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Development of a questionnaire to measure the knowledge, expectations, and challenges of parents of children with cochlear implants

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Abstract

Objectives: When children are diagnosed with loss of hearing, different aspects will influence the parents' decision-making process of cochlear implantation. Little information is available for coping experience and challenges associated with parenting cochlear implanted children. The objective of this work was to study parental knowledge of parental expectations versus experiences about CI children and to explore the challenges they might face.

Material and methods: Participants were parents of 50 Egyptian children with CI (28 males and 22 females). The children's ages ranged from 5 to 8 years with a mean age of 6.55 years. An Arabic questionnaire was designed to evaluate parental perspectives and challenges during the CI procedure.

Results: Most of the parents were satisfied with the amount of knowledge they received before implantation. Nearly half of parents (48%) received their knowledge about CI from the experience of others. Parents who d a sufficient awareness of the prerequisites of the protocol of CI in the general national health insurance were (48%). Most of the parents had challenges with a length of the CI procedure, expensive spare parts, and the cost of language therapy. Parents showed high expectations regarding academic achievements. Parental expectations regarding communication ability and social skills were met. Parents were most satisfied with the improved wellbeing and future life skills of their children.

Conclusions: This study declares that the parental questionnaire is an important instrument that gives insight into the knowledge, expectations, and challenges of parents of children with cochlear implants in order to achieve a successful consequence following implantation.

Keywords: Cochlear implant, Knowledge, Parental expectations, Parental experiences, Challenges

Background

Cochlear implants are now the premier treatment in the rehabilitation of children with bilateral, profound sensorineural hearing impairment. Several studies evaluated the parents' perspective with regard to the evolution of their child with a cochlear implant (CI) [1, 2]. Because parents are primary decision makers for their children, it is essential to have enough knowledge regarding cochlear implantation. Also, families need to know the realistic expectations regarding outcomes from CI [3].

Parents mainly expect improvement from the cochlear implants regarding communication abilities, social skills, and academic achievements of their children, as well as a change in their future life [4]. The wishes of parents should be taken seriously during the planning of implantation and rehabilitation [5].

Understanding the challenges of families of CI children is required in order to improve service supply [6]. The most prominent challenges reported by parents centered on financial difficulties [7]. Parents specified that

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communication problems were major sources of everyday difficulty [8]. Many children may face barriers to access rehabilitation care [9]. A lack of educational support for pediatric CI recipients may intensify parental anxiety [6, 10]. Many parents cited that their CI children's immature social competence and lack of peer relationships as problematic [11].

Few studies have been conducted to explore the parental perspectives and parental stress of cochlear implanted children [4–12]. There was a need to investigate the parents' perspectives of the CI children through a detailed questionnaire that could draw enough pictures of parents' expectations and challenges they might face during the procedure of cochlear implantation.

Methods

Participants

Participants were parents of 50 Egyptian children with cochlear implants (CIs) who are attending at the Phoniatric Unit in Kasr Alainy Hospital Cairo University. All children suffered from congenital bilateral severe to profound sensori-neural hearing loss since birth. They all fitted the criteria for cochlear implant candidacy set by the Egyptian National Health Insurance Committee for Cochlear Implantation. They all had a unilateral cochlear implant. All Children were prelingual cochlear implanted with average intellectual abilities. The parents participating in this study were literate, as it is expected that the literacy of parents could affect the results of the questionnaire. Both parents responded to the questionnaire.

Exclusion criteria were children with neurological, psychological disorders, or with other disabilities. The study was approved by the ethical committee of the Ear, Nose, and Throat Department, Cairo University.

Procedures

Parent interview and history taking

All children were subjected to the protocol of assessment applied at the Phoniatric Unit, Kasr Alainy Hospital. History taking involved the age of the child, the age of cochlear implantation, duration of language therapy, family history of similar conditions, perinatal history, developmental history, and history of childhood illness

Parent questionnaire

An Arabic questionnaire specifically constructed for this work was designed to evaluate parental knowledge and parental expectations versus experiences about cochlear implants and to explore the challenges they might face. This questionnaire was introduced to all parents who were instructed to answer each statement of the questionnaire by choosing one of the responses: yes or no. Positive responses were scored 1 point, and negative responses were scored 0 point. The parent questionnaire included the following:

Parental knowledge before cochlear implantation

In this component, the parents were asked to evaluate their knowledge before the CI procedure about hearing aid and cochlear implant device, costs of the device and the surgical procedure, benefits of the cochlear implant procedure, and rehabilitation after implantation.

Parental knowledge about the protocol of cochlear implantation procedure in General National Health insurance was assessed, the parents were asked about their awareness of the following prerequisites for CI procedure in the general national health insurance:

- The age range of implantation for a prelingual child is 1–5 years.
- For the prelingual child more than 5 years old, his language age should be >3ys (3–4 word sentences) or the child must be good speech reading if his language age was <3years.
- The child should receive continued language therapy (from 24 to 36 sessions) 3 months before CI.
- The child's IQ should be >85 by Vineland test at the age of <2 years or the IQ via Stanford-Binet 4th test should be >80 for the child at the age of 3years.
- Full neurological and psychological assessment should be done for the child before CI to exclude any neurological or psychological disorder.
- CI procedures could not be done for autistic, ADHD, or MR children.
- A written consent should be taken from the parents of the CI child before the procedure which should include the child has to do language stimulation for the duration at least 2 years post-implantation (2–3 sessions/week), the child has the right for CI mapping 1st time 4–6 weeks post-implantation.

Parental expectation versus experience about cochlear implant

This component is for comparison between parents' expectations before implantation and their experiences after implantation. The parents were asked about the communication skills of their cochlear implant child, social skills and participation, well-being and happiness, academic achievement, and future life.

Challenges that might be faced in the cochlear implantation procedure

It evaluates the problem that might be seen during the cochlear implantation procedure. The parents were asked about the financial load, equipment breakdowns and failures, devices limitation, limited support service, and accessibility of services.

Statistic analysis

Data were coded and entered using the statistical package SPSS version 22. Data were statistically described in terms of mean and standard deviation. Categorical data were described as frequency and percentage and analyzed using chi^2 test. Analyses of variance (ANOVA) with multiple comparison post hoc tests were used to compare quantitative variables. Correlations between quantitative variables were done using the Pearson correlation coefficient [13].

A pilot study was carried out prior to the study to ensure the clarity and applicability of questions by interviewing eight parents. No modifications were applied.

Evidence of validity

Three independent and experienced phoniatricians judged all items of the questionnaire for being completely relevant. The questionnaire included 94 items, divided into three components: knowledge about CI procedure and knowledge about Egyptian protocol of CI in general national Health Insurance (43 items); parental expectation versus experience regarding communication abilities, social skills, academic achievement, well-being, and future life skills (35 items); and challenges that might be faced during CI procedure (16 items). A high degree of content validity was obtained in this study. Face validity of the questionnaire was also determined by asking 10 parents to assess how easily the questionnaire could be understood and undertaken.

Reliability

A test-retest analysis was carried out at 2 weeks to determine the questionnaire's reliability. The test-retest showed excellent reliability with an intra-class correlation coefficient (ICC) of 0.997 (95% confidence interval, 0.990–0.999) for knowledge, 0.981 (95% confidence interval, 0.929–0.995) for knowledge about protocol in health insurance, 1 for both expectations and experience, and 0.990 (95% confidence interval, 0.962–0.998) for challenges (Table 1).

Table 1 Intra-class correlation coefficient reliability testing

	Intra-class Correlation	95% Confidence interval	
		Lower bound	Upper bound
Knowledge	.997	.990	.999
Expectations	1.00		
Experience	1.00		
Challenges	0.990	0.962	0.998
Egyptian protocol	0.981	0.929	0.995

Results

The mean age of the studied children was 78.6 ± 13.49 months. The mean age of children at the time of implantation was 50.44 ±14.78 months. The average duration of language therapy was 22 ±14.27 months (Table 2).

The correlation study between the duration of language therapy and components items of the questionnaire showed that the duration of language therapy for CI children had a significant positive correlation with parents' experience (r=0.480) (p value < 0.001). However, there was no significant correlation betwthe een duration of therapy and (knowledge, expectations, or challenges of the parents) (Table 3).

The question about the source of parental knowledge showed that nearly half of the parents (48%) received their knowledge about CI from experience from others and 20% of them received their knowledge from doctors and experience from other. Sixteen percent received their knowledge from doctors. Eight percent of the parents received their knowledge from experience from others and the Internet, and 8% of them received their knowledge from doctors, experience from others, and from the Internet (Fig. 1).

The questionnaire on parental knowledge before CI showed that nearly half of parents of parents found to have sufficient (>50%) knowledge about hearing aid and CI device. Most of the parents (88%) were found to have sufficient knowledge about the benefits of CI and rehabilitation. The percentage of parents who had

Table 2 Descriptive data of CI children

	Mean	Standard deviation
Age (ms)	78.6	±13.49
Age of CI (ms)	50.44	±14.78
Duration of therapy (ms)	22	±14.27

ms Months

Table 3 Correlation analysis between duration of therapy and component items of the questionnaire

		Knowledge	Expectation	Experience	Challenges
Duration of therapy	r	-.193	-.243	.480**	.107
	P value	.180	.089	.000*	.460

r correlation coefficient

*Significant *P* value≤0.05

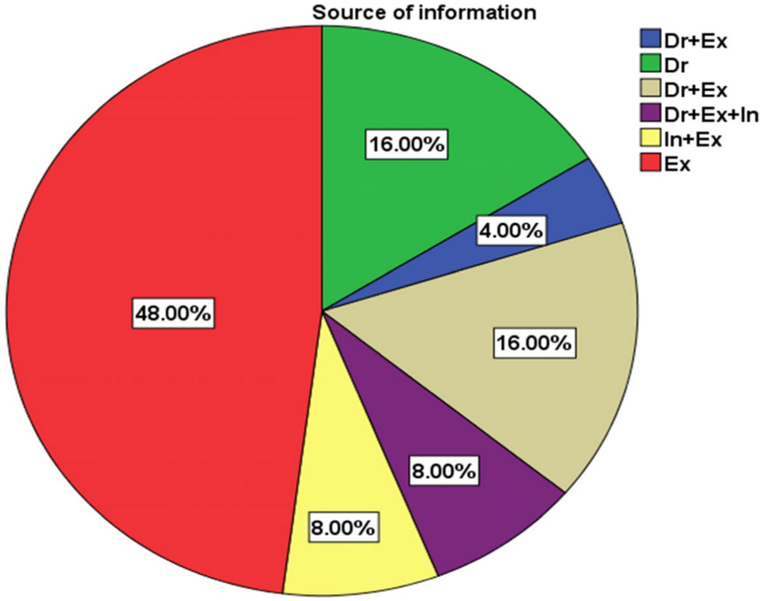

Fig. 1 Source of parental information before CI. Dr: parental knowledge from doctors. Ex: parental knowledge from experience of others. In: parental knowledge from Internet

Table 4 Questionnaire of parental knowledge before cochlear implant (CI)

	>50% of knowledge	<50% of knowledge
Hearing aid	56%	44%
CI	52%	48%
CI cost	72%	28%
CI surgery	64%	36%
Benefits of CI	88%	12%
Rehabilitation	88%	12%
Satisfaction	76%	24%

sufficient knowledge about the cost of CI procedure and CI surgery was (72% and 64%, respectively). Most of the parents (76%) were satisfying about amount of knowledge they received before implantation (Table 4).

A questionnaire about parental knowledge of the protocol of cochlear implantation in the General National Health Insurance showed that parents who have awareness about 50–70% of the Egyptian protocol were (48% of parents) followed by (40% of parents) who have awareness of more than 70% about the protocol while (12% of parents) found to have awareness less than 50% (Fig. 2).

A questionnaire about challenges that might be faced in cochlear implantation procedure showed that most of the parents (80–100%) had challenges with: the length of the procedure period and its steps, expensive spare parts, and cost of language therapy. Many parents (60–80%) had challenges with the maintenance of the device, inability to use the device during sleeping, a distance of the place for language therapy, inability to use the developed device if a new one appears, and absence of services for the child in school. Some of the parents (40–60%) had challenges with the unavailability of the device at operation time, inability to use the device in bathing or swimming, and difficulty hearing noise. Less than 40% of parents reported that the device was broken and had a problem with the cost of the programming session (Table 5).

The comparison between expectations of parents of CI children and their experiences showed that parental experiences were significantly high than parental expectations regarding scores of questions about well-being and the future life (*p* value =0.014, 0.006); however, parental expectations about academic achievements were significantly higher than parental experiences (*p* value 0.001). Regarding parental expectations versus parental experiences about communication ability, social skills, and participation, there was no significant difference (*p* value >0.05) (Table 6).

Discussion

The literature investigating the benefits and problems associated with cochlear implantation as seen by parents is limited. In this study, a parental questionnaire was

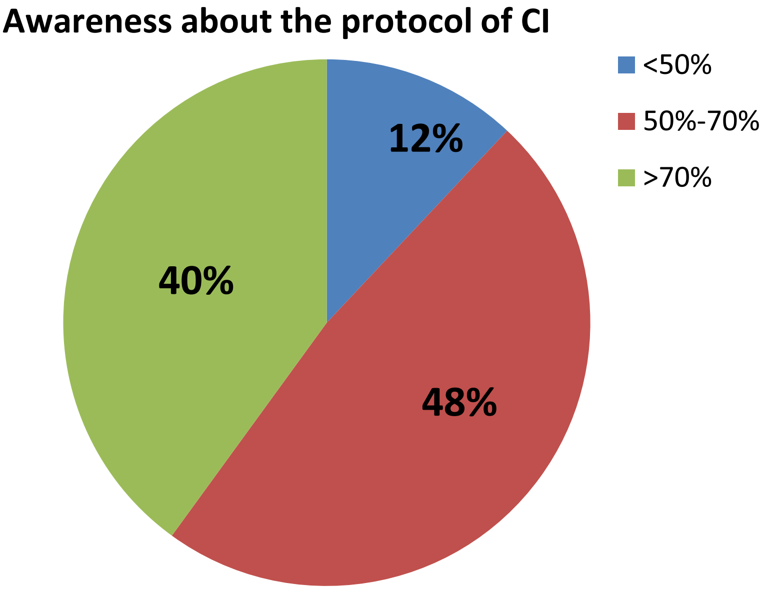

Fig. 2 Parental awareness about protocol of CI in health insurance. <50%: Parents who are aware of <50% of the Egyptian protocol of CI in health insurance. 50–70%: Parents who are aware of 50–70% of the Egyptian protocol of CI in health insurance. >70%: Parents who are aware of >70% of the Egyptian protocol of CI in health insurance

specifically designed, which could be more informative than generic implements of CI.

In this study, we assessed the ways in which the parents gathered information before cochlear implantation for their children. The results showed that almost half of parents (48%) received their knowledge from (the experience of others) such as relatives and other parents who had CI children. Twenty percent of parents received their knowledge from doctors and experience from others, and 16% of parents received their knowledge from doctors only (Fig. 1). These findings indicated that parents mainly preferred to get information from others who had a previous experience with CI which is easy, reassuring, a cheaper way, and does not need effort or money. This is in compliance with the literature, which has acknowledged that the parents contact other families with CI children, and this influences their experiences of coping and emotional support [3]. Many of the parents in our study were able to receive their information from doctors, so health professionals were the second source that provides the information the parents needed prior to CI surgery. However, a study done by Sahli et al. [14] revealed that information on cochlear implants was most commonly learnt from audiologists (63.1%), also Aloqaili et al. [15] found that nearly three-quarters of parents in their survey (73%) reported that their health professional was their ideal source of information, followed by websites and social media. Eight percent of parents in our study cited the use of the Internet besides the experience from others to obtain information regarding CI and 8% of parents received their knowledge from (doctors, the experience of others, and from the Internet) (Fig. 1). The use of the Internet as a source of information for parents is still restricted because the use of the Internet is dependent on the socioeconomic status of the parents and the Internet is a relatively recent technology.

In this study, the results of the questionnaire about parental knowledge before cochlear implantation showed that about half of parents agreed that they received sufficient information (> 50% of knowledge) regarding hearing aids and cochlear implant devices. We found that most of the parents received adequate information (> 50%) regarding CI surgery, the cost of CI procedure, and benefit of CI and rehabilitation options after CI. Seventy-six percent of parents in our study reported satisfaction with the overall quality of information they received before cochlear implantation (Table 4). These results indicate that information plays an important role in parents' coping process and in considering CI for their children and there is a strong need for providing a wide range of information for parents of children with hearing loss.

Regarding parental awareness of the prerequisites for CI procedure in the national health insurance, we found that nearly half of parents (48%) have awareness about 50–70% of the protocol of CI followed by (40% of parents) who have awareness more than 70% about the protocol of CI, while (12% of parents) found to have awareness less

Table 5 Descriptive results of the questionnaire about the challenges during cochlear implantation procedure

Questions		**Percent**
Q.1. Did the length of the procedure period cause any problem for you?	Yes	80%
	No	20%
Q.2. Did you feel that the steps are too much before the operation?	Yes	80%
	No	20%
Q.3.Did the unavailability of the device at the present time causes a problem for you?	Yes	48%
	No	52%
Q.4. Have the problems of maintenance, expensive spare parts, and the possibility of device breakage worried you?	Yes	**100%**
Q.5. Have you really had any problems with maintenance?	Yes	60%
	No	40%
Q.6. Were excessive spare parts an obstacle for you?	Yes	**100%**
Q.7. Did the device broke before?	Yes	20%
	No	80%
Q.8. Did you face problems about not using the device while bathing, or when going to the sea, or in the stadiums?	Yes	40%
	No	60%
Q.9. Did you face problems from not using the device while sleeping (for example for calling him in the morning to wake up)?	Yes	68%
	No	32%
Q.10. Does your child face any problems from not being able to hear properly in the noise?	Yes	40%
	No	60%
Q.11. Did remote programming sessions cause any problems for you?	Yes	32%
	No	68%
Q.12. Did the programming session costs cause any problem for you?	Yes	20%
	No	80%
Q.13. Does the distance from the communication sessions cause any problem for you?	Yes	60%
	No	40%
Q.14. Are the costs of the communication sessions causing any problem for you?	Yes	88%
	No	12%
Q.15. Do you think that you could not be able to develop the device if a new, more advanced device appeared?	Yes	68%
	No	32%
Q.16. Do the absence of any services for our children in schools, either classroom equipped to reduce surrounding noise like certain walls or using FM system technologies cause any problem for you?	Yes	76%
	No	24%

Table 6 Comparison between expectations of parents of CI children and their experiences

	Expectations Mean ±SD	**Experiences Mean ±SD**	***P* value**
Communication ability	12.64±5.48	10.88±4.2	0.06
Social skills and participation	3.12±2.01	3.6±1.25	0.14
Well-being and happiness	1.52±0.71	1.84±0.37	0.014*
Academic achievements	4.76±1.94	3.4±2.16	0.001*
Future life	2.08±1.34	2.8±0.86	0.006*
Total score	24.12±8.93	22.52±6.20	0.2

SD Standard deviation

*Significant *P* value≤0.05

than 50% about the protocol of cochlear implant (Fig. 2). These results highlight the need to raise the awareness about Egyptian protocol of cochlear implantation; we need to distribute more flyers and brochures in health insurance to increase parents' awareness. Parents should have as much information as possible when considering implantation for their child, including the prerequisites for cochlear implant procedure in the national health insurance. This goes in line with other authors who suggested that parents who invest a large amount of time gathering information and making the decision about CI are those parents who are likely to continue a high level of involvement in their children's post-implant rehabilitation [16].

Descriptive results of the questionnaire about the challenges during CI procedure in this study showed that most of the parents (80–100%) had challenges with the length of the procedure period and agreed that the steps of the procedure was too much (audiological assessment, language assessment, IQ test, and MRI), most of the parents also had problems with the expensive spare parts and cost of language therapy. We found that many parents (60–80%) had challenges with the maintenance of the device, distance to the place of language therapy, and absence of services for the child in school (Table 5). These results highlight the barriers that could be faced as lack of facilities and long waiting lists which will lead to delay of the CI procedure besides parents' financial difficulties for language therapy and getting spare parts of the device. Most parents do want to help their children perform better, but they lack the time, resources, and knowledge to do so. Efforts should be directed toward parental counseling and initiating more parent-inclusive rehabilitation programs where parents learn to become effective language models for their children at home. Parents should also gain a deeper understanding, thus promoting treatment adherence. Several studies are consistent with our study in reporting financial difficulties; a study conducted in South East Asia reported that the costs and maintenance of the CI device is a major challenge to parents [17]. On the level of developing countries also Khan et al. [18] reported that the cost of the procedure is the biggest limiting factor for cochlear implantation.

The comparison between the expectations of parents before implantations and their experiences after implantations in this study showed that the parental experiences of wellbeing and the future life were significantly high than parental expectations (*p* value =0.014, 0.006) (Table 6). This result reflects that CI could improve the quality of life of the CI children and indicates that parents were most satisfied with improved social relations and self-dependence of their children. CI is known to promote language development and auditory perception, but it also seems more generally to improve quality of life. Our result was in agreement with the study of Clark et al. [19] which showed that the speech perception results were correlated with the quality of life of children. Similar studies showed that children with CIs experience a quality of life similar to that of normal-hearing peers [20, 21].

In our study, parental experiences of academic achievements were significantly lower than the score of academic achievements expectations (*p* value=0.001) (Table 6). These results revealed high expectation of parents regarding the academic achievements toward children using a cochlear implant. Although parents stated an improvement of the communication and social skills of children after CI, these improvements were insufficient to give satisfied results for academic achievements for the parents. This could be explained by that academic achievement depends on many factors, such as good attention, working in groups, and how to listen to background noise. These results highlight the need for more developments in the assistive technology and improvements in classroom acoustics that will facilitate academic skills development for pediatric CI recipients. Additionally, it is necessary to establish strong communication links among teachers, parents, and implant professionals and it is important for the educators involved with CI children to realize the needs of children with CI.

Our results showed that there was no significant difference between parental expectations and experiences regarding communication ability, social skills, and participation of their CI children (Table 6) which indicate that parents' expectations and their experiences about these skills were met, so CI achieved what the parents were hoping for. However, Zaidman-Zait [22] in his study reported that the parents' response to questions asked about communication abilities revealed their high expectations. A similar study done by Kumar et al. [4] reported that the expectations of parents from CI were substantially high across all the outcomes of communication and the development of language. Sach and Whynes [23] reported that outcomes are highly individualistic, although parents had a shared hope of the implant facilitating the child to function in a hearing world.

Related specialists should understand the needs and expectations of the families; proper counseling on realistic expectations should be given at the different implantation stages: pre-implantation and post-implantation. The field of CIs has many pressing important questions that would benefit substantially from a broader questionnaire about parental perspective to achieve a successful outcome following implantation. This study only sheds light on the parental perspectives of a relatively small number of cochlear implanted children, larger scale multi-centric studies are needed to assess adequately the long-term outcomes post-implantation. Another limitation is that correlation studies between parental perspectives and the linguistic profile of CI children will be needed to know the effect of parents' perspectives on the language development outcomes.

Conclusion

In our study, we constructed a detailed questionnaire for parents of CI children as an additional tool for the evaluation and monitoring process of pediatric cochlear implantation. The findings of this study showed that information was relatively sufficient for many parents to make their decision on CI and parents mostly preferred to get information from others who had a previous experience with CI, also many parents were satisfied with the information and support they received from doctors. The results highlight the need to raise awareness about the prerequisites for CI procedure in the national health insurance when considering implantation for their child.

One of the main challenges to the parents was the financial aspect. There is a need to reduce the impact of the economic burden on the families of hearing-impaired children and to provide easier services. Support for CI children in school environment by using hearing assistive technology is important as we found that the issue of education is a major concern for families. Parents were most satisfied with the improved wellbeing and quality of life of their children. This study emphasizes that a parental questionnaire is an essential addition to language and speech perception tests to quantify the CI outcomes, explore parental challenges, and gain the most benefits from cochlear implantation.

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Authors' contributions
NS acquired the data. DO analyzed the data. RS analyzed and revised the data. HMF conceived the study and wrote the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials
The dataset generated during this study is available from the corresponding author.

Declarations

Ethics approval and consent to participate
The study was approved by the ethical committee of the Ear, Nose and Throat department, Cairo University number 22/ 2019. Informed consent was obtained from the parents for their children participation in this research.

Consent for publication
Not applicable

Competing interests
The authors declare that they have no competing interests.

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