stand me. I think that's something that left a very strong mark on me. I don't know exactly how it changed me or in what way, but it definitely affected me—how I saw myself.

Such experiences are not without impact on the patients' perception of themselves and the world. It is important to recognize that certain personality traits—especially in professions involving direct human contact—should be taken into account in hiring. When inappropriate behavior is reported to a supervisor, appropriate action should be taken immediately. Unfortunately, those who experience such mistreatment are not always able to report the trauma that they endure.

Because my respondents are bloggers, the role of the virtual environment in coping with difficult situations must also be considered. Maciąg (2013) refers to this as a virtual space of social life, in which certain norms, values, and rules of functioning develop. The online world not only co-creates contemporary culture but also meets various needs; it is both a tool and an environment in which we live. In one of her classifications, Tomaszewska (2012) identifies four functions of new technologies: building group cohesion, shaping individual identity, organizing daily life, and providing access to information and assistance. These same functions can be observed in the blogs analyzed for this study. Other authors see blogs as a form of communication, a tool for building community, a way of expressing experiences of illness and social exclusion, and, for some, a form of self-creation or even self-therapy.

What became clear in my research is that blogging serves multiple functions in the lives of the authors whose narratives I analyzed. One blogger wrote that she publishes posts "to relive emotions that feel powerful now, even though I know myself—and in a week they'll fade. That's why I collect, photograph, and publish things: to strengthen my memories." Most of the narratives function as diary-like accounts of experiences, enriched by potential interactions with readers. In the posts examined, a process of sharing experiences and forming connections between authors and readers was evident. One blogger described the self-therapeutic role that writing plays for her:

> When I first disclosed here that I live in a DPS (a social welfare center), I didn't expect anyone to find that information useful (…). I think I did it partly as therapy for myself, because for quite a long time I didn't like saying out loud that I was a resident of a DPS.

Simply "telling" one's story requires a degree of reflection one's own life and circumstances.

The influence of blogging on learning new coping strategies can also be viewed from another angle. Blogs are interactive spaces, and the authors' narratives are subject to readers' reactions. Bloggers may receive both support and criticism. Both confronting negative feedback and finding others who think the same way often becomes a motivation for personal growth. In the online environment, people with disabilities may be exposed to hate speech, but their posts also help normalize issues related to illness and disability. The virtual world has its own peculiarities, such as a sense of anonymity, immediacy, and the lack of face-to-face communication. This may facilitate certain phenomena, but they do not determine them outright.

In special education, the virtual environment is sometimes portrayed in an overly simplistic way—either as a "window to the world" that removes all barriers, or as an escape from reality that leads to addiction. Plichta (2017) describes these extremes as techno-optimism and technophobia. Plichta and Pyżalski (2016), however, propose a more nuanced view of the Internet: as a catalyst or a unique environment that amplifies existing predispositions. In my research, bloggers frequently emphasized that barriers are an inherent part of life for people with SMA. Yet it is individual perception that determines the degree of their impact. In line with principles of equality, efforts should be made to eliminate these barriers, for example, by submitting petitions regarding high curbs or the lack of ramps and elevators. The Internet plays an important role in facilitating the visibility and advocacy of these issues.

The presence of these obstacles, though undeniably negative, often became a motivating force for the bloggers. The proactive attitudes of the parents of four participants helped them develop task-oriented coping strategies and a readiness to seek support. In crisis situations, people may experience personal growth through transgression, which can be understood as the act of transcending one's own limitations (Kozielecki, 1987). One blogger described how she is actively working through her tendency to avoid difficulties by engaging in self-reflection. She realized

Multidisciplinary Journal of School Education • Vol. 14, 2025/2 No. 28
Family and School: Educational Partnership

that her parents had exhibited anxiety, embarrassment about her illness, and a tendency to withdraw. Over time, however, she encountered people who motivated her, encouraged her self-development, and helped her recognize her strengths. Educational and other supportive environments can partially compensate for early-life deficits. The developmental trajectory of individuals in adulthood may be interpreted through the lens of resilience, understood as a form of post-traumatic growth (Kaźmierczak, 2017).

Conclusions and recommendations

The Internet should also be considered a living environment, rich with opportunities. For people with disabilities, blogs can be extraordinarily valuable, particularly when seen as a “window to the world.” They can serve therapeutic purposes and build a sense of community. At the same time, they may function as a form of self-therapy or even as an escape from the real world. Blogs also play an important role in raising awareness about rare diseases and normalizing disability. Even viewing photographs of people with disabilities in everyday contexts helps humanize them, revealing their interests, personalities, and values—not just their medical condition.

For educators, electronic diaries can be a valuable research resource, particularly in studies that focus on environmental context. First-person autobiographical narratives have a tremendous power to move readers through language and to make the themes of transgression and resilience visible. Such narratives allow readers to “enter into” the author’s world (Miąso, 2014). This is especially valuable in the education of future medical professionals and teachers: in helping to cultivate sensitivity, empathy, and a fuller understanding of difficult life situations.

The aim of this study was to describe the role of the environmental context—family, school, and society—in the process of learning to cope with illness among young bloggers with SMA. The research focused on key turning points and the influence of significant others. Because this

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was a qualitative study, it does not allow for broad generalizations or the identification of universal patterns. Nevertheless, careful interpretation of the blogs reveals several important themes. As demonstrated, the development of coping strategies is influenced by multiple environmental factors, including the attitudes of parents, living conditions, interactions with significant individuals, and the functioning of institutions such as government agencies, hospitals, and other support systems. Government policy also plays a role in shaping these processes.

At this point, I would like to put forward several recommendations related to this article, which stems from my doctoral dissertation. When it comes to developing appropriate coping mechanisms, it is very important to support parents of children with disabilities and to sensitize professionals to the difficulties faced by people with disabilities. Several factors may negatively affect a child's self-image and self-perception:

- isolation of the child,
- overprotection,
- avoidance of challenges,
- limiting the child's opportunities to develop effective coping strategies independently,
- lack of parental involvement or excessive permissiveness.

In this context, the mechanism of learning through behavioral modeling (observation and imitation) appears particularly important (Plichta, 2017).

These challenges also concern universities, which educate the medical professionals, teachers, and specialists whom children with disabilities encounter throughout their lives. Their knowledge, as well as their sensitivity and attitudes toward illness, can influence how children and families understand and respond to disability—which my respondents also emphasized. Using blogs as source materials in education can help instill empathetic attitudes among future professionals.

In conclusion, the coping strategies that people with disabilities develop are significant at the individual and social levels. It should be self-evident that people with disabilities have full rights to self-determination, development, education, employment, and participation in shaping social policy. As Radziewicz-Winnicki (2002) notes, the role of educators is to raise public awareness of the various social barriers that limit people's ability to participate fully and satisfactorily in society. Studying blogs written by people with disabilities can contribute to this aim. I hope that my research has, in some measure, helped to illuminate the environmental context of coping with illness and demonstrated the value of blogs as a source of knowledge about the experiences of people living with disease.

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