Issues, challenges, and experiences of individuals with cerebral palsy from the perspective of personal assistants: a qualitative study

Problemi, izazovi i iskustva osoba s cerebralnom paralizom iz perspektive osobnih asistenata: kvalitativno istraživanje

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Abstract

Introduction: Cerebral palsy is a common lifelong neurological disorder. Caring for individuals with cerebral palsy presents ongoing emotional, physical, and social challenges. The purpose of this study was to explore the experiences of supporting individuals with cerebral palsy from the perspective of personal assistants, with particular attention to daily care challenges, communication processes, social participation, environmental barriers, and the professional demands associated with providing personal assistance.

Methods: Participants included six personal assistants employed within a regional cerebral palsy association in Slovenia. All participants were directly involved in providing daily support to individuals with cerebral palsy. The assistants supported service users with varying levels of functional independence, including adolescents, adults, and mixed age groups. A purposive sampling strategy was used to recruit participants with direct experience of the phenomenon under investigation. Data were collected through focus groups, and verbatim transcripts were analysed using Braun and Clarke's thematic analysis.

Results: We identified eight key themes related to supporting individuals with cerebral palsy. Personal assistants described variability in service users' emotional and psychological states, communication challenges that require interpretation of non-verbal cues, and difficulties in motivating engagement in daily and physical activities. Themes related to social inclusion highlighted the importance of relationships alongside persistent societal barriers. Structural themes included infrastructural limitations, gaps in professional psychological support, and challenges related to the personal assistant role, including emotional strain, financial precarity, and training needs. Technology emerged as both a facilitator of independence and a selective tool for social connection.

Discussion with conclusion: Personal assistants working with individuals with cerebral palsy operate within a demanding nexus of emotional investment, structural limitations, and professional precarity, while providing critical support that enhances service users' autonomy, social integration, and quality of life.

Keywords: cerebral palsy, personal assistants, qualitative research, focus groups, coping strategies, social support

Short title: Cerebral palsy and personal asistant

Sažetak

Uvod: Cerebralna paraliza čest je doživotni neurološki poremećaj. Skrb za osobe s cerebralnom paralizom nosi trajne emocionalne, fizičke i socijalne izazove. Cilj ovog istraživanja bio je istražiti iskustva pružanja podrške osobama s cerebralnom paralizom iz perspektive osobnih asistenata, s posebnim naglaskom na izazove svakodnevne skrbi, komunikacijske procese, socijalnu participaciju, prepreke iz okoline te profesionalne zahtjeve povezane s pružanjem osobne asistencije.

Metode: U istraživanju je sudjelovalo šest osobnih asistenata zaposlenih u regionalnoj udruzi za cerebralnu paralizu u Sloveniji. Svi sudionici bili su izravno uključeni u pružanje svakodnevne podrške osobama s cerebralnom paralizom. Asistenti su pružali podršku korisnicima usluga s različitim razinama funkcionalne neovisnosti, uključujući adolescente, odrasle osobe i mješovite dobne skupine. Za odabir sudionika korištena je namjerna strategija uzorkovanja kako bi se uključile osobe s izravnim iskustvom s fenomenom koji se istražuje. Podaci su prikupljeni metodom fokus grupe, a doslovni transkripti analizirani su primjenom tematske analize prema autoricama Braun i Clarke.

Rezultati: Identificirano je osam ključnih tema povezanih s pružanjem podrške osobama s cerebralnom paralizom. Osobni asistenti opisali su varijabilnost emocionalnih i psiholoških stanja korisnika usluga, komunikacijske izazove koji zahtijevaju interpretaciju neverbalnih znakova te poteškoće u motiviranju korisnika za uključivanje u svakodnevne i tjelesne aktivnosti. Teme povezane sa socijalnom uključenošću istaknule su važnost međuljudskih odnosa uz istodobno postojanje trajnih društvenih prepreka. Strukturne teme uključivale su infrastrukturna ograničenja, nedostatke u profesionalnoj psihološkoj podršci te izazove povezane s ulogom osobnog asistenta: emocionalno opterećenje, financijsku nesigurnost i potrebu za dodatnom edukacijom. Tehnologija se pokazala i kao čimbenik koji olakšava neovisnost i kao selektivan alat za socijalno povezivanje.

Rasprava sa zaključkom: Osobni asistenti koji rade s osobama s cerebralnom paralizom djeluju unutar zahtjevnog okruženja obilježenog emocionalnim angažmanom, strukturnim ograničenjima i profesionalnom nesigurnošću, istodobno pružajući ključnu podršku koja doprinosi autonomiji korisnika, njihovoj socijalnoj integraciji i kvaliteti života.

Ključne riječi: cerebralna paraliza, osobni asistenti, kvalitativno istraživanje, fokusne skupine, strategije suočavanja, socijalna podrška

Kratak naslov: Cerebralna paraliza i osobni asistent

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Introduction

Cerebral palsy (CP) is one of the most common lifelong neurological disorders, resulting from injury or abnormal brain development during early childhood [1]. According to the Centers for Disease Control and Prevention [2], CP affects approximately one to four newborns per 1,000 live births, with a higher prevalence among preterm infants. It is characterized by impairments in movement, muscle tone, posture, and coordination, often accompanied by difficulties in sensory, perceptual, cognitive, and speech functions. Although the condition itself is non-progressive, its clinical manifestations may evolve [1, 3]. Cognitive and emotional comorbidities are common; individuals may experience challenges related to vision, hearing, perception, learning, speech, epilepsy, and digestive difficulties [3, 4]. The National Health Service (NHS) [5] provides a more clinical definition, describing CP as a condition affecting movement and coordination that results from brain injury occurring before, during, or shortly after birth.

Individuals with CP often face long-term challenges related to movement, independence, and social participation. Motor impairments can restrict mobility and make daily tasks more difficult, leading to a reliance on others. Research shows that for adults with CP, mobility is linked to independence, dignity, and social belonging [6]. Similarly, young adults with CP have described meaningful participation as a source of achievement, fulfilment, and connectedness [7]. For children with milder forms of CP, participation in daily activities improves quality of life (QoL) [8]. Their participation is often limited because of architectural, social, or psychological barriers. Pashmdarfard et al. [5] highlight obstacles such as inadequate support, low self-confidence, and restricted opportunities for autonomous decision-making. Adults with CP participating in the study by Gaskin et al. [9] emphasised perseverance, adaptability, and environmental support as key to coping with daily challenges, noting that quality of life depends not only on physical capacity but also on opportunities for engagement, purpose, and acceptance.

Caring for individuals with CP is a long-term responsibility that affects the QoL of parents and caregivers. Parents often feel overwhelmed, lack time for themselves, face employment restrictions, and experience social isolation. Although health and social systems offer various forms of support, parents report a lack of coordination between services, prolonged procedures, and unequal access to rehabilitation [10, 11]. In recent years, personal assistance has become a key mechanism for improving independence and social inclusion among people with CP [12].

Personal assistance in Slovenia is regulated under the Personal Assistance Act (2017). It represents a comprehensive system of services designed to enable individuals with long-term physical, intellectual, sensory, or other disabilities to live independently and participate actively in society. The service is individualized and tailored to the user's needs, preferences, and life circumstances. To qualify for personal assistance, individuals must demonstrate a need for support in activities related to independent living, social inclusion, education, or employment; be residents of Slovenia; be aged between 18 and 65; live or wish to live outside institutional care; and require at least 30 hours of assistance per week. Eligibility is formally assessed by a social work centre commission based on professional evaluation. Personal assistance encompasses several types of support, including personal care (e. g., hygiene, mobility, feeding, medication management), household assistance (e. g., cooking, cleaning, administrative tasks), accompaniment (e. g., transportation and participation in social, cultural, and healthcare activities), support in education and employment (e. g., assistance with documentation, use of equipment, and information-communication technologies), and communication support (e. g., interpretation and use of assistive communication tools). Services are delivered by registered provider organisations that must meet legal requirements, including employing qualified coordinators and ensuring service quality and organisation. Personal assistants may also be family members if formally employed by a provider. Mandatory training is required before employment and includes legal, ethical, safety, and communication components, with ongoing annual training obligations. The system is primarily publicly funded through the national budget, although service users receiving certain care allowances are required to co-finance part of the service. In terms of working conditions, personal assistants are employed through provider organisations, and their work is defined by legislation that includes provisions on working hours, coordination, and professional standards; however, previous reports indicate challenges such as low pay, financial precarity, and ongoing legislative adjustments. Overall, personal assistance is a key mechanism for promoting autonomy, reducing reliance on institutional care and family members, and improving the quality of life and social inclusion of persons with disabilities in Slovenia.

Personal assistants provide essential daily support with mobility, communication, and social engagement. Their contribution extends beyond practical help with significant emotional and social support. However, personal assistants face challenges such as emotional strain, fatigue, and insufficient psychological resources, which impact their performance and well-being [13, 14]. The purpose of this study was to explore the experiences of supporting individuals with cerebral palsy from the perspective of personal assistants, with particular attention to daily care challenges, communication processes, social participation, environmental barriers, and the professional demands associated with providing personal assistance.

Methodology

This study employs a qualitative research methodology to gain an in-depth understanding of the experiences, challenges, and coping strategies of family members and personal assistants caring for individuals with CP [15].

Sample

The study was conducted in collaboration with a regional cerebral palsy association in Slovenia. Participants included six personal assistants (five women and one man). Four participants were mothers of the individuals with cerebral

palsy they supported, while two participants were not related to the service users. All participants were directly involved in providing daily personal assistance. A purposive sampling strategy was used to recruit individuals with direct experience of providing support. The personal assistants provided support to individuals with varying levels of functional ability and independence. The service users required assistance with daily activities, mobility, and social participation. Some individuals used wheelchairs and required support with transfers and mobility, while others required assistance primarily with organisation, communication, or social inclusion. The assistants worked in both home and community environments, including urban settings. The sample was purposive, as it was essential to include individuals directly experiencing the phenomenon.

Data Collection Procedure

Data collection was carried out in two phases by two researchers: 1) focus group discussions, in which personal assistants reflected on key themes related to their roles and everyday challenges; and 2) transcription and analysis of interviews, where statements were coded and categorised using thematic analysis by Braun & Clarke [16]. Participants were recruited through a regional association for individuals with cerebral palsy. The researchers contacted the association, which then informed personal assistants about the study and invited those interested to participate. Individuals who expressed interest were contacted by the researchers and received detailed information about the study aims, procedures, and ethical considerations before providing informed consent. Data were collected through one focus group conducted in February 2025. The focus group included all six participating personal assistants, and each participant took part in only this single session. The discussion was conducted in a meeting room at the regional cerebral palsy association. The focus group was moderated by two researchers. One researcher facilitated the discussion using a semi-structured interview guide and ensured that all participants had the opportunity to contribute. The second researcher observed group dynamics and took field notes, particularly focusing on non-verbal communication and interaction patterns. The focus group lasted approximately 90 minutes. The discussion was audio-recorded using a digital recorder. No video recording was performed. Field notes were used to supplement the audio data and to capture contextual observations. All participants were assigned anonymised codes (e. g., Personal Assistant 1 – PA1) to ensure confidentiality. A semi-structured focus group guide was developed based on the study objectives and existing literature on personal assistance and cerebral palsy. The guide included open-ended questions exploring participants' experiences with daily support, communication with service users, challenges in motivating participation, perceived systemic barriers, and professional challenges related to the personal assistant role. Follow-up questions were used to clarify responses and explore emerging themes. The focus group guide is provided in Appendix 1. *Data Analysis Method*.

The data were analysed using thematic analysis following the six-phase framework of Braun and Clarke [16]. First, both researchers familiarised themselves with the data by repeatedly reading the transcripts and reviewing field notes. Initial open coding was then conducted to identify meaningful units of text related to the research questions. In the second phase, codes were compared and grouped into broader categories based on conceptual similarities. Through an iterative process of discussion and comparison, categories were refined and organised into preliminary themes. In the final phase, themes were reviewed, defined, and named to ensure they accurately reflected the dataset and the study aims. Both researchers were actively involved in the coding and theme development process. Coding was initially performed independently and then compared. Any differences in interpretation were discussed until consensus was reached. To improve trustworthiness, themes were continuously checked against the original transcripts to ensure consistency and accurate representation of participants' perspectives.

Ethical Considerations

All participants were informed before participation about the study's purpose, procedures, and data processing methods. The study posed no risks to participants, and all data were treated with strict anonymity and confidentiality. Participants signed informed consent forms confirming voluntary participation and granting permission for audio recording. They were informed of their right to withdraw from the study at any point without consequences. The study followed all ethical principles outlined in the Code of Ethics in Nursing and Care of Slovenia [17]. Ethical approval was obtained from the Ethics Committee of the Faculty of Health Sciences, University of Maribor, before data collection.

Results

The findings are grouped into eight main themes presented in table 1.

I. User Emotional and Mental State

During the focus group, participants described the emotional and psychological state of individuals with cerebral palsy as highly variable and sensitive to multiple contextual factors, including health status, academic demands, family relationships, and social interactions. Participants noted that periods of illness, academic pressure, or interpersonal conflict often led to emotional distress, withdrawal, or reduced motivation. One personal assistant noted their acute sensitivity to external pressures: "Their psychological state is completely dependent; it varies from day to day." (Personal Assistant 1 – PA1). This instability worsens during stressful periods, such as academic deadlines: "Today, for example, she had an exam. I went to see her, and she was a complete wreck" (PA 5).

II. Communication and Recognition

During the focus group discussions, participants emphasised that effective assistance depends heavily on the ability to interpret non-verbal communication, particularly when individuals with CP experience difficulties expressing

Table 1. Codes, Sub-themes, and Main Themes

Themes	Sub-themes	Code
I. Individuals with CP Emotional and Mental State	Variability of Disposition	Mood varies drastically; it can be affected by stress.
	Influencing Factors	Psychological state depends on health, relationships and social group.
	Specific Conditions	Cerebral palsy, autism, and psychological difficulties.
II. Communication and Recognition	Importance of Non-Verbal Cues	Recognising signs, facial mimicry, and body movement is an unexplained cause of their distress.
	Assistant's Role in Recognition	Personal assistants must know the individual with CP well enough to recognise needs.
III. Activities and Motivation	Relaxing Activities	Social games, conversation and distraction, reading books, music/radio.
	Physical Activity and Motivational Challenges	Encouragement in exercise (e. g., stairs, walking to the balcony) is essential; hard to motivate; unwilling to cooperate; find activities pointless; cannot be forced; animals can be a stimulus for movement.
IV. Social Integration and Support	Significance of Social Networks	Good relationships are highly important for the well-being.
	Isolation and Societal Barriers	Feeling unaccepted; being pushed away; after gaining friends and support, becoming highly talkative; social isolation, due to fear, uncertainty or a lack of knowledge on how to approach or initiate a conversation; very restricted social circle.
	Social Integration	Integration into society; some prefer the company of similar people, while others prefer "normal" people; social gatherings in shopping centres.
V. Systemic and Infrastructure Barriers	Educational Facilities	Lack of functional elevators at universities severely limits the educational choices of students with disabilities.
	Urban Infrastructure and Public Transport	Ramps/slopes are unsuitable; narrow sidewalks; difficult parking situation in the city centre; cobbled surfaces (e. g., city park) are unsuitable for wheelchairs; bus transport accessibility gap.
VI. Healthcare and Professional Support	Needs for Psychological Services	Independent psychologists are needed and beneficial; they provide an objective perspective and a confidential relationship. Personal assistants often function as de facto psychologists.
	Assistant Training	Additional psychoeducation or training for assistants is suggested, but not to replace formal psychological services.
VII. Personal Assistant Challenges (Work Environment)	Financial Precarity	Low valuation of the work; low pay grades; difficult to support a family; seeking multiple jobs.
	Emotional Boundaries	Maintaining a "healthy boundary" is difficult due to daily close contact and emotional involvement, and a high risk of burnout.
	Legislative Stagnation	Legislative changes regarding the profession have been pending for years.
VIII. Technology Use	Technology for Independence and Interest	Technology is essential for individuals with writing limitations; improved QoL; some show no or minimal interest in technology.
	Social Connection	Technology is sometimes used to maintain social contact (e.g., Facebook, communicating with distant friends).

needs, discomfort, emotions, or requests verbally. Recognising signs is crucial, as "… in fact, the greatest emphasis is on nonverbal communication." (PA 1). Furthermore, personal assistants must "…know how to recognise certain signs." (PA 4). Individuals with CP are often hesitant to reveal their problems: "They are not always willing to say what the actual problem is." (PA 3). To adapt their approach, the personal assistant must possess a deep understanding of individuals with CP. As PA 5 said: "Essentially, it's about you, as his personal assistant, recognising what would help him most in that moment".

III. Activities and Motivation

Participants described motivation as a recurring challenge, particularly regarding participation in physical exercise, rehabilitation activities, social outings, and sometimes everyday functional activities such as leaving the home or engaging in structured daily routines. common difficulty is that individuals with CP are often unwilling to participate, viewing activities as pointless: "They don't want to cooperate because they are not prepared to." (PA 6). Personal assistants emphasised that their role is limited to encouraging: "We can encourage, but we cannot force." (PA 1). Personal assistants (PAs 1 and 5) described the use of distractions and environmental changes such as going outdoors, changing daily routines, engaging in conversation, listening to music, interacting with animals, or visiting community settings as strategies to improve mood and engagement. While mobility limitations exist, encouragement for exercise is prioritised: "It suits him very well, that we go swimming, go to fitness or exercise at home" (PA 6). Although interest can be variable, animals can be a powerful motivator for movement: "Animals help them a lot. They are quite a big stimulator for movement." (PA 1).

IV. Social Integration and Support

Participants emphasised that positive relationships play a protective role because individuals with CP are often aware of their physical differences and social limitations. Negative feelings appear when they feel unaccepted, as described: "If someone pushes them away, or if they feel unaccepted" (PA 6). Participants suggested that social isolation was often not the result of withdrawal by individuals with CP themselves, but rather uncertainty or discomfort among others about how to approach or interact with them: "They don't know how to approach her, and people are afraid of doing so." (PA 5). Making friends can dramatically improve communication and confidence: "He was previously quite isolated and only played by himself; he is now thriving." (PA 1). Some individuals experience severely restricted social environments: "Her social circle: it's me, her father and sometimes other personal assistance." (PA 6). Some are highly proactive and extroverted: "He knows how to include himself... he greets them and strikes up a conversation." (PA 1).

V. Systemic and Infrastructure Barriers

The urban environment and the educational system present major physical obstacles to achieving independence. Architectural limitations in educational facilities limit their choices. One of the personal assistants noted that the individual with CP chose their current faculty because "…it is one of the few faculties in our city with an elevator." (PA 5). Municipal infrastructure is frequently insufficient or dangerous: "The ramps in the city are catastrophic. Sidewalks are terribly inaccessible, dangerous" (PA 6). They mentioned an emphasis on the following areas: "sometimes the sidewalk is so narrow that physically we cannot walk side-by-side" (PA 6) and "City Park is a catastrophe. Those granite cubes... when you push a person in a wheelchair, you feel everything" (PA 1). Despite the existence of a system for accessible public transport, its practical implementation is problematic.

VI. Healthcare and Professional Support

Participants agreed that independent psychological support would be beneficial for service users. "I think the fact that they would have a psychologist would definitely be a very good change." (PA 6). An external psychologist can offer objectivity and confidentiality: She is an independent person, so it might be easier for her to tell her some things, seeing her once every 14 days or once a month." (PA 1). Assistants frequently take on the role of an informal therapist, leading to emotional strain: "Every assistant is, to some extent, a psychologist." (PA 1). This professional overlap contributes to high stress and burnout risk: "It leads to burnout among personal assistants too." (PA 1). While formal psychological services are preferred, supplementary training for assistants was suggested: "It would definitely not be foolish to have some psychoeducation or additional training." (PA 1).

VII. Technology Use

Participants reported that technology was essential for specific functions, particularly for service users with motor limitations, though general interest remains low among some individuals. "…she cannot write, so she is essentially tied to the computer." (PA 6). Despite its usefulness, many users show little interest in modern social technology. One individual "has everything from a computer, tablet, phone, but has no interest in it... " (PA 6). However, technology is selectively utilised for specific interests, such as library resources: "… for example, she goes to an online library." (PA 6).

VIII. Personal Assistant Challenges (Work Environment)

The profession is marked by financial instability and challenges in maintaining professional boundaries: "It will be difficult when one day I will have to say goodbye because of the financial situation." (PA 6). Another confirmed they needed secondary employment: "Without this [private nursing care], I would not be supporting my family. It's a big burden that you carry." Those closely involved in service users' daily lives, often beyond working hours, which contributes to emotional strain and burnout: "Today is the first free day that I have. And I had six or seven calls." (PA 1). Participants emphasised that changes to legislation and pay structures have been anticipated for many years, reflecting broader dissatisfaction and prolonged waiting for reform.

The conceptual model presented in Figure 1 was developed by the authors based on the themes identified through thematic analysis. The model illustrates how individual factors (emotional state, communication, motivation), relational factors (personal assistants and social networks), and structural factors (healthcare support, infrastructure, and policy context) interact to shape the daily experiences, participation opportunities, and quality of life of individuals with cerebral palsy.

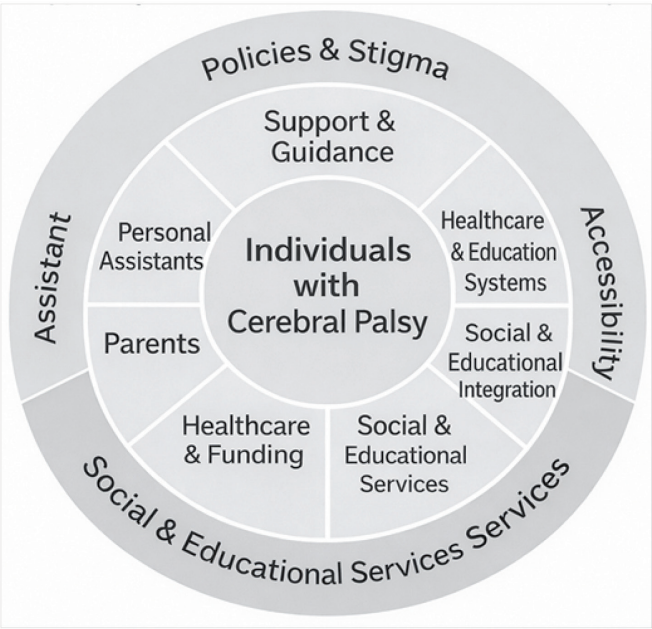

Figure 1. Conceptual model of the personal assistance ecosystem

Discussion with conclusion

This study provides insight into the experiences of personal assistants supporting individuals with cerebral palsy within the Slovenian context, highlighting the complex relationship between individual, relational, and structural factors that shape daily life, participation, and quality of life. The findings extend existing knowledge by demonstrating that while personal assistance has the potential to enhance independence and social inclusion, its effectiveness is mediated by emotional, environmental, and systemic constraints. A key finding relates to the variability in emotional and psychological states of individuals with CP, which significantly influences their motivation and engagement in daily activities. These findings align with research that emotional and psychological challenges in CP are often under-recognised, yet they significantly affect participation and QoL [18]. Our findings suggest that personal assistants play an important but limited role in facilitating engagement. While they actively encourage participation in physical, social, and daily activities, they are constrained by service users' fluctuating motivation and the ethical boundary that participation cannot be enforced. This indicates that engagement is not solely an individual responsibility but emerges from the interaction between personal capacity, support systems, and broader contextual factors. Communication appeared to be another critical dimension of personal assistance. This requires caregivers and assistants to rely on behavioral indicators [19]. Some personal assistants found technological tools indispensable for educational tasks and communication. This supports findings that digital tools can enhance independence and participation among people with physical disabilities [19]. Motivation for daily and physical activities was another challenge identified by participants. Personal assistants emphasised that small achievements (walking short distances, minimal physical activity) are important progress. These findings are consistent with research showing that participation in activities contributes to autonomy, competence, and well-being among individuals with CP [7]. Participants observed that individuals with CP are often excluded because others lack the confidence, knowledge, or willingness to interact with them. Similar findings are reported by Pashmdarfard et al. [8], who emphasised social and environmental barriers to social participation. As described in the focus group, supportive friendships reinforce the belief that social connectedness is an essential factor in psychological well-being. However, many have restricted social networks. Systemic and infrastructural barriers further complicate daily life. These limitations reduce opportunities for independence and participation, echoing international findings that inadequate infrastructure undermines QoL and increases caregiver strain [20]. In Slovenia, although personal assistance is formally established as a right, the findings suggest that its practical implementation is still evolving, particularly in relation to coordination with other support systems. Personal assistants are frequently described as acting as informal counsellors, a pattern also noted in studies of caregiver burnout, where emotional investment contributes significantly to stress and fatigue [21]. The challenges of the work environment raise concerns about professional sustainability. Participants described relying on secondary employment, difficulty balancing work/private life, and long-awaited legislative reforms. Research shows that caregiver burden is linked to financial strain and unclear professional expectations [22]. Consequently, the sustainability of personal assistance as a support model depends not only on user outcomes but also on the well-being and professional support of assistants themselves.

Practical implications

The findings of this study have several implications for practice. First, there is a need to strengthen training programs for personal assistants, particularly in communication, motivational strategies, and basic psychological support, while clearly maintaining professional boundaries. Second, integrating formal psychological services into the support system could reduce the emotional burden placed on assistants and improve outcomes for service users. Third, greater emphasis should be placed on interdisciplinary collaboration among healthcare, social services, and educational institutions to support more effective participation. Finally, improvements in infrastructure and public awareness are essential to reduce societal barriers and enhance inclusion, as personal assistants alone cannot compensate for systemic deficiencies.

Research implications

Future research should expand on these findings by including larger and more diverse samples of personal assistants across different regions and organisational settings. Comparative studies examining different models of personal assistance across countries could provide valuable insights into best practices. Additionally, research should include the perspectives of individuals with cerebral palsy to understand better the alignment between the support

provided and user needs. Longitudinal studies would also be beneficial for exploring how relationships, motivation, and participation evolve, as well as for assessing the long-term impact of personal assistance on quality of life.

Limitations of the study

This study has several methodological limitations that should be considered. First, the small sample size (n = 6) and the use of a single focus group limit the generalisability of the findings. Second, including participants who were also family members may have influenced responses, potentially introducing bias related to dual roles and emotional involvement. Third, data were collected within a single regional association, which may not fully reflect practice variability across Slovenia. Fourth, the absence of triangulation with other data sources (e. g., observations, user perspectives) limits the depth of interpretation.

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Nema sukoba interesa.

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Appendix 1: Focus group guide

Main questions:

1. Can you describe your experience working as a personal assistant for a person with cerebral palsy?
2. What are the main challenges you encounter in your daily work?
3. How do you communicate with the person you support, especially when they have difficulty expressing their needs?
4. What motivates or discourages users from participating in activities?
5. What barriers do individuals with cerebral palsy face in everyday life (e. g., environmental, social, institutional)?
6. What types of support do personal assistants need to perform their work effectively?
7. How does this work affect you personally and professionally?
8. What improvements would you suggest for the personal assistance system?