

A Profile of Visually Impaired Children: A Ten-Year Retrospective Study

* Areej Okasheh-Otoom¹, Yazan Gammoh²

¹ Department of Allied Medical Sciences / Optometry, Faculty of Applied Medical Sciences, Jordan University of Science and Technology, Irbid, Jordan.

² Department of Optometry Science, Faculty of Allied Medical Sciences, Al-Ahliyya Amman University, Amman, Jordan.

Abstract

Background: Causes of visual impairment among children vary worldwide. While there is a scarcity of such data, this study aims to describe the profile of a large cohort of visually impaired children. In addition, it will provide evidence to advocate the importance of the provision of low vision services to children and improve referrals for such services.

Methods: A retrospective study reviewed the profile of visually impaired children who attended a multidisciplinary vision rehabilitation service in the period of 2011-2021. Recorded data included demographics, clinical attributes (Binocular best-corrected distance visual acuity BCVA, near visual acuity, contrast threshold, causes of visual impairment, the presence of concurrent disability or disorder, whether the child was underweight or premature at birth), and the prescribed low vision aids. Data were analyzed using SPSS 20.0.

Results: Demographic and clinical records of 443 children (54% boys and 46% girls; median age 6 years) were analyzed. The median best corrected binocular distance visual acuity and contrast threshold were significantly improved from 0.86LogMAR to 0.62LogMAR and from 25% to 10%, respectively. The main source of referral to the association was ophthalmologists (35.5%) followed by schools/kindergartens (33%), whereas the least frequent source of referral was pediatricians (1.6%). The major causes of visual impairment were retinopathy of prematurity and cortical visual impairment.

Conclusion: visual functions were improved with the appropriate low vision aids, which explains the necessity for early referral of children to low vision services. Awareness training for pediatricians is important regarding the need for early detection and timely referral of visually impaired children. There is also a need for an awareness campaign about the causes and risk factors of retinopathy of prematurity.

Key Words: Impairment, Low Vision Aids, Pediatrics, Retinopathy of Prematurity, Vision Rehabilitation.

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*Corresponding Author:

Areej Okasheh-Otoom, Department of Allied Medical Sciences / Optometry, Faculty of Applied Medical Sciences, Jordan University of Science and Technology, Irbid, Jordan. Email: aaokashah@just.edu.jo

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1- INTRODUCTION

In 2010, there were more than 285 million people with visual impairment, among whom there were 19 million visually impaired children aged less than 15 years (1). In addition, childhood blindness attributes to 4% of the causes of blindness worldwide, and this is fourfold the blindness due to diabetic retinopathy (1). Childhood visual impairment impacts different aspects of children's life including education, social life, activities of daily living (ADLs), cognitive development, independence, self-esteem, and future career choice. Scheiman and Wick (2013) reported that about 85% of what children learn depends on visual presentation (2). In children with a visual impairment, the risk of traumatic injuries to the teeth and mouth was higher compared to normally sighted children (3). Moreover, about 90% of visually impaired children do not receive a quality education (4, 5).

Causes of childhood visual impairment vary worldwide and the majority of these causes, such as refractive error, cataract, and amblyopia, are preventable or treatable (6, 7). Other causes of visual impairment, such as retinal disorders, corneal opacity, and unexplained vision loss, have been also reported in different countries (8-10). In the UK, the most prevalent cause of visual impairment in children is reported to be cortical disorders (i.e. cortical visual impairment) (11, 12). In Jordan, there is a scarcity of literature evaluating the causes of visual impairment in children. A retrospective study on 135 records of low vision patients who attended an optometry clinic in the north district reported that albinism and retinitis pigmentosa were the most frequent causes of low vision for all age groups (13). Albinism also accounted for the leading cause of visual impairment among 53 children aged 15 years or younger (13). Another retrospective study analyzed the causes of visual impairment

among low vision patients referred from an ophthalmology department at a government hospital to a private specialist low vision clinic (14). There were only 15 children under the age of 18 years who were referred to the low vision service provider and the main cause of vision impairment among them was retinitis pigmentosa. However, because of the small sample studied, the patients' limited access to the clinics, and the system of patient referral, these studies are not representative of the causes of visual impairment in children.

Low vision rehabilitation involves the provision of a range of services for visually impaired to enable them to use the remaining visual functions to achieve maximum potential. Rehabilitation services can be standard hospital-based services provided by optometrists, or low vision therapists and/ or multidisciplinary services where additional services can be provided by other health professionals such as occupational therapists, mobility and training specialists, psychologists, and in association with social services (7, 15-19). Low vision rehabilitation has been found to be effective in improving visual functions and quality of life (7, 18-23). However, some other studies have reported that low vision rehabilitation did not improve visual functions or quality of life (24-26). In Jordan, there is a lack of such studies evaluating outcomes of vision rehabilitation program/ intervention.

This study is important to help understand demographics, visual functions, clinical attributes, quality of life, teaching methods, requirements, and limitations in visually impaired children. It will also help us to improve our knowledge of the causes of visual impairment in a large cohort of children and to compare our situation with those of the other developing or developed countries. The study will provide peer-reviewed scientific evidence for recommendations to improve awareness

and adoption of vision rehabilitation in children to improve the quality of their lives.

The aim of this study is to describe the profile of visually impaired children attending a multidisciplinary vision rehabilitation service and to understand the causes of visual impairment among children. In addition, it will provide evidence to advocate the importance of the provision of low vision services to children in need and to improve referrals for such services.

2- MATERIALS AND METHODS

This retrospective study reviewed the profile of visually impaired children attending a multidisciplinary vision rehabilitation service for visually impaired children, during the period of September 2011 to September 2021. Al-Dhia'a Association for Visually Impaired Children is a not-for-profit association and is the only organization in Jordan that provides rehabilitation and education services exclusively for children. Anonymous records of 489 children attending the service were reviewed. Only records of children whose parents/guardians had previously authorized the use of their information were included in the analysis. So, the data of 46 children were removed from the analysis. The records included children's demographics (age, gender, district), clinical characteristics including Binocular best corrected distance visual acuity BCVA, near visual acuity, contrast threshold, as measured by the use of Hiding Heidi low contrast face test for children less than 4 years, and LEA symbols contrast test for children aged 4 years and older, the main ocular disorder or the cause of visual impairment, the presence of concurrent disability or disorder, whether the child was underweight or premature at birth, and the prescribed low vision aids or assistive devices; data was analyzed using SPSS 20.0.

3- RESULTS

A total of 443 records of children (54% boys, 46% girls) who had attended the service were analyzed. The median age of children was 6 years (IQR 6-7, Range 2-13). The majority of children who attended the service lived in the middle district (90.1%; 79% of them lived in the capital city) whereas only 9.9% lived in the northern district.

3-1. Referral

Visually impaired children who had attended the service were referred mainly by ophthalmologists (35.5%) and schools or kindergarten (33%). Sources of referral of children are shown in **Fig. 1**.

3-2. Visual functions

Those who attended the service had a median best corrected binocular distance visual acuity (BCVA) of 0.86 LogMAR (IQR 0.78-1.00, Range 0.60- NLP), a median contrast threshold of 25% (IQR 10-50%, Range 1.25-100%), and a median near visual acuity of 1.00 LogMAR (IQR 0.80-1.30, Range 0.40-1.60). Visual functions of visually impaired children are shown in **Table 1**.

3-3. Causes of visual impairment

The main cause of visual impairment affecting the children was retinopathy of prematurity (ROP, 14.9%), followed by cortical visual impairment (CVI) (13.8%), other retinal disorders (12.6%), and glaucoma (10.8%).

Causes of visual impairment among children attending the service are shown in **Table 2**.

3-4. Concurrent disabilities

Concurrent disabilities or morbidities were also recorded among visually impaired children who had attended the service. About 7% of the service users have had other disabilities including encephalopathy, cerebral palsy, hearing impairment, speech difficulties, Usher

syndrome, and Down syndrome. Also, about 10.8% of children had other ocular conditions including high refractive error, amblyopia, strabismus, and other binocular vision anomalies. In addition, about 29% of children attending the service were premature or underweight at birth.

3-5. Functional limitations or concerns

The most frequent functional limitations reported by children or their parents were in the following tasks or activities: social play (45.3%), visual communication (39.2%), educational activities (39%), mobility (37.8%), self-care and hygiene (34.7%), as well as developmental delay and cognitive impairment (24.9%).

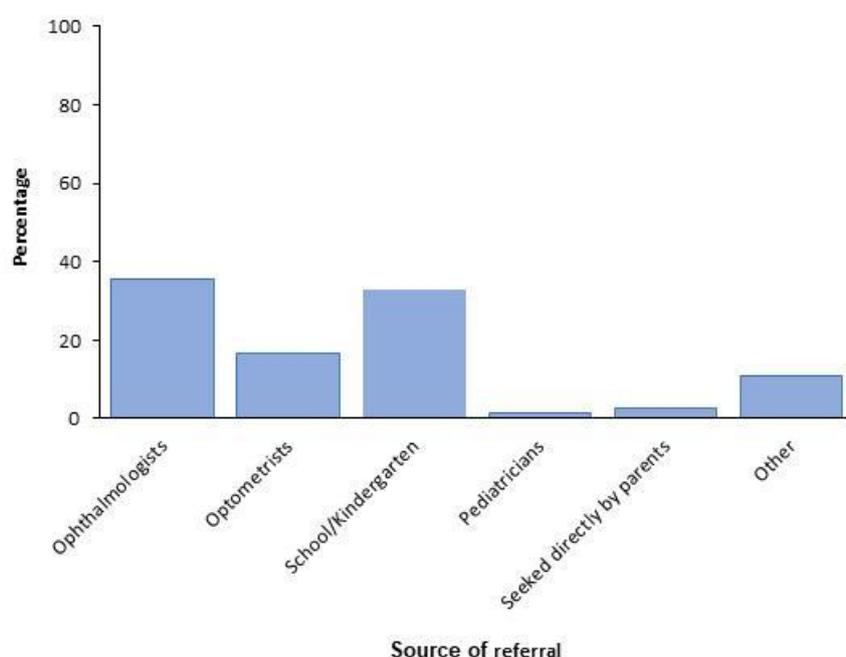


Fig. 1: The distribution of children who attended the service (n= 443) by the source of referral. Other: include children referred by other sources of referral such as friends, teaching institutes’ clinics, word of mouth, or community screening programs.

Table-1: Visual functions of children who attended the service. Low contrast threshold and near visual acuity not measurable for 93, because they have visual acuities such as light perception, hand motion, and no light perception (NLP) or were unable to see 10M letter or whose visual acuity is less than 1.6 LogMAR.

Visual functions		
Best corrected binocular LogMAR distance visual acuity (n=443)	Median	0.86
	IQR	0.78-1.00
	Range	0.60-NLP
Low contrast threshold (n=350)	Median	10%
	IQR	2.5-25%
	Range	1.25-100%
LogMAR Near visual acuity (n=350)	Median	1.00
	IQR	0.80-1.30
	Range	0.4-1.60

Table-2: Causes of visual impairment among children who attended the service (n= 443).

Causes of visual impairment	Frequency	Percentage
CVI ^a	61	13.8
RP ^b	15	3.4
ROP ^c	66	14.9
Glaucoma	48	10.8
Cataract	46	10.4
Macular disorders	11	2.5
Optic nerve disorders	41	9.3
Nystagmus	32	7.2
Albinism	22	5.0
Corneal disorders	26	5.9
Other retinal disorders	56	12.6
Other congenital disorders	19	4.3

a: Cortical Visual Impairment , b: Retinitis Pigmentosa, c: Retinopathy of Prematurity

3-6. Low vision aids and assistive devices prescribed

The most prescribed low vision aids were non-optical or assistive devices (26%) followed by electronic vision enhancement

systems (EVES) (25.3%) and stand magnifiers (19%). The prescribed low vision aids are shown in **Fig. 2**. For about 17.8% of the participants, more than one low vision aid were prescribed.

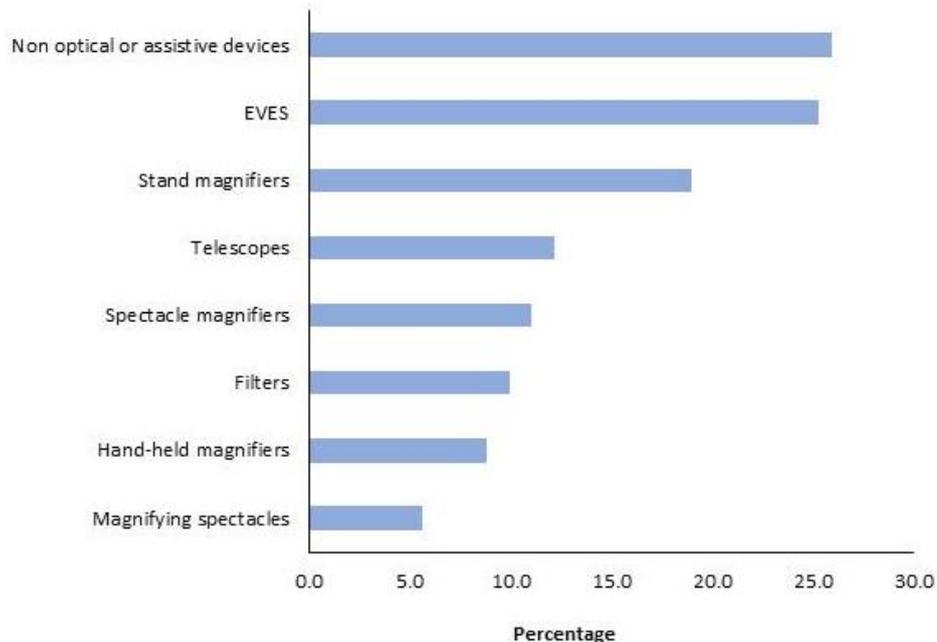


Fig. 2: Low vision aids that were prescribed for children who attended the service (n=443). About (79, 17.8%) were prescribed more than one low vision aid.

3-7. Teaching method

The main teaching method used was modified text/ material-based teaching (179, 39.3%) such as enlarged text-books

followed by regular text/ material-based teaching (119, 26.8%) and Braille-based teaching (68, 15.3%). However, all children aged 4 years and older (346,

78.1%) used Braille-based teaching regardless of their need to learn with this method. Teaching methods used in this service are shown in **Fig. 3**.

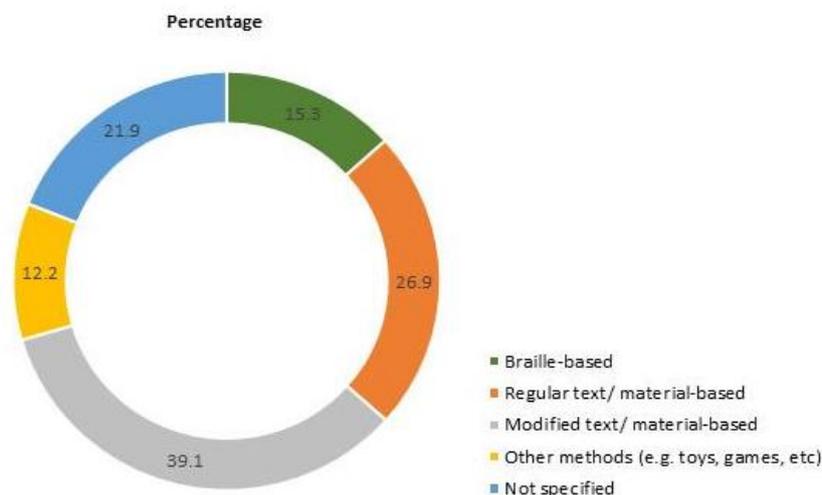


Fig. 3: Teaching methods used at the service (n=443). All children aged 4 years and older (346, 78.1%) used Braille-based teaching regardless of their need to learn with this method.

3-8. Aided visual acuity

Visual acuities were improved with low vision aids. The median distance and near visual acuities with low vision aids were 0.62 (IQR 0.34-0.80) LogMAR and 0.30 (0.12-0.54) LogMAR, respectively. On the other hand the contrast threshold with low vision aids was improved to a median of 10% (IQR 2.5-25%).

4. DISCUSSION

This study illustrates the first detailed profile of vision impairment among children in Jordan. A previous study in the region have been conducted a small number of children attending an optometry clinic in the north district, an area with a known concentration of albinism (13). On the other hand, data from cases referred to a private low vision service provider is very limited in terms of the number of children and do not represent the actual causes of visual impairment among children due to restricted access to the

tertiary hospital from which the cases are referred (14). The situation of the multidisciplinary vision rehabilitation service, in our study, being the only institution for blind and visually impaired children is not unique as Eretria shares the same setting, having Abraha Bahta School for the Blind, the only institution for visually impaired and blind children (27). Although in two different continents, the institutions share common characteristics of having most of the children attending from the region/district where the institution is based, thus underrepresenting the profile of visually impaired children from other regions that are far away from the center or of lower socio-economic status. Nevertheless, the results of the current study provided the most complete profile of vision impairment among children in Jordan.

Retinopathy of prematurity was the main cause of visual impairment (14.9%), followed by CVI (13.8%) and glaucoma

(10.8%). This is in alignment with a study conducted on the legally blind by the medical committee for the evaluation of disabled persons where the main reason (29.7%) of legal blindness was ROP (28). ROP is associated with low birth weight (≤ 1500 grams) or gestational age of less than 30 weeks (29). The current finding is not surprising as 1.3% of children were born with births less than 1500 grams; this rate is twice more than the reports in year 1990 (30). Meanwhile, more than a quarter of the children (28.6%) who are premature or with low birth weight suffer from TOP (31). Most pediatricians (95.8%) are aware of the risk factors of ROP; however, around 75% of them would refer the baby for ROP screening, leaving a potential number of infants at risk without screening due to a lack of referral (32). Also with pediatricians being the least source of referral of visually impaired children in the current study, it is imperative to foster collaborations between pediatricians and the association. ROP remains one of the main reasons for vision impairment in many developing countries, especially in Latin America (33). There is a need for a wide awareness campaign on the causes and risk factors of premature birth and low birth weight in hope of reducing the seemingly increasing trend of low weight births, thus reducing the risk of developing ROP which may lead to a reduction in vision impairment among children. Furthermore, pediatricians need to be trained to refer infants at risk of ROP for screening as early as possible to prevent avoidable vision impairment in premature and low birth weight children. Several methods are available for screening ROP including traditional bedside indirect ophthalmoscopy, RetCam which is a contact fundus imaging system designed for tele-screening of ROP, or smart-phone based systems for fundus imaging (34). RetCam has been shown to be a reliable and accurate method of screening ROP in several countries (35, 36) nevertheless no

peer-reviewed data are available for Jordan. Although, it is expected that due to the high cost of equipment such as RetCam (34), and the limited resources that Jordan has as a developing country, policy makers and stakeholders should adopt policies and support the use of such equipment to provide the best neonatal eye care possible.

CVI was the cause of vision impairment among 13.8% of children in the current study. CVI is the main cause of blindness in high and middle-income countries (37). Jordan is classified as an upper-middle-income country as per the World Bank classification (38). In Brazil; an upper-middle-income country, CVI has been found to be one of the main causes of vision impairment in children (10.5%) attending a pediatric low vision center (39). CVI was not reported as a cause of vision impairment in Eretria, a low-income country (27). This shows that despite the fact that the current study and that conducted by Gyawali and Moodley have been performed based on the data from the only institutions in the respective countries (27), this does not necessarily mean that the causes of vision impairment would be similar, as different socio-economic conditions and access to health care would result in different profiles of vision impairment. Despite the fact that CVI is more common in high-income countries, many children in developed countries are underserved in terms of refractive error correction and low vision aids (40). Children with CVI in Cincinnati, USA were not provided with a refractive correction despite a need for it in 10% of the cases (37). It was advocated that children with CVI should be thoroughly examined and provided with the appropriate optical correction (40). In our study, Children who were provided with appropriate low vision devices showed an improvement in visual acuities which would potentially provide them with a better visual outcome.

Glaucoma was among the common causes of vision impairment in the current study (10.8%). In Brazil, similar to Jordan, glaucoma is considered one of the main causes of vision impairment among children (39). Glaucoma is also a cause of vision impairment among children attending the school of the blind in Eretria, though at a much lower rate (4.2%), which is in alignment with reports of glaucoma in the African continent (27). Many factors would potentially explain such a prevalence of glaucoma among the children involved in this study. More than 13% of pediatricians have been reported to misidentify some signs such as leukocoria (13.3%) and red eye (20.8%) as signs of glaucoma (32). In addition, around half of the pediatricians were able to correctly identify the signs of congenital glaucoma (32). In our study, pediatricians were the least source of referral to the service. As pediatricians are the first medical doctor whom the parents seek medical care for their children, misdiagnosing or underdiagnosing causes of glaucoma in children would consequently affect children's vision. This also indicates that glaucoma in children may be higher than expected due to under-or misdiagnosis which may, ultimately, lead to a higher prevalence of vision impairment among children.

Cataract was the cause of vision impairment among 10.4% of children. This is in contrast with data from Latin America where cataract is the main cause of visual impairment and blindness among adults and children (33-39). Data from the only school of the blind in Eritrea also showed that cataract was the most common cause of vision impairment in children (12.7%) (27). It is of interest that cataract is not a cause of legal blindness in Jordan (28). Symptoms and signs of cataract were found to be identified by most pediatricians which would potentially allow for timely referral of children (32).

Furthermore, cataract surgeries are offered at a level similar to that of developed countries which would have reduced the burden of vision impairment in children in Jordan due to cataract (41).

All the children aged 4 years and over who attended the service are provided with Braille-based teaching as the only source of teaching material. This was observed in India as well though there was evidence that many children would have benefited from print-based teaching material (42). A study on children attending blind schools in India has demonstrated that when proper low vision devices were prescribed to children who were deemed to benefit from low vision service, distance and near vision improved in more than one-quarter of the children assessed (43). A similar observation was also reported from the school of the blind in Eretria, where many children benefited from the low vision aids prescribed and were moved from Braille material into printed material (44). The current study has also proved that visual acuity and contrast threshold improved in children who were examined and provided with the proper low vision aid. The national Higher Council for the Rights of Persons with Disabilities, along with the Ministry of Education has launched the 10-year strategy (2020-2030) for inclusive education which calls for the integration of children who benefit from low vision devices into mainstream schools (45). Providing the referred children with the proper vision assessment and the necessary low vision device can assist some of them to be included in the mainstream education rather than being limited to schools of the blind due to the unwarranted use of Braille-based teaching materials rather than print-based materials. This will potentially provide better future prospects to the children and improve their quality of life (43). About 25.3% of children in this study used EVES. Okashah reported that younger patients were more likely to be

prescribed EVES, where about 36.5% of children who attended Low Vision Service Wales were prescribed for EVES compared to 10% of adult patients (46). This might be explained by the ergonomics, comfort, or ease of use of EVES. Also, technological development and the fact that all age groups have access to a high-tech device may explain the ratio of children in the current study who used EVES. We do not have access to records of children who attended the service before 2011 to find a change in the prescribing trend of low vision aids. However, it is important to study possible changes in the future trends of prescribing low vision aids at the service.

This study raises the issue of vision screening for children in nurseries and pediatric clinics. It has been shown that vision screening is of importance as it allows for early detection of vision-threatening conditions which would lead to early referral, hence proper management (47). This is especially important since parents and caregivers are not usually aware of the consequences of early detection and management (47). Guidelines are usually issued by policy makers or organizations regarding vision screening protocols such as the American Academy of Ophthalmology (48). There is no systematic vision screening in Jordan, where limited studies have been conducted; and the focus has been on children above the age of 6 years targeting mainly on screening for amblyopia (49, 50). It is recommended that national guidelines for vision screening in the pediatric population should be adopted, and a national vision screening program be conducted to understand the prevalence and causes of vision-threatening diseases and conditions among Jordanian children. This is of importance as the prevalence of disorders presented in the current study may not represent the actual prevalence of ocular disorders among children in Jordan. This is mainly due to the nature of children

referrals, and the lack of proper guidelines for screening and referral pathways.

5- CONCLUSION

The study has provided the first detailed profile of visual impairment among children nationwide. ROP, CVI, and glaucoma are the three main causes of visual impairment. With the high prevalence of ROP among low weight births, there is a need for an awareness campaign about the causes of ROP and how to reduce the risk factors for developing ROP. Glaucoma can also be addressed with early detection to reduce its sight threatening consequences. Awareness training among pediatricians is necessary regarding the need for early detection and timely referral of visually impaired children to provide the needed intervention. Children who received the appropriate low vision aid demonstrated an increased visual acuity and contrast threshold which indicates the necessity for early referral and intervention as it may help in improving the performance of vision-based activities.

6- ETHICAL CONSIDERATIONS

Ethical approval for conducting this study was granted by the Institutional Research Committee and the Institutional Research Board of Jordan University of Science and Technology. The study was conducted in line with the tenets of the Declaration of Helsinki. Written informed consent was obtained from the service's manager to access the anonymous dataset.

7- CONFLICTS OF INTEREST

None.

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