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## BRIEF ORIGINAL ARTICLE

# Experiences of deafblind people about health care<sup>☆</sup>

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### KEYWORDS

Deafblind disorders;  
Sensation disorders;  
Nursing care;  
Health services

**Abstract** Deafblindness is a disability resulting from the combination of visual and auditory sensory impairments, which can manifest in different levels causing special communication problems. Deafblind people have special needs that derive from difficulties in sensing, understanding, attention and a lack of the skills required to function effectively in society. Deafblindness requires specialised services, personnel specifically trained in its care and special methods for communication.

**Objective:** The main objective of this study is to explore the experiences of deafblind people in relation to health care throughout their lives. This study was developed at the St. Ángela de la Cruz Centre, belonging to the Association of Parents of Deafblind People in Spain.

**Method:** Phenomenological qualitative study, through semi-structured interviews with deafblind people at the St. Ángela de la Cruz Centre, Salteras (Seville), carried out in 2015, with the help of interpreters in Spanish sign language. Topics covered in the interviews refer to facilities, human resources, time waiting and health care.

**Results:** Coinciding statements were obtained, where the participants point out architectural and educational barriers in health care and stand out better if the professionals know sign language.

**Conclusions:** It can be highlighted that healthcare professionals lack knowledge of all aspects of deafblindness, sign language in particular, and there is a shortage of signs and information for the deafblind. Moreover, alternatives are required to reduce waiting times and improve direct communication with health professionals.

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**PALABRAS CLAVE**

Trastornos sordoceguera;  
Trastornos de la sensación;  
Atención de enfermería;  
Servicios de salud

**Experiencias de las personas sordocegas sobre la atención sanitaria**

**Resumen** La sordoceguera es una discapacidad, resultado de la combinación de las deficiencias visual y auditiva, manifestándose en diferentes grados y provocando problemas comunicativos únicos. Las personas sordocegas presentan necesidades especiales debidas a la dificultad para percibir, conocer y desenvolverse, requiriendo servicios especializados, personal formado y métodos especiales de comunicación.

**Objetivo:** El objetivo principal de este estudio es explorar las experiencias vividas por las personas sordocegas del Centro Santa Ángela de la Cruz, perteneciente a la Asociación de Padres de Sordocegos de España, en relación con la atención sanitaria recibida a lo largo de su vida.

**Método:** Estudio cualitativo fenomenológico, mediante entrevistas semiestructuradas a personas sordocegas del Centro Santa Ángela de la Cruz de Salteras (Sevilla). Este trabajo se llevó a cabo en el año 2015 con ayuda de intérpretes en lengua de signos española. Los temas tratados hacen referencia a las infraestructuras, los recursos humanos, el tiempo de espera y la atención sanitaria.

**Resultados:** Se obtuvieron discursos coincidentes en señalar como principales dificultades las barreras arquitectónicas y formativas en el ámbito sanitario y destacan mejor atención si los profesionales manejan lengua de signos.

**Conclusiones:** Entre las principales barreras en la atención a las personas sordocegas se destaca la falta de conocimiento de los profesionales sanitarios sobre todos los aspectos que engloban a la sordoceguera, en especial la lengua de signos, además de la escasez de señalizaciones e información. Se demandan alternativas para disminuir los tiempos de espera y favorecer la comunicación directa con los profesionales de la salud.

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**What is known?**

Deafblind people suffer from certain limitations which may impede their access and use of healthcare services.

**What do we contribute?**

The importance of the study is based on the wealth of information which deafblind people have offered us about their healthcare experiences and helps us to understand their particularities and needs. Data obtained enables us to act on the shortcomings, from the needs perceived by the users themselves.

**Introduction**

Deafblind people have difficulty perceiving what is happening around them and in making social contact due to the combined impairments of not being able to see or hear. When one of these senses fails, the other tries to compensate and due to this, the most reliable measurement of the degree of impairment is to what extent the person is able to function.<sup>1</sup> They often require help from sign language interpreters (SLI). It has been confirmed in the field of

education that development is more favourable when sign language is used; when structural modifications are made and when information is sufficient.<sup>2-5</sup> However, the literature on healthcare is limited and only covers early detection or the need for SLI. It is therefore important to analyse the particularities of this group in order to establish guidelines for direction in this field.<sup>6</sup>

The aim of this paper is to explore the healthcare experiences of deafblind people.

**Method**

A phenomenological exploratory qualitative study, given that the protagonists' experiences were the subject under study.<sup>7</sup> The study was conducted using semi-structured interviews to probe into the experiences of deafblind people with regards to the healthcare they had received. Due to the complexity of recruiting participants for this study and also saturation of information, 8 people were included in the study from the Santa Ángela de la Cruz Centre which belongs to the Spanish Association of Families of Deafblind Peoples (APASCIDE), located in Salteras (Seville), the only association in Spain committed to the comprehensive care of this group. It is both a day care centre and a care home. After several meetings with the staff from the centre, it was considered appropriate that the participants would mainly come from the day care unit, due to their greater cognitive and communicative development. Specifically, 7 participants belonged to the day care centre and 1 to the care home. Two of them were deafblind from birth and the others were born deaf and

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