

PERSPECTIVES OF MOTHERS ON THE QUALITY OF LIFE OF CHILDREN WITH EPIDERMOLYSIS BULLOSA AND THEIR PARENTS

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Abstract: *The aim of the study was to gain insight into some domains of the quality of life of children with epidermolysis bullosa and their parents from perspectives of mothers. Semi-structured interview was used as method for data collection with six mothers of children with epidermolysis bullosa. Thematic analysis was a method of analysing data. The results show that the quality of life of parents of children with epidermolysis bullosa is determined by parents' good health, job satisfaction and received support from different sources, as well as the family's financial well-being and their limited possibilities of participating in leisure activities. The quality of life of children with epidermolysis bullosa is determined by the children's affiliation to the community, poorer health condition of children, children's abilities to perform certain everyday activities, as well as appropriate support from the formal support system. It is clear that this rare disease affects the quality of life of all family members. Families of children with epidermolysis bullosa need informational, practical, emotional, and financial support from informal and formal support system, especially from highly specialized and well networked professionals.*

Keywords: *epidermolysis bullosa, children with epidermolysis bullosa, parents of children with epidermolysis bullosa, quality of life, domains of quality of life*

INTRODUCTION

Persons with rare diseases (RD) are often socially excluded, especially those whose diagnoses have been determined as one or less cases per 100,000 people (Croatian Association for Rare Diseases, 2021). In terms of the overall population, RD afflict a small number of people, with around 6,000-8,000 RD diagnosis (Eurordis, 2022; Orphanet, 2022). There are currently around 300 million persons with RD in the world, including about 30 million in Europe, i.e., a prevalence of 5 persons per 10,000 citizens in Europe (Eurordis, 2022; Orphanet, 2022). RD are most often chronic and progressive genetic diseases that can appear in childhood (50-75%) (Eurordis, 2022; Lenderking et al., 2021) and/or in adulthood (50%) (Lenderking et al. 2021). Most RD are incurable, however, medicines and appropriate medical care can improve the quality of life (QOL) and prolong the life expectancy of persons

with RD. Persons with RD face different symptoms and slowness in developing treatment, lack of necessary diagnostics, prevention, therapy and development of medicines (Eurordis, 2022; Lenderking et al., 2021; Richter et al., 2015). The lack of the relevant education for professionals and rarity or variety of symptoms means that people with RD often wait a number of years just to get a diagnosis (Wright et al., 2018).

One such RD is *epidermolysis bullosa* (EB). It is sometimes diagnosed at birth however, the symptoms often appear as the child becomes more physically active (U. S. National Library of Medicine, 2021). The prevalence is one per 30,000-50,000 people, while in EU countries is 2,4 persons per 100,000 people (Diem, 2009; Fine et al., 2008). Inherited EB is characterised by blisters and wounds on the skin, as well as sensitivity of the mucous membranes (Debra International, 2022). Various forms and types of EB depend on

the depth of skin layers peeling away with respect to its three main layers. Persons with EB experience pain on a daily basis, mostly associated with wounds and blisters on the skin: this pain increases when dressing the wounds (Murat-Sušić et al., 2014).

Types of EB are categorized depending on the depth of skin layers peeling away. There are four types of EB: epidermolysis bullosa simplex (EBS), junctional epidermolysis bullosa (JEB), and dystrophic epidermolysis bullosa (DEB), as well as Kindler syndrome. The types vary depending on the differences in wounds, scars, blisters, pain, difficulties in movements, changes on nails and hair, finger fusion, mouth cavity, problems with kidneys and urethra, feeding difficulties, rashes and the possibility of cancers (Debra International, 2022; Murat-Sušić et al., 2014; Pustišek et al., 2012).

Early diagnosis and prompt treatment prevents EB complications. Treatment is based thorough hygiene and bandaging wounds, and strengthen immunity (Pustišek et al., 2012). When dressing wounds, particular care must be taken to avoid further damaging the skin. Selecting proper footwear and clothing makes living with EB more comfortable. Physical therapy helps persons with EB maintain their ability to move their joints, and finger fusion is rectified by surgery. Pain can be mitigated by taking salty baths and medicines. Gene therapy is one of the therapies that will be used in the near future to treat EB (Sarkar et al., 2011).

EB can affect an individual both socially and psychologically. Reactions from the individual's immediate surroundings can sometimes cause anxiety and withdrawal for persons with EB, resulting in the avoidance of human contact (Diem, 2009) and reduced QOL of family members. QOL is defined as an individual's perception of their existential situation in the context of culture and a system of values in which they live, as well as in relation to their goals, expectations, standards, and concerns (WHO, 2022). Both objective and subjective QOL indicators are crucial. In developing standardised instruments for measuring QOL, the WHO (1998) recommended address-

ing multiple domains, including physical aspects, psychological aspects, level of independence, social relationships, environment, spirituality, as well as overall quality of life and general health perceptions. According to the same resource, the physical domain includes conditions such as pain and discomfort, energy and fatigue, and sleep and rest, while the psychological domain includes positive feelings, thinking, learning, memory and concentration, self-esteem, bodily image and appearance, and negative feelings. The level of independence domain includes mobility, activities of daily living, dependence on medicinal substances and medical aids, and work capacity, while the social relationships domain includes personal relationships, social support, and sexual activity. The environment domain includes physical safety and security, home environment, financial resources, health and social care, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment, and transport, while the spirituality domain includes religion and personal beliefs (WHO, 1998).

There is also the concept of family quality of life (FQOL) that addresses multiple domains [health, financial well-being, family relationships, support from other people, support from disability-related services, spiritual and cultural beliefs (values), careers and preparing for careers, leisure and enjoyment of life (leisure), and community and civic involvement (community interaction)] (Brown et al., 2006). Research on QOL often includes individuals who take care of persons with RD. Previous studies have shown that persons with better functionality of the hands experience better QOL (Eismann et al., 2014), women sometimes experience EB symptoms more intensely, and EB symptoms are more serious in children (Taboli et al., 2009; Togo et al., 2020; Yazdanshenas et al., 2020). On the other hand, there were no differences between persons with various types of EB (Cestari et al., 2016; Taboli et al., 2009; Yazdanshenas et al., 2020). Rashes are the greatest problem for children with EB, including pain, limitations, physical disability, and the stigma from noticeable signs of EB (van Scheppingen et al., 2008). EB

has an effect on interpersonal relationships and involvement in activities outside of home. Persons with EB often experience a sense of frustration, sadness, shame, depression, and anxiety (Brun et al., 2017). Adults and children with EBS and DEB are estimated to have a similar QOL as a person with some other skin disease, emphasising that though EBS is considered a milder form of EB, it has a greater effect on the QOL than is the case for DEB (Horn & Tidman, 2002). The quality of parenting children with EB is affected by the pain these children experience, daily care of the child, conflict between a working and family role, fear of what the future holds, stigma, limited activities, financial costs, and their mental health (Angelis et al., 2016; Diem, 2009; Pagliarello & Tabolli, 2010). Research on the QOL of persons with RD and members of their family is important because these results can be used to improve their QOL (Lenderking et al., 2020).

METHODS

The aim of this phenomenological qualitative study is to gain insight into some of the domains of the QOL for children with EB and their parents from the perspective of mothers. The research questions were 'What are mothers' perspectives of their children's QOL?' and 'What are mothers' perspectives of parents' of children with EB QOL?'. The study sample is purposive. The participants had to be the parents of child with EB, members of DEBRA, Society of Bullous Epidermolysis, live on the territory of the Croatia and to assessed as good informants. The study included six mothers of children with EB, aged 31-46 years. Two participants had full-time jobs, two had the status of parent-caregiver, one was on prolonged maternity leave, and one was on regular maternity leave. The average number of children in these families was 3.33 children, of which the smallest families had two children, and the largest family had five children. The average age of the children with EB was 8.16 years, where the youngest child was only a year old and the oldest child was 16 years old. The children included three boys and three girls, three were diagnosed with EBS, one with JEB, and two with DEB. The average house-

hold earnings were around 1,500 Euros per month, ranging from 1,300-2,000 Euros. The participants came from five different counties. The study applied the criterion of data saturation.

Semi-structured interview was method for data collection. The interview protocol comprised of questions about sociodemographic information and open-ended questions on QOL as defined in the six domains of QOL provided by the WHO mentioned earlier. The intention of the open-ended questions was not to suggest any answers, but to enable the participants to speak freely about the assessments and experiences related to that particular question (e.g., 'How would you describe the current state of your health?; Please describe financial status of your family; Please describe social network of your child.'). The workers from DEBRA, Society of Bullous Epidermolysis invited parents to participate in the study if they met the inclusion criteria. If they consented to participate, there were contacted via email. Upon making initial contact with the parents, there were invited to participate in the study in which the goal, purpose, and conditions of the study were explained in detail and were subsequently sent a written informed consent form. After receiving the signed informed consent, an interview schedule was organised with each of the participants individually. The study was conducted in the period from June to August 2021. The interviews were recorded to be later transcribed, and lasted on average 47 minutes, with the shortest lasting 30 minutes and the longest taking 1 hour and 10 minutes.

According to the Ethics Committee of the Faculty of Law, ethical approval must be obtained when participants are children or people under guardianship, and the topic is very sensitive. This study did not need ethical approval according to the Ethics Committee of the Faculty of Law, and it is in accordance with the ethical standards of University of Zagreb, Faculty of Law and was performed in line with the principles of the Declaration of Helsinki. Written informed consent was obtained from all individual participants included in the study. The ethical aspects of the study included voluntariness, presenting the researchers to participants, familiarising participants with the study, informed consent, creating a relationship of

trust, confidentiality, data anonymization, ability to cancel the interview at any time, ability to not reply to questions, and caring for the participants during and upon completion of the interview.

DATA ANALYSIS

The analytic method used in this study was thematic analysis. It is a method of identifying, analysing, and reporting on themes or topics defined within the data, requiring familiarity with data through repetitive reading and noting initial ideas, creating initial codes, grouping codes into common themes, verifying the created themes, defining and naming final themes, as well as writing reports (Braun & Clarke, 2006). Each theme included the most illustrative citations. Researcher triangulation and theory triangulation were used to ensure data trustworthiness and credibility.

RESULTS

Table 1. Themes about QOL of parents of children with EB

| Themes | Sub-themes |
|--|--|
| Good health | Good physical health Good mental health |
| Received support from informal and formal sources of support | Received support from persons with whom the participants have close interpersonal relationships Received support from DEBRA, Society of Bullous Epidermolysis Inadequate support from social welfare centres |
| Job satisfaction | Satisfaction with their full-time job Satisfaction in achieving status as a parent-caregiver |
| Family's financial well-being | Financial needs of family are satisfied Care costs have an impact on the family's financial status |
| Limited possibilities of participating in leisure activities | Participation in recreational activities Demanding nature of caring for a child result in the inability to get involved in certain leisure activities |

The themes mentioned in Table 1 provide insight into the main domains of the QOL concept that was defined earlier. Good health encompasses the physical and psychological aspects of health, received support highlights social relationships and one's environment, while job satisfaction,

family's financial well-being, and possibilities of participating in leisure activities address levels of independence, as well as one's environment.

The participants mentioned satisfaction with physical and mental health and described their health status as 'good':

"My husband is very healthy, since I've known him, he hasn't been to the doctor not even once. I too hardly see my doctor for anything." (M5)

"I don't have any psychological problems...I'm happy, positive." (M3)

Some of the participants highlighted the importance of spirituality and religiosity in their lives, and mentioned that the acceptance of EB was linked to their mental health:

"Religion has a big role...it is a great hope and consolation for us." (M4)

The participants reported that they received support from informal and formal sources of support. The results show their satisfaction with the support they receive from members of informal networks with whom they have close interpersonal relationships:

"I have a husband who is great support, what I can't do, he'll do it because I maybe don't have the time, he does it without any further discussions." (M5)

"I have a lot of support from my immediate and wider family." (M4)

Support was also received from formal support sources. They highlighted their satisfaction with the support received from DEBRA, Society of Bullous Epidermolysis, whom they described as adequate and good, as well as the inadequacy of the support received from social welfare centres:

"So we're in the DEBRA society, they really help us with whatever we need, they've guided us in a lot of ways. I think that whatever I want to ask, they always answer in case they don't know the answer, they try together with me, meaning, to find an answer, doctors solve it." (M2)

"We have a lot of support from DEBRA, which I value a lot, and whatever I need, we can always call on them." (M4)

“The social welfare centres and similar, I can't say I've received much support from them. We don't have our own social worker or anything else...they've been deprived us for a number of years.” (M2)

Job satisfaction was indicated through their ability to work full-time jobs or their satisfaction in achieving status as a parent-caregiver:

“I'm very happy, very satisfied and like what I do. I'm doing the type of job for which I went to school.” (M5)

“I have the status of a career.” (M6)

In terms of material bliss, participants were asked to describe their family's financial well-being. They expressed partial satisfaction with their family's financial status, given that they were partially satisfied with the level of household income, and pointed out that care costs can have a significant impact on the family's financial status:

“You spend as much as you earn, but it's OK, I would say, to kind of live properly.” (M1)

“We are able to pay utilities fees, we can afford for our children, things in the general situation. I can't afford extra things for them. They're not hungry or thirsty.” (M2)

“I have to buy special things for her because her skin reacts immediately to everything, but I would not say anything extra, not really.” (M1)

“We always have to buy everything at once in order to be able to later, and then we allocate, let's buy this month this cream, then in February the other. We've learnt to live with it. Our biggest problem is footwear. That means that we search a lot and we've spent in the past a long of money, but the footwear wasn't adequate for him.... Is it expensive, yes, it is.” (M2)

The participants indicated their limited possibilities of participating in leisure activities: some participants stated that they participate in recreational activities outside of their home, while some of them pointed to the demanding nature of caring for a child that resulted in their inability to get involved in leisure activities:

“Sometimes we go to the shopping mall, visit friends, relatives and the like... When I bathe her,

it takes me 4 hours at least to bathe here and dress her wounds and all that.” (M6)

“No, I don't have time. I'd really like to go out and exercise, but I just don't have the time.” (M5)

Table 2. Themes about QOL of children with EB

| Themes | Sub-themes |
|---|---|
| Children's affiliation to the community | Acceptance of the child in its surroundings Child's participation in community activities |
| Poorer health condition of the child due to EB | Problems relating to the child's oral health Pain as a consequence of EB Frequency of caring for skin and treating wounds |
| EB affects everyday activities of child | Lack of autonomy in some everyday activities Autonomy in performing certain activities Child's acceptance of EB Performing activities related to everyday life |
| Adequate support from the formal support system | Quality healthcare Support within the education system |

The themes listed in Table 2 also provide insight into the main domains of the QOL concept that was described earlier. The results regarding health conditions and everyday activities highlight the physical aspects, level of independence, social relationships, environment, and spirituality, while environment, physical care, and social relationships can be recognised through support received from the formal support system.

The participants described the children's affiliation to the community through the acceptance of the child in its surroundings, as well as the child's participation in community activities:

“At first worried...which means hair doesn't grow, and then still when they saw it all, no one passed by to touch her hair or I don't know what... And the reactions... I didn't notice that anyone was disgusted because of that or something.” (M1)

“He runs and plays sport, plays dodgeball.” (M3)

One of the determinants of QOL is poorer health condition of the child due to EB, which

is evident in problems relating to the child's oral health, pain as a consequence of EB, and frequency of caring for skin and treating wounds:

"We have some problems a little with gums, meaning, a lot of ulcers have eaten away at the gums and teeth, oral hygiene is really bad, he knows how to wash his teeth, but it hurts. Bullae immediately appear, tongue straight away bullae if he eats a little something solid." (M3)

"Has difficulty in swallowing, problems with teeth, teeth falling out, bleeding of the teeth happens quickly." (M6)

"I spray the wound or prick the blister...those bandages they are special bandages for patients, we turn on the air-conditioning, paracetamol.... she's a healthy child trapped in serious diseased skin." (M4)

"When we go somewhere, we can't sit there too long, she begins feeling pain, doesn't have that much energy. Her wounds hurt, throughout her body." (M6)

EB affects everyday activities in a child's life, meaning that there is lack of autonomy when some children perform certain everyday activities, while others have a degree of autonomy in performing certain activities:

"Does not walk due to EB, cannot eat on her own due to the disease, she can't go to the toilet on her own...I mean, she needs me 24 hours a day." (M6)

"He mostly does everything on his own, there are moments when he needs help, I don't know, get dressed because that's the biggest problem." (M2)

"I don't really let him carry anything heavy, nothing that will cause him pain or difficulties... some things that don't have anything to do with chemicals. For instance, to arrange pillows on the couch and the light vacuum cleaner...he gets on the bus on his own sometimes." (M3)

Performing activities from everyday life definitely affects the child's acceptance of EB:

"He's a very active child, it's nothing to him... he's obviously grown with the certain pain...In re-

gards to energy, I can hardly wait when he goes to sleep." (M5)

"He's accepted the fact that he's like that, he knows how to protect himself outside in that regard, when sensing some kind of danger. He accepted it and I can say that he copes well though he does have pain, but as I said, he already knows when to drink the syrup, when he needs to react." (M2)

Finally, the participants indicated that they received appropriate support from the formal support system because the children receive quality healthcare and support within the education system:

"At the physical exercises xxx, they're all kind to us, really kind of, maximum help and effort, we're really tracking it all in a multidisciplinary way, they have everything, a gastroenterologist, nutritionist, guide us also at the Faculty of Dentistry. Really, there you have it, I have to admit, I think if I were abroad somewhere, with a lot of money, I think I wouldn't get that much service as here in Croatia." (M4)

"We are a small community and the teacher and everyone else at school know that she has this problem. We didn't even have to explain much, besides, naturally, some personal things which I had to point out, say, but really that all accepted... They were really approachable." (M2)

DISCUSSION

The results of this study offer insight into certain domains of the QOL of families of children with EB. The results show that parents highlight their good health, emotional and practical support received from persons with whom they have close interpersonal relationships, and informational and practical support from DEBRA. The results also show the lack of emotional and informational support from social workers employed in social welfare centres. Previous studies have highlighted parents' satisfaction with informal sources of support (Jones & Passey, 2004) and adequate support from society of persons with RD (Čagalj et al., 2018; Neik et al., 2014; Pansini, 2011). In addition, previous studies have indicated the same

or similar results relating to inappropriate support from the formal support system to families of children with RD (Chaij et al., 2014; Čagalj et al., 2018; Griffith et al., 2014; McGarvey & Hart, 2008; Pansini, 2011): that is based on professionals' lack of education, lack of information provided to parents etc. This leads to the conclusion that parents of children with EB do not receive appropriate emotional and informational support from professionals. To a certain extent, the formal support system does not contribute to improving the QOL of families with children with EB. Children with RD need support from highly specialised and well-networked professionals (McGarvey & Hart, 2008), whose support can improve the QOL of these children and their parents.

Material bliss of the participants was estimated to be partially satisfactory. They reported job satisfaction based on their job status, and they mentioned that the family's financial well-being was subject to costs stemming from caring for the child with EB. According to the results, mothers of children with EBS generally had full-time jobs, whereas mothers of children with JEB and DEB had achieved parent-caregiver status or initiated the process to achieve that status. Recognising the right of a parent to achieve parent-caregiver status ensures certain financial security. It is important to point out that all their spouses have a full-time job. Previous studies have shown that caring for children with RD is marked by high financial expenditure for the family, because they have to pay for additional medicines, healthcare services, medical aids, as well as adequate footwear and clothing (Cavazza et al., 2016; Diem, 2009; Gallo et al., 2008; López-Bastida et al., 2016; Wright et al., 2018). The average annual costs for persons with EB amounts to between 9,509-49,233 Euros, depending on the EU member state they live in (includes costs related to healthcare, existential costs, and losses due to the inability to gain employment or work) (Angelis et al., 2016).

The possibilities of participating in leisure activities were limited and this was determined by taking care of their children. The results show that some of the participants expressed satisfaction with participation in leisure activities along with

their children. These activities took place mostly in natural surroundings and around the house, which was also subject to the fact that two-thirds of the participants (Lenderking et al., 2021) lived in rural settings, and more recreational amenities were available only in urban areas. Some of the participants did not participate in leisure activities due to the emotional circumstances related to taking care of the child. Parents of children with RD need time to relax, which is not related to their obligations as a carer for their child (Eatough et al., 2013; Kerr et al., 2007; van Scheppingen et al., 2008).

The children's QOL indicates that children are members of their community because they are accepted and participate in community activities. The main problems encountered by children with EB were the noticeable symptoms of the disease, the feeling of being uncomfortable around their peers, their inability to participate in activities due to their health condition, exclusion from their peers, and a lack of understanding for their health condition (Brun et al., 2017; Eismann et al., 2014; Pagliarello & Tabolli, 2010; van Scheppingen et al., 2008; Williams et al., 2011). It should be pointed out that occupational therapy with children with EB provides them better opportunities for social participation in community activities such as recreational activities (Chan et al., 2019; Duers et al. 2,011). Social problems for persons with RD are sometimes greater than the psychological problems they encounter (Horn & Tindman, 2002; Yan et al., 2021), because a large part of the child's everyday life is planned around medical care (van Scheppingen et al., 2008).

The results show that EB has an impact on the child's everyday activities, where children show various levels of (or lack of) autonomy in performing various activities in everyday life. As reported in Togo et al. (2020), children with EBS have a high level of autonomy and actively play some type of sports, while children with JEB and DEB require more assistance and support from others because they have more intense symptoms and lower QOL. Performing activities in everyday life is also associated with hand functionality, given that most children have difficulties in per-

forming activities with two hands rather than one hand (Togo et al., 2020). Their environment often fails to understand their health condition, and therefore their ability to perform certain activities (Williams et al., 2011). Their abilities to perform certain activities from everyday life are linked to their health condition, as well as the child's ability to cope with EB (Goldschneider & Lucky, 2010; Pagliarello & Tabolli, 2010).

LIMITATIONS

The results of this study must be considered in the light of certain limitations. The first limitation is that the findings cannot be generalised because the sample is small and purposive. The second limitation is that only mothers of children with EB participated in this study, and only the mother's perspective was obtained. The third limitation is that all participants were members of DEBRA Croatia. It must be pointed out that the majority of families of children with EB are members of DEBRA, but there is a possibility that a potential participant who is not a member of the organisation can provide a different perspective about QOL.

CONCLUSION

The QOL of parents of children with EB is characterised by their good health, job satisfaction, and support received from different sources, as well as the family's financial well-being and their limited possibilities of participating in leisure activities. The QOL of children with EB is characterised by their sense of belonging to the community, their poor health condition due to EB that also affects their ability to perform certain activities in everyday life, as well as appropriate support received through the healthcare and education systems. The results indicate that some personal factors affect the QOL of the participants, such as the way in which they cope with EB, spirituality, and certain personality traits that are essential for the everyday functioning of children with EB. The results also highlight the role of the formal support system in determining the QOL of families living with EB. Families with

EB need adequate, efficient, timely, and specific emotional, informational, practical, and financial support from formal sources of support. Professionals should provide parents with specific information, knowledge, and advice regarding the child's daily care. Medical care provided to their children on daily basis is time consuming, and it results in high costs and their inability to have free time for themselves and to meet their own needs: these factors define their QOL. Parents of children with EB need emotional, practical, and informational support from health professionals, emotional and informational support from professionals working in NGOs, social welfare centres, and other institutions, as well as financial support from state. The results show the importance of health, independence, social relationships, spirituality, coping mechanisms, and different types of support in achieving better QOL among families living with EB. The availability of prompt and appropriate support and healthcare is important for achieving better QOL among children with EB because there is no cure for EB. The health condition largely affects the QOL of individuals, but one should not forget the impact that emotional and financial stability has on the quality of life, as well as support and spirituality.

The QOL of children with EB and their parents is determined by healthcare for children and support received from informal and formal support systems. The results show that professionals should provide adequate, efficient, timely and specific support to families living with EB. Social and healthcare professionals should provide informational, practical, and emotional support to families of children with EB. They must provide specific knowledge, advice, and tips to parents of children with EB regarding ways in which to provide care for their children with EB, and they should be aware that EB affects all family members of the child with EB, both socially and psychologically. This study shows that the community should sensitised to the challenges faced by families of children with EB. Based on these results, it can be concluded that future studies about the QOL of families with EB should include fathers of children with EB, children with EB, as

well as professionals from the formal support system. More detailed, as well as different insights on the QOL of these families could be obtained through the perspectives of a wide range of participants. One of the recommendations is that the formal support system should provide systematic education to all professionals working with children with developmental disabilities on how to improve the QOL of these families. Finally, the families of children with EB, especially parents who have status as a parent career, need additional emotional support from professionals because it can result in better QOL for the entire family.

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Declaration of Conflicting Interests

The authors declare that there are no conflicts of interest.

Data Availability

Due to the nature and the ethics of this study, and based on the written informed consent statement, the study participants did not agree to share their data publicly. Therefore, supporting data is not available.

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