Exploration of strategies that promote resilience among caregivers in the field of deafblindness in Greece.

University of Groningen

MSc Pedagogical Sciences/Deafblindness

Year: 2023-2024

Name: Asteriou Ioanna

Student number: S5676452

Supervisors: Marja Cantell & Paul Hart

Second evaluator: Johannes Westberg

Total number of words: 9926

December 2024

Acknowledgements

First and foremost, I wish to thank the participants in this study. Their contribution enabled me to gain insight into the current situation in the field of deafblindness in Greece.

I am deeply thankful to my supervisors, Dr. Marja Cantell and Dr. Paul Hart. Your expertise and dedication have truly inspired me, and I feel fortunate to have had the opportunity to learn from you. Your guidance has not only strengthened my academic skills but also fostered my personal and professional growth.

In addition, I cannot mention Mrs. Erika Boers, my internship supervisor. Without her support and trust, completing this journey would not have been possible. Through our collaboration, I had the privilege of meeting individuals with deafblindness, their caregivers, and other professionals in the field. Mrs. Erika Boers gave me the opportunity to work alongside her, sharing her invaluable knowledge and feedback, but most importantly, her genuine care and compassion for people. Thank you for believing in me.

I would also like to extend my heartfelt gratitude to the academic professionals of the Master's program in Deafblindness at the University of Groningen. Their expertise and experience played a crucial role in expanding my horizons, deepening my understanding of the field of deafblindness. Furthermore, a sincere thank you goes to my fellow students, who have been a continuous source of support since the very beginning.

I am also deeply grateful to academic counselors Irene Niessen and Wouter van Egmond, who supported me during a very challenging moment in my life. Additionally, I wish to thank you Erwin Uildriks, who is responsible for the Thesis Support Group. The group members, with whom I shared common difficulties and thoughts, made this journey feel less isolating.

Moving on, I would like to thank my friends for their encouragement and support. Special thanks to Elena Leonoglou, Maria Takla, Vicky Kalaitzi, Anestis Andrikou, Despina Telioglou, and Dwra Kotsoni. Their constant love, understanding, and trust helped me overcome the most challenging moments of this journey.

Finally, I would like to extend my deepest gratitude to my family and my godmother, Elpida. Their love and unwavering support have been the foundation that allowed me to turn my dreams into reality.

> “I would rather walk with a friend in the dark, than alone in the light.”
>
> Heller Keller (n.d.)

Contents

Abstract

The present study aims to identify the challenges faced by Greek caregivers (informal and formal) when working or coexisting with individuals who are deafblind. The obstacles of deafblindness in Greece, such as limited services, insufficient training, and lack of expert experience, highlight the need to understand how caregivers navigate these barriers. Consequently, through this study, the strategies/coping mechanisms that caregivers employ to be resilient were examined. A mixed methods research design was applied to answer the main research question: How do caregivers define and describe the challenges that arise when they are supporting or communicating with people who are deafblind? An online survey with a self-designed and two standardized questionnaires was filled out by a group of 17 participants (mean age 39). The study revealed that the Greek caregivers experienced challenges in the areas of communication, health, emotion, and diversity in needs and characteristics. Three types of obstacles were reported, conduct of intervention, services issues, and training. Furthermore, the findings revealed moderate resilience and professional satisfaction levels among the caregivers, highlighting the necessity of tailored interventions and strategies to cope better with the practical and psychological conditions they face. Notably, the participants selected social coping as the most preferred mechanism (7 out of 17), followed by problem-focused coping as the next most preferred (5 out of 17). These results set the stage for further research into the relationships between resilience and quality of life among caregivers in the field of deafblindness, and offer added value to the investigation and enrichment of strategies that could be more effective than existing approaches.

Keywords: Greek Caregivers, challenges, strategies/coping mechanisms, deafblindness, resilience, questionnaires

1. Introduction

The present thesis explores various strategies that could ensure and promote resilience among Greek caregivers in the field of deafblindness. This specific research selection and content orientation is a result of various factors, as the landscape of caregiving for people who are deafblind in Greece is marked by numerous barriers. These barriers include a shortage of specialized services, insufficient training programs, lack of professional experience, and financial obstacles (Nellopoulou, 2021; Nikolaraizi et al., 2021). Furthermore, Zografou (2022) highlighted that Greek society is not aware of deafblindness, and that awareness is mostly limited to those who live with it. In 1992, in Athens, the capital of Greece, a group of families with children who were deafblind founded the Panhellenic Association of Deafblindness, named "ILIOTROPIO. This association remains the only organization in Greece focused on deafblindness. To this day, the Panhellenic Association of Deafblindness is supported by friends, professionals, and volunteers. Additionally, Athens has the only special school for students who are deafblind (Nellopoulou, 2021).

This study also examines the challenges experienced by caregivers, however its aim is not to focus on the possible negative aspects. Instead, it seeks to use this information as a fundamental basis to enhance their coexistence and cooperation for both sides, caregivers and people who are deafblind. In line with this, Hart (2010) argues that the partnership between caregivers and individuals with deafblindness is not linear, but dynamic and mutual. By understanding the challenges and needs of one group we can gain insights that help support the other, and vice versa.

The findings of this study are in line with those of other research conducted by both Greek and international academics investigating issues related to deafblindness and special needs populations. Recent studies focusing on the Greek context provide valuable insights. For instance, Nellopoulou (2021) investigated the availability of support services and the level of awareness regarding congenital deafblindness in Greece, incorporating the perspectives of academics, families, and professionals. The findings revealed that the majority of support services provided by the Greek government for individuals with congenital deafblindness are inadequate. Similarly, Papazafiri and Argyropoulos (2021) shed light on the experiences of Greek professionals working in various educational settings with children with deafblindness or multiple impairments. Their study highlighted the challenges faced by these professionals, including mainly the lack of experience and training in the field of deafblindness.

Furthermore, a study by Lembcke et al. (2016) focused on caregiver’s cognitive and emotional reactions to challenging behavior among individuals with deafblindness. It was among the first studies that examined the measurement of a communicative attribution to challenging behavior, considering various factors, such as the impact of attributions to stimulation, behavioral processes, environment, emotions, and biological basis. The outcomes of this study depicted that challenging behaviors of individuals with deafblindness can be caused by intense internal emotions and physical factors, such as insecurity, excitement, illness, and internal pain. Some other factors that increase the occurrence of challenging behaviors are related to unpleasant feelings towards the activity, the caregiver's demands, and when their routine is changed or interrupted. In addition, from the caregiver's side, the ways that they react to challenging behaviors are various. For example, some of them ignore the incident, others prefer to redirect the focus and attention of a person with deafblindness, and others try to communicate and calm the person with this behavior (Lembcke et al., 2016).

Resilience is also a concept that explores the skills and resources individuals may develop in response to challenging and transformative life events (Proctor, 2017). This study will examine the strategies employed by caregivers of individuals with deafblindness to sustain their resilience. In addition, this could form the basis for future research, aiming to investigate the correlation between resilience, the quality of their relationship, and communication between caregivers and people with deafblindness.

Last but not least, given these obstacles, the contributions of two significant Greek figures in the field of deafblindness, Kalliopi Karanikola and Michael Anagnos, are particularly relevant. Their pioneering work in education, advocacy, and social awareness played a crucial role in laying the foundation for current support structures. In this context, the challenges caregivers face today, including lack of resources and specialized training, mirror the struggles that these pioneers sought to address. Both Kalliopi Karanikola and Michael Anagnos are associated with organizations that provide information and support to individuals with deafblindness and their families. Furthermore, through the information presented below, we recognize the role of social networks as a "coping strategy" in promoting awareness, collaboration, and education on issues related to deafblindness.

2. Literature Review

2.1. Greek Pioneering Figures in the field of deafblindness

2.1.1. Michael Anagnos

The name of Michael Anagnos belongs to Greece, his fame belongs to the United States, but his service belongs to humanity." These words were marked by Guild, the Governor of Massachusetts, aiming to describe the loss to humanity at the death of Michael Anagnos (AHEPA History, n.d, para. 1).

According to Arnott (2022) Michael Anagnos, born in 1837 in Papingo, Greece, attended high school in Ioannina city before traveling to Athens to study Greek, French, Latin, and philosophy. His support for Crete led him to meet and connect with Samuel Gridley Howe who helped also the Greek Revolution. In addition, Howe, was the founding director of Perkins in the United States, the first school for children with cognitive and intellectual impairments (Goldstein, 2024).

After that, Howe encouraged Anagnos to travel to Boston. At 31, Anagnos arrived in the city and began working as a tutor for the Howe family while also teaching Greek to pupils at Perkins School and Boston colleges. Afterward, Michael Anagnos became the second director of Perkins Institution, focused on improving the printing department and expanding the organization's funding (Sanborn, 1907). His efforts to raise $100,000 for books for the blind and to establish a printing plant for braille and embossed books were among his first and most significant achievements. In fact, Anagnos wrote several reports and books, widely sharing his ideas and experiences about education for people who were blind through correspondence and school publications (Arnott, 2022).

In addition, he took care of the musical education of Perkins students because he believed that music could be a field of vocational rehabilitation for the blind. He adopted courses as well as pedagogical techniques for the optimal physical and mental development of pupils with deafblindness and operated programs for the employment of the blind in industry, intending to make the blind self-sufficient adults for the society (Metapedia, n.d.).He also focused on the need for a kindergarten for children who were blind younger than nine years old, and finally, he founded the first one outside Boston. Before that, the kindergarten legislation was available only for students nine years old or older as a requirement (Arnott, 2022).

"Mr. Anagnos became familiar with the whole history and method of instructing the deaf-blind, and was himself an ardent advocate of the articulating method for the deaf in general" (Sanborn, 1907, p. 13). His efforts to assist people with deafblindness have received international recognition, particularly for his collaborations such as with Helen Keller a girl with deafblindness and her teacher Anne Sullivan, a partnership in which Anagnos was responsible for the collaboration among these two women (Goldstein, 2024).

2.1.2. Kalliopi Karanikola

Kalliope Karanikola was born and raised in Athens (1924–2000). She studied in the field of agriculture. However, beyond her contributions to agriculture, she also participated in missions in Africa and Seoul. With her organizational talent, she greatly assisted in structuring the life of the mission. "Kalliopi offers and is offered" (Dimitriou, 2017, p.83)

In the last decade of her life, she decided to adopt a young boy who was deafblind and abandoned. Meanwhile, she traveled to Amerika, and Australia to enhance her knowledge in the field of deafblindness, aiming to support her son better. Kalliopi organized meetings with other families and experts to exchange knowledge and share updates on new skills and experiences she had learned from her travels (Dimitriou, 2017). In 1992, she invited the French psychologist Jacques Souriau, the director of the School for Deafblind in Poitiers, to Greece. He provided advice and planning for the teachers and visited the homes of each family to offer guidance to the parents. She also collaborated with the John Tracy Clinic, which provided services for families and children with hearing loss in Los Angeles, California (John Tracy Center, 2024). She took correspondence courses and sent letters to inform them about the progress of her son, Kosmas, with specialists actively responding to her updates (Dimitriou, 2017).

Additionally, Dimitriou (2017) mentioned that Kalliopi distributed leaflets containing theories, information, and experiences she had gained from the special centers she had visited, as well as brochures she collected that could be useful to others. In 1992, Kalliopi, along with other parents of children with deafblindness, they also founded the first association for people with deafblindness in Greece, called “ILIOTROPIO”. This initiative encouraged both Greek and international parents and professionals to support the cause, helping raise awareness and increase resources for people with deafblindness (Dimitriou, 2017; Nellopoulou, 2021).

In Dimitriou’s book, it is also mentioned that "She was always a proud and tireless mother to little Kosmas" (Dimitriou, 2017, p. *86*). In particular, there is a reference to Kalliope in relation to Kosmas that highlights her unconditional love and support. In January 2000, the traffic situation in Athens was very difficult due to a taxi strike. However, Kalliope used public transport to attend the doctor’s appointment she had scheduled for Kosmas. From the previous night, Kalliope had been experiencing intense pain caused by a heart attack. Yet, nothing stopped her from caring for the people she loved (Dimitriou, 2017).

2.2. Deafblindness (DB)

According to the World Federation of the DeafBlind (2018), deafblindness (DB) is a distinct disability, affecting 0.2% to 2% of the worldwide population. Similarly, the European Parliament (2004) recognized this condition as unique due to the symptoms of deafblindness and the challenges in defining it (Orfanos, 2004). Consequently, deafblindness is classified based on when the symptoms first appear and the degree of autonomic functioning in a person. Individuals with deafblindness have different degrees of hearing and sight impairment, leading to their categorization into two main groups (congenital and acquired). From a deafblind individual's perspective, whether this condition is congenital or acquired, three daily life challenges are common: obstacles in communication and social interaction, information gathering and spatial orientation, and unrestricted movement (Jaiswal et al., 2018).

In a letter to PanHellenic Association of DB in Greece named “ILIOTROPIO”, in 2018, psychologist Souriau mentioned, among other things, that deafblindness can easily be overlooked due to its rarity and the likelihood of being mistaken for other handicaps (PanHellenic Association of Deafblindness “ILIOTROPIO”, 2024). Deafblindness has numerous causes, such as infections, illnesses, and metabolic problems in newborns.

However, Usher Syndrome, a genetic condition, is considered the most frequent cause (Charmpatsis et al., 2023). Deafblindness presents profound challenges not only for those who experience it but also for their families, relatives, and the professionals who work and interact with them (Miles, 2008). The aforementioned data underline the importance of a caregiver's presence in the lives of people with deafblindness, as a multidimensional condition like this requires targeted care from educated and dedicated individuals (Boers, 2015).

2.3. Caregivers

A caregiver is an individual who assists another person by helping to meet their everyday needs. In this point, we can distinguish between informal and formal caregivers. Formal caregivers have received specific training and education in caregiving and are compensated for their services. On the other hand, informal caregivers, known as family caregivers, provide support and care to friends or family members, typically unpaid. A caregiver assists an ailing or vulnerable person, an elderly parent, another relative, or an unrelated person, usually in their home (Oh et al., 2024).

Being a caregiver is not always easy, and often comes with a variety of challenges. In more detail, throughout recent years, research has revealed the physical, emotional, and financial consequences for caregivers who ceaselessly cooperate and coexist with people in need, as well as their high levels of stress. These consequences might affect their quality of life (QoL) (Jia et al., 2021). The concept of QoL attempts to describe an individual’s or population’s well-being concerning all aspects of their life, both negative and positive, at a specific point in time (Glozman, 2004).

According to Ding et al. (2021), caregiving can sometimes lead to positive outcomes, such as feelings of satisfaction and emotional rewards from supporting family members. However, caregivers also face a high risk of experiencing psychological challenges and mood swings (Lloyd, 2016). There is a plethora of studies that focuses on the relationship between caregivers and people who are in need. Some prioritize studying professional, financial, and practical issues. In contrast, others focus on analyzing the feelings, the thoughts, and the overall experience of both parties involved. Ferraris (2023) examined this reciprocal relationship, highlighting that the interaction between caregivers and their close ones is an important factor in both parties' well-being. In particular, the findings showed that the carers had higher wellbeing results when they were supported by a collaborative network of friends and family which, in turn, positively impacts the care recipient. In addition, except for the external assistance and support, also for the caregivers the interaction among the people who cared was important, by making caregivers feel more connected to the care recipient, less stressed, and more willing to continue providing care, implying that there is a mutual benefit from these dynamics.

2.4. Caregivers and Deafblindness

In the domain of deafblindness, the term communication partners is often used to describe the role of caregivers. This term perhaps captures elements of the relationship between both communication partners and draws attention to the necessity of accommodating an individual’s varied communication needs so that multimodal ways of communication are considered, including a blend of spoken language, signs, gestures, and symbols (Cockerill, 2009). Indeed, creating communicative ways to achieve meaningful conversations with a person with deafblindness is the biggest challenge faced by communication partners (Boers, 2015).

These kinds of responsibilities, combined with a strong sense of duty, can be quite tiresome and even exhausting (Cejalvo et al., 2021). As a result, caregivers of people who are deafblind may face various challenges, including psychological pressure as well as social and economic difficulties (Arcous et al., 2024). However, one of the most common challenges for caregivers is understanding how to communicate meaningfully with a child who is deafblind (Miles, 2008).

The challenges caregivers face can be complex, but with targeted strategic methods, they can certainly be addressed (Miles, 2008). It is of great importance to provide social and psychological support. This kind of help provided to the caregivers is a fundamental step to decrease their stress and handle their physical or mental health issues by receiving professional assistance (Simmons, 2022). Of course, at the very same time, caregivers of people with deafblindess also have a lot of positive effects on their lives, as a result of their special bond with the people that they help and communicate with, thus obtaining happy feelings and meaningful moments (Damen et al., 2021).

The family is usually the first support system in children's lives; for this reason, it plays a crucial role in their overall development (Frosch et al., 2019). This is especially true for people with deafblindness, since a lot of them have additional cognitive and physical impairments and rely on the caregiver's support, depending also on the degree of disability and its type (Dammeyer, 2014). According to Arcous et al. (2024), the quality of life for a person with deafblinness is significantly impacted by the quality of support that they receive from their caregivers, the way that they communicate, and interact.

According to Hart (2010), to succeed in an equal and positive relationship between individuals with deafblindness and their communication partners, a common touchpoint needs to be created through mutual respect and trust. Based on "relationship's elements", both partners play a co-creative role, in developing a common way of communication when "both partners bring their complete selves to communicative exchanges" (Hart, 2010, p. 67). Through this collaborative approach, where both members actively influence each other, they can discover strategies and use their potential to adapt to and overcome challenges together in a supportive way.

2.5. Caregivers’ Resilience

An important factor for the wellbeing of the caregivers is their resilience. Particularly, the caregiver's resilience is related to their general ability to fulfill their duties without compromising their daily functioning or psychological health (Thurgood &Schuldt, 2013). As Raja and Ashrafi (2018) state, people who educate themselves on how to adopt healthy coping skills from an early age could have the ability to overcome problems effectively and enhance their resilience. Over the years, studies have revealed that teaching children a variety of coping strategies, such as seeking social support, practicing deep breathing, using humor, and engaging in problem-solving, etc., can improve their ability to manage stress effectively (Dalley & McMurtry, 2016; Hildenbrand et al., 2011; Yadav et al., 2020) .

However, resilience is a challenging term to define since a precise and straightforward identification of this term does not exist. Specifically, its definition as a construct can vary amongst individuals, organizations, societies, and cultures(Southwick et al., 2014). However, the American Psychological Association states that resilience refers to the ability of an individual to effectively cope with adversity and hardship in life, particularly by exhibiting mental, emotional, and behavioral adaptability and adjusting to internal and external demands. In addition to "bouncing back" from these challenging times, resilience can entail significant personal development (APA Dictionary of Psychology, 2018).

This study, however, will focus on the positive aspects of the coexistence of caregivers and people who are deafblind by exploring coping strategies and resources that could ensure caregivers' resilience in hopes of more effective interaction between them (Martens et al., 2017).

2.6. Resilience and Coping Mechanisms

The coping mechanisms are identified as the emotional meta-strategies, methods, and skills needed to cope with and adapt to stressful conditions (de la Fuente et al., 2021).In other words, they are strategies that indicate an essential element for the adjustment process to difficult situations(Sampogna et al., 2021). In fact, coping mechanisms are strategies such as meaning-focused, problem-focused, social coping, seeking social support, and emotion-focused that people employ to deal with stressful factors (Algorani & Gupta, 2023). Effective application of these coping mechanisms helps people become more resilient over time by enhancing their capacity to overcome challenges and obstacles (Sampogna et al., 2021). The relationship between coping strategies and resilience is mutually supportive. Macía et al., (2021) mention that resilience is a result of the application of effective coping mechanisms, and resilience allows individuals to employ these mechanisms in more adaptive ways (Booth & Neill, 2017).

3. Research purpose and questions

The objective of this study is to identify and display the challenges faced by Greek caregivers of individuals who are deafblind during their professional and personal duties. This study specifically aims to comprehend the potential impact of these challenges on caregivers' lives while also investigating the coping strategies they employ to maintain their resilience.

Finally, the present inquiry, with a focus on the Greek context, aims to enhance the existing research in the domain of Deafblindness by gaining insight into the strategies employed by professionals, family members, and relatives who coexist or work with people who are deafblind. Through this exploration, this study seeks to provide a basis for further research about the potential association between resilience and quality of life for caregivers and individuals with deafblindness.

3.1. Research Questions

How do caregivers define and describe the challenges that arise when they are supporting or communicating with people who are deafblind?

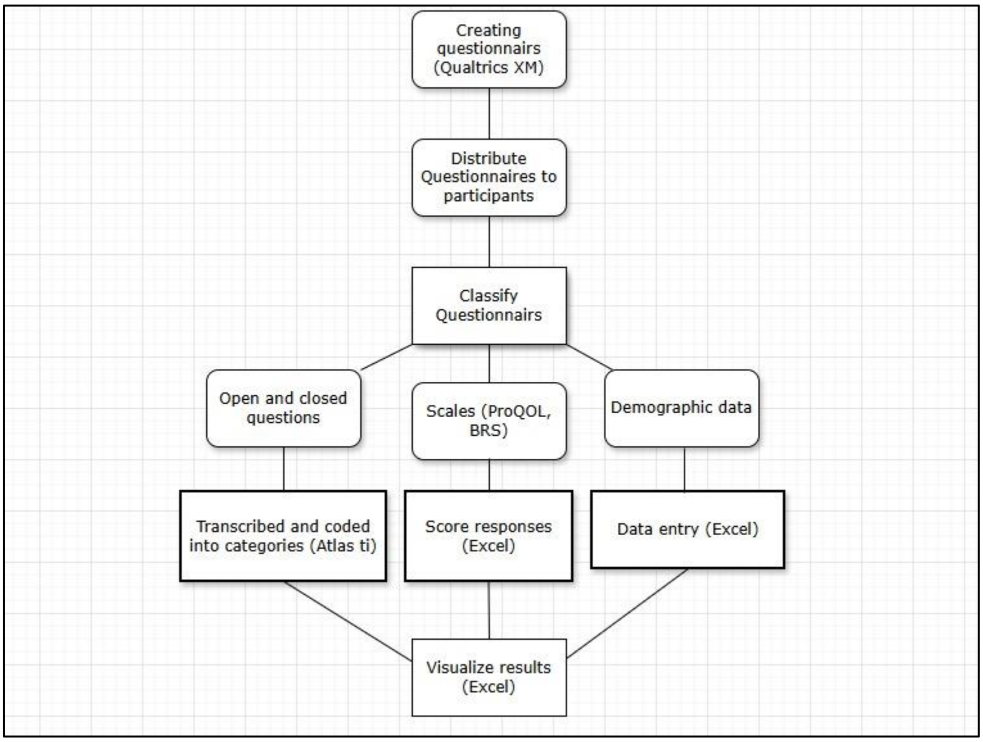
This then leads to the following sub-questions to further examine this topic:

1. What resilience strategies do caregivers apply while interacting with people who are deafblind?
2. In what ways do caregivers describe how strategies help them overcome challenges?
3. What changes can be made to support and strengthen resilience in caregivers, both psychologically and practically?

4. Methods

This chapter focuses on the methodology used to address the study's research question. The research design adopted is a cross-sectional one, with a mixed-methods approach. For the purpose of this research, data were collected from a questionnaire created by the researcher, that included open-ended and closed questions, standardized scales, and a

Figure 1. Flowchart illustrating the process of questionnaire creation, distribution, classification, data entry, and analysis.



sociodemographic questionnaire. Data analysis was conducted using ATLAS.ti 24 for qualitative data and Microsoft Excel for quantitative data, managing to identify key themes, patterns, and relationships. Ethical considerations, including informed consent and participant anonymity, were prioritized throughout the study. This methodology was selected to investigate caregivers' coping mechanisms when interacting with individuals who are deafblind in Greece and assess their ability to manage related demands. It explores caregivers’ definitions of caregiving and communication with deafblind individuals, as well as the relationship between these variables and the participants' resilience and their overall quality of life. The complete methodology is also shown in the flowchart in Figure 1.

4.1. Research Design

This study follows a cross-sectional research design and employs mixed methods to examine the challenges and coping strategies of caregivers working with individuals who are deafblind. Both qualitative and quantitative research tools were used, in order to combine the strengths of each research method (Denscombe, 2021).

Specifically, the primary data was extracted from three types of research tools. First, a self-designed questionnaire was used, incorporating both open-ended and closed questions. The open questions provide the participants with the ability to freely express themselves, decreasing the possibility of biased answers (Denscombe, 2021). Second, two pre- existing standardized scales were applied: the Professional Quality of Life Scale (ProQOL) (Stamm, 2010) and the Brief Resilience Scale (BRS) (Smith et al., 2008). Those were selected as secondary tools, that could give a more objective idea of the caregiver’s experience and help us make some observations (Burke et al., 2019). Lastly, a sociodemographic questionnaire was designed to collect background information, ensuring contextual understanding of participants' responses.

4.2. Procedure

Participants completed the entire survey online. To begin with, the participants were introduced to the general supporting information about the survey and the consent form that they had to fill in. Additionally, they were informed that their anonymity was ensured throughout the survey. However, the questionnaire included a section where participants could optionally provide their email addresses to receive a summary of the results when the study was completed. In the next steps, they answered the questions in the order described in the research design section. The survey took approximately 10 minutes to fill out.

Lastly, following the approval of the research proposal, the study was officially included in the list of student research of the Pedagogical and Educational Sciences, department at the Faculty of Behavioral Sciences, University of Groningen.

4.3. Participants

Regarding the sampling of this questionnaire, the participants consisted of caregivers from different deafblind institutions/schools in Greece, and a variable group of communications partners, including psychologists, educators, caregivers, occupational therapists, social workers, and family members/ relatives. The total number of participants was 17: two family members/relatives of individuals with deafblindness, eleven professional caregivers, and four other experts (a psychologist, a special education teacher, a social worker, and an occupational therapist). The participants' ages were between 27 and 60 years. Table 1 details the sample's demographics, including gender, age, education, etc. The educational level of the participants in the study was as follows: 1 participant held a High School diploma, 4 participants had a Bachelor's Degree, 10 participants possessed a Master's Degree, 1 participant had a Ph.D. or higher, and 1 participant listed their education level as "Other" (IEK).

Table 1. Demographics of the sample.

Demographic	n	%
Gender		
Male	4	24%
Female	13	76%
Age		
Group 1: 20-30	4	23%
Group 2: 30-40	6	35%
Group 3: 40-50	4	24%

Group 4: 50:60	3	18%
Education Level		
High School	1	6%
Bachelor's Degree	4	23%
Master's Degree	10	59%
Ph.D or higher	1	6%
Other	1	6%
Years of Experience		
Experience: 1-5	7	41%
Experience: 5-10	3	17%
Experience: 10-15	3	18%
Experience: 15-20	3	18%
Experience:More than 25 years	1	6%
Relationship		
Family member/relative	2	12%
Professional Caregiver	11	65%
Other: psychologist, social worker, special educator, ooccupational therapist	4	23%

4.4. Instruments

The platform used for the three questionnaires is Qualtrics.xm, which is simple in its use and easily distributed digitally. Furthermore, the use of Qualtrics.xm ensures the anonymity of participants, as it allows the researcher to collect responses without accessing personal data (Qualtrics XM, n.d.). Furthermore, the data from the questionnaires was analyzed by using the ATLAS.ti 24 software which can be applied to distinguish different codes, patterns and themes (Schebesta, 2018). Atlas.ti 24 is a software designed to help in qualitative data analysis, and can be used in various areas, such as engineering, education, healthcare and more. In general, a free demo version of ATLAS.ti is available for small-scale projects. If individuals need to upload more than 10 documents, they should use the demo version by purchasing a license key (Soratto et al., 2020).

4.4.1 Questionnaire developed by the researcher

In this part of the survey, the participants were invited to answer the following self-structured questions:

1) Do you use specific coping mechanisms (thoughts and behaviors used to manage stress in both internal and external situations) while interacting with people who are deafblind?
   This is a closed question. The participant could choose between the following answers: A) All (B-D) B) Problem-focused C) Emotion-focused D) Meaning- focused E) Social Copying C) Other
2) Could you please elaborate on your answer to Question 1 shortly, and give an example?

This is an open-ended question.

3) Which communication tools do you frequently utilize while being a caregiver?

This is a closed question. The participant could choose between the following answers: A) Sign Language B) Tactile Sign Language C) Haptic Signs D) Other

4) What kind of challenges do you face when you are supporting or communicating with people who are deafblind?

This is an open-ended question.

5) What specific barriers to communication do you face in your caregiving relationships with people who are deafblind, and could you elaborate on how and why you experience them?

This is an open question.

4.4.2. Standardized questionnaires

Professional Quality of Life Scale (ProQOL)

ProQOL is a thirty-item self-report questionnaire, that measures Burnout, Secondary Traumatic Stress, and Compassion Satisfaction in helping professionals. It takes approximately 5 minutes to fill out. A quantitative evaluation of the participants' professional quality of life will be obtained by having them assess their experiences on a Likert scale (scale from one to five). While higher scores on Burnout and Secondary Traumatic Stress may point to potential difficulties, higher scores on Compassion Satisfaction indicate a positive work experience(Stamm, 2010). Furthermore, ProQOL has been shown to have strong validity and reliability, making it a widely used tool in assessing the professional quality of life for various experts, such as nurses, child protection workers, psychologists, etc., (Boni et al., 2022; Geoffrion et al., 2019; Hegarty & Buchaman, 2021).

Each participant's score on the Compassion Satisfaction, Burnout, and Secondary Traumatic Stress subscales is grouped as follows: Low: Scores of 22 or less, Moderate: Scores between 23 and 41, High: Scores of 42 or more (Stamm, 2010).Concerning BRS, the analysis is conducted with items 3 and 5 are reverse-scored. The total score is calculated by adding the scores for all six items, and the average score is calculated by dividing the total score by the number of items. The scores are categorized into high resilience (above 4.0), moderate resilience (around 3.0), and low resilience (below 3.0).

For this study, an overall score was used to provide a comprehensive measure of the caregivers’ experiences. Moreover, professionals could find the scale helpful for self-monitoring their level of satisfaction and as a reminder to take care of themselves. In addition, service managers who want to promote employee well-being can also use ProQOL to monitor professional quality of life, in order to guide decisions regarding leave, workload, and other matters.

Brief Resilience Scale (BRS)

Smith et al. (2008) developed the 6-item Brief Resilience Scale (BRS). The six items measure a person's capacity for recovering from stress. The BRS was found to be valid and reliable across various groups and cultures, such as caregivers, students, patients etc., (Lai & Yue, 2014; Sánchez et al., 2021; Shukla et al., 2022). Resilience levels will be evaluated primarily by using the BRS as the outcome measure, with the scores ranging from

1 (strongly agree) to 5 (strongly disagree). In order to score the BRS, items 2, 4, and 6 are reverse coded, and then, the mean of the six items is calculated (Konaszewski et al., 2020). The higher the score, the greater the level of resilience. The scores are categorized into low resilience (1–2.99), moderate resilience (3–4.30), and high resilience (4.31–5).

4.5. Data Analysis

The data extracted from the closed and open-ended questions were analyzed with ATLAS.ti 24, which is mainly used for coding, categorizing, and identifying themes within qualitative data, such as interview transcripts, focus group discussions, and textual documents (Boya, 2023; Souto-Gómez et al., 2023). An important part of the analysis, to ensure clear and structured findings, was to categorize participants’ answers into codes, based on patterns and themes identified in the data. (Soratto et al., 2020). The data from the questionnaires revealed two code themes, challenges and coping mechanisms. Additionally, this software, the access to which was provided by the University of Groningen, was used to answer the main research question and the sub-questions, respectively. Microsoft Excel was utilized as well for data visualization. The following paragraphs aim to describe the analysis.

First of all, the researcher uploaded the seventeen documents from the questionnaires to ATLAS.ti 24. Additionally, the study’s key questions were written into ATLAS.ti 24, which were used to classify the responders’ answers based on the answer’s underlying theme. For an accurate classification using ATLAS.ti 24, the researcher first highlighted words or sentences from each response that were considered key points, and then made quotations, based on the main research question and sub-questions, that served as the themes.

Following the creation of themes, codes were formed. The researcher studied the themes and identified repeating patterns or trends within and among the themes. For instance, many participants mentioned barriers related to communication, while others discussed emotional difficulties and other challenges. Based on the discovered patterns, the coding categories were formed, reflecting the challenges and coping mechanisms participants face:

Challenges identified were transcribed into the following codes (Appendix 2): Communication Barriers, Health Issues, Emotional Obstacles, Diversity in the needs and characteristics, and Intervention, Training, and Service Obstacles/Limitations. Throughout the analysis, it was important to examine whether these challenges were not only related to the experiences of individuals with deafblindness, but also whether they reflected the caregivers' difficulties. For instance, one participant's response addressed the hurdle they faced due the individual's with deafblindness struggle to communicate their needs. Caregivers seemed to struggle as well with communication, as the caregiver lacked knowledge of alternative communication methods and did not know how to communicate with the person with deafblindness. The codes helped at identifying and clarifying such distinctions.

However, in the case of coding coping mechanisms, additional literature was used to support the final code selection (Appendix 3). Lazarus and Folkman's transactional theory of stress and coping categorized coping in problem-focused and emotion focused coping (Lazarus & Folkman, 1984; Stanisławski, 2019). Algorani and Gupta (2023) added two more categories to the ones Lazarus and Folkman identified, meaning-focused and social-coping. Those four categories are also used for the purpose of this research.

The coding process was reviewed to ensure the themes accurately reflected the participants' responses. Additionally, university seminars (Qualitative Research Group) on coding techniques and supervisor feedback ensured the correct use of those analysis techniques in this step.

The final step was to identify the perspective from which these responses were given. In that regard, Microsoft Excel was used to calculate the scale scores and the average scores of the two standardized questionnaires (Smith et al., 2008; Stamm, 2010), as well as for the demographic data. Excel was also used to create tables and graphs, achieving a clear and appealing visualization of the results.

5. Results

In this section, the results of the coding process, the scale scores, and the sociodemographic data from the questionnaires will be presented.

5.1. Challenges

Based on participants' responses regarding the challenges, the following categories were identified: 1) communication challenges from the perspective of the person with deafblindness and the caregiver, 2) health-related issues, 3) emotional difficulties, 4) diversity in needs and characteristics, and 5) challenges of intervention, training obstacles and services' limitations.

1) Communication Challenges
a) The perspective of individuals with deafblindness.

Caregivers report challenges in expressing, understanding, and receiving information, identifying and expressing personal needs and their emotions, and overall perception of their environment from the perspective of individuals with deafblindness. One participant remarked, "The most common issue is that they struggle to communicate their emotions and needs".

b) The perspective of caregivers.

From the caregiver's perspective, communication challenges include personal difficulties, knowledge of alternative communication methods, consistent use of these methods between caregivers, and difficulty in giving clear instructions. One participant mentioned that "The main obstacle is often the difficulty in understanding instructions when giving a directive or command to the person. In Greece, intervention efforts, such as teaching sign language and Braille, are still lagging. Additionally, alternative communication methods, such as Applied Behavior Analysis (ABA), are not widely known among educators, and consequently, not among students either".

2) Health issues

In relation to the second category: health issues, the participants identified challenges for people with deafblindness, including physical pain, comorbidities, variations in sensory impairments, and limited cognitive abilities. One participant listed this as follows: "Not all individuals with deafblindness have the same ability to understand tactile programs that would help them perceive time, people, and other projects. Some children have cerebral palsy, which makes it difficult for them to use their hands for producing signs, etc.". In addition, another respondent pointed out that "Aggressive behaviors arise when they experience physical pain".

3) Emotional Obstacles

Caregivers reported various emotional obstacles faced by people with deafblindness, including barriers to emotional expression, feeling misunderstood, and unwillingness to participate in activities. Other challenges include anxiety, social anxiety, low mood, refusal or lack of motivation, passiveness, and psychological-emotional struggles. For instance, one participant explained, "Psychological-emotional challenges, mainly due to lack of communication. The person shows refusal and lack of motivation to communicate because they feel misunderstood."

From the perspective of professionals and caregivers, emotional obstacles include a lack of patience and feelings of anxiety. One participant shared, "I can’t communicate. I am not familiar with individuals who are deafblind, and there is no interaction. Similarly, another participant mentioned, "I find it difficult to be patient while waiting for them to understand the concepts." Another important factor, according to participants' responses, was the difficulty families had in fully accepting the condition of deafblindness. One participant pointed out, "The family plays an important role in the design and success of the program. Sometimes, there is partial acceptance of deafblindness. Lack of acceptance or denial of the situation".

4) Diversity

The fourth category is about the challenges referenced to diversity in the needs and characteristics of the individuals with deafblindness. These consist of heterogeneity, regarding the chronological age, and communication level of the person with deafblindness. The need for individualized approaches is also emphasized, along with variations in learning capacities, sensory impairments, and individual strengths and weaknesses. Specifically, one participant's response was, "Deafblindness has a vast range of conditions, and each individual has unique strengths and weaknesses". Additionally, one participant identified accessibility barriers regarding people with deafblindness," difficulties accessing various points in the city we live in".

5) Intervention, training and services’ limitations

The last category of challenges is about the barriers that both caregivers and people with deafblindness experience in relation to the intervention process, training, and services. One participant shared, "Many people with deafblindness have comorbidities that create additional problems in conducting interventions, whether in open or enclosed spaces." Furthermore, some participants referenced obstacles related to cooperation among schools and families. For example, one participant noted, "Lack of cooperation between school and family". In addition, families face difficulties in selecting the proper school or organization for their people. One participant also stated, "One challenge is selecting the proper support framework, as each individual is unique and faces specific difficulties. Additionally, intervening and training the individual's family can be quite demanding."

Similarly, the caregivers pointed out that there was an inconsistency in the communication method, or the efforts shown toward individuals with deafblindness. For instance, one participant mentioned, "Everyone must communicate consistently with each student, using the communication method that has been chosen as the most suitable for them. This approach must be upheld by all professionals, at home, and in other settings. This is often a challenge". Other caregivers mentioned unwillingness or ignorance by educators and caregivers to apply or adopt particular interventions.

Notably, the deafblind population is often overlooked in several areas, including access to alternative communication systems, the provision of tailored services, and involvement in decision-making about their own lives. One participant characteristically said that "Students with deafblindness and multiple impairments often grow up learning to be passive. Developing the ability to make choices and advocate for their own needs and desires is a skill that must be taught, yet it is frequently overlooked".

It is of interest to mention as well that many caregivers and educators were unfamiliar with the unique needs of individuals with deafblindness. These challenges are made worse by limited learning opportunities, inadequate implementation of communication strategies, and time constraints, which were among the clearest issues reported. One participant in the study noted, "The child may not have received services tailored to their specific needs, resulting in insufficient support and limited learning opportunities. Consequently, this lack of intervention can lead to restricted intellectual and cognitive development".

5.2. BRS and ProQOL Scales

Table 2 demonstrates the results of the two questionnaires. In the table were gathered the information for each participant about the BRS and the ProQOL, as the total average. The ProQOL scale categorizes scores into three subscales: Compassion Satisfaction, Burnout, and Secondary Traumatic Stress, with the following groupings: Low (22 or less), Moderate (23–41), and High (42 or more) (Stamm, 2010). Similarly, the BRS scores indicate levels of resilience, classified as high (above 4.0), moderate (around 3.0), and low (below 3.0). This suggests the challenges caregivers face and the potential impact these challenges have on them.

Table 2. Questionnaire results.

Subject Number	**(ProQOL)**		**(BRS)**
1	CS:45, B:20, STS:24	High Satisfaction, Low Burnout, Moderate STS	4,1
2	CS:41, B:20, STS:22	Moderate Satisfaction, Low Burnout, Low STS	3,6
3	CS:41, B:19, STS:24	Moderate Satisfaction, Low Burnout, Moderate STS	4
4	CS:35, B:26, STS:24	Moderate Satisfaction, Moderate Burnout, Moderate STS	3,1
5	CS:24, B:35, STS:30	Moderate Satisfaction, Moderate Burnout, Moderate STS	2,5
6	CS:49, B:16, STS:23	High Satisfaction, Low Burnout, Moderate STS	3,3
7	CS:29, B:31, STS:33	Moderate Satisfaction, Moderate Burnout, Moderate STS	3
8	CS:39, B:25, STS:29	Moderate Satisfaction, Moderate Burnout, Moderate STS	3,5
9	CS:49, B:17, STS:22	High Satisfaction, Low Burnout, Low STS	4,5
10	CS:45, B:27, STS:20	High Satisfaction, Moderate Burnout, Low STS	3
11	CS:41, B:20, STS:20	Moderate Satisfaction, Low Burnout, Low STS	3,8
12	CS:32, B:29, STS:31	Moderate Satisfaction, Moderate Burnout, Moderate STS	3,1

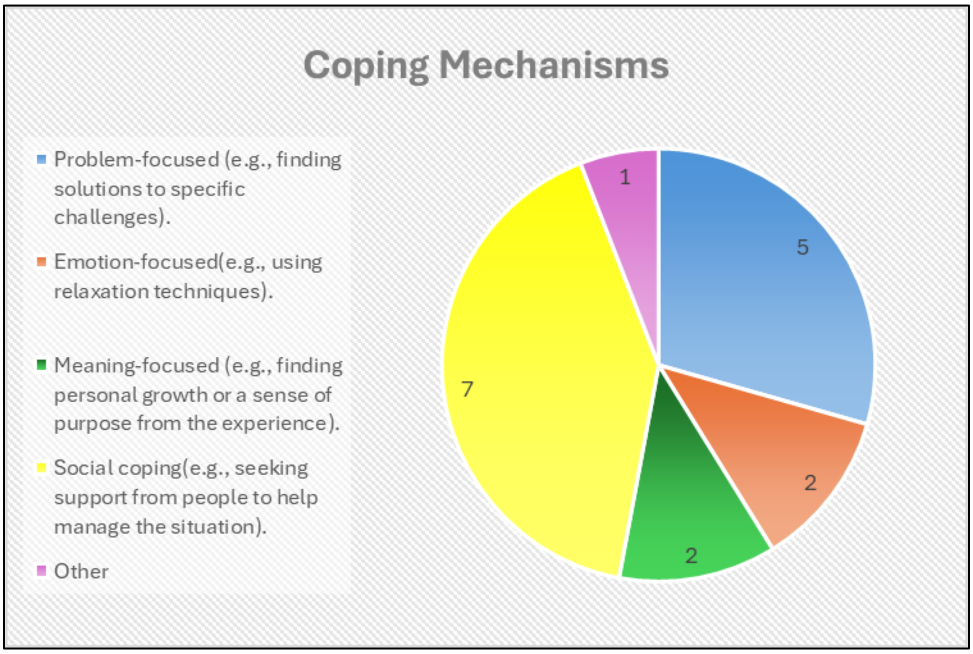
13	CS:45, B:25, STS:33	High Satisfaction, Moderate Burnout, Moderate STS	2,1
14	CS:39, B:32, STS:35	Moderate Satisfaction, Moderate Burnout, Moderate STS	2,5
15	CS:35, B:31, STS:30	Moderate Satisfaction, Moderate Burnout, Moderate STS	2,1
16	CS:40, B:26, STS:22	Moderate Satisfaction, Moderate Burnout, Low STS	3,5
17	CS:38, B:26, STS:24	Moderate Satisfaction, Moderate Burnout, Moderate STS	3,5
		AVERAGE	AVERAGE
		(CS): 39.24 Moderate	3.25
		(B): 25.00 Moderate	Moderate Resilience
		(STS): 26.24 Moderate	

The scores on both scales depict that, on average the caregivers' BRS is 3.25% (moderate). Similarly, the ProQOL scores indicate moderate levels across the dimensions of Compassion Satisfaction (CS): 39.24, Burnout (B): 25.00, and Secondary Traumatic Stress (STS): 26.24 as well.

5.3. Coping Mechanisms

First, the author of this study presents a pie chart (Figure 2) that displays the number of participants who chose specific coping mechanisms. In addition, Table 3 provides more detailed information on how these strategies are defined.

Figure 2. Coping Mechanisms based on the author's questionnaire.



Most participants (7 out of 17) chose social coping as their most preferable coping mechanism which was referenced in bseven ways. In more detail, it seems that the caregivers help them to seek support and help from other caregivers, their psychologist, and an interdisciplinary team. Furthermore, it is important also to gather information and discuss it with the family of the person who is deafblind, together with being in contact with relatives and acquaintances.

The next more popular response is problem-focused (5 out of 17), a fact that depicts that caregivers prefer to find immediate solutions when a difficulty arises. In fact, they try to give attention to all facial and body expressions of the individual who is deafblind. Other caregivers place great emphasis on trying to determine the potential reasons that affect the person with deafblindness, identifying also the communication signs, and ruling out the physical pain. Another tactic is to be present and attentive to the person in order to make the necessary behavioral adjustments.

The other two strategies received an equal number of responses. Specifically, the emotion-focused strategy was selected by 2 participants. Notably, these participants mentioned techniques such as promoting relaxation for people with deafblindness and using joy and distraction techniques to relieve stress. However, one caregiver, chose as an option "other": The caregiver prefers to use a combination of techniques, recognize the potential of individuals with deafblindness, and build a therapeutic connection with them.

Table 3. Coping mechanisms and examples based on the open and closed questionnaires. The most frequently mentioned example is on the top of each column. The examples that were mentioned several times are written in bold.

Coping Mechanisms	**Description**
Problem-focused	**- Attempting communication** - Absence of physical pain **- Being more present, observant, and prepared** - Finding solutions to specific challenges - Clarifying the issue - Finding the appropriate approach - Identifying external triggers
	- Attention **- Attention to facial and body language** **- Patience and attentiveness** - Understanding non-verbal communication and sign language - Efforts to alleviate or stop dysfunctional behavior - Observation of expressions - Behavioral adjustment
Meaning-focused	- Purpose reminder - Building self-confidence in individuals with deafblindness
Social coping	**- Assistance from the person's caregivers** - Communication with the organization's psychologist and social worker - Communication with educators - Family guidance - Interviews with the individual's parents and therapists
	- Support from relatives/acquaintances **- Help from caregivers** - Discussion with personal psychologist **- Collaboration with the interdisciplinary team**
Emotion-focused	- Promoting relaxation and joy - Distraction techniques for stress relief
Other	- Use of combined techniques - Recognizing the potential of individuals with deafblindness - Building a therapeutic connection

6. Discussion

Throughout the years, several studies have explored the challenges and the impact felt by caregivers, including families and siblings of people who have impairments. However, the literature about the impact of the challenges and the strategies employed by the caregivers of those with deafblindness remains limited. This research aimed to shed light on obstacles encountered and the coping mechanisms that Greek caregivers (family members/relatives and professionals) utilize to maintain resilience.

Specifically, a review by Arcous et al. (2024) worked on finding the social and psychological consequences of deafblindness for siblings. In more detail, some of the consequences are based on their feelings, such as the emotion of anxiety, embarrassment, neglect, resentment, and jealousy. At the same time, obstacles were observed also in relation to forming relationships outside for the family system, and to avoid, or have limited interaction with their siblings with deafblindness. These aspects, except for anxiety, were not identified in that study, however it could be interesting to explore those aspects of psychological and social impact on Greek caregivers as well, by including family members/relatives and professionals.

Additionally, some of the findings by Lembcke et al. (2016) regarding how caregivers manage the challenging behaviors of individuals with deafblindness align with those of the current study. For example, in both studies, some caregivers choose to divert the individual's attention and focus, while others try to communicate and calm them. Additionally, challenges related to individuals with deafblindness exhibiting difficult behaviors when experiencing internal pain or when they dislike an activity are in line with the findings of this study. However, according to Lembcke et al. (2016), two other factors correlated with challenging behaviors in individuals with deafblindness are the demands placed on caregivers and when their routine is changed or interrupted. In the present study, participants did not mention these two factors.

Furthermore, the findings of this study also reveal that some participants found it challenging to collaborate with other caregivers, due to inconsistencies in the practices followed. In addition, participants face a major challenge when interacting with individuals with deafblindness, because they are not always trained in communication methods specifically designed for this population. These findings align with the work of Papazafiri and

Argyropoulos (2021), who highlight that some Greek professionals who work in therapeutical and educational settings with students who have deafblindness typically have a special education background but lack of targeted knowledge on this domain. In fact, only 8.7%. of the professionals who had specialization in these areas. Consequently, the findings showed that the professionals believed they were unprepared to evaluate, train, plan, and carry out inclusion programs for the students with deafblindness.

Similarly, Nellopoulou (2021) highlights a significant gap in Special Education training in Greece. Her findings shed light on Greek legislation in this field. Specifically, according to Greek law, professionals with degrees in Braille and Greek Sign Language can work in primary Special Education schools for students with deafblindness. Furthermore, students in Special Education programs may never learn about congenital deafblindness unless they choose a specific course during their studies. In this context, all three studies, highlight the same need for modifications in training, and the importance of ongoing professional development and regular updates to their skills to effectively meet the needs of individuals with deafblindness.

In relation to the outcomes from both scales, the findings show that, on average, the caregivers exhibit moderate resilience and a moderate professional quality of life. However, caused to the limited sample of the participants, these findings might not fully represent the broader situation in caregiving in Greece, in the field of deafblindness. Nevertheless, we can use this information in a way to provide some recommendations.

Notably, the majority of participants reported 5–10 years of working experience in the field of deafblindness. The years of their work experience could correlate with their percentages of BRS and ProQOL respectively. In other words, this could suggest that we may notice these scores change over time. In addition, their moderate scores may also be influenced by the kind of strategies that caregivers use to cope with the challenges of working with people who are deafblind to help or maintain their resilience and quality of life. Hence, this could, in turn, help to prevent possible circumstances of burnout and stress for caregivers.

On the other hand, the findings of Papazafeiri and Argyropoulos (2021) show that professionals in the field of Special Education often experience higher levels of anxiety and burnout, especially in the early years of their careers, compared to general education professionals. Additionally, they appear to show tendencies to leave their profession.

Meanwhile, a study by Poejo et al. (2024) focused on resilience in patients and family caregivers who living with someone who has congenital disorders of glycosylation and showed that the family caregivers showed higher resilience coping scores when they received professional support or had contact with families that experience the same condition or with individuals who have similar or same health issues, compared to unsupported individuals. Through these results and based also the Greek caregivers' answers about the necessity of having help from other colleagues, professionals and deafblind's family, we could suggest that with targeted interventions based on social coping mechanisms could enhance coping skills and improve the overall quality of life.

Similarly, another study tried to find the relationship between the professional quality of life, burden, suppressive mechanisms, and resilience of the caregivers (Merlo et al., 2021).In particular, there was a negative correlation between resilience and compassion satisfaction but a positive relationship with secondary traumatic stress and burnout. Through this study it is supposed that it would be possible that caregivers who have high levels of Compassion Satisfaction are already content with their jobs and do not need to build more resilience to deal with stress or difficult situations. On the other hand, Burnett & Wahl (2015) support that the resilience can be positively linked to burnout and Secondary Traumatic Stress, as caregivers build resilience to cope with challenges.

Based on the aforementioned points, it is essential to mention a study by Zografou (2022) that explored the quality of life of Greek individuals with acquired deafblindness, providing valuable insights into their experiences. The findings revealed that, despite the lack of state support, participants reported having a good quality of life, trying to be independent. Furthermore, the study highlighted their positive attitude, personal strength, and willpower, which can be understood as effective coping strategies.

In summary, the findings indicate that the resilience levels and the quality of life are affected by many factors. These include the working background, years of experience, the relationships between caregivers and the individuals they work with or coexist with, and the strategies applied by the caregivers and the people with deafblindness. These factors, among others, should be taken into consideration in order to gain a broader understanding and provide the necessary support and assistance for both parties.

With regard to the selection of strategies, it is important to note that the participants in this study selected emotion-focused coping mechanisms, using strategies that were aimed at supporting the person with deafblindness, rather than focusing also on their own well-being. For instance, they would use distraction techniques to relieve the stress of the individual with visual and hearing impairments. In that sense, their answers suggest that they do not take practical actions towards helping themselves. Consequently, it is recommended that the caregivers receive training regarding their emotional awareness, needs, and soothing techniques, such as mindfulness, meditation, open dialogue, etc. (Anderson et al., 2017; Rambo, 2013).

The open dialogue is a principle that we find mainly in the systemic family therapy (Wampler & McWey, 2020). As Papadioti-Athanasiou and Softa-Nall (2018) mentioned creating a supportive environment through open dialogue, allows the people to express their true feelings and thoughts while also noticing their behavioral patterns. This process can help them release emotional difficulties and potentially adopt new attitudes and behaviors. In this way, an atmosphere of mutual respect, understanding, and empathy can be fostered among members.

Furthermore, as it appears from the answers given regarding the challenges and the copying mechanisms, other factors such as the working environment and the relationship with their colleagues, and family members, play a significant role. On that note, apart from focusing only on the person who is deafblind, it is important to take action regarding the organization of the working places and the relationships and communication between employees.

To sum up, this data could inform potential strategies within which the caregivers might use them as a prompt for self-care and, at the same time, provide the organizations with insights to facilitate policy alterations and decision-making to enhance working conditions.

Some participants found it challenging to collaborate with other caregivers, as well as the inconsistency in practices followed between caregivers. Additionally, the caregivers do not receive specialized training regarding the care of people with deafblindness. Within this framework, it is suggested that it could be helpful if the caregivers participate in trainings, seminars, and workshops regarding the caregiving techniques and stay up to date with the current methods.

Finally, at this point, both Michael Anagnos and Kalliope Karanikola, through their work and contributions in the field of deafblindness, collaborated with experts such as teachers, psychologists, families of individuals with deafblindness, and the individuals themselves. Their efforts were aimed at helping people with deafblindness and their families, by distributing books and pamphlets to provide information, knowledge, and raise awareness. At the same time, they focused on the potential of individuals with deafblindness, rather than the obstacles they face. Finally, they worked hard to integrate people with deafblindness more actively into society. The methods and measures they utilized align with the findings of this study, where participants selected social coping strategies as the most preferable. This highlights the importance of seeking assistance from colleagues, psychologists, or the families of individuals with deafblindness. Additionally, the findings also point to the need for ongoing education, training workshops, and collaborations to better support those working with the deafblind community.

7. Recommendations, Limitations and Future Research

As a systemic psychotherapist and now in my new role as an educationalist / orthopedagogue in the domain of deafblindness, I believe it is crucial for experts to convey the importance of listening to both families and also to caregivers and address the challenges they face, aiming for a more comprehensive holistic approach for all members.

Parental-Family Intervention (PFI), is a clinically based approach designed to equip family members/ relatives and caregivers with the skills needed to manage the stressors of everyday life and raise a child with significant challenges (Durand, 2021). This approach is grounded in the concept that parental self-efficacy directly and indirectly influences child behavior. In practice, Mcintyre (2008) mentioned that by offering parent training support to families who have children with developmental disabilities, the outcomes showed reduced negative child-parent interactions and child behavior problems. Hence, Greek professionals could made aware of such interventions for positive behavior support (PBS) to caregivers of individuals with deafblindness.

Another significant method is the Contact intervention program, developed by Janssen et al., (2003) for the domain of deafblindness. This intervention aimed to enhance daily interactions between children who are deafblind and their educators, caregivers, and family members. Interaction coaches specifically instructed teachers to recognize the children's cues and adjust their behaviors, utilizing video analysis as a primary tool. Respectively, in the future, if specialist training can provide, such tools could be applied also in Greece. Similar interventions such as High-Quality Communication (HQC) investigated by Damen et al. (2015) in which video feedback is used to facilitate reflective learning and strategy development among families and professionals, could be applied to enhance communication dynamics and promote meaningful interactions for Greek children with CDB.

Another suggestion for the supportive and diagnostic services and experts could be groups that include all the parties (professional caregivers, family members/relatives, experts and people with acquired deafblindness). The participants could have the chance to learn how to work more efficiently with each other and develop strategies to deal with psychological and practical challenges that may arise in the interaction. In addition, individuals with acquired deafblindness have the right to take part in expressing their needs, sharing experiences, and influencing the decisions that affect them, thus determining their appropriate support needs. The family, friends of the people with deafblindness could also express their experiences related to deafblindness, so as to co- create a common interactive space.

Through this process, all the participants have the opportunity to investigate new or alternative strategies that could assist them to strengthen communication and collaboration among them, via mutual understanding and sharing. This collaboration can also be used as an occasion for awareness of deafblindness, creating a greater impact on Greek society, communicating the results and benefits, perhaps through a workshop and social media.

To sum up, it is essential to consider the perspectives of both individuals with deafblindness and their caregivers to foster an inclusive environment that benefits everyone involved.

Limitations

While this study attempted to shed light on the perspective of caregivers, in Greece. Nevertheless, this approach did not come without limitations.

Firstly, while the number of participants in the study may be considered limited, valuable insights can still be gained. One of the reasons that the participants were limited might be that the questionnaires were distributed online, and therefore they might not have reached enough people. Additionally, the online form might have not been appealing to some potential participants, especially those of older ages, as they might not be as familiar with technology, or maybe did not feel comfortable sharing this information online. Also, caregivers, especially those family related, might have very limited personal time to participate.

An additional limitation would be that the answers of the participants might have been influenced by several factors. This topic might be quite sensitive for some participants, which could have made them less objective. For instance, in Greece caregiving family members are considered an “obligation” and it is more socially accepted (Evason, 2019; Stavrianou et al., 2018). As a result, talking about the difficult aspects of it might cause feelings of shame or guilt. On this account, it might have been helpful to have an additional question regarding the type of relationship that the family caregivers had with people with deafblindness, to explore if there are significant differences in the participants' answers regarding the challenges they face and the strategies they utilize, depending on the type of person with deafblindness they care for.

Although the research included the sub-question 'In what ways do caregivers describe how strategies help them overcome challenges?', the data collected in this study did not provide sufficient details to answer this fully. While participants mentioned some strategies they use, they did not explain how these strategies help them overcome challenges.

Lastly, we did not have any information regarding the type of deafblindness that the caregivers were dealing with, whether it was acquired or congenital. This type of information might have provided more insight regarding the difficulties that the caregivers are facing. Moreover, it might have been helpful to include a question regarding the type of education/information that the caregivers have received, as it might not have been the same for everyone, and consequently to observe if this could be an indicator /factor that affects the caregivers’ resilience levels.

Future Research

In the long run, when comparing the Greek data with data from other countries we can begin to understand what kind of role resilience plays in the perceptions of life, and quality of life in caregivers in the domain of deafblindness.

Meanwhile, the findings show that people who had high or moderate resilience levels, tend to report a better quality of life respectively. There seems to be a link or a correlation there. So future research could actually observe and measure this relationship in practice settings to examine its dynamics. This research in the field of deafblindness could prove helpful for offering targeted support methods and programs to both parents, siblings of people who are deafblind, and the professionals in this domain.

Moreover, this data, or similar data, could be used to explore whether families suffer more stress than professionals. It is well known that most professional organizations provide access to debriefing strategies, supervision sessions on a monthly basis, counseling, and all of those support practices (Snowdon et al., 2017). On the other hand, according to Nellopoulou (2021) and Rotarou (2018) families and siblings in Greece experience numerous barriers to receiving help from support services sector and social supports. In particular, they do not have easy access to support due to their financial situation, there are only few institutions and they have long waiting lists and limited available spots. Hence, exploring this difference among the professionals and the family and siblings of individuals with deafblindness may could take into consideration and design prevention measures and tailored strategies to support them more effectively.

8. Conclusion

To sum up, this study highlights the strategies and the challenges that caregivers face in the field of deafblindness in Greece. Despite experiencing the challenges, with regard to the service limitations, the emotional and communication barriers (from both caregivers' and the individuals' with deafblindness side), and issues about diversity, the caregivers had moderate resilience and moderate levels across the three dimensions of Professional Quality of life: Compassion Satisfaction, Burnout, and Secondary Traumatic Stress as well. This fact might be a result caused by the employment of coping mechanisms such as social interaction and problem-solving, etc., which they rely on to address challenges effectively.

Targeted interventions like collaborative workshops, caregiver training, and emotional support networks are suggested to address these obstacles. Historical figures such as Michael Anagnos and Kalliope Karanikola highlight the significance of advocacy, collaboration, and innovation in developing the field of deafblindness' caregiving.

Future studies could explore how resilience and quality of life are connected for caregivers, taking into consideration available support systems, different types of deafblindness, caregiver role, years of engagement, and their educational level. By considering these factors, it is possible to enhance both caregiver resilience and the quality of support offered to individuals with deafblindness, as both sides have a bidirectional influence on each other.

9. References

AHEPA History. (n.d.). Michael Anagnos (1837—1906). Retrieved December 7, 2024, from https://ahepahistory.org/biographies/Michael-Anagnos-Anagnostopoulos-1837-1906.html

Algorani, E. B., & Gupta, V. (2023). Coping Mechanisms. In StatPearls. StatPearls Publishing. http://www.ncbi.nlm.nih.gov/books/NBK559031/

Anderson, F. G., Sweezy, M., & Schwartz, R. (2017). Internal family systems skills training manual: Trauma-informed treatment for anxiety, depression, PTSD & substance abuse (1–1 online resource (159 pages)). PESI Publishing & Media; WorldCat. http://public.eblib.com/choice/PublicFullRecord.aspx?p=6253997

APA Dictionary of Psychology. (2018). Resilience. https://dictionary.apa.org/

Arcous, M., Potier, R., & Dumet, N. (2024). Psychological and social consequences of deafblindness for siblings: A systematic literature review. Frontiers in Psychology, 15. https://doi.org/10.3389/fpsyg.2024.1102206

Arnott, J. (2022, December 15). Michael Anagnos. Perkins School for the Blind. https://www.perkins.org/michael-anagnos/

Boers, E. (2015). Beyond the eyes: The development of a dynamic assessment procedure to measure the communication potential of people with congenital deafblindness. [Thesis fully internal (DIV), University of Groningen], University of Groningen]. 978-90-367-7725-4

Boni, R. L., Dingley, C., & Reyes, A. (2022). Measuring Professional Quality of Life in Nurses: A Realist Review. Clinical Journal of Oncology Nursing, 26(3), 318–323. https://doi.org/10.1188/22.CJON.318-323

Booth, J. W., & Neill, J. T. (2017). Coping strategies and the development of psychological resilience. Journal of Outdoor and Environmental Education, 20(1), 47–54. https://doi.org/10.1007/BF03401002

Boya, K. S. (2023). Who Qualifies to Manage the Church? Exploring Historical and Biblical Accounts of Management and Agency Theories in Not-For-Profit Organisation (NPO) Sector in Gauteng, South Africa. Studia Historiae Ecclesiasticae, 18 pages-18 pages. https://doi.org/10.25159/2412-4265/12340

Burke, S. L., Burgess, A., & Cadet, T. (2019). Utilizing evidence-based assessment instruments to detect well-being and distress in English- and Spanish-speaking caregivers of individuals affected by dementia. Dementia, 18(6), 2062–2084. https://doi.org/10.1177/1471301217739095

Burnett, H., & Wahl, K. (2015). The Compassion Fatigue and Resilience Connection: A Survey of Resilience, Compassion Fatigue, Burnout, and Compassion Satisfaction among Trauma Responders. International Journal of Emergency Mental Health and Human Resilience, 17, 318–326. https://doi.org/10.4172/1522-4821.1000165

Cejalvo, E., Martí-Vilar, M., Merino-Soto, C., & Aguirre-Morales, M. T. (2021). Caregiving Role and Psychosocial and Individual Factors: A Systematic Review. Healthcare, 9(12), Article 12. https://doi.org/10.3390/healthcare9121690

Charmpatsis, C., Sarris, D., Zaragas, H., & Papadimitropoulou, P. (2023). Case Study: A psychoeducational intervention program in children with deafblindness. European Journal of Special Education Research, 9. https://doi.org/10.46827/ejse.v9i1.4704

Cockerill, H. (2009). Communication. In E. Bower (Ed.), Finnie's Handling the Young Child with Cerebral Palsy at Home (Fourth Edition) (pp. 227–242). Butterworth-Heinemann. https://doi.org/10.1016/B978-0-7506-8810-9.00018-6

Dalley, J. S., & McMurtry, C. M. (2016). Teddy and I Get a Check-Up: A Pilot Educational Intervention Teaching Children Coping Strategies for Managing Procedure-Related Pain and Fear. Pain Research and Management, 2016(1), 4383967. https://doi.org/10.1155/2016/4383967

Damen, S., Janssen, M. J., Ruijssenaars, W. A. J. J. M., & Schuengel, C. (2015). Intersubjectivity Effects of the High-Quality Communication Intervention in People With Deafblindness. The Journal of Deaf Studies and Deaf Education, 20(2), 191–201. https://doi.org/10.1093/deafed/env001

Damen, S., Schuengel, C., Ruijssenaars, W., & Janssen, M. J. (2021). Comparison of Social Validity Ratings With the Effects of a Video-Feedback Intervention for Communication Partners of Individuals With Deafblindness. Frontiers in Education, 6. https://doi.org/10.3389/feduc.2021.578969

Dammeyer, J. (2014). Deafblindness: A review of the literature. Scandinavian Journal of Public Health, 42(7), 554–562. https://doi.org/10.1177/1403494814544399

de la Fuente, J., Santos, F. H., Garzón-Umerenkova, A., Fadda, S., Solinas, G., & Pignata, S. (2021). Cross-Sectional Study of Resilience, Positivity and Coping Strategies as Predictors of Engagement-Burnout in Undergraduate Students: Implications for Prevention and Treatment in Mental Well-Being. Frontiers in Psychiatry, 12. https://doi.org/10.3389/fpsyt.2021.596453

Denscombe, M. (2021). The good research guide: Research methods for small-scale social research projects (Seventh edition). Open University Press, McGraw Hill; WorldCat.

Dimitriou, N. (2017). “Apo tin Helen Keller stin Kalliopi Karanikola: Symvoli stin istoria tis ekpaidefsis ton tyflokofon stin Ellada”[From Helen Keller to Kalliopi Karanikola “Contribution to the History of the Education of Deafblind People in Greece”]. https://deafblind-hellas.gr/index.php/home/from-helen-keller-to-kalliopi-karanikola

Ding, Y., Fu, X., Liu, R., Hwang, J., Hong, W., & Wang, J. (2021). The Impact of Different Coping Styles on Psychological Distress during the COVID-19: The Mediating Role of Perceived Stress. International Journal of Environmental Research and Public Health, 18(20), Article 20. https://doi.org/10.3390/ijerph182010947

Durand, V. M. (2021). Supporting Families with Children Who Display Severe Challenging Behavior. Research and Practice for Persons with Severe Disabilities, 46(3), 199–207. https://doi.org/10.1177/15407969211019802

European Parliament. (2004). Declaration of the European Parliament on the Rights of Deafblind People. https://www.europarl.europa.eu/doceo/document/TA-5-2004-0277_EN.html

Evason. (2019, January 1). Greek—Family. Cultural Atlas. https://culturalatlas.sbs.com.au/greek-culture/greek-culture-family

Frosch, C. A., Schoppe-Sullivan, S. J., & O’Banion, D. D. (2019). Parenting and Child Development: A Relational Health Perspective. American Journal of Lifestyle Medicine, 15(1), 45–59. https://doi.org/10.1177/1559827619849028

Geoffrion, S., Lamothe, J., Morizot, J., & Giguère, C. (2019). Construct Validity of the Professional Quality of Life (ProQoL) Scale in a Sample of Child Protection Workers. Journal of Traumatic Stress, 32(4), 566–576. https://doi.org/10.1002/jts.22410

Glozman, J. M. (2004). Quality of Life of Caregivers. Neuropsychology Review, 14(4), 183–196. https://doi.org/10.1007/s11065-004-8158-5

Goldstein, K. D. (2024). Education as spectacle: Helen Keller and the impossible performance of blindness at the Perkins Institution. Paedagogica Historica, 60(4), 634–645. https://doi.org/10.1080/00309230.2024.2367151

Hegarty, D., & Buchaman, B. (2021, November 29). Psychologist Norms for the Professional Quality of Life Scale (ProQOL). NovoPsych. https://novopsych.com.au/news/psychologist-norms-for-the-professional-quality-of-life-scale-proqol/

Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011). Coping With Pediatric Cancer: Strategies Employed by Children and Their Parents to Manage Cancer-Related Stressors During Treatment. Journal of Pediatric Oncology Nursing, 28(6), 344–354. https://doi.org/10.1177/1043454211430823

Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M., & Finlayson, M. (2018). Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. PloS One, 13(9), e0203772. https://doi.org/10.1371/journal.pone.0203772

Janssen, M. J., Riksen-Walraven, J. M., & Van Dijk, J. P. M. (2003). Contact: Effects of an Intervention Program to Foster Harmonious Interactions between Deaf-Blind Children and Their Educators. Journal of Visual Impairment & Blindness, 97(4), 215–229. https://doi.org/10.1177/0145482X0309700403

Jia, Y., Shi, J., Sznajder, K. K., Yang, F., Cui, C., Zhang, W., & Yang, X. (2021). Positive effects of resilience and self-efficacy on World Health Organization Quality of Life Instrument score among caregivers of stroke inpatients in China. Psychogeriatrics, 21(1), 89–99. https://doi.org/10.1111/psyg.12635

John Tracy Center. (2024, December 19). John Tracy Center, The leading diagnostic and education center for children with hearing loss. John Tracy Center. https://www.jtc.org/

Kennedy, A. (2022). Child Guarantee National Action Plans Targets, EU funding and governance. https://www.europarl.europa.eu/RegData/etudes/BRIE/2022/734003/IPOL_BRI(2022)734003_EN.pdf

Konaszewski, K., Niesiobędzka, M., & Surzykiewicz, J. (2020). Validation of the Polish version of the Brief Resilience Scale (BRS). PLoS ONE, 15(8), 1–16. https://doi.org/10.1371/journal.pone.0237038

Lai, J., & Yue, X. D. (2014). Using the Brief Resilience Scale to Assess Chinese People's Ability to Bounce Back From Stress. SAGE Open, 4. https://doi.org/10.1177/2158244014554386

Lazarus, R. S., & Folkman, S. (1984). Stress, Appraisal, and Coping. Springer Publishing Company.

Lembcke, H., Ask Larsen, F., & Janssen, H. (2016). Influence of causal attributions on Emotional and Behavioral Reactions of care workers towards challenging Behavior among persons with deafblindness. Journal of Deafblind Studies on Communication, 2(1), 22–44.

Lloyd, A. (2016). Caregivers: Practices, challenges and expectations. In Caregivers: Practices, Challenges and Expectations (p. 148).

Macía, P., Barranco, M., Gorbeña, S., Álvarez-Fuentes, E., & Iraurgi, I. (2021). Resilience and coping strategies in relation to mental health outcomes in people with cancer. PLOS ONE, 16(5), e0252075. https://doi.org/10.1371/journal.pone.0252075

Martens, M. A. W., Janssen, M. J., Ruijssenaars, W. A. J. J. M., Huisman, M., & Riksen-Walraven, J. M. (2017). Fostering Emotion Expression and Affective Involvement with Communication Partners in People with Congenital Deafblindness and Intellectual Disabilities. Journal of Applied Research in Intellectual Disabilities, 30(5), 872–884. https://doi.org/10.1111/jar.12279

Mcintyre, L. (2008). Parent Training for Young Children With Developmental Disabilities: Randomized Controlled Trial. American Journal of Mental Retardation : AJMR, 113, 356–368. https://doi.org/10.1352/2008.113:356-368

Merlo, E. M., Sicari, F., Frisone, F., Alibrandi, A., & Settineri, S. (2021). Burden and professional quality of life of caregivers: The clinical role of suppression and resilience. Life Span and Disability, 24(1), 55–83.

Metapedia. (n.d.). Μάικλ Ανάγνος—Metapedia. Retrieved December 7, 2024, from https://el.metapedia.org/wiki/%CE%9C%CE%AC%CE%B9%CE%BA%CE%BB_%CE%91%CE%BD%CE%AC%CE%B3%CE%BD%CE%BF%CF%82

Miles, B. (2008). Overview on Deaf-Blindness. https://www.nationaldb.org/media/doc/Overview-Deaf-Blindness_a.pdf

Nellopoulou, D. (2021). A survey on the available services and awareness of Congenital Deafblindness in Greece: The perspectives of families, professionals and academics [Master's Thesis]. University of Groningen.

Nikolaraizi, M., Argyropoulos, V., Papazafiri, M., & Kofidou, C. (2021). Promoting accessible and inclusive education on disaster risk reduction: The case of students with sensory disabilities. International Journal of Inclusive Education, 1–15. https://doi.org/10.1080/13603116.2020.1862408

Oh, E., Moon, S., Chung, D., Choi, R., & Hong, G.-R. S. (2024). The moderating effect of care time on care-related characteristics and caregiver burden: Differences between formal and informal caregivers of dependent older adults. Frontiers in Public Health, 12, 1354263. https://doi.org/10.3389/fpubh.2024.1354263

Orfanos, P. (2004). Odigos ekpaideftikon se themata tyflokofosis kai proteinomeno analitiko programma gia tin anaptyxi tis epikoinonias[Teacher's Guide on Issues of Deafblindness and Proposed Curriculum for the Development of Communication]. [Text]. http://repository.edulll.gr/edulll/handle/10795/989

PanHellenic Association of Deafblindness "ILIOTROPIO",. (2024). I tyflokofosi stin Ellada[Deafblindness in Greece]. https://deafblind-hellas.gr/index.php/home/deafblindgr

Papadioti-Athanasiou, V., & Softa-Nall, L. (2018). Scholes Oikogeneiakis—Systimikis Therapeias [Schools of Family—Systemic Therapy]. ΤΟΠΟΣ (ΜΟΤΙΒΟ ΕΚΔΟΤΙΚΗ). https://www.politeianet.gr/books/9789604992553-sullogiko-topos-motibo-ekdotiki-scholes-oikogeneiakis-sustimikis-therapeias-289065

Papazafiri, M., & Argyropoulos, V. (2021). Epangelmaties kai paidia me pollaples anapiries i tyflokofosi: Synchrones prokliseis kai protaseis [Professionals and Children with Vision and Multiple Disabilities or Deafblindness: Contemporary Challenges and Recommendations]. Education Sciences, 2021(2), Article 2. https://doi.org/10.26248/.v2021i2.1535

Poejo, J., Gomes, A. I., Granjo, P., & dos Reis Ferreira, V. (2024). Resilience in patients and family caregivers living with congenital disorders of glycosylation (CDG): A quantitative study using the brief resilience coping scale (BRCS). Orphanet Journal of Rare Diseases, 19, 98. https://doi.org/10.1186/s13023-024-03043-x

Proctor, C. (2017). Positive Psychology Interventions in Practice. Springer.

Qualtrics XM. (n.d.). Qualtrics XM - Experience Management Software. Qualtrics. Retrieved December 15, 2024, from https://www.qualtrics.com/

Raja, S., & Ashrafi, J. R. (2018). The PTSD Survival Guide for Teens: Strategies to Overcome Trauma, Build Resilience, and Take Back Your Life. New Harbinger Publications. http://ebookcentral.proquest.com/lib/rug/detail.action?docID=4819715

Rambo, A. H. (2013). Family therapy review: Contrasting contemporary models (1–1 online resource (xxix, 277 pages)). Routledge; WorldCat. http://site.ebrary.com/id/10596363

Rotarou, E. S. (2018). Greece Fact Sheet on Social Care & Support Services Sector for Persons with Disabilities. https://easpd.eu/fileadmin/user_upload/Factsheets/EASPD-Greece_fact_sheet_v2.pdf

Sampogna, G., Del Vecchio, V., Giallonardo, V., Luciano, M., Albert, U., Carmassi, C., Carrà, G., Cirulli, F., Dell'Osso, B., Menculini, G., Nanni, M., Pompili, M., Sani, G., Volpe, U., Bianchini, V., & Fiorillo, A. (2021). What Is the Role of Resilience and Coping Strategies on the Mental Health of the General Population during the COVID-19 Pandemic? Results from the Italian Multicentric COMET Study. Brain Sciences, 11(9), Article 9. https://doi.org/10.3390/brainsci11091231

Sanborn, F. B. (with American Printing House for the Blind, I.). (1907). Michael Anagnos, 1837-1906. Wright and Potter Printing Co. http://archive.org/details/michaelanagnos1800fran

Sánchez, J., Estrada-Hernández, N., Booth, J., & Pan, D. (2021). Factor structure, internal reliability, and construct validity of the Brief Resilience Scale (BRS): A study on persons with serious mental illness living in the community. Psychology and Psychotherapy, 94(3), 620–645. https://doi.org/10.1111/papt.12336

Schebesta, H. (2018). Content Analysis Software in Legal Research: A Proof of Concept Using ATLAS.ti. Tilburg Law Review, 23(1–2). https://doi.org/10.5334/tilr.1

Shukla, R. S., Ghogare, A. S., & Patil, P. S. (2022). Relationship between the caregiver burden and the resilience among primary caregivers of individuals suffering from schizophrenia attending tertiary care rural hospital from central India: A cross-sectional observational study. Medical Science, 26(120), 1. https://doi.org/10.54905/disssi/v26i120/ms56e2005

Simmons, M. (2022). A Guide to the Mental Health of Children and Young People: Q&A for Parents, Caregivers and Teachers. Cambridge University Press. https://doi.org/10.1017/9781911623908

Smith, B., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The Brief Resilience Scale: Assessing the Ability to Bounce Back. International Journal of Behavioral Medicine, 15, 194–200. https://doi.org/10.1080/10705500802222972

Snowdon, D. A., Leggat, S. G., & Taylor, N. F. (2017). Does clinical supervision of healthcare professionals improve effectiveness of care and patient experience? A systematic review. BMC Health Services Research, 17, 786. https://doi.org/10.1186/s12913-017-2739-5

Soratto, J., Pires, D. E. P. de, & Friese, S. (2020). Thematic content analysis using ATLAS.ti software: Potentialities for researchs in health. Revista Brasileira De Enfermagem, 73(3), e20190250. https://doi.org/10.1590/0034-7167-2019-0250

Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C., & Yehuda, R. (2014). Resilience definitions, theory, and challenges: Interdisciplinary perspectives. European Journal of Psychotraumatology, 5(1), 25338. https://doi.org/10.3402/ejpt.v5.25338

Souto-Gómez, A.-I., Talavera-Valverde, M.-Á., Márquez-Álvarez, L.-J., & García-de-la-Torre, M.-D.-P. (2023). Occupational Therapy and Professional Identity: Narratives of Professionals Through Life History. Study Protocol. International Journal of Qualitative Methods, 22, 16094069231195155. https://doi.org/10.1177/16094069231195155

Stamm, B. (2010). The Concise ProQOL Manual: The concise manual for the Professional Quality of Life Scale , 2 nd Edition.

Stanisławski, K. (2019). The Coping Circumplex Model: An Integrative Model of the Structure of Coping With Stress. Frontiers in Psychology, 10, 694. https://doi.org/10.3389/fpsyg.2019.00694

Stavrianou, A., Kafkia, T., Mantoudi, A., Minasidou, E., Konstantinidou, A., Sapountzi-Krepia, D., & Dimitriadou, A. (2018). Informal Caregivers in Greek Hospitals: A Unique Phenomenon of a Health System in Financial Crisis. Materia Socio-Medica, 30(2), 147–152. https://doi.org/10.5455/msm.2018.30.147-152

Wampler, K. S., & McWey, L. M. (2020). The Handbook of Systemic Family Therapy (1st ed.). John Wiley & Sons, Ltd. https://doi.org/10.1002/9781119438519

World Federation of the DeafBlind. (2018). WFDB Global Report 2018 – WFDB. https://wfdb.eu/wfdb-report-2018/

Yadav, M., Malar Kodi, S., & Deol, R. (2020). Effect of Preoperative Educational Schedule on Anxiety and Coping Mechanism Among Children and Their Parents: A Randomized Controlled Trail. Journal of Pediatric Surgical Nursing, 9(4), 127–135. https://doi.org/10.1097/JPS.0000000000000260

Zografou, M. R. (2022). Exploring the Quality of Life of people with Acquired Deafblindness in Greece [Master's Thesis, University of Groningen]. https://gmwpublic.studenttheses.ub.rug.nl/1502/

10. Appendices

Appendix 1. Consent Form

Dear Participants,

You are invited to participate in Asteriou Ioanna's Master's Thesis entitled "Exploration of strategies that promote resilience among caregivers in the field of deafblindness."

The study is being conducted as part of the University of Groningen's "MSc in Deafblindness" at the Faculty of Behavior and Social Sciences.The research is listed as one of the student projects at the Ethics Committee of the University of Groningen's Pedagogical and Educational Sciences. The project is co-supervised by Dr. Marja Cantell and Dr. Paul Hart.

Study's goal: The study aims to investigate the coping mechanisms employed by caregivers while working with individuals who are deafblind in Greece. It seeks to assess the extent to which caregivers can manage the demands associated with interaction with the deafblind. The research explores the definitions and descriptions provided by caregivers regarding caring and communicating with the deafblind. Additionally, the study examines the relationship between these variables and the participants' self-perceived resilience, as well as their overall quality of life.

The survey has closed and open questions and takes about 10 minutes to fill out.

Anonymity and Confidentiality. This survey ensures participants anonymity; it is conducted online, and the respondents cannot be identified through their answers or any other means. The researchers will not be able to access the participants' IP addresses, nor are any email addresses collected.

Contact Details & Information. The people who are responsible for this project are the student and researcher Asteriou Ioanna (who can be contacted via email on i.asteriou@student.rug.nl), and the project supervisors Dr. M. Cantell and Dr. Paul Hart (who can be contacted via email on m.h.cantell@rug.nl and/or phart@sensescotland.org.uk).

Consent:

By participating in this study, you indicate that:

●You have read the information about the research and had enough opportunity to ask questions about it.

●You understand what the research is about, what is being asked of you, the potential consequences of participation, how your data will be handled, and your rights as a participant.

●You understand that participation in the research is voluntary. You choose to participate of your own free will. You can stop participating at any moment without needing to explain why. Stopping will have no negative consequences for you.

I have read the above information, and consent to participate in this survey:

Yes, I consent

No, I do not consent

I am interested in receiving the final results of the study by giving my email address (this will not compromise my anonymity or confidentiality)

Appendix 2.

Coding with Atlas24.ti

Table 1- Challenges reported by caregivers

Communication Barriers	Health Issues	Emotional Obstacles	Diversity in needs and characteristics	Intervention, Training, and Service Obstacles/Limitations
Person with deafblindness • Barriers to Accessing Information • Conceptual Confusion • Difficulty in Descriptive Language • Expression of Needs • Difficulty understanding / receiving information • Expression Difficulty • Comprehension Difficulty • Conceptual understanding • Identification of Personal Needs • Distraction of attention • Limited vocabulary • Absence/lack of Meaning • Unfamiliar Environment • Limited channels of expression and communication • Lack of communication • Perception of the world **Professionals/Caregivers** • Alternative Ways of Communication • Consistency in the communication method professionals • Inconsistent Communication Methods • Unfamiliar Environment • Personal Difficulty • Instructions Barriers • Lack of Knowledge of Alternative Communication • interaction	• Comorbidities • Health Issues • Physical Pain • Variations in Sensory Impairments • Limited Cognitive Abilities	**Person with deafblindness** • Emotional Expression Barriers • Feeling Misunderstood • Unwillingness of participation • anxiety • Social Anxiety • Lack of Mood • Refusal, lack of motivation • Passiveness • Psychological-emotional challenges **Professionals/Caregivers** • Lack of Patience • Partial acceptance • Anxiety • Lack of acceptance	• Diversity in Communication Level • Diversity in chronological age • Heterogeneity • Variations in Sensory Impairments • Stigma • Integration • Differentiation of Strengths and Weaknesses • Variations in Learning Capacity • Vast Range • Personalization/Individualization • Negative Perception • Accessibility	• Assessment Difficulties • Consistence of effort • Lack of cooperation between school and family • Consistency in the communication method professionals • Training of Family • Unfamiliarity with deafblindness • Selection of organization • Neglect of Decision-Making Education • Specific Training • Intervention Conduct • Unwillingness/ Ignorance of Educators and Caregivers • Inconsistent Communication Methods • Lack of Tailored Services • Selection and establishment of alternative communication systems • Services Barriers for Deafblind Population • Limited Learning Opportunities • Limited Progress in Communication Interventions • Limited Time • Lack of Knowledge of Alternative Communication

Appendix 3.

Coding with Atlas24.ti

Table 2- Coping mechanisms reported by caregivers

Problem-focused (e.g., finding solutions to specific challenges).	Meaning-focused (e.g., finding personal growth or a sense of purpose from the experience)	Social coping (e.g., seeking support from people to help manage the situation)	Emotion-focused (e.g., using relaxation techniques).	Other
• A solution to a specific problem • Absence of physical pain • Identifying External Triggers • Attempting of communication • Clarifying the issue • Finding the Appropriate Approach • Being More present, observant, and prepared • Attention • Attention to facial and body language • Patience and Attentiveness • Understanding of non-verbal communication and Sign Language • Effort to Alleviate or Stop Dysfunctional Behavior • Observantion of expressions • Behavioral Adjustment	• Purpose Reminder • Built self-confidence in individuals with deafblindness	• Assistance from the person's caregivers • Communication with the psychologist and social worker of the organization • Communication with educators • Family's guidance • Interviews with the individual's parents and therapists • Support from relatives/acquaintances • Help from caregivers • Discussion with my personal psychologist • Collaboration with the interdisciplinary team	• Promoting Relaxation and Joy • Distraction Techniques for Stress Relief	• Usage of techniques combination • Recognizing Deafblind Potential • Therapeutic Connection