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Contents

EDITORIAL

ORIGINAL RESEARCH

LETTER TO EDITOR

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CONTENTS

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Editorial

Parents, Teachers and Rehabilitation Professionals: Are all needed in enabling children with disabilities?

Recent discussions taking place in the early Childhood Development task force (ECDtf) for Global Partnership on Children with Disabilities centre around arguments in favour of de-medicalisation of early child and family support. Yet, it is almost a déjà vu of discussions held in the past and one wonders at times 'what is new?'. In fact, it was in the mid-eighties of the last century that one of the leading disability activists in Africa addressed 'the three enemies of the disabled child' in his presentation at a conference in Lesotho, apparently a discussion which is still relevant. This activist was trying to convince the audience that it was parents of children with disabilities, followed by teachers and finally social workers who were forming the biggest barriers towards equal opportunity and participation in society. When reading his paper again a short while ago, I thought he must have had a miserable youth. And at the same time, in spite of all those barriers, he became a prominent activist. Could it have been his parents and family who helped him get the right education, which ultimately made him able to obtain a master's degree? Was it the commitment of teachers and rehabilitation professionals which contributed to his career? Or was he right from the onset a charismatic leader whom, without any support, could achieve such a fantastic career?

I learned over the years of working in African and Asian contexts that parents – in spite of all shortcomings (and which parents anywhere in the world don't have shortcomings?) – are key to the development of their children. Yes, I am aware of some parents who are overprotecting. Yes, when reflecting upon bringing up my own children, I realise I made mistakes too. And yes, I know that unfortunately there are parents who neglect their children, who may even abuse them in several ways. I am however convinced that most parents – even those who have children with disabilities – do their utmost best to help their children become responsible and independent citizens of their communities.

Teaching staff – certainly on the African continent – are often faced with a bare minimum of resources and classes with far too many students. Further, the quality of their teaching, especially when faced with children with special needs, although not optimal is often unrelated to negative attitudes. Most likely, they are not sufficiently equipped to work with children with disabilities; most likely, they work under miserable conditions with too many children in the classroom; too few chairs and tables, let alone having access to the necessary assistive technology that will benefit children with special needs.

Rehabilitation professionals including social workers are hard to find, certainly in rural communities and slums in most African and Asian countries, even today. If you find them working in such areas, one can be assured that these are the most committed professionals who with little means and support from government do their utmost best to offer their services to those who are in need. This journal has shown over the past 30 years many examples of people in African, Asian and South American countries, working within impoverished conditions, at time on the fringes of society.

Isn’t it timely to make very clear that those who criticise parents, teachers and rehabilitation professionals living and working in low- and middle- income countries should first start recognising and appreciating the context in which they live and work? Isn’t it also of great importance to realise that children with disability and their families require both medical and non-medical support as early as possible?

Many parents in low- and middle- income countries are struggling to come to terms with the challenges of having a child with a disability. In many of such countries, the only recourses for them to turn to are either traditional or faith healers. If they are lucky and living close to town where secondary health care services are available, they can ask for support from the health sector. However, even in those cases it is not assured that they and their children can access rehabilitation services or schools where teachers have been trained to work with children with special needs. The following example may give some insight into the reality of being a child with a disability and raising a child with a disability in a low-income country:

During a recent CBR programme evaluation in the capital city of an African country, our team was visiting a large regular secondary school, which proudly stated that out of the 1200 children they were serving, approximately 50 were children with various types of disabilities. There was some excitement in our evaluation team about visiting a disability-inclusive school without having that label of being disability-inclusive. When talking with the headmaster and some teachers, they informed us about children with visual impairment and hearing difficulty. They had decided in both cases that it would be useful for those children to sit in the front row of the class; to write in large letters on the whiteboard and to pay attention to their own way of speaking i.e. speaking slower and articulating more. At first sight, we all were very positive about such interventions. However, when asking them if they had referred these children to the nearby primary health care centre for eye exams and audiometric (hearing) tests respectively by a nurse, the answer was no.

The above example shows us a glimpse of the challenges faced by the child with a disability and parents in a low-income country. In the above country, the national educational policy aims to ensure that all children and youth — including those with disabilities — have access to equitable, inclusive, and quality education. The reality is that the policy is fine, but practicing that policy is something else given a large number of eco-social factors. What we, however, can learn from the above example is that headmasters, teachers and parents are committed to the best of their knowledge and ability to support the child with a disability.

In view of the current discussions aforementioned in this editorial, it is important to stress how careful we should be in our debates about possible opposing fields; in this case the role of the education sector versus the role of the health sector. Such opposing views may all too easily exist between professionals and activists as well. In addition to this, there may be views presented and promoted by professionals and activists living in high-income countries. They should especially be careful in critiquing those who live and work in low-income countries and make sure that they very well understand the existing realities. And instead of criticising systems and structures, they should seek workable solutions that fit the child, the parents, the teachers and the scarce number of rehabilitation professionals. The child with a disability will only optimally develop if the parents, the teachers and health staff – including rehabilitation professionals – work together in a system that takes into consideration the needs of the child and of the parents, and look for culturally appropriate interventions and solutions.

While the needs of children with disabilities and their parents are well documented, the tragedy is that in low- and middle- income countries, resources (both human and material) in offering appropriate services/interventions to such children remain scarce. In practice, it means that there is a continued shortage of competent special needs teachers, rehabilitation professionals and field workers as well as a large unmet need for appropriate assistive technology. An article (Ghosh et al., 2021) in this issue refers to the importance of training and employing mid-level rehabilitation workers in low-and middle-income countries and propose that they are a solution that may be more appropriate than copying training programmes and deploying highly specialised rehabilitation professionals. The latter being an old idea promoted in the early eighties by the World Health Organisation, but which never got the attention it deserved in spite of some successful pilots in some African, Asian and South American countries.

I hope that the large diversity of manuscripts presented in this issue is of interest to many of our readers. We wish you well, stay healthy and continue to play your role in making this world a better and more inclusive place for all.

Huib Cornielje
Editor-in-Chief

ORIGINAL RESEARCH

Greek Secondary Education Teachers’ Views on Inclusive Education of People with Intellectual Disabilities

Panagiotis Giavrimis*

ABSTRACT

Purpose: *This paper aimed to investigate Greek secondary education teachers’ views on people with intellectual disabilities, their inclusion in the typical educational system, and the dimensions of social and educational exclusion that may be associated with it.*

Method: *The qualitative research design involved semi-structured interviews with 18 Greek secondary school teachers.*

Results: *It was revealed that people with intellectual disabilities face educational exclusion for two reasons. The first is because the structure of the education system itself cannot meet their increased needs, and the second is due to the fact that a percentage of secondary education teachers feel negative about their inclusion in the typical education system.*

Conclusion and Implications: *The implemented policy for the co-education of people with intellectual disabilities in Greece is not effective due to endogenous difficulties. It is necessary to orient the educational policy towards an education for all without "filters" of social exclusions.*

Key words: *secondary school teachers, intellectual disability, inclusion, educational exclusion*

INTRODUCTION

Inclusion of people with disabilities is often part of the educational discourse and, at the same time, its evaluation influences the way educational policies and specific educational practices are implemented. Investigating teachers’ views on the issue can highlight aspects of this discourse, enhance their interaction with

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* Corresponding Author: Associate Professor, Department of Sociology, University of the Aegean, Greece.
Email: giavrimis@soc.aegean.gr

people with disabilities, and support the latter's right to be included in typical education. Within this context, typical education teachers' views on people with intellectual disabilities and their inclusion highlight the most important school-mediating factors for the biggest group with a disability within the education system.

About 3% of the general population has an IQ of less than two standard deviations below the average. In 1998, people with intellectual disabilities in Greece accounted for 23.64% of all people with special educational needs (Kotaridis et al, 1998). The Eurostat report (1995a,b) states that 25.4% of people with intellectual disabilities are illiterate, 59.9% are primary school graduates, 5.7% are junior high school graduates, 5.6% are high school graduates and 3.4% are higher education graduates. During the school year 2005–2006 there were 2389 students with intellectual disabilities in primary education (Ministry of Education, 2008; Georgiadi et al, 2012), whereas during the school year 2009-2010 there were 9272 students with intellectual disabilities at all levels of education. Here it should be noted that there is no official data on intellectual disability in general, a fact that makes it difficult to assess the situation in Greece (Anagnostopoulos & Soumaki, 2011).

The American Association for Mental and Developmental Disabilities (AAIDD, 2018) mentioned that intellectual disability is defined as significant limitations on one's cognitive functioning and adaptive behaviour in the environment before the age of 18 (Luckasson et al, 2002). This definition has important implications in Greece, for the evaluation procedures of the official diagnostic institutions of the education system and the treatment of children with intellectual disability (Bablekou & Kazi, 2016). Laws 3699/2008 and 4547/2018 define a strict framework for the categorisation of persons with special educational needs, despite the provisions for inclusive education. Nowadays the term 'learning disabilities' covers, with a more functional and social manner, the definition of intellectual disability. A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life (Mencap, 2014). According to the definition above, intellectual disability is perceived as an individual's functioning in the social and environmental context.

The older definitions were based on the conceptual and epistemological context of the medical model, presented as an illustration of a given objective reality, which is articulated as a reference to the power of the majority of people without disabilities. On the contrary, within the social model, intellectual disability is perceived as a social construct that provides these individuals with an alternative way of approaching their social interaction and coexistence (Rapley, 2004). Despite criticism that the social model has received (Shakespeare, 2006) and the emergence of other approaches (e.g., Multidimensional Learning Model), the emphasis on social approaches to disability is focused on mediating factors of the context, without silencing the body's constraints (Beaudry, 2016).

At the same time, the term 'intellectual disability' was used in the past decade instead of the medical term 'mental retardation', in order to emphasise the interaction of the individual with the environment and the adaptability of the social context to the individual's diversity (Stainton, 2001; Schroeder et al, 2002). The term 'intellectual disability' further facilitates modern career practices which focus on functional behaviour and environmental factors and place the individual's support within a socio-ecological context. This term is less unpleasant or offensive to people with disabilities and is consistent with international terminology. In addition, in recent years the term 'learning disability' has been used to cover a wide range of learning difficulties, including people with intellectual disabilities and specific learning disabilities (Russell et al, 2017; Franklin, 2018; Siegel, 2018).

Greek Teachers' Attitudes towards Inclusive Education of People with Intellectual Disabilities

Inclusive education is an educational reform against failure, social and educational exclusion (Slee, 2011). According to Booth and Ainscow (2011), inclusive education encompasses: (a) support given to each individual so that she/he feels that she/he belongs to the educational community; (b) reduction of exclusion, discrimination, and barriers to learning and participation; and (c) modification of culture, policies, and practices, so that education can respond to the diversity of the student population in an unprejudiced and egalitarian manner. Inclusive education is a political and cultural change, a deconstruction of the conservative reality of educational frameworks (general - specific) and shapes them into an area of equality, social justice, solidarity and respect for diversity (Ballard, 1997). Furthermore, inclusive education indicates the need for a radical reform of the educational policy, and organisation of the curriculum and pedagogy (Skidmore, 2004).

Both special and typical education teachers seem to have a positive attitude towards including people with an intellectual disability into the typical education system (Karelou, 2007; Memisevic & Hodzic, 2011; Ojok & Wormnæs, 2013), with the former being more positive (Balboni & Pedrabissi, 2000). Research has also found that the type of disability and its severity (Burge, 2017), teachers' experience (Balboni & Pedrabissi, 2000; Karelou, 2007), their information and appropriate training (basic and in-service) (Balboni & Pedrabissi, 2000; Vernier, 2012; Ojok & Wormnæs, 2013; Sermier Dessemontet et al, 2014) play an important role in the effectiveness of inclusive processes. Teachers' confidence in their skills and training is important as well (Alshemari, 2016). At the same time, Malki and Einat (2018) report that inclusion of people with an intellectual disability, as supported by Israeli teachers, fails mainly due to the inadequacy of the school curriculum and the limited skills of teachers, factors that push teachers to use informal inclusion strategies. Thus, Israeli teachers propose to increase the number of hours, improve the teacher education curriculum and develop cooperation between typical and special education teachers, as well as between experts in inclusive education. In addition, in a research conducted in Bosnia and Herzegovina, teachers have suggested that in order to successfully implement inclusive education: (a) additional support should be given to teachers of typical education by the school administrators and to special education teachers so that personalised programmes for children with intellectual disabilities can be developed; and (b) it is important to develop more appropriate teaching materials and reduce the number of students in typical classrooms (Memisevic & Hodzic, 2011).

Within this context in Greece, it should be noted that from Law 4397/1929 where there is a fragmentary approach to the education of people with intellectual disabilities, it has been observed to date that special education, initially, and the contemporary demand for inclusive education, are founded on an organisational structure without systematic and strong scientific basis. Administrative decisions are the result of the centralised system of development of the Greek educational system, which is usually hindered by the inability of the Greek state to cope with its pathogens (Lambropoulou & Panteliadou, 2000; Charoupias, 2011). Within the Greek educational system, the medical-biological model is dominant when educational policies for people with disabilities are to be implemented. Classification and segregation remain, and the integration of a person with disabilities is done through assessment procedures, not to better regulate his/her inclusion but rather to adapt the person to a structured educational environment. Moreover, there is an evident contradiction within the Greek educational policy between the democratic discourse of the official reports of the state on special and inclusive education and the teachers' daily educational practices and the way that educational policies are implemented. The Greek Ombudsman reports (2014, 2015) point out the lack of support for students with disabilities who attend general schools, the shortage of specialised teachers and the underfunding of special education in Greece. Whereas the official discourse of the state is oriented towards education for all, it is not translated into practice within the educational framework and context (Deropoulou-Derou, 2012). Also, in Greece, while existing research is more general and based on attitudes towards disability (e.g., Coutsocostas & Alborz, 2010; Tsakiridou & Polyzopoulou, 2014; Stefanidis & Strogilos, 2015; Soulis et al, 2016), there is insufficient research on intellectual disability and teachers' attitudes towards the co-education of these students.

Objective

In the context of the North Aegean (Greece), which is an island region and a gateway for immigrants and refugees, no relevant research on the aforementioned topic has been carried out. Therefore, the purpose of this paper is to investigate teachers' views on people with intellectual disabilities, their inclusion in the typical educational system, and the dimensions of social and educational exclusion that may be associated with it. (The research data presented here is part of a more general research into the Greek education system which aims to investigate the attitudes of teachers towards different categories of people with disabilities and their integration into the education system.)

METHOD

Participants

The study participants were 18 Greek secondary education teachers from schools of the largest cities of the three islands that constitute the prefecture of the North Aegean (Greece). Of the 21 secondary schools, 11 were drawn by lot. Based on the population of teachers in these schools, the voluntary participation was requested of a certain number of teachers who lack special education and training.

There were 12 women and 6 men among the 18 participating teachers. Most of them were philologists, between 30 and 55 years of age.

Study Design

The research was conducted using semi-structured interviews.

The respondents were informed about the nature and objectives of the research and the details of the interview were clarified to conclude the "narrative contract." They were also assured that their personal data was protected so as to ensure anonymity and confidentiality, and permission to record the interviews was obtained.

Data Collection

The data collection was done in the participants' personal space (i.e., home, office, etc.). The discourse was then transcribed and analysed. The validity and effectiveness of categorisation were ensured through the application of the rules of objectivity, exhaustiveness, appropriateness and mutual exclusion.

Data Analysis

Based on the participants' discourse, the researcher could understand the reality and the reconstruction of its parts.

The parts of reality are framed and reconstructed based on the context in which fragments are placed and drawn from their semantic part. Every part of this reality is delineated and specified in a particular way (Tsiolis, 2006). Social scientists, when analysing interviews, try to reconstitute how individuals identify and conceptualise the particular cases they face. This understanding and the subjective approach of reality highlight both the individuality of the case and the perception of social representations and legitimate models of disability that exist within the Greek society and the educational system. Individuals' understanding and conceptualisation is socially structured and historically shaped by their negotiation and experiential experience in their own ecosystem (Tsiolis, 2006).

The current research endeavoured to formulate categories and sub-categories with thematic analysis, so that in a dialectical way the transformation of reality is revealed through individuals' meanings and their perceptions of social reality. All of this, of course, was done under the theoretical perspective of disability approaches, and the interviewees' diachronic lived experience over the past and their current perspective on their narratives. After transcribing the participants' interviews, their responses were codified by highlighting the categorisations of the reality that the teacher-participants had given through their conceptualisations.

The aforementioned were then analysed using the theoretical framework of disability (e.g., Finkelstein, 1980; Barnes et al, 1999; Zoniou-Sideri & Vlachou, 2006; Booth & Ainscow, 2011; Slee, 2011), without having forgotten that new categorisations of social reality may be emerging through the participants' discourse.

To achieve the above and for the research content to be valid in relation to the subject investigated, the interview guide was constructed on the basis of the following interrelated factors: (1) theoretical disability models (Finkelstein, 1980; Barnes et al, 1999; Zoniou-Sideri & Vlachou, 2006; Booth & Ainscow, 2011; Slee, 2011); (2) the globalised education framework (Gewirtz et al, 2009); (3) the situation of the special welfare state; and (4) the situation of special education in Greece (Stasinos, 1991; Charoupias, 2011; Chronopoulou-Pantazi, 2011). In conducting the research, the interview guide included questions about: (a) the concept of disability; (b) educational policies for inclusive education; (c) teachers' attitudes towards including people with intellectual disabilities into the typical educational system; (d) barriers and difficulties in inclusive education; and (e) the attitudes of other members of the educational community (i.e., pupils, parents).

RESULTS

From the analysis of the interviews, four thematic categories emerged that concerned: a) Views on inclusion, b) Relationships of students with disabilities and teachers, c) Views of typical students' parents, and d) Educational policy. These are analysed, based on the sub-categories that emerged, while excerpts from the participants' dialogues are listed.

Views on Inclusion

When asked about the access to education that students with intellectual disabilities have, the participating teachers mentioned that the severity of intellectual disability plays a key role and that the inclusion of students with intellectual disability into the typical Greek education system would not have a positive impact on them. Also, their reference to the term 'mental retardation' reflects the reality that teachers are poorly informed about current developments and claims of the disability movement and continue to use terms previously used in the medical model.

> *"It depends on the case. Children and young people with mobility problems, for example, can clearly join… mental retardation and other disabilities want their own environment in which these individuals can more easily be included; that is, inclusion … Children and young people with mental retardation want their own space and their own inclusion process" (Teacher D).*

> *"I get fearful when a person has severe mental retardation and slows down the classroom" (Teacher E).*

> *"In mental retardation, it is self-evident, that the students can neither always cooperate and understand - nor perceive and participate in what we provide" (Teacher L).*

> *In addition to the above, most of the teachers (11 out of 18) considered the inclusion of students with intellectual disabilities in the typical Greek education system either as something that could produce negative results, or as something difficult to handle which may even be disturbing to the others in the classroom.*

> *"… Wouldn't it be a little bad for a child with Down's syndrome, or mental retardation, to go to a regular school? Just think about the way these children will be treated... would be unfair because they would also feel rejected" (Teacher N).*

> *"I find mental retardation more difficult than any other physical disability, eh, due to the fact that a person has a real problem with communicating and getting what she/he is taught; that is, in order for one to be taught, one should be calm" (Teacher E).*

> *"Mental retardation is the most difficult due to the fact that it is difficult to approach these children and young people, and keep their attention which is needed to assimilate what you are trying to teach them" (Teacher F).*

Relationships of Students with Disabilities and their Teachers

The 18 teachers did not seem to have firm views about their interactions with students with intellectual disabilities and their inclusion in their classroom. Opinions ranged from positive and democratic (6), to neutral (4) or conflicting (8).

> *"I think it's not my personal choice about which students to put in my classroom or not, that is not up to me to choose and it is also very bad to choose which*

children enter and which ones do not. A classroom should be an environment where everyone is accepted, and that is what we must promote" (Teacher B).

"No, I do not think it is democratic, since there is no such infrastructure and organisation to help these children and young people to be included in the school properly. No, it is not democratic" (Teacher L).

Views of Parents of Typical Students

Most of the interviewed teachers (12 out of 18) reported the negative behaviour of some parents. Feelings such as fear and ignorance are inherent in the behaviour of members of the educational community, although this has changed in recent years. Moreover, very few teachers (2 out of 18) thought that some parents of other students believe that people with disabilities are a 'punishment' for their parents, without themselves embracing this attitude.

"…… typical pupils reproduce the fear of some parents. Some parents are the first to react, out of fear and ignorance... " (Teacher C).

"……… this racist behaviour is expressed by parents who do not accept the view that their children can be educated in the same place and are not properly informed. In recent years, of course, this situation has changed slowly; parents have been informed and they know that typical pupils must learn to live with these children in order for us (as a whole) to reach a holistic approach, social acceptance, and meaningful help (of these children)" (Teacher A) .

"Some believe that a child with a disability is a 'punishment' for their parents. Indeed, such a belief is held by some. In no way do I accept this. It has to do with (bad) luck if the disability comes from an accident or from nature or if it is by birth" (Teacher G).

Furthermore, some teachers (4 out of 18) referred to the importance of the family's role in the development of attitudes of students towards their class peers with disabilities.

"Here, of course, we can't talk about a rule, and that it is always the case. There are children who have become aware of these children at home and in school; they are very receptive to diversity, and we can say that these children many times embrace diversity" (Teacher F).

Finally, most of the teachers (15 out of 18) referred to information about disability issues that should be provided to parents.

> *"……. of course, it is the parents of other students. Primarily, they should be more informed, so to be able to our society to include children with disabilities" (Teacher K).*

Educational Policy

School Infrastructure, Facilities and Teaching Staff

At the same time, all the teachers referred to the shortcomings of logistical infrastructure and the conditions inherent in the education system, although they felt that efforts have been made to become more inclusive. Typical issues of infrastructure, organisation, syllabuses and modern teaching were among the most important issues that were discussed.

> *"The education system does not provide equal opportunities for everybody. I think that some efforts are being made at the moment, but for the most part I think there are serious shortcomings. The education system should be reorganised, to review some things such as curricula, the way the school functions, the infrastructure, and, more generally, I think that the state should take more care of the infrastructure" (Teacher A).*

> *"The mainstream school sometimes finds it difficult to include some children into its school unit and there are no proper conditions. When there is no proper awareness (of the special needs of students with disabilities), the school culture is such that it neither has nor provides proper infrastructure..." (Teacher H).*

Moreover, a good number of teachers (10 out of 18) mentioned that there are difficulties because most teachers in special education are substitutes, and they move to different schools every school year. This does not help build strong supporting social networks.

> *"I do not think there is safety or trust……. in special education, teachers are substitutes ……… children do not have persons for permanent reference point; the teacher is forced to change classes every year, and as a result, no close relationship of trust and safety is established, something that is needed in cases of people with disabilities" (Teacher M).*

Teacher Training

All teachers were of the opinion that: (a) their education and training on disability is an important issue so that people with disabilities can be better included in the school; (b) the lack of training is an obstacle and a factor that creates fear and insecurities among teaching staff; (c) training and teacher training for children and youngsters with intellectual disabilities in the Greek educational system is inadequate; and (d) teacher training helps them in raising awareness about disability and, eventually, can contribute to change the culture of schools.

> *"… and of course, there is the lack of information, proper training of general education teachers on special education issues so these children ……… are still aimed at and labelled" (Teacher A).*

> *"As I have said, I think that general education of teachers is inadequate, and I think there should be continuous and compulsory training" (Teacher C).*

> *"…teachers are not adequately trained to accept the inclusion of students with disabilities in mainstream schools, but there is a growing awareness of the needs of these students and there is an increasing awareness of students with disabilities and so, cowardly in recent years, this culture has been changing shyly and slowly …." (Teacher H).*

> *"Nowadays teachers should be educated and trained on the issues of inclusion of all pupils i.e., mainstreaming … there is a need for training with programmes aimed at the inclusion of all pupils, regardless of their particularities" (Teacher F).*

DISCUSSION

This research study attempted to investigate teachers' views on students with intellectual disabilities, their inclusion in the typical educational system, and the dimensions of social and educational exclusion that may be associated with it. Teachers seemed to agree that students with intellectual disabilities have difficulties in accessing the typical Greek mainstream education system and, even after inclusion in it, they are confronted with discrimination and prejudice by some stakeholders in the educational community (e.g., parents of students without disabilities). The rhetoric of inclusive education in the public discourse does not seem to be implemented in pedagogical practices. Some teachers refer to "*mental retardation*", thus emphasising the shortcomings of the person with disabilities and transferring the responsibility for his/her difficulties to the student with an intellectual disability himself/herself. The frequent reference to the term 'mental retardation' reflects the reality of poor knowledge among teachers regarding the developments and claims of the disability movement about their rights and entitlements and refers to old ideas embedded in the medical model (Angelides et al, 2006; Koutrouba et al, 2008; Soulis, 2013; Giavrimis, 2018, 2019). People with intellectual disabilities, both within society and the education system, are confronted with perceptions and stereotypes that can potentially lead to social and educational exclusion (Yuker, 1976; Oliver 1990; Azizi-Kalantzi et al, 1996; Dimou, 1996; Zoniou-Sideris, 2000; Holt 2003; Lambropoulou, 2004; Rabiee et al, 2005). This is an outcome of how both the social and environmental structures and dominant social representations function within a given society (Barnes & Sheldon, 2010).

At the same time, teachers are sceptical about the inclusion of children and youngsters with intellectual disabilities. Their disagreements relate, on the one hand, to the severity of intellectual disability and, on the other hand, to inadequate education and training of teachers to effectively work with such children and youngsters. These findings are in line with research data in international and Greek literature (Wishart & Manning, 1996; Zoniou-Sideri & Deropoulou-Derou, 1998; Avramidis et al, 2000; Zoniou-Sideri, 2000; Avramidis & Norwich, 2002; Soulis, 2002; Avramidis & Kalyva, 2007; Reversi et al, 2007; Fyssa et al, 2014; Genova, 2015). This is a confirmation of both the inadequacy of the education system to include students with disabilities in the typical mainstream school system in a more appropriate and functional way, and teachers' inability to handle such children and youngsters (Tsakiridou & Polyzopoulou, 2014; Tzivinikou, 2015; Mavropalias & Anastasiou, 2016). At this point, it should be noted that teachers' expectations of children and youngsters with intellectual disabilities resemble the medical-biological model. This is despite Greek legislation and educational proclamations of social justice and equality in educational opportunities, grounded in a globalised and post-modern environment, which should allow for freedom of teaching and pedagogical choices that would challenge the established patterns of daily educational practices (Slee, 2003).

Moreover, in the current educational policy for special education in Greece, there is a lack of attention towards the importance of special infrastructure for those children and youngsters with special needs, and there is a failure to adequately inform the general public about the importance of inclusion of children and youngsters with intellectual disabilities in the mainstream classroom. The deficiencies in the administrative and organisational structures, and the confusion while the necessary educational practices are being implemented, aggravate the existing problems (Lambropoulou & Pandeliadou 2000; Hellenic Statistical Authority- HAS, 2007, 2008; OLME, 2008). Besides, teacher training for secondary school teachers does not include specific attention to the importance of special needs education and co-education of children and youngsters with disabilities (Avramidis & Norwich, 2002; Kalyva et al, 2007; Giavrimis, 2018; Pappas et al , 2018).

CONCLUSION

It may be concluded that children and youngsters with intellectual disabilities face educational exclusion due to the fact that on the one hand, the education system itself cannot respond to their special needs, and, on the other hand, a percentage of secondary education teachers react negatively towards the inclusion of such children in the mainstream education system. It is therefore imperative that: (a) the pedagogical training of secondary education teachers in special needs education during their university education should be developed and enhanced, so that they become aware of and able to adequately respond to the needs of children and youngsters with learning disabilities; (b) a culture of solidarity and inclusion in schools should be developed, through processes supported by local community initiatives, school principals, and the Ministry of Education ; and (c) it should be realised and recognised that when an educational policy aimed at the inclusion of people with disabilities is being pursued, it is necessary to transform existing infrastructures, professionally upgrade teaching staff and raise the general population’s awareness and acceptance of diversity.

Despite the limitations of this qualitative research, it appears that the implemented policy for the co-education of children and youngsters with intellectual disabilities in Greece is not effective. Further research is necessary to establish the critical factors for successfully including children and youngsters with intellectual disabilities in mainstream schools in Greece.

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Impact of Visual Impairment and Correction on Vision-Related Quality of Life: Comparing People with Different Levels of Visual Acuity in Indonesia

The Maria Meiwati Widagdo[1*], Yunita Rappun[1], Aprilia Vetricia Gandrung[1], Edy Wibowo[2]

1. Department of Public Health, Faculty of Medicine, Universitas Kristen Duta Wacana, Indonesia
2. Department of Ophthalmology, Bethesda Hospital, Indonesia

ABSTRACT

Purpose*: This study assessed the extent to which visual impairment impacts on vision-related quality of life in Indonesia, by comparing four groups of people: those with 1) normal vision, 2) corrected visual impairment, 3) uncorrected visual impairment, and 4) blindness.*

Method: *Purposive sampling was used. There were 162 respondents, between 21 and 86 years of age. Participants with normal vision and blindness were community-dwellers in Yogyakarta, Indonesia. Those with corrected and uncorrected visual impairment were recruited from an eye clinic. This cross-sectional study used NEI VFQ-25 to assess vision-related quality of life. The total scores and 11 NEI VFQ-25 subscales scores of four respondent groups were analysed using ANOVA, followed by post-hoc analyses to reveal between group differences.*

Results*: There was a significant difference in the NEI VFQ-25 total scores among the four respondent groups. Respondents with normal vision had the highest score and those with blindness had the lowest. There were also significant differences among the four groups for the 11 subscales. Post-hoc analyses revealed no significant difference between respondents with normal vision and corrected visual impairment in the total and 9 NEI VFQ-25 subscales. Respondents with uncorrected visual impairment and blindness had significantly lower vision-related quality of life compared to those with normal vision or corrected visual impairment in the total and 5 NEI VFQ-25 subscales, indicating that visual impairment decreases vision-related quality of life.*

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[*] **Corresponding Author:** The Maria Meiwati Widagdo, Department of Public Health, Faculty of Medicine, Universitas Kristen Duta Wacana, Indonesia. Email address: maria_widagdo@staff.ukdw.ac.id

***Conclusion**: Visual impairment has a detrimental impact on a person's vision-related quality of life. The negative impact of visual impairment can be minimised by correction. Failure to correct visual impairment leads to significantly lower vision-related quality of life.*

***Key words:** quality of life, visual acuity, blindness, visual correction, Indonesia*

INTRODUCTION

The Global Burden of Diseases project, conducted in 2017, reported that blindness and visual impairment caused 1.19% of DALYs globally (Institute for Health Metrics and Evaluation - IHME, 2017). The World Health Organisation's World Report on Vision, released in 2019, estimated that the number of people with visual impairments worldwide was 2.2 billion (WHO, 2019). The Ministry of Health of the Republic of Indonesia reported that the population with severe visual impairment was more than 2 million people and the number of people with blindness was more than 900,000 (Ministry of Health, 2013).

People with visual impairments experience limitations in carrying out various activities in their lives. They need more time to complete tasks like eating and drinking as they have difficulty in identifying food on a plate or pouring liquid into a glass because of their visual impairment (Pardhan et al, 2015). Independence in conducting activities of daily living decreases as the visual impairment worsens (Christ et al, 2014). Reduced visual acuity, decreased visual field and blurred vision have been associated with lower quality of life (Medeiros et al, 2014; Kim et al, 2017).

There are several studies on the prevalence of visual impairment in Indonesia. Mahayana et al (2017) studied primary school children in 3 districts in Yogyakarta Province and 1 district nearby to find the prevalence of uncorrected refractive error in urban, suburban, exurban and rural children. Sasongko et al (2017) reported the prevalence of diabetic-related blindness of people residing in Yogyakarta. Muhit et al (2018) examined 195 children aged 0-15 years in Sumba and Yogyakarta to study the epidemiology of childhood blindness.

Although much is known about the number of people with visual impairment, Indonesia still lacks studies on how visual impairment affects vision-related quality of life. Asrorudin (2014) investigated the effect of eye diseases and visual impairment on vision-related quality of life in a population with severe visual impairment and blindness in Indonesia. However, no studies have compared vision-related quality of life between people with normal vision and people with different levels of visual impairment. The comparison between subjects with varying visual function will help elucidate the impact of visual impairment on vision-related quality of life in Indonesia.

Objective

Unlike previous studies conducted in Indonesia, this study aimed to compare the quality of life of people with normal vision, corrected visual impairment, uncorrected visual impairment and blindness.

METHOD

Study Sample

For this cross-sectional study, adults aged 18 years and older were recruited using purposive sampling.

The respondents were classified into 4 groups: Group 1 - people with normal vision, Group 2 - people with corrected visual impairment, Group 3 – people with visual impairment that remained uncorrected although using visual aids, and Group 4 – people who were legally blind. Respondents in Group 2 had either mild or moderate visual impairment, while those in Group 3 had moderate to severe visual impairment.

Those with normal vision and blindness were community dwellers, while participants with visual impairment were recruited from the eye clinic of Bethesda Hospital in Yogyakarta. The respondents with blindness were clients of Badan Sosial Mardi Wuto, a social organisation for people with low vision or blindness.

WHO defines normal vision as visual acuity of 6/6, and blindness as visual acuity worse than 3/60 in the better eye with best correction (WHO, 2019). Visual acuity of respondents with visual impairment was examined by an ophthalmologist, and people with normal vision and blindness were examined by a trained research assistant. People with corrected visual impairment could reach 6/6 visual acuity with visual aids. People with uncorrected visual impairment had visual acuity below 6/6 despite the use of visual aids.

Data Collection

Vision-related quality of life was assessed using National Eye Institute – Vision Function Questionnaire – 25 (NEI VFQ-25). This questionnaire has been used to measure vision-related quality of life among Asian people as well (Suzukamo et al, 2005; Gyawali et al, 2012; Cortina and Hallak, 2015; Saboo et al, 2017; Nickels et al, 2017). NEI VFQ-25 has 12 subscales. The total score is the sum of the 12 subscales scores. The respondents with blindness did not drive, so all of them scored '0' in the driving subscale. Multivariate ANOVA was conducted to test the differences of the NEI-VFQ total and 11 subscale (excluding driving) scores among the four groups with age and sex as covariates. Post- hoc analyses using Dunnett C were conducted to find differences between respondent groups.

Ethics Approval

Ethical clearance was obtained from the Ethics Committee of the Faculty of Medicine, Universitas Kristen Duta Wacana. Detailed explanations were given to the participants to obtain their written informed consent. They were assured that the data would be kept confidential and anonymity would be maintained.

RESULTS

Data was collected from 162 respondents: 41 people with normal vision (Group 1), 41 people with corrected visual impairment (Group 2), 40 people with uncorrected visual impairment (Group 3), and 40 people with blindness (Group 4). There were 28 females and 13 males in Group 1, 25 females and 16 males in Group 2, 19 females and 21 males in Group 3, and 26 females and 14 males in Group 4. The mean and standard deviations of age were: 33.59 ± 7.194 years in Group 1; 52.85 ± 14.307 years in Group 2; 60.98 ± 15.58 years in Group 3; and 46.83 ± 12.09 years in Group 4.

The most common cause of visual impairment in Group 2 was cataract (61%), followed by refractive disorders (24%) and glaucoma (7%). Cataract was also the most common cause of visual impairment in Group 3 (65%), followed by glaucoma (15%), diabetic retinopathy (12.5%) and age-related macular degeneration (2.5%). Meanwhile, among respondents with blindness, measles (87.5%) was the most common cause of blindness since childhood, followed by congenital cataracts (7.5%) and glaucoma and retinal detachment (2.5% each) respectively. The majority of respondents in Group 2 (85%) and Group 3 (65%) had visual impairment for less than 5 years, while respondents in Group 4 had been blind for more than 10 years (100%).

Most respondents had high school education in Group 1 (47.5%) and Group 3 (62.5%). In Group 2, 52.5% had college education, while respondents with blindness had the lowest level of education, as 27.5% had never been to school and 50% had elementary school education.

The majority of respondents in Group 1 and Group 2 were working people (75% and 57.5%, respectively). Half of the study participants in Group 3 worked, and most of those who did not work were pensioners. Almost all of the respondents with blindness (97.5%) worked as masseurs. In Indonesia, the department of social affairs provides free masseur training programmes for people with blindness.

The vision-related quality of life of respondents with normal vision, corrected visual impairment, uncorrected visual impairment and blindness, the results of multivariate ANOVA and post-hoc analyses are presented in Table 1.

Table 1: Vision-related Quality of Life of People with Normal Vision (Group 1), Corrected Visual Impairment (Group 2), Uncorrected Visual Impairment (Group 3) and Blindness (Group 4), the Results of Multivariate ANOVA and Post-hoc Analyses of the 4 Groups

Vision-related Quality of Life	Group 1 (G1)	Group 2 (G2)	Group 3 (G3)	Group 4 (G4)	Multivariate ANOVA		Post-hoc Analyses
	Mean ± SD	Mean ± SD	Mean ± SD	Mean ± SD	F	p	
Total	946.84 ± 47.240	946.84 ± 47.240	781.29 ± 128.690	418.90 ± 89.468	282.469	<0.001	G1>G2** G1>G3*** G1>G4*** G2>G3*** G2>G4*** G3>G4***
General health	59.76 ± 15.690	55.610 ± 13.332	40.000 ± 21.780	44.375 ± 18.334	7,391	<0.001	G1>G3*** G1>G4*** G2>G3*** G2>G4**
General vision	81.95 ± 6.008	77.561 ± 6.626	58.500 ± 12.310	15.000 ± 19.612	243,605	<0.001	G1>G3*** G1>G4*** G2>G3*** G2>G4*** G3>G4***

Ocular pain	90.55 ± 14.344	82.317 ± 17.280	83.438 ± 21.067	75.300 ± 22.562	4,197	0,007	G1>G4***
Near vision activities	99.02 ± 2.650	96.37 ± 6.495	64.782 ± 20.283	39.574 ± 11.757	204,248	<0.001	G1>G3*** G1>G4*** G2>G3*** G2>G4*** G3>G4***
Distance vision activities	98.63 ± 3.048	98.80 ± 3.487	69.995 ± 22.713	28.936 ± 8.427	285,248	<0.001	G1>G3*** G1>G4*** G2>G3*** G2>G4*** G3>G4***
Social functioning	93.54 ± 8.571	88.83 ± 12.221	90.625 ± 12.894	55.000 ± 14.925	88,360	<0.001	G1>G4*** G2>G4*** G3>G4***
Mental health	98.00 ± 5.996	86.37 ± 18.208	65.625 ± 14.572	67.506 ± 15.453	31,393	<0.001	G1>G2*** G1>G3*** G1>G4*** G2>G3*** G2>G4***
Dependency	97.95 ± 5.882	86.66 ± 15.106	64.787 ± 16.616	57.275 ± 17.314	56,033	<0.001	G1>G2*** G1>G3*** G1>G4*** G2>G3*** G2>G4*** G3>G4***
Role difficulties	89.98 ± 22.469	79.80 ± 31.610	68.750 ± 24.677	56.563 ± 19.812	10,615	<0.001	G1>G3*** G1>G4*** G2>G3*** G2>G4***
Colour vision	99.39 ± 3.904	97.56 ± 15.617	98.750 ± 7.906	18.750 ± 30.356	208,119	<0.001	G1>G4*** G2>G4*** G3>G4***
Peripheral vision	99.39 ± 3.904	96.95 ± 16.003	85.000 ± 24.547	5.000 ± 14.097	330,665	<0.001	G1>G3*** G1>G4*** G2>G3*** G2>G4***

** $p<0.01$

*** $p<0.001$

Multivariate ANOVA that included age and sex as covariates, revealed a significant difference in the NEI VFQ-25 total scores among the four groups of respondents. Group 1 had the highest mean total vision-related quality of life score and Group 4 had the lowest. Post- hoc analyses revealed there was no significant difference between Group 1 and Group 2 respondents, but Group 1 and Group 2 respondents had significantly higher scores than those in Group 3 and Group 4. The total vision-related quality of life score of Group 3 respondents was significantly higher than that of respondents in Group 4.

The mean vision-related quality of life scores of 11 subscales for the four groups of respondents varied, although the mean scores of almost all subscale scores in Group1 tended to be the highest, and those of Group 4 were likely to be the lowest.

In the general health subscale, post-hoc analysis showed that respondents in Group 1 and Group 2 had significantly higher general health scores than those in Group 3 and Group 4. Respondents in Group 1 and Group 2 were reasonably healthy, as the percentage with self-reported chronic diseases was below 20%. Almost half of the respondents in Group 3 (47.5%) and 35% of those in Group 4 reported having a chronic health condition.

In the general vision subscale, there was no significant difference between Group 1 and Group 2. The correction of Group 2 respondents' vision had a positive impact on the vision-related quality of life general vision subscale. Respondents in Group 1 and Group 2 had significantly higher scores than respondents of Group 3 and Group 4. Failure to make visual correction, leading to uncorrected visual impairment or even blindness, resulted in lower vision-related quality of life general vision subscale.

The results of near vision activities and distance vision activities subscales showed that visual correction improved people's ability to conduct near vision activities like reading a book, cooking, sewing or fixing things at home, as well as distance vision activities such as reading street signs, watching movies, and going up and down stairs at night.

In the social functioning subscale, the respondents in Groups 1, 2 and 3 had significantly higher scores than those in Group 4. Despite their visual limitations, Group 2 and Group 3 respondents were able to understand other people's reactions during conversation or behave as expected when they were visiting people or attending a party. People with blindness had more difficulties in fulfilling their social function which affected their vision-related quality of life.

In the mental health subscale, Group 1 had a significantly higher score than the other three Groups. Group 2 respondents worried about their vision, felt some frustration, had less control over what they did, and worried about being embarrassed due to their visual impairment. Group 3 and Group 4 individuals had bigger problems compared to Group 2 respondents, leading to lower vision-related quality of life.

Post- hoc analysis showed that respondents in Group 1 and Group 2 had significantly higher vision-related quality of life role difficulties subscale than those in Group 3 and Group 4. Respondents in Group 3 and Group 4 thought that they could not complete tasks on time and their performance was lower because of their visual problem. Group 2 individuals did not think that their visual impairment affected their performance.

In the dependency subscale, Group 1 had a significantly higher score than the other Groups. Respondents in Group 2 felt some dependency on what other people said, and needed help from other people because of their visual problems. Individuals in Group 3 and Group 4 had more difficulties than those in Group 2. Group 4 respondents even felt they were forced to stay at home most of the time because of their blindness.

Group 1 and Group 2 individuals had significantly higher peripheral vision subscales than those in Group 3 and Group 4. People in Group 2 did not think that they had significant difficulties in seeing things on the sides, while those in Group 3 and Group 4 did.

There was no significant difference among respondents in Groups 1, 2 and 3 in the colour vision subscale. The three groups had significantly higher scores than those in Group 4. Individuals in Group 2 and Group 3 did not have a significant problem in matching clothes, but those in Group 4 had a lot of problems in performing this task.

DISCUSSION

People with normal vision had the highest total NEI VFQ-25 score and those with blindness had the lowest, indicating that vision-related quality of life decreases with the worsening of visual acuity. This is in accordance with other studies conducted in other countries(Fleming et al, 2019; Tharaldsen et al, 2020; Yibekal et al, 2020).

Based on the NEI VFQ-25 subscale analysis, general health was found to be higher in respondents with normal vision and corrected visual impairment than among those with uncorrected visual impairment and blindness. This result suggests that visual acuity may be an indicator of general health. Vision impairment has been associated with chronic conditions in older adults(Court et al, 2014; Crews et al, 2017). People with visual impairment are more likely to have health problems compared to individuals with normal vision. Other researchers found cataract as a predictor of mortality in people aged over 50 years (Zhu et al, 2016; Zhu et al, 2019). A recent review reported poor vision as a risk factor of falls in older adults that may lead to fatality (Joseph et al, 2019).

Subscales of general vision, near vision activities, distance vision activities and peripheral vision showed a significant difference, where respondents with normal vision and corrected visual impairment had higher levels of functioning than individuals with uncorrected visual impairment or blindness. Visual correction may improve vision-related quality of life, while more severe visual impairment may have a more adverse effect on vision-related quality of life. This finding is consistent with other studies showing that best-corrected visual acuity can have positive impact on vision-related quality of life(Råen et al, 2019).

There was no significant difference in the ocular pain subscale among respondents with corrected vision, uncorrected vision and blindness. Ocular pain is commonly associated with ocular surface disease found in most people with glaucoma. The number of respondents with glaucoma in this study was low, and this might explain the result(Baudouin et al, 2013; Tirpack et al, 2019).

This study suggests that visual acuity does not affect social functioning until someone becomes blind. This finding is similar to studies that reported no significant difference in social function between people with normal vision and those with visual impairment(Dev et al, 2014; Heine et al, 2019). Respondents with visual impairment could still carry out their social functions despite obstacles in doing so. Respondents with blindness had many difficulties in carrying out their social functions, and experienced social isolation. Although most of the study participants with blindness worked as masseurs, they waited for clients to visit them because they had problems in moving around the city due to their visual condition.

This study indicates that vision affects mental health. A study on older people has associated self-reported visual impairment with depression(Frank et al, 2019). Vision problems have been associated with worse psychosocial outcomes. Visual impairment causes problems in doing everyday activities, i.e., reading newspapers, recognising people. People with these problems have been reported to have lower life satisfaction, increased depressive symptoms and decreased positive affect(Hajek et al, 2020).

Dependency was different among all four groups; it increased with decreasing visual acuity. This study shows that uncorrected visual impairment can lead to role difficulties, which is consistent with other researchers' findings that greater visual impairment affects psychosocial parameters, including role difficulty(Zhu et al, 2015). Visual impairment forces the individual to take longer over completing tasks, leading to lower performance.

Despite their corrected vision, respondents in Group 2 had lower quality of life in the dependency subscale than those with normal vision. More than half of the participants in Group 2 wore glasses to correct their visual impairment. Glasses help people perform many activities, but those who wear them complain about the inconvenience of having frequent eye check-ups and getting replacements to keep good vision(Kandel et al, 2017). Without glasses, they need help from others to accomplish tasks. Visual impairment decreases one's independence in doing activities of daily living, and increases dependence on other people. Individuals with uncorrected visual impairment or blindness have more dependency on others in their daily lives.

This study suggests that neither corrected nor uncorrected visual impairment creates a significant problem in colour vision, but blindness does. This finding is consistent with other researchers who reported a similar result(Zhu et al, 2015).

Limitations

This study assessed vision-related quality of life based on the levels of vision, and did not analyse by specific diagnosis.

Comparison between the Groups may have been hampered by the differing sources of research participants. Participants in Groups 1 and 4 were recruited from the community, while participants in Groups 2 and 3 were clients from a hospital eye clinic.

CONCLUSION

It can be concluded that there are significant differences in vision-related quality of life related to people with normal vision, corrected visual impairment, uncorrected visual impairment and blindness. Visual impairment has a detrimental impact on a person's vision-related quality of life. However, it has differential impacts on different elements of vision-related quality of life. There are no significant differences between people with normal vision and corrected visual impairment in most subscales, suggesting that visual correction can improve vision-related quality of life, and thereby highlighting the importance of visual acuity correction.

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Views and Experiences of People with Intellectual Disabilities to Improve Access to Assistive Technology: Perspectives from India

Fleur Heleen Boot [1,2*], Ritu Ghosh[3], John Gerard Dinsmore[4], Malcolm MacLachlan[2,5]

1. Department of Primary and Community Care, Radboud University Medical Centre, Nijmegen, The Netherlands.
2. Department of Psychology and Assisting Living & Learning (ALL) Institute, Maynooth University, Ireland.
3. Mobility India, Rehabilitation Research & Training Centre, Bangalore, India.
4. Centre for Practice and Healthcare Innovation, School of Nursing & Midwifery, Trinity College Dublin, Ireland.
5. Olomouc University Social Health Institute (OUSHI), Palacky University, Olomouc, Czech Republic.

ABSTRACT

***Purpose**: People with intellectual disabilities are deeply affected by health inequity, which is also reflected in their access to and use of assistive technology (AT). Including the perspectives of adults with intellectual disabilities and their caregivers, together with the views of local health professionals, suppliers of AT and policy-makers, this paper aims to provide an overview of factors influencing access to AT and its use by people with intellectual disabilities in Bangalore, a southern region of India.*

***Method:** Face-to-face interviews were conducted with 15 adults with intellectual disabilities (ranging from mild to profound) and their caregivers, and with 16 providers of AT. This helped to gain insight into the current use, needs, knowledge, awareness, access, customisation, funding, follow-up, social inclusion, stigma and policies around AT and intellectual disability.*

***Results:** Access to AT was facilitated by community fieldworkers and services to reach out and identify people with intellectual disabilities. Important barriers were stigma, and lack of knowledge and awareness among parents. Factors related to continued use were the substantial dependence on the care system to use AT, and the importance of AT training and instructions for the user and the care system.*

***Conclusion and Implications:** The barriers and facilitators related to AT for people with intellectual disabilities differ from other populations in need. The*

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[*] **Corresponding Author:** Fleur Heleen Boot, Research Fellow & Physician, Intellectual Disability Medicine, Department of Primary & Community Care, Radboud University Medical Centre, Nijmegen, The Netherlands. Email: fleur.boot@radboudumc.nl

findings of this study can be used to inform and adjust country policies and frameworks whose aim is to improve access to AT and enhance the participation of people with intellectual disabilities within their communities.

Key words: *developmental disability, assistive devices, assistive products, health inequity, inclusion, stigma.*

INTRODUCTION

The seventy-first session of the World Health Assembly in 2018 stipulated the need for improving access to AT worldwide. Following the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Sustainable Development Goals (SDGs), especially SDG 3, it is shown that equitable and affordable access to AT needs to be an integral part of universal health coverage (World Health Organisation, 2018). However, there is a current gap in research and practice regarding the need, demand and supply of AT, as well as evidence of good practices for innovation and recommendations to improve access (WHO, 2018). The WHO Global Cooperation on Assistive Technology (GATE) programme was initiated to identify those contributions which provide scientific and/or practical inputs to improve the current situation of AT policy, products, provision, personnel and users (people).

A specific group of people who should not be excluded from AT initiatives and contributions are people with intellectual disabilities. People with intellectual disabilities are deeply affected by health inequity, are still regarded as a stigmatised and devalued group, and often marginalised from healthcare services (WHO, 2000; Hatton and Emerson, 2015). This is also reflected in their access to and use of AT services (Boot et al, 2017). Intellectual disability is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD), the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) and the International Classification of Diseases (ICD-10, mental retardation) as an IQ below 70, manifested during the developmental period (onset before 18 years of age), with impairments in adaptive functioning, such as communication skills, social skills, personal independence, school or work functioning (AAIDD, 2013; American Psychiatric Association, 2013; WHO, 2016). It has been found that people with intellectual disabilities use fewer ATs compared to other people in need (Wehmeyer, 1995; Carey et al, 2005, Kaye et al, 2008; Hatton and Emerson, 2015), despite the fact that people with intellectual disabilities could greatly benefit from AT (Patja et al, 2000; Haveman et al, 2011; Hatton and Emerson, 2015;

Carmeli et al, 2016; Owuor et al, 2017). The benefits that relate to AT are that it (1) could be used to support cognitive limitations in order to enhance independence and inclusion, (2) could facilitate better management of chronic health conditions and comorbidities which people with intellectual disabilities experience more often compared to the general population, such as sensory impairments, speech and language impairments, and dementia(Jansen and Kingma-Thijsen, 2011; Hatton and Emerson, 2015), and (3) could support those with early onset of functional decline (Haveman et al, 2011; Schoufour et al, 2015). People with intellectual disabilities follow the same ageing trend as the general population, and their demand for AT increases as they get older.

Although the UNCRPD and the SDGs stipulate the importance of access to AT for anyone in need, access to AT and AT use for people with intellectual disabilities is still a significant neglected area in research and practice (Hatton and Emerson, 2015; Boot et al, 2018). It is not known how many people with intellectual disabilities have access to AT globally, and which factors influence their access. Difficulties in accessing services and unmet healthcare needs for people with intellectual disabilities are more prevalent in low- and middle-income countries, but there is also a significant inequity in high-income countries.

In collaboration with the GATE programme, Boot et al started in 2016 an international research project called GATE-ID which aimed to identify the current barriers and potential facilitators for people with intellectual disabilities to access and continuously use AT in differently resourced settings. One of the countries included in the GATE-ID programme was India.

India is classified as a lower middle- income country according to the World Bank data (World Bank, 2018). The country has a variety of social-economic classes, healthcare systems and cultures. Healthcare resources and facilities are unevenly distributed and, in general, services are concentrated in urban areas. The prevalence of people with intellectual disabilities in India is estimated at 2-3% (Kalgotra and Warwal, 2017), but most of these individuals have not been formally identified. It is estimated that 26 million people have intellectual disabilities in India, out of which more than 15 million are under the age of 10 years (Kalgotra and Warwal, 2017). The prevalence is higher in rural compared to urban areas. According to the national sample survey, the main causes of intellectual disabilities in India are illness during childhood (42%), head injury during childhood (10%), and pregnancy or birth-related impairments (3%) (Kalgotra and Warwal, 2017). The majority of individuals live at home, supported by family caregivers (Meena, 2015). India ratified the UNCRPD in 2007, which led to the adaptation of the Rights of Persons with Disabilities Act in 2016. To monitor and achieve the SDGs and associated targets, a National Indicator Framework (NIF) has been developed which serves as a key tool for policy making, implementation strategies, and allocation of resources, researchers and other stakeholders (India, 2015).

Objective

An important aspect of the current research project was to include the views and experiences of people with intellectual disabilities and their families. These perspectives are the key to a better understanding of the barriers they currently encounter in accessing and continuing to use AT. Together with the views of local health professionals, suppliers of assistive products and policy-makers, this paper aims to provide an overview of factors influencing access to and use of AT for people with intellectual disabilities in the Bangalore region of southern India.

A phenomenological approach was used to answer the following research questions: Which barriers and facilitators to provide the essential assistive products for people with intellectual disabilities are currently present in India? And, how can the improved provision of AT aspired to by GATE, specifically for people with intellectual disabilities, be realised?

METHOD

This study is part of the larger cross-sectional GATE-ID research project. The methods described below are similar to the methods of the GATE-ID research project conducted in South Africa and Ireland (Boot et al, 2019). A full description of the development of the interview guides, the interviewing method and analysis has been published elsewhere (Boot et al, 2019).

Study Design

This study consisted of a qualitative research design using semi-structured face-to-face interviews with a phenomenological approach. Relatively few people with intellectual disability are able to read, write and fill in written questionnaires. Therefore, interviewing is the most appropriate method to elicit personal views from people with intellectual disabilities.

Participants

Purposive sampling was used to recruit participants. They were put into two main groups: 1) adults with intellectual disabilities, and 2) providers of AT.

Participants of group 1 - adults with intellectual disabilities - were approached through an Indian rehabilitation centre in Bangalore. The manager of the rehabilitation centre and the community fieldworkers were informed about the study and asked to recommend adults with intellectual disabilities who might be willing to participate in an interview, either as users or non-users of AT. The information leaflet and consent form were adjusted to the cognitive level of the participants (i.e., easy to read, larger font size, few words per row and the use of symbols) and were translated into the three main local languages of the Bangalore region: Kannada, Tamil and Urdu. If the participant was not able to give informed consent, his or her legal representative (family member) did so.

Participants of group 2 - providers of AT- consisted of health professionals, community field- workers, suppliers or retailers of AT, and governmental commissioners. They were approached through the network of the rehabilitation centre in Bangalore and snowball sampling was used.

Data Collection

Interviews of the participants took place in July 2018. The semi-structured interview guide focused on the current use of AT, needs, knowledge, awareness, access, customisation, funding, follow-up, social inclusion, stigma, and policies. At the start of each interview, ATs were defined using a booklet containing images of different varieties of ATs. These included any low- or high-tech product to maintain or improve a person's functioning in the domains of vision, hearing, mobility, communication, cognition, environment and personal care. The questions were adjusted to the level of persons with intellectual disabilities, and the family members aided participants in understanding questions they found challenging.

Data Analysis

The recorded interview data was first transcribed verbatim. The technique of constant comparison analysis, as described by Elliott and Timulak (2005), was used to analyse the data. Accordingly, the data was divided into meaning units – units by which the analysis was conducted. Meaning units are segments of the data that, even if interpreted out of context, would provide adequate information to the reader. To organise participants' responses, the meaning units were sorted into three themes: 1) stigma, 2) access to AT, and 3) continued use of AT. The meaning units were subsequently organised as per theme into broad headings or domains, to provide a conceptual framework for each theme. Next, the meaning units were coded into categories within each of the domains. The categories emerged from the meanings in the meaning units.

Ethics Approval

Ethical approval for this study was granted by the Bangalore Baptist Hospital Institutional Review Board. Ethical approval for the overall GATE-ID research project was obtained from the Health Policy & Management/Centre for Global Health Research Ethics Committee, Trinity College Dublin, Ireland (04/2017/01) and Maynooth University Research Ethics Committee, Ireland (SRESC-2017-053). The study adhered to the Declaration of Helsinki for research involving human subjects.

RESULTS

The results represent the perspectives of the participants of both groups, shown as an overview of factors (both facilitators and barriers) related to stigma, access to AT and continued use of AT for people with intellectual disabilities.

Participants' Characteristics

In total, 31 participants were interviewed. Table 1 presents the characteristics of participants in group 1 - adults with intellectual disabilities (n=15), and group 2 - providers of AT (n=16). Three participants of group 1 were professionally assessed for their intellectual function prior to the interview. The level of intellectual disability of the other 12 participants was assessed by the researcher at the time of the interview, based on the researcher's experience as a specialist intellectual disability physician, and categorised as either mild-moderate or severe-profound intellectual disability. All adults with intellectual disability were accompanied by their caregivers (family member or carer) during the interview, to support them where needed. Often parents would take the lead in answering the questions intended for their child with intellectual disability. Six adults were non-verbal and/or had a severe-profound intellectual disability, in which case the caregivers answered all the questions on their behalf.

Table 1: Participants' Characteristics

Characteristics	People with intellectual disabilities (n=15)
Age (mean)	31 years
Female gender	8
Level of intellectual disability	
Mild-Moderate	11
Severe-Profound	4
Aetiology	
pre- or perinatal infection	2
Down syndrome	1
Meningitis / encephalitis	1
Rhesus disease	1
Asphyxia	1
Unknown	9
Care setting	
Centralised setting	5
With Family	10
Semi-urban	6
Urban	9

Characteristics	Providers (n=16)
Age (mean)	50 years
Female gender	4
Work field	
S&L therapist	1
Audiologist	1
Ophthalmologist	1
Physiotherapist	1
Social worker	1
Special educator	1
Community fieldworker	2
Supplier of AT	2
Manager care facility	1
Policy maker	5
Urban	16

S&L = Speech and language

Assistive Technology in Use

Table 2 shows the AT which participants were currently using. On average, participants from group 1 - adults with intellectual disability - used two products per person, ranging from 0-3, with one participant using nine products. The products most commonly used were in the domains of communication (mobile phones) and environment or self-care (shower stools or chairs).

Table 2: Current AT in use by Participants of Group 1 - Adults with Intellectual Disabilities

Code participants	Total no. of AT in use	Hearing	Vision	Communication	Mobility	Cognition	Environment and self care
INT_ID_IND_001	1	0	0	1	0	0	0
INT_ID_IND_002	0	0	0	0	0	0	0
INT_ID_IND_003	9	0	5	1	1	0	2
INT_ID_IND_004	0	0	0	0	0	0	0
INT_ID_IND_005	2	0	0	1	0	0	1
INT_ID_IND_006	1	0	0	1	0	0	0
INT_ID_IND_007	2	0	0	2	0	0	0
INT_ID_IND_008	3	0	0	1	0	0	1
INT_ID_IND_009	2	1	0	1	0	0	1
INT_ID_IND_010	3	0	0	1	1	0	1
INT_ID_IND_011	2	0	0	0	1	0	1
INT_ID_IND_012	2	0	0	1	1	0	0
INT_ID_IND_013	3	0	1	0	0	0	2
INT_ID_IND_014	2	1	1	0	0	0	0
INT_ID_IND_015	1	0	0	0	1	0	0
Total	33	2	7	10	5	0	9
Average	2	0	0	1	0	0	1

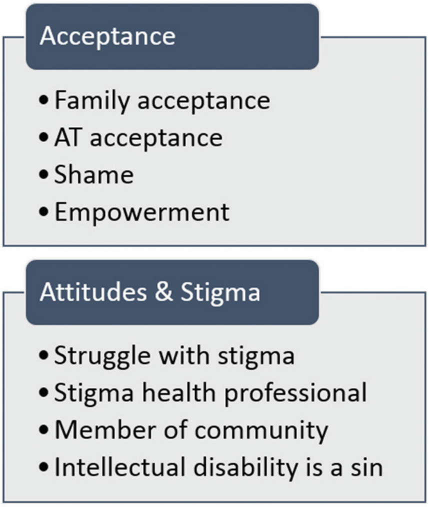
Qualitative Analysis

The results of the qualitative analysis are presented below, with the themes and domains as headings and subheadings respectively. Domains and categories per theme are illustrated schematically in Figures 1-3; these domains are not presented in order of importance, nor do they imply any hierarchy.

Theme 1 - Stigma

Data analysis resulted in two domains for stigma: Acceptance, and Attitudes and Stigma. The meaning units were coded into four categories for both domains (see Figure 1).

Figure 1: Domains and Categories for Stigma



Acceptance

Family acceptance and shame played an important role in AT provision for people with intellectual disabilities. Participants explained clearly how shame had influenced isolation of both the person with intellectual disability as well as the family members. For example, one mother explained that she did not accept that her child had intellectual disability, which led to her keeping her child indoors all the time. As a result, her child had never been assessed for any AT support. One participant clearly described the importance of family acceptance as a first step before AT can be accessed.

> *"The family gives up on them, thinking that he is good for nothing, then he becomes a burden in the family and that makes them feel even lower all the*

> *time….they are made to believe they are not wanted….. These are all necessary [pointing at AT] but this is even secondary. Make them believe that they come out, and work and succeed." (INT_PRO_IND_004)*

Acceptance of AT also played a role and was influenced by modern mainstream AT developments.

Participant: *"But in India people will have that feeling, nobody should notice I am wearing a hearing aid."*

Researcher: *"Do you think it is more stigma then as well?"*

Participant: *"It is a bit, but now it has changed, because now everyone goes with the headphones."* (INT_PRO_IND_008)

Attitudes and Stigma

Worldwide, people with intellectual disabilities still have to face stigma which negatively influences access to and use of AT services. In many regions of India, and within many beliefs, intellectual disability is still seen as a sin.

Participant: *"It is still considered as something linked to your karma and all those things and a lot of superstitious beliefs and other things. And in some places that some of those people have been sacrificed in the name of this or that." (INT_PRO_IND_002)*

Some parents struggled with negative attitudes from other family members towards their child with intellectual disability. Others shared their experience of positive attitudes from neighbours and the local community. However, in general, the community did not see people with intellectual disability as productive members of society. These attitudes were more present in urban than in rural areas, which was explained by lower expectations within rural areas and the type of work that people with intellectual disability could do there. In addition, stigma from health professionals was also present. Participants with intellectual disability explained that health professionals did not include them during consultation and would mainly focus on the parents.

Researcher: *"And could you choose the glasses, choose yourself which glasses you want?"*
Participant: *"My parents selected." (INT_ID_IND_003)*

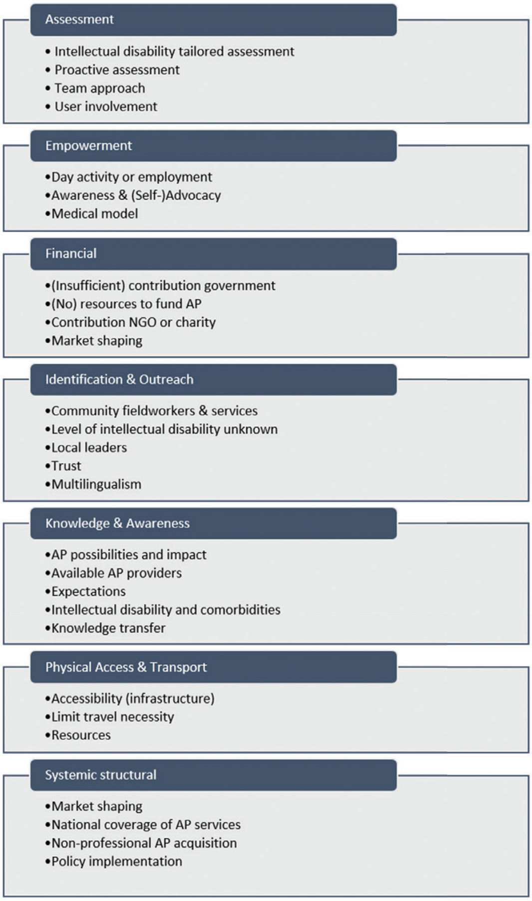
Health professionals also misled parents, providing incorrect information on intellectual disability.

Participant: *"Some of them are also misled by doctors. Professional doctors where they go for a treatment. They say your child will become alright after ten years. They want to escape from the parents asking questions so they say something and send them out. So these parents are in the impression that my child will become alright one day."* (INT_PRO_IND_015)

Theme 2 - Access to AT

Data coding developed into seven domains for access to AT: Assessment; Empowerment; Financial; Identification & Outreach; Knowledge & Awareness; Physical access & Transport; and Systemic Structural (e.g., policies, resources and the organisation of AT services) (see Figure 2). The meaning units were coded into 3-5 categories per domain.

Figure 2: Domains and Categories for Access



Assessment

- Intellectual disability tailored assessment
- Proactive assessment
- Team approach
- User involvement

Empowerment

- Day activity or employment
- Awareness & (Self-)Advocacy
- Medical model

Financial

- (Insufficient) contribution government
- (No) resources to fund AP
- Contribution NGO or charity
- Market shaping

Identification & Outreach

- Community fieldworkers & services
- Level of intellectual disability unknown
- Local leaders
- Trust
- Multilingualism

Knowledge & Awareness

- AP possibilities and impact
- Available AP providers
- Expectations
- Intellectual disability and comorbidities
- Knowledge transfer

Physical Access & Transport

- Accessibility (infrastructure)
- Limit travel necessity
- Resources

Systemic structural

- Market shaping
- National coverage of AP services
- Non-professional AP acquisition
- Policy implementation

Assessment

Proactive and intellectual disability tailored assessments were rare. The majority of participants from group 1 were never tested for hearing, vision, or communication and did not go to the dentist. Participants from group 2 explained the difficulties in assessing a person with intellectual disability.

Researcher: *"Can you test every person with intellectual disability and low vision?"*

Participant: *'It is difficult for me to assess an intellectual disability child's vision. Assessment is very, very difficult because they do not have language skills, they do not have understanding of objects. So, difficult." (INT_PRO_IND_015)*

Providers of AT did mention that they were aware of the importance of including the user with intellectual disability during AT assessment. Participants from group 2 highlighted an important facilitator for access to AT, namely networking and collaboration, to ensure assessments for different health needs. For example, the local rehabilitation centre worked closely together with other professionals to provide those ATs which the rehabilitation centre could not provide. Networking was mentioned as a substantial aspect of the work of the community fieldworkers.

Empowerment

It is expected that empowerment of people with intellectual disabilities will lead to greater access to AT. It was mentioned that after liberalisation took place in India, people became more aware and demanding of their rights. However, various answers were given related to this topic. On the one hand participants stated a lack of advocacy.

Participant: *"Persons with mental illness and intellectual disability, they are not able to voice their needs….. We don't have such an association who speak for them." (INT_PRO_IND_010)*

On the other hand, participants believed that people with intellectual disabilities were well able to advocate for themselves. During the interviews it became clear that the medical model of disability was still very much in place.

Researcher: *"Are there any ATs that she doesn't have but she thinks she could use it?"*

Participant: *"She does not require any assistive device according to her* [mother] *when she* [mother] *is with her." (INT_ID_IND_001)*

The voice of the person with intellectual disability was often neglected.

Researcher: *"Do persons or their parents, do they always know what they need?"*

Participant: *"….Sometimes the children do express that need. But parents could deny that need, thinking that this person is not capable enough to express such needs."*

Another participant: *"The needs expressed by the person and the caregivers are totally different. So many times we professionals go with the caregivers, neglecting the person with intellectual disability." (INT_PRO_IND_010)*

Perhaps as a reflection of the medical model, it was observed during the interviews that parents were often taking the lead in answering the questions for their child with intellectual disability, even though the person with intellectual disability would have been capable of answering questions.

Related to empowerment is having a day activity or employment, which can also function as an access point to AT(Boot et al, 2019). However, most of the participants did not have a day activity or employment.

Financial

The government in India provides identity cards (Aadhar), below poverty level cards, and disability certificates, which assist in entitlement for a monthly pension for people with intellectual disabilities, travel concession passes and funding for certain ATs (Ministry of Railways, 2009; MoSJE, 2017). The introduction of disability certificates has resulted in carers taking their family members outside the home, instead of hiding them, in order to visit the health professionals and qualify for funding. The type and quality of AT funded by the government was limited to certain basic varieties. For example, communication devices were not eligible for government funding. In addition, the implementation of funding policies did not always happen, according to some participants.

Participant: *"They* [the government] *have formulated 10 schemes and they said that these schemes will be implemented now…..Now after two years the whole thing is in a state of collapse. These 10 schemes are now put in cold storage. Why, they have no money. They don't release the funds for that." (INT_PRO_IND_014)*

People with intellectual disability or their families were not always in a position to afford ATs or afford the correct AT that would suit the person's need. In the Bangalore area there were some NGOs and charities to raise funds to support the costs for ATs. Participants did notice a change in the AT market, making AT more affordable. However, specific ATs with a low demand remained very expensive.

Identification and Outreach

Community fieldworkers played an important role in identifying people with intellectual disability and linking them to AT providers.

Participant: *"With these people we can definitely access the person who is in the far remote area of the village. We can identify the person with disability in a particular village and find out what are all his needs and bring him to the district level hospital and see that all the needs are fulfilled." (INT_PRO_IND_011)*

Community fieldworkers required the help of local leaders, such as ward councillors, who would know their area and are in touch with the community members. Yet it was not always known which community members had intellectual disabilities, and assessments rarely took place. The multilingualism in India was also mentioned as a big challenge to reach out to people with intellectual disability and their families.

Knowledge and Awareness

Lack of knowledge and awareness regarding intellectual disabilities and AT, and the possibilities for AT to effectively address impairments, were often mentioned by the participants as a barrier to acquiring AT.

Participant: *"The receiver does not know what to ask for. The service provider also does not know what to offer. So there is a gap." (INT_PRO_IND_002)*

Some participants explained that they did not think about AT possibilities for people with intellectual disabilities because their main focus was on the intellectual disability aspect of the person. Parents often thought that AT would have a negative impact on their child's development and were convinced the child did not need any AT, such as for example communication AT.

Participant: *"This is not going to make the child speak, so why are we doing this?" (INT_PRO_IND_009)*

Participants were not aware of the higher prevalence of comorbidities among people with intellectual disabilities, and officials misunderstood the definition of intellectual disability.

Participant: *"According to them, intellectual disability means that they should have a mongoloid face, there should be liquid coming out from their mouth, and also they should be doing some seizure moments. If all of these are absent, according to them the child does not have intellectual disability." (INT_PRO_IND_015)*

The importance of training and education were clearly stated.

Participant: *"First we have to educate the people, then only whatever changes will come, we benefit. Otherwise it won't work." (INT_PRO_IND_013)*

Opportunities noted for knowledge transfer and raising awareness included online training initiatives and peer learning activities organised by community fieldworkers or local leaders. The participants with intellectual disabilities all mentioned that they would ask their family members if they needed information on AT.

Physical Access and Transport

The lack of accessibility was often mentioned as a barrier to access AT services.

Participant: *"The road….Any hospitals…….slowly it's developing, but not everywhere. Only high-level hospitals, normal hospitals don't have. If I go to any hospital or the dentist we have to carry him." (INT_ID_IND_010)*

To be physically able to travel is one thing, but people with intellectual disabilities often need cognitive support to be able to travel and to understand the information provided by the health professional.

Researcher: *"And how do you get to* [X], *if you need to go there?"*

Participant: *"Father will drop me." (INT_ID_IND_003)*

Instead of letting the user travel to different professionals, some professionals collaborated over the phone or online to discuss AT needs or customisation for a specific user. Sometimes on-site visits were organised to help people with intellectual disability who found it difficult to travel or simply lacked the money to do so.

Systemic Structural

Lack of AT resources (services and professionals) especially in the rural areas was often mentioned by participants.

Participant: *"We do design, we do plan the programmes in such a way to reach the services and to reach the population, but due to lack of manpower, lack of qualified persons' availability in the rural areas, it tends to be a difficult task." (INT_PRO_IND_011)*

Available AT services often did not provide professional help. Participants mentioned that people in India often buy ATs in the so called 'surgical-pharmacy shop' without any professional assessment or advice, and according to availability in the shop.

Participant: *"They usually don't go to the rehabilitation centre because they are not aware. So straight they will go to the surgical shop. With brake, without brake, whatever, they will just buy it." (INT_ID_IND_010)*

Lack of policy implementation was stated as a systemic barrier to access AT.

Participant: *"The government has lots of schemes and grants for various kinds of assistive devices. But to access these grants is so difficult. There are so many channels, and so many things….to get the file moved from here to that ministry of Delhi, it becomes a nightmare." (INT_PRO_IND_002)*

The implementation of the Disability Act (2016) was limited.

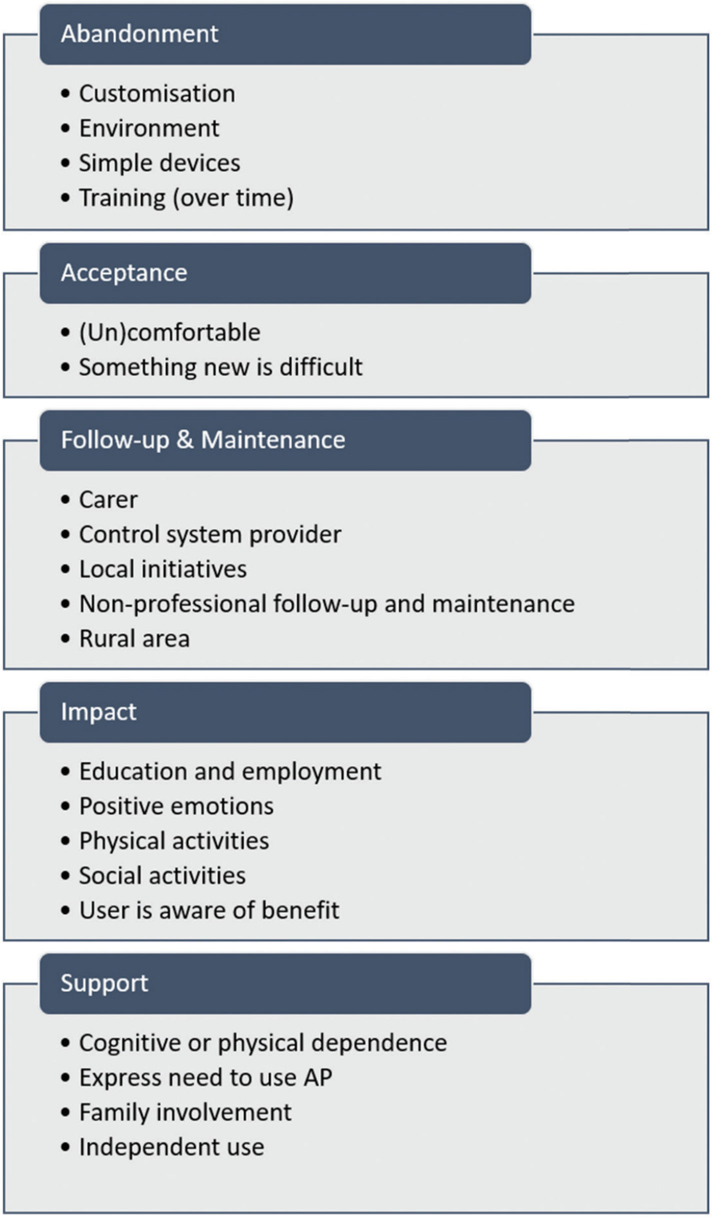
Participant: *"The Act is very clear, which is on paper. It doesn't happen in reality." (INT_PRO_IND_015)*

The need for an AT policy adapted to the Indian context was often supported.

Theme 3 - Continued Use

Data coding developed into five domains for continued use of AT: Abandonment; Acceptance; Follow-up and Maintenance; Impact; and, Support (see Figure 3). The meaning units were coded into 2-5 categories per domain.

Figure 3: Domains and Categories for Continued Use



Abandonment

- Customisation
- Environment
- Simple devices
- Training (over time)

Acceptance

- (Un)comfortable
- Something new is difficult

Follow-up & Maintenance

- Carer
- Control system provider
- Local initiatives
- Non-professional follow-up and maintenance
- Rural area

Impact

- Education and employment
- Positive emotions
- Physical activities
- Social activities
- User is aware of benefit

Support

- Cognitive or physical dependence
- Express need to use AP
- Family involvement
- Independent use

Abandonment

The importance of customisation to prevent abandonment of AT and ensure continued use was stated by all professionals. Parents and users were not aware of the advantages of customisation or the possibilities on offer. Those who acquired AT without assessment of a (health) professional did not receive customised

AT. In addition, AT acquired and funded through the government often did not involve a health professional and did not include customisation.

Participant: *"With the tender only a few fabricated assistive devices are available, for example, walker, crutches, wheelchair; one design for everyone. ….. People are receiving the product that is not suiting them. Because government is free of cost, so they go and collect it. By the end of the day the collector tries to use it, they are not able to use it effectively. It's not useful to them. So they keep the devices somewhere in stored places." (INT_PRO_IND_001)*

Logistical barriers also resulted in AT abandonment, such as the difficulty in transporting the AT from one place to another due to its size or the inaccessible infrastructure of India. It was stated that with the development of new technologies, AT had become easier to use for people with intellectual disabilities, and had resulted in less abandonment. Training was needed for people to understand how to use the AT which was provided. To prevent abandonment, training was essential for the users, for their caregivers, and also for people involved with their daily activities or employment.

Participant: *"I go to the workplace, where we explain to the employee this is what the person's problem is; this is how he does work. This is what he needs to work. And this is what we're providing him. And you should collect it from him every evening, send him home without that; when he comes back next morning, give it to him to use for during the work." (INT_PRO_IND_015*

Acceptance

If the person with intellectual disability felt comfortable using AT, the product was easily accepted. If there was any discomfort, the users did not want to use the AT.

Participant: *"She is not willing to use that shoe. She used to cry. When she used to wear that shoe, she would start crying, screaming, I don't want this, like that."*

Researcher: *"Do you think she also felt ashamed that she had to use it?"*

Participant: *"No not like that. She was not feeling comfortable, so she was screaming." (INT_ID_IND_002)*

Participants stated that acceptance of new AT can be difficult for people with intellectual disability and it takes time for them to get used to it.

Follow-up and Maintenance

Users indicated that they did not know how often they would have to go for follow-up; they depended on their carers to indicate the need and arrange the follow-up. They also indicated that if their AT broke, they would go to a family member to ensure repair.

Researcher: *"How often do you have to go back to the shop, to check if the glasses are still ok?"*

Participant: *"My brother came and took me." (INT_ID_IND_013)*

Frequent follow-ups, according to international standards, were not organised by most providers. Some families were very punctual regarding follow-up, but the majority would only attempt follow-up if the AT had broken down.

Participant: *"Maybe after 6 months. We ask for 3 months, but maybe after 6 months they come, because at that time the belt might be broken or they want to repair it. So not according to our instructions, but according to their need they may come, that way." (INT_PRO_IND_001)*

As an alternative, some providers arranged for parents to contact them for follow-up if visiting the professional was not an easy option. For example, there was the option to phone the provider or send photos by email. Based on these photos, the provider could send the parts that were needed for the AT. Living in rural areas was definitely seen as a barrier to follow-up. The equipment needed to repair the AT would not be available in rural areas and people would not be able to travel to urban areas. This led to non-use of AT in some cases. Participant: *"Prescribed hearing aid, it expired after some time, but repair was not possible there. So we dropped it for some years." (INT_ID_IND_014)*

Local initiatives where professionals would make on-site visits for follow-up were seen as a good method to ensure continuing contact with users. If individuals with intellectual disability lived at a great distance from the service provider, they would be allocated an option for follow-up and maintenance at a local centre. Community fieldworkers and self-help groups were mentioned as important facilitators to ensure follow-up when professional resources were scarce. Providers indicated the importance of follow-up and maintenance by a professional and not by people who are untrained or not equipped to do so. However, most parents did not see any problem in going to a non-professional shop. AT provided through the government did not receive any follow-up.

Participant: *"That's a good question actually. No, we don't have any follow-up…. We distribute to the people. Following up is not there." (INT_PRO_IND_005)*

Impact

The impact or benefit that AT has for a user or the carer can be regarded as a very important facilitator for use of AT in daily life. Some participants were well able to describe the benefit of the AT they were using.

Researcher: *"And how will the crutches help you?"*

Participant: *"With the crutches I have a support and I'm able to slowly walk."*

Researcher: *"Can you walk without the crutch?"*

Participant: *"No." (INT_ID_IND_003)*

Another participant attended adult classes where he used a recorder.

Participant: *"Sometimes volunteers won't be available to explain to him* [in classes]. *Another thing, classes will be noted, so many classes he will miss, that time he uses recording." (INT_ID_IND_003)*

One aspect of impact was the emotions generated by using the AT, which could influence continued use.

Researcher*: "And how does it make you feel to use the iPad, does it make you happy or sad?"*

Participant: *"Happy, satisfied." (INT_ID_IND_007)*

Using AT also enabled some users to increase social interaction.

Researcher: *"Does it make her feel more included in society?"*

Participant: *"Yes……… All her difficulties e.g., school issues, she expresses* [over the phone]*." (INT_ID_IND_004)*

Support

Users frequently needed their carer to help them use the AT on a daily basis, either because they did not understand how to use a specific AT or were physically unable to do so. For example, a lot of adults with intellectual disability and motor disabilities enjoyed using the mobile phone to call friends or family, but they would need their parent to dial the number and hold the phone to their ear. Some users would forget to use their AT and depended on their carer to remind them.

Researcher: *"Do you remember yourself to use the glasses?"*

Participant: *"I know."* [Mother does not agree, laughing]

Mother: *"For anything I need to remind him 10 times." (INT_ID_IND_003)*

To ensure continued use of AT, it helped if the users could indicate and say when they wanted to use their device.

Researcher: *"And it's the phone of father?"*

Participant: *"Yes, father's…….She can express that she wants to talk, then he* [father] *gets the phone." (INT_ID_IND_004)*

Providers indicated the importance of involving parents when new AT was acquired. When the family did not support the AT, the person with intellectual disability would not use it.

Participant: *"If we work with the whole family, the rehabilitation will happen. If you only do it for the person with disability* [it does not work]*….and if we withdraw, the family will take care." (INT_PRO_IND_003)*

If the person with intellectual disability were able to use the AT independently, without any support, continued use would be guaranteed. Some providers indicated the importance of working with them individually, to encourage independent use.

Researcher: *"Can you remember to get the crutch and use it, or does somebody help to remind you?"*

Participant: *"I take it." (INT_ID_IND_012)*

DISCUSSION

This study presented the views and experiences of people with intellectual disabilities, their carers, local AT providers, health professionals and government officials in the Bangalore region of India, regarding access and continued use of AT for people with intellectual disabilities. The findings showed that stigma and negative attitudes towards intellectual disabilities were still present as an important barrier to access AT. Empowerment and self-advocacy were mentioned as opportunities to break this. However, the strong medical-model approach to disability seen within India may present a challenge to individual AT user empowerment. The medical model of disability may create low expectations for some individuals with intellectual disability and may lead to individuals actively reducing independence, choice and control of their own lives. People with intellectual disability are seen as persons who need carers and professionals to make decisions for them. People with intellectual disability want to be empowered to individually choose and use AT, but they cannot do this in an environment that is not supportive of such choices (Shogren and Broussard, 2011). While in Indian policy documents there has been a shift from a charity model to a rights-based model, in daily practice this shift remains limited for people with intellectual disability (Chavan and Rozatkar, 2014).

Another important barrier to access AT was a lack of knowledge and awareness on the impact and possibilities of AT for people with intellectual disability. First, the possibilities of AT to support people with intellectual disability in their limitations of cognitive functioning were not known; none of the participants were using any type of AT which supported cognition. Second, AT which could be used to support any co-existing impairments or health problems that the person with intellectual disability might have, was often not assessed; it was found that it was difficult for carers, or others involved, to look beyond the intellectual disability of the person. Parents also had difficulties in accepting their child with intellectual disability, as they had expectations for typical development, which in turn led to a non-acceptance of supporting AT, e.g., communication AT. This expectation of typical development was, on occasion, fed by health professionals providing parents with incorrect information on intellectual disability, including the changes to be expected over the course of an individual’s life. Increasing knowledge and providing education on intellectual disability and assistive technology for both professionals and carers was mentioned as a facilitator to increase access to AT. Methods of knowledge transfer and education around AT that participants mentioned were via interactions with community fieldworkers and by accessing information online. E-learning is often defined as the use of online information technology to enhance or support learning. E-learning is becoming more frequently used as a method of delivering education and training in isolated and rural areas, and it has been suggested that E-learning is a potential sustainable option for capacity building in low- and medium-resource countries (Karly Michelle et al, 2015). Indeed, E-learning through mobile devices could be applicable, as smartphones are becoming more affordable worldwide. However, it will remain a challenge to ensure that E-learning is accessible and adjusted to the specific needs of people with intellectual disabilities.

Abandonment was found to be an important barrier which negatively influenced continued use of AT by people with intellectual disability. Factors which led to abandonment were the lack of customised ATs, unsuitable environments to use AT, and a lack of training over time. As this study also showed, people with intellectual disability often need daily support from their care system to use (or be reminded to use) the AT. For a person with intellectual disability to be capable of using AT independently, training that is adjusted to the level of the respective intellectual disability is needed during the introduction of AT. In addition, recurrent training is required to remind the user how to use the AT over time. Training methods also have to be adjusted to the communication method preferred by persons with intellectual disabilities e.g., use of visuals and gestures (van Schrojenstein Lantman-de Valk and Walsh, 2008).

Recommendations

The findings of this study can be used to inform and adjust AT implementation programmes of countries whose aim is to improve access to AT for people with intellectual disabilities. The barriers and facilitators related to AT for people with intellectual disabilities are different from other vulnerable populations and should be taken into account in country-specific policies and frameworks. AT can have a huge impact on the quality of life and inclusion for people with intellectual disabilities. Training programmes on AT selection and use should be implemented to support community-based initiatives to identify people with intellectual disabilities and refer them to the appropriate services.

Challenges and Opportunities

The health needs of people with intellectual disabilities are often unrecognised and unmet (Hatton and Emerson, 2015). This is also reflected in a lack of assessments and under-diagnoses of health problems, such as hearing and vision loss, which could be better managed with AT. People with intellectual disabilities have twice as many health problems as the general population (van Schrojenstein Lantman-de Valk and Walsh, 2008). Outreach and identification of people with intellectual disabilities and, if possible, their cause, need to be prioritised in order to proactively screen for health problems in these people. Intellectual disability assessments are needed, to know which members of the community actually have the condition. It may be particularly important to identify people with mild intellectual disability who often go unrecognised. The government in India has shown commitment to improve information on epidemiology, support systems and services for people with intellectual disabilities in the country, but there is still a long way to go (Girimaji and Srinath, 2010). The results of the current study also indicate the importance of aiming to address the five strategic Ps - policy, products, personnel, provision and people - whilst also taking into account the five contextual Ps - procurement, promotion, pace, partnership and place - which strongly influence the extent to which the strategic Ps can be addressed, and may suggest alternative ways of doing this, through a systems-thinking approach (MacLachlan and Scherer, 2018).

CONCLUSION

The findings of this study provide opportunities to support implementation of the UNCRPD through AT and to advance population health by realising basic human rights for people with intellectual disability. Countries such as India, who have ratified the UNCRPD and who have also agreed to work towards the achievement of the SDGs, will need to take action to realise these commitments, so that every person with intellectual disability in need of AT can have access to quality affordable products.

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Barriers to Utilisation of Dental Services among Children with Disabilities in a Coordinated Healthcare Programme in Mangalore in India: A Mixed Methods Study

Lekshmi Radhakrishnan Suresh[1], Kavitha Rai[1], Amitha Mahesh Hegde[1*], Cynthia Vinitha D'Souza[1]

1. NITTE (Deemed-to-be University), AB Shetty Memorial Institute of Dental Sciences, Department of Paediatric and Preventive Dentistry, Mangalore, India

ABSTRACT

Purpose: *Unmet oral health needs affect the quality of life of individuals, especially if they are already at a disadvantage like children with special health care needs. Strategies to mitigate these disparities in India's diverse healthcare settings have hitherto been largely ineffective. This study was aimed to assess the utilisation and barriers to the use of dental health services among children with special health care needs, against the background of a coordinated healthcare programme implemented in Nitte (Deemed to be University), Mangalore, India.*

Method: *The study was conducted over a 6-month period, from September 2018 to February 2019. A mixed-methods design was concurrently employed for data collection. Utilisation of dental services was assessed quantitatively, and the barriers to dental services utilisation were assessed qualitatively through caregiver interviews, with a sequential data integration strategy.*

Results: *The quantitative data revealed gross underutilisation of dental resources by children (only 16% availed some form of dental treatment), and the prevalence of avoidance behaviour (63% showed reluctance and did not turn up for appointments). Restorative needs formed the highest unmet dental component among the children (67% required secondary dental care). In-depth interviews with the children's caregivers revealed that the presence of cognitive barriers could have a direct effect on the time and quality of dental care delivered to their children.*

Conclusion: *Cognitive barriers among caregivers appear to have a profound impact on the underutilisation of dental services in their children with special*

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[*] **Corresponding Author:** Prof. Dr. Amitha M Hegde, NITTE (Deemed-to-be University), AB Shetty Memorial Institute of Dental Sciences, Department of Paediatric and Preventive Dentistry, Mangalore, India. Email: N18PHDD101@nitte.edu.in

healthcare needs. These barriers may be addressed within the integrated healthcare programme and the dental curricula through provisions for continued individual and community dental education, and motivational efforts that simultaneously target the caregivers and their children with special healthcare needs.

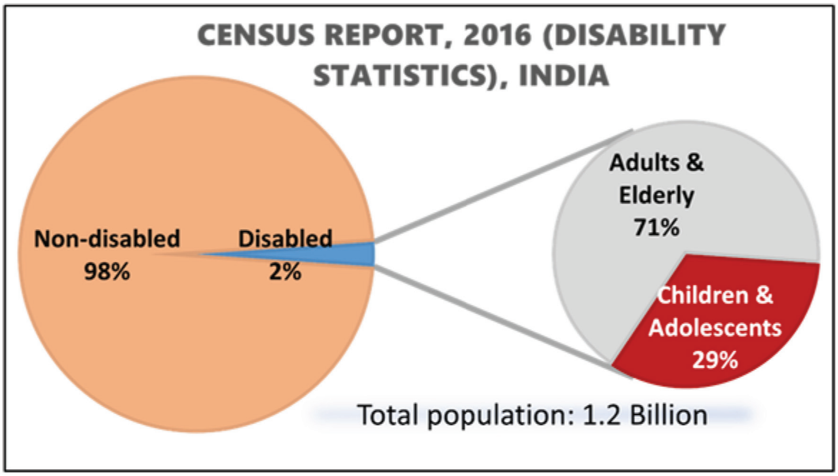
Key words: *caregiver perceptions, dental avoidance, mixed-methods study, dental education, dental health outcomes*

INTRODUCTION

The 2011 population estimates by the World Health Organisation's Disability report suggest that more than 15% of the world's population falls under the disabled category, and among them an approximate 93 million are children below 15 years of age (WHO & World Bank, 2011). Insights from the Global Burden of Diseases study 2019 further reports that these numbers are on the rise, with an acute need for health systems to catch up to the increasing trends in noncommunicable diseases and disabilities (Murray et al, 2020). In India, the Social Statistics Division of the Ministry of Statistics and Programme Implementation summarised the statistical profile for persons with disabilities in their 2016 release (Figure 1):

> *"As per Census 2011, in India, out of the 121 Cr population, about 2.68 Cr persons are 'disabled' which is 2.21% of the total population…The National Policy for Persons with Disabilities (2006) recognises that Persons with Disabilities are a valuable human resource for the country and seeks to create an environment that provides equal opportunities, protection of their rights, and full participation in society" (Ministry of Statistics & Programme Implementation, 2016).*

Figure 1: Diagrammatic representation of the Nation's Disability Statistics, adapted from the 2016 Census report



From the report it also follows that nearly one-third of these individuals are children and adolescents.

Since India is often considered "a continent masquerading as a country," there is an ever-present need for unique, informed policies that are specific to the population that needs to be benefited. To this end, the country's state governments have been tasked with the responsibility to ensure that all children, irrespective of their disability status, can enjoy their fundamental rights without fear of discrimination. This goal remains unrealised as many of the state governments' existing policies and healthcare services, including dental services, are underutilised (Mehta et al, 2015; Gambhir & Gupta, 2016; Kharbanda & Dhingra, 2017; Pathak, 2017; Krishnan et al, 2018).

Could this be because of a lack of understanding of the difficulties faced by the children and their families, or a failure to adequately incorporate their views in the policy making and refining process (Seymour, 2001; Singh, 2017)? With minimal coverage in the National Health Policies and budgetary allocations (Gambhir & Gupta, 2016), how does this reflect on the dental needs of these children with disabilities?

Good oral health has been associated with better physical, social, psychological, and behavioural outcomes, with a direct impact on an individual's quality of life (WHO & World Bank, 2011; Krishnan et al, 2018). However, this aspect of health is usually given least weightage by the individual and by many health professionals as well. This disparity becomes more evident while dealing with children with disabilities or special health care needs, and gets reflected as such in dental literature (Oredugba & Akindayomi, 2008; Mehta et al, 2015; Pathak, 2017; Mandic et al, 2018). It has also been shown that specific allocations for oral health-related activities receive minimal attention in the National budget, despite the need, and not many have enabled a systematic attempt to address these issues (Gambhir & Gupta, 2016; Petrova et al, 2014). A deeper understanding of the caregivers' perspectives on dental problems of their children with disabilities (also known as children with special health care needs) could go a long way in informing policy-makers and organisations about the reforms needed to enable better utilisation of the dental services offered to them.

Barriers that are most often cited in literature as reasons for the underutilisation of dental health services among children with special health care needs include: financial burdens, high cost of dental treatments, inadequate access to care, non-availability of trained dentists willing to undertake their treatments, inflexibility of dentists, and fear and behaviour of the child in the dental office (Nicopoulos et al, 2007; Brickhouse et al, 2009; Lai et al, 2012; Melbye et al, 2013; Weiner et al, 2016; Aljabri et al, 2018; Krishnan et al, 2018; Rajput et al, 2019).

The NITTE Special Child Care (NSPECC) programme is a unique integrated healthcare services platform that was instituted with the aim of facilitating easy access to affordable and subsidised health services under the organisation's health coverage network. Since 2015, the programme has run in tandem with the "Sarva Shiksha Abhiyana" (education for all) initiative of the state government of Karnataka, India. The platform serves to organise comprehensive and coordinated healthcare for children with special health care needs who are enrolled into the system through the Board of Education offices in the locality (Mangalore in Karnataka state), and for such children seeking care in the university hospital.

The integrated effort allows for an initial diagnostic screening and check-up for medical and dental complaints while providing the option for emergency, preventive, and minor corrective dental treatments to be done on-site. The dental coverage is done free of cost, by postgraduate residents of the Department of Paediatric and Preventive Dentistry, under supervision, and with appointments scheduled around the needs of the children and their caregivers. A key feature of this programme is the free transportation facility to and from their location that is made available to the children and their caregivers, every fortnight, as part of the package from the hospital administration. This has led to a rise in the number of children with special health care needs being screened for their dental needs at NSPECC. Even so, the total number of children with special healthcare needs who avail these dental services has remained low, with only 5.2% of them reporting for their follow-up dental appointments (Statistics from 2016-2018). Thus, even after elimination of a majority of the barriers recorded in literature, the organisation's attempts to reach this population have been unfruitful in terms of their oral health recorded.

Objective

The present study was conducted to observe the dental needs and utilisation of dental services by children with special health care needs reporting to the NSPECC centre, from September 2018 to February 2019 (a 6-month period), and to explore the problems reported by their caregivers in availing the dental services on offer to the children.

METHOD

Bearing in mind the ongoing nature of the NSPECC programme, the current study was conducted simultaneously and without causing any overt disruption to the quality of services and healthcare guidance offered to the parents and their children with special health care needs.

Study Design

A dental record maintenance system was instituted at the beginning of the study period (September 2018) and it was made mandatory to record all dental information onto the system at NSPECC. Regular training sessions were given to the postgraduates in the Department of Paediatric and Preventive Dentistry to ensure uniform oral health screening and recording of data. These records were maintained prospectively by the postgraduate residents in attendance at the centre and by the Special Educators at NSPECC to form the dental records repository. The dental repository was regularly monitored by the Head of the Department of Paediatric and Preventive Dentistry, in close coordination with the NSPECC volunteers and organisers. The data for all the children who enrolled during the study period (population sampling for Quantitative data) was then collected by the principal investigator at the end of the study period (February 2019), with due permissions from the Department Head and the Dental Care Coordinator at NSPECC. All information relating to patient identifiers (such as child's name, caregiver name, home address, transport locations, etc.) were redacted by the

NSPECC coordinator before handing over to the principal investigator, in order to avoid bias and ensure child and caregiver confidentiality and privacy. The compiled dental statistics were then used to assess and analyse the dental needs of the children and the utilisation of dental services during the study period.

Study Participants

During the 6-month study period, all the children and their attending caregivers were observed and approached for recruitment into the study. To ensure maximum heterogeneity and variability of the opinions reported, the caregivers were shortlisted for interviews according to the nature of their children's disability and their willingness to participate in the informal interview conducted by the principal investigator (purposive sampling for Qualitative data). Neither the prior dental experiences of the child and caregiver, nor the caregivers' educational status or occupation were considered before inclusion into the study, in order to limit the extent of selection bias and ensure some level of representativeness. After getting their written informed consent to participate, a one-to-one interview was set up on-site with the caregivers in the presence of the NSPECC care coordinator.

Data Collection

Following dental screening of the children with special health care needs who reported to NSPECC between September 2018 and February 2019, their oral health status was communicated to the accompanying adults (usually their respective caregivers) and treatments were advised as part of the programme protocol. They were also informed about the dental services available to the children at free or reduced prices, including support services like transportation and assistance. The adults were then asked whether they would like to start their children's dental treatment at the centre, on the same day. Those who expressed reluctance were asked to elaborate on their reasons, before setting up an appointment for the treatment of the children. The caregivers were also encouraged to exchange telephone numbers with the dental team, to allow for flexibility in scheduling appointments to suit their convenience. The investigators in the study did not interfere in these interactions other than to ensure that adequate records were maintained in the NSPECC registry.

This informal approach enabled the researchers to work within the current system, and the open, qualitative nature of the study ensured that the caregivers did not feel judged. It was believed that the approach of handling the qualitative and quantitative data collection separately, was useful in encouraging the caregivers to be open about their difficulties in meeting the dental needs of their children, without fear of upsetting and/or disturbing the postgraduates who were treating them.

Quantitative Data Analysis

The dental records obtained from the NSPECC registry were compiled and analysed for patient demographics, nature of the dental visit and reasons for non-utilisation of treatment. A summary of their dental profile (primary, secondary and tertiary treatments needed versus treatments availed of) was compiled The data was then entered into MS Excel® before exporting to EZR software - version 1.37 (Kanda, 2013) for analysis. Descriptive summaries were computed, and Chi-square test was used to find any statistical significance in the trend of dental treatment utilisation.

Qualitative Data Analysis

The qualitative interview responses were audio-recorded with the consent of the caregivers, and transcribed and translated into English in MS Word®. Each transcript was then screened by the NSPECC coordinators for any personal information, before being assigned an alphanumerical reference code derived from the dental registry, unknown to the investigators in the project.

The data from the interview transcripts was coded manually by the principal investigator using an inductive strategy. Identifiers used for coding included "teeth", "treat", "treatment", "dental" and "dentist". The codes were analysed using an interpretative phenomenological approach (Groenewald, 2004; Pringle et al, 2011) to analyse and identify relevant themes emerging from the dataset. These themes were then analysed against the Health Care Access Barriers (HCAB) model proposed by Carrillo et al (2011) (Fig. 2).

To ensure rigour, the validity of these themes was questioned and discussed with the co-investigators in the project. All conflicts were resolved by retracing the matched interview transcripts of the caregivers for discussion.

Ethical Considerations

The required ethical permissions were obtained from the institution and the information was relayed to the caregivers of the children at their visit to NSPECC to adhere to the ethical guidelines of the university central ethics committee [NU/CEC/2019/0219]. Informed consent was obtained from caregivers and from children with the cognitive ability to make an informed decision (in the local language). Utmost care was taken to preserve the confidentiality and privacy of the participants in the study.

RESULTS

The total number of children who attended the NSPECC dental programme during the study period was 114. Of these, 96 were new enrolments and 18 were revisits to avail dental treatments. There were 69 males and 45 females. The mean age of the children was 12.5 ± 3.21 years (range 5-21 years). A summary of the children's special health care needs and their caregivers who were interviewed are indicated in Table 1.

Table 1: Distribution of Children enrolled at NSPECC during the Study Period (September 2018 – February 2019) and the Caregivers Interviewed, based on the Children's Special Health Care Needs

Special Healthcare Need (Disability Diagnosis)*	Number of Children enrolled	Number of Caregivers interviewed
Autism Spectrum Disorders	11	2
Behavioural Disorders	4	1
Down Syndrome	5	1
Intellectual Disabilities	17	3
Learning Disorders	27	2
Locomotor & Neuromuscular Disorders	17	4
Physical Impairments	4	1
Medical Disorders	8	1
Orofacial Cleft Deformities	2	1
Speech, Hearing & Language Impairments	11	2
Visual Impairments	12	2
Complex (Multiple) Disorders & Developmental Delays	5	1

*Categories are not mutually exclusive

Quantitative Aspect – Dental Treatment Needs

It was noted that 42 children required preventive and prophylactic dental care (oral prophylaxis, pit and fissure sealants, topical fluoride applications, etc.); 76 children required secondary dental care (carious and non-carious lesion restorations, restorations for teeth with deep carious lesions, prophylactic crown placements, minor surgical procedures, etc.); and 25 children were in need of tertiary dental care (including orthodontic corrections, periodontal lesion repairs, space managements, etc.). In each of these treatment bands, despite the dental needs being conveyed to their caregivers and attenders, the proportion of children who availed the advised primary, secondary, and tertiary dental treatments remained as low as 7%, 6% and 20%, respectively (Table 2). No statistically significant associations were seen between the treatment needs and the treatments availed (p=0.159). Similar observations were also derived from the statistics for the secondary needs of the children (p=0.338).

Table 2: Summary of the Dental Profiles of the Children reporting to the Centre (treatment needs vs. treatment availed) between September 2018 and February 2019

Type of Dental Treatment*	Treatment Needed (% of total clients)	Treatment Availed (% of treatment needed)	Chi-square test^{+}
Preventive/Prophylactic Care	42 (36.8%)	3 (7%)	X^2=5.25 p=0.262
Secondary Care	76 (66.7%)	5 (6%)	
Tertiary Care	25 (21.9%)	5 (25%)	
Comprehensive Care	3 (2%)	1 (33.3%)	
Recall Examinations	108 (94.7%)	18 (16.7%)	
Type of Secondary Dental Care*	**Treatment Needed**	**Treatment Availed**	**Fisher's Exact test^{+}**
Restorative Care	177	3	p=0.338
Endodontic Care	62	0	
Minor Surgical Care	83	3	

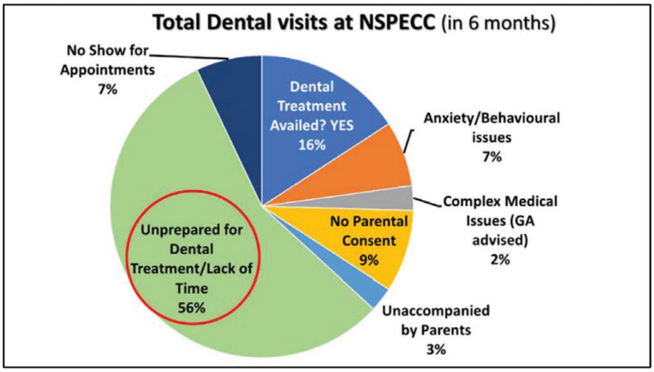
*Categories are not mutually exclusive. +p- values >0.05–not significant; <0.05–significant

Dental education and oral hygiene instructions were imparted to all the children, regardless of their dental needs, in the presence of their caregivers and/or attenders. Those who did not require any dental intervention (5 children had good oral health) were also included. Since this was part of the programme protocol at NSPECC, the statistics on this mandatory intervention were not included in the study data.

Semi-Quantitative Aspect – Treatment Delays (Utilisation)

A total of 6 children with special health care needs opted for dental treatment at NSPECC on the day of their dental screening, while appointments at a later date were scheduled for the rest. The reasons for delaying treatment were recorded and summarised (Figure 3). Of the children who were given appointments, only 12 reported for their respective dental treatments (including 1 child admitted for comprehensive oral rehabilitation under general anaesthesia).

Figure 2: Nature of Dental Visits at the Centre from September 2018 to February 2019 (6 months)



Thus, the reasons for requesting an appointment (and delaying the dental treatment) given by the caregivers and attenders of the children with special health care needs, where a majority of them did not show up, were listed and analysed. The following observations were made:

All the primary caregivers who accompanied the children were females, mostly mothers; the exceptions were an aunt, a grandmother, and a stepmother who accompanied one child each.

In 8 cases, despite the willingness of the parents, dental treatments could not be carried out because of anxiety and behavioural issues associated with the child. For 3 children with complex medical problems related to the severity of their special care needs, comprehensive oral rehabilitation was advised under general anaesthesia, but they did not report for treatment. Ten parents were unwilling to comply with dental treatments for their children and were reluctant to give a reason for the same. Three children were accompanied by their school teachers and their parents did not give their consent for dental treatment (Figure 2).

The caregivers of 72 children reported that they expected only the medical evaluation to be conducted and that there would be no time afterwards for the dental procedures. Among them, 8 had readily agreed for a revisit but did not show up on the scheduled appointment date. The parents of the remaining 64 children showed varying degrees of reluctance and avoidance behaviour before agreeing to make an appointment (for which they did not report) (Figure 2).

Qualitative Aspect – Problems and Opinions

It was possible to conduct informal, in-depth interviews with the parents of 19 of the 64 children who were reluctant to avail of dental treatment and appointments. Their opinions are outlined below.

Opinion 1:

It was a common opinion among most of the interviewed parents that the primary teeth would *"eventually fall off"* and *"new, healthy teeth would come".*

Opinions 2 and 3:

Nine of the parents informed the researchers that the last time they had taken their child for dental treatment, the child was *"very uncooperative," "the dentist had a lot of difficulties"* and that *"it took a lot of time"*. In two of these cases, the dentists themselves had informed the parents that they could *"delay the dental treatment till the primary teeth fall off"*.

Opinion 4:

Seven of the interviewed parents reported that they had been to a doctor (physician) when their child had an infection in the gums and that they were *"prescribed medicines"* and *"there are no complaints now"*.

Opinion 5:

In 4 of the interviews, the parents noted that they were referred to a dentist by their child's treating physician, but that they were unhappy with the referral and commented that the *"dentist was not good"*. When asked why they had felt so, the parents replied that it was because the doctor (in this case, the dentist) *"did not make the pain go away"*. The parents were able to *"go to another doctor"* (meaning, another physician) and *"get pain medicines"*.

Opinion 6:

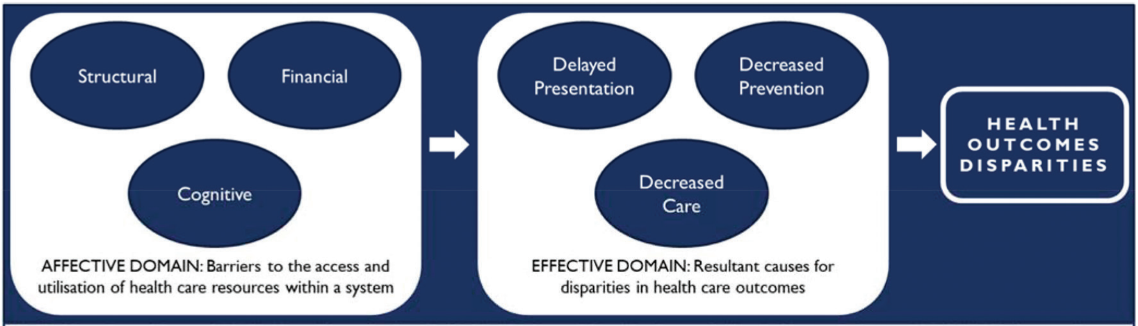
One parent had already become frustrated with the healthcare system, remarking that *"You doctors take so much time, making us walk left and right, never telling us anything. You do not understand that we risk losing what little money we earn just by wasting time for all these useless treatments. My child doesn't need his teeth treated; they will fall off"*.

Opinion 7:

When discussing the dental needs of 5 of the children, the parents remarked, *"What is the need? My child does not have any problem* (symptoms) *now"*.

The emergent codes and themes identified from the caregivers' opinions were assessed and then compared against the HCAB model adapted for the study (Figure 2), in order to shed some light on how the dental perceptions of the caregivers had contributed to the high prevalence of oral health care needs among these children, screened at NSPECC (Table 3).

Figure 3: The Health Care Access Barriers (HCAB) model, adapted for the present study, to analyse the Themes emerging from the opinions of the Primary Caregivers



Health Care Access Barriers Model adapted from: Carillo, E.J., Carillo, V.A., Perez, H.R., Salas-Lopez, D., Natale-Pereira, A., Byron, A.T. (2011). Defining and Targeting Health Care Access Barriers. J Health Care Poor Underserved.; 22: 562–575.https://doi:10.1353/hpu.2011.0037

Table 3: Understanding the Barriers to Utilisation of Dental Services, based on the Opinions of the Caregivers

Reason for Unwillingness*	Theme Identified	Cognitive Barrier	Undesirable Outcomes	
"Teeth will eventually fall-off"	Temporary nature of deciduous teeth	Health literacy	Decreased care & Decreased prevention	**Oral Health Disparities**
"New teeth will come"				
"Treatment is wasted"		Understanding of treatment		
"Child is uncooperative & difficult to treat"	Past dental experiences & Awareness of health resources		Decreased care & Late presentation	
"Treatment takes time"	Prioritisation of dental needs	Health literacy	Late presentation	
"Cannot come again and again (for treatment)*"*				
"Medicines can be given to get rid of dental problems"	Understanding of diagnosis & treatment			
"No problems in teeth (pain, swelling, bleeding) *now"*				
Inappropriate/ incomplete dental advice	Health literacy & Awareness of health resources			
Improper dental referrals				

*Categories are not mutually exclusive

DISCUSSION

A vast majority of the studies pertaining to dentistry fall under the category of quantitative research. The most obvious drawback of such study designs is that in trying to ensure robustness and generalisability, intricacies such as the individual experiences of the research participants are lost. Adding a qualitative component to the research design limits these disadvantages and enables a well-rounded representation of participant experiences. However, each of these research methods requires specific skill-sets that do not easily inter-mix. Thus, mixed-method studies are, in general, complicated and more difficult to undertake. While such studies are increasingly rare in the field of dentistry, they add a wealth of information and have the capacity to inform, monitor and direct the flow of public health efforts, such as those outlined in this study.

Here, the simplicity and robustness of the quantitative design was informative about the dental needs of the children with special health care needs and the utilisation of dental services offered; while the qualitative strategy permitted exploration of the mindset of the children's caregivers,and analysis of their rationale for not utilising the dental services.Quantitative Aspect

The findings in this aspect point to the gross underutilisation of dental services made available to the children with special health care needs who enrolled in the comprehensive and integrated health care programme at the institute – NSPECC (Table 2, Figure 3). In addition, they also indicate the presence of barriers to providing dental treatments to these children at outpatient centres and camp sites. It appears that the primary concern for the caregivers is meeting the demands and mitigating the constraints of the special health circumstances of their children; amidst this, dental needs receive low priority.

The low statistics appear counter-intuitive in light of the well-documented need for such an integrated dental and comprehensive healthcare programme (DeMattei et al, 2012; Dagli et al, 2017; Kharbanda & Dhingra, 2017; Pathak, 2017; Mandic et al, 2018). While the numbers show a definite improvement from previous years in the form of revisits (from 5.2% across 2016-18 to 16% during the short 6-month study period), they are still disappointing. The observed rise in the percentage could be due to the timing of the study which coincided with two long-vacation periods in the Indian school curricula as well as numerous festival holidays. This trend is often observed in various healthcare organisations that cater to the needs of children. Among children with special health care needs, this period could also be one of reduced stress and greater convenience for their caregivers, thus resulting in higher compliance in the form of dental treatment visits (Chi et al, 2014; Eigbobo & Etim, 2016). There is also a possibility that the researchers' insistence on collecting data regarding the reason for delay/avoidance of dental care could have prompted the caregivers to take part in the study and, therefore, increase the number of dental revisits.

The findings suggest that the most significant unmet oral health need among the study population was the secondary treatment, more specifically the restorative dental needs (Table 2). Considering the proportion of children who availed the advised secondary dental care, our results are in agreement with those of Mehta et al (2015) and Mandic et al (2018). While maintaining that the preventive and restorative treatment needs of children with special health care needs should be a priority for public health efforts, this study highlights the need to explore a different aspect. We observe that there is a need to direct our focus toward a pre-existing problem that has received inadequate attention – that administrative solutions to public dental health problems must be met with awareness efforts at the primary level and within the population as well. This is highlighted by the lack of association between the treatment needs and the treatments availed across the dental dimensions documented here (Table 2). It was understood that despite preliminary dental education efforts at the centre, sufficient awareness had not been generated to effect a change in the behaviour or attitude of the caregivers.

Semi-Quantitative Aspect

Regarding the increase in revisits at NSPECC, it remains unclear why the caregivers' response was better than that observed in the previous years. If this was a result of being asked for their reasons by the attending postgraduates, it seems reasonable to assume that an inquisitive approach might simulate the appearance of concern towards the circumstances of the caregivers and their children. This further strengthens the view that in dealing with disadvantaged groups, even within the scope of dentistry, greater levels of empathy and reflective thinking become a prerequisite for creating a positive change in the pattern of utilisation of healthcare services. It also brings into question the empathy and emotional quotient levels of dental practitioners, particularly among postgraduate residents in the field of Paediatric and Preventive Dentistry. Aggarwal et al (2016) commented on the likelihood of a decline in empathy for patients among dental students who are ranked higher in the hierarchy of learning. They suggested that dental educators must consider strategies to improve communication and understanding, thereby improving patient management and interpersonal relationship skills among students at an early stage.

The current study laid the foundation to address the problems raised by this lacuna, by qualitatively exploring the reasons behind the avoidance behaviours of caregivers of the children with special health care needs enrolled in the programme (Table 3, Figure 3).

Qualitative Aspect

Chi et al (2014), in their research, remarked on the negative association between caregiver burden and preventive dental care utilisation. In the current study, by relying on the caregivers' opinions, an understanding had emerged of the various barriers to the effective utilisation of dental services made available to children with special health care needs.

An overall lack of understanding and knowledge regarding dental disease, more specifically related to dental caries and its management, is evident among the caregivers (opinions 1, 2 and 3, 6, and 7). These appear to be, in part and to some extent, perpetrated also by the dentists and physicians who treat them (opinions 2 and 3, 4, and 6).

An underlying theme (from opinions 2 and 3) is the hidden reference to the temporary nature of treatments performed on primary teeth as these teeth are destined to fall off. According to the caregivers, dental needs were a low priority among the children's healthcare concerns, unless they encountered any overt distress in the form of symptoms like pain or swelling. Highlighted repeatedly, in many of the other opinions, is a lack of understanding about the importance of the primary teeth in the child's oral cavity (opinions 1- 5, and 7).

It also becomes evident (from opinions 4 and 5) that there has been minimal effort on the part of their physicians and treating dentists to educate the caregivers. Whether in providing treatment or prescribing medicines, it is the healthcare provider's duty to make sure that their patients understand the gravity of the disease and the treatment options presented. Without this, the practice of medicine and dentistry will soon become a poor imitation of the entire institution upon which the organisation of the healthcare industry was built. It is often said that "a little knowledge is a dangerous thing." Presenting the children and their caregivers with any amount of incomplete or inaccurate knowledge (opinions 2 and 3, 4, 5, and 6) is a precarious patient management strategy. Adding on from literature, this suggests that specialists, as well as general dentists, must be trained to handle information with care when dealing with disadvantaged and minority groups such as children with special health care needs and their caregivers (Brickhouse et al, 2009; Delli et al, 2013; Duker et al, 2017; Krishnan et al, 2018; Farlina & Maharani, 2018).

It can also be observed (from opinions 4 and 5) that there is a general trend among parents and caregivers to explicitly trust their consulting physicians since the children with special health care needs often require repeated medical attention. However, the dentist is only consulted if and when the physician requests a referral. This entails that the doctors and other healthcare workers, in the caregivers' eyes, shoulder the responsibility for the oral as well as general health of the child, necessitating the need for increased cooperation among the various factions of the healthcare system.

On the other hand, even in the presence of a knowledgeable physician instituting a timely referral, the caregivers' satisfaction is more closely related to the symptomatic relief of oral infection than the management of the disease itself. This points firmly to the fact that many parents are unaware of the implications of adopting appropriate oral care strategies for their children with special health care needs, and resort to late presenting symptoms such as pain (and in some cases swellings or white discharge and bleeding gums) before seeking dental treatment. This destructive behaviour results from a lack of awareness and understanding, which can be met through more intense or incremental dental education efforts.

Educational efforts will be more effective if timed right; for instance, the parent who brings the child with a dental concern is already aware that a problem exists. The parent will be more alert and, on receiving dental education, the full implications of maintaining good oral health will quickly become apparent.

Krishnan et al (2018) commented on the disparity among dentists (who reported to have provided dental education to their patients), and parents (who reported to have received no dental education from their respective dentists). This calls for a reform in strategy among dental care providers, to consciously focus on imparting dental education in their patients, especially when dealing with children with special health care needs and their caregivers. Moving a step further, such dental education must also be imparted to other healthcare professionals, to enable them to make easy and ready dental referrals, with particular emphasis on deferring medical prescriptions for dental problems until the appropriate dental consultations are made (Waldman et al, 2001; Waldman & Perlman, 2002; Dagli et al, 2017).

Another hidden theme that emerges, after careful consideration of opinions 2 and 3, is that of guilt and shame associated with the specific behavioural concerns of their wards in a public setting such as the dentist's office. Past dental experiences of this nature often lead to a sense of hopelessness and increase the likelihood of improper prioritisation of the child's dental needs. These issues tend to have a cumulative effect on the caregivers' mindset, contributing over time to their strain and burden, which further escalates the possibility of late presentation of dental needs among their children with special health care needs (Chi et al, 2014; Weiner et al, 2016).

Opinion 6 belies a matter of grave concern among the interviewed responses. It is clear from the parents in this situation that they have been scorned by the healthcare system, which remains unsympathetic to the plight of caregivers of children with special health care needs. This highlights the need for an integrated and charitable healthcare system, such as the one offered by NSPECC. However, without proper dissemination of knowledge and information along with the sincere cooperation of professionals within the healthcare community, any mistrust present in the minds of these caregivers would tend to persist.

The nature of the NSPECC programme limits the barriers to dental health care within the structural and financial domains; but even so, there is no accounting for the lost income among parents who are daily wage earners and who suffer most from the additional financial burden that comes with the long-term care of their children (Weiner et al, 2016). Unique solutions are required to cover these concerns among this disadvantaged population

Recommendations

On presenting these study results before an expert panel of paediatric dentists within the institution, the following suggestions were made to effect a change in the behaviour and raise dental awareness among caregivers of children with special health care needs (Figure 4):

- Make a conscious effort to build rapport with the child and the caregivers.
- Discuss the unmet dental needs of the child and where possible, include the child and the caregiver in the dental examination, demonstrating and describing the lesions in the oral cavity of the child.
- Dental education is best given following the clinical examination and discussion of the treatment needs of the child.
- Dental education efforts are more impactful if done in the presence of the child, engaging the caregiver and the child simultaneously.
- Oral hygiene instructions may be given to the child, but in the presence of the caregiver, including them in the discussion of directions in such a way that it modifies and adds onto their current oral care practices.

- Dental education and counselling must take into consideration the past dental experiences of the caregiver and the child, taking care to address as many of their issues as possible. Be patient and accommodating.
- It is recommended to keep the dental educational session, at the first visit of the child, taking care to explain every aspect of the unmet dental needs of the child. Following visits must be compounded with short motivational reinforcements as well.
- Always take into consideration the nature and extent of the child's special health care needs. It is crucial to find a way to work around the child's health circumstances.
- Instituting a timely reminder, reinforcement and recall period is as important as any educational effort.
- Be cognizant of the amount of dental information imparted and reinforced at each dental visit. Avoid overloading the child and the caregivers.
- It may be beneficial to institute a re-evaluation system against the educational efforts of the dental team.
- Always maintain adequate and accurate records of all dental procedures, including any special instructions given to the caregiver or child.
- Use colourful pedagogy charts for children and informative pointers in the form of pamphlets for caregivers to make for useful, at-home reminders.

Figure 4: Recommendations for Dental Practitioners working with Children with Special Health Care Needs and their Caregivers

Recommendations:

- Build rapport & actively listen to their concerns.
- Discuss unmet dental needs of the child. (Demonstrate during dental examination.)
- Dental education – *Reiterative & Reflexive.* (Best done following clinical examination, along with the discussion of treatment needs and treatment schedule.)
- Consider past dental experiences & address as many issues as possible.
- Remember: Caregivers know their children best! ***Work with them!*** (Be patient and accommodating.)
- Short counselling and motivational reinforcements at follow-up visits.
- Always consider nature & extent of the child's special health care needs. (Find ways to ***work around the child's health circumstances***.)

3R's: ***Reminder-Reinforcement-Recall.***

- Adequate & accurate records of dental procedures & instructions.
- Periodically re-evaluate & re-assess educational efforts of the dental team.
- Wherever possible: Use additional education aids – colourful pedagogy charts (children), A/V models# & informative pointers/pamphlets (caregivers).

#A/V: Audio-Visual aids

Implications

In addition to the above, it is suggested that dental educators, administrators, and policy-makers in the field of preventive dentistry and dental public health must focus their undergraduate and postgraduate curriculum towards redefining and restructuring the art of imparting dental education to the public, particularly to those with special health care needs (Kenney et al, 2008; DeMattei et al, 2012; Petrova et al, 2014). The current study, like many others previously published in dental literature, clearly elicits the need to revamp our educational strategy for the next generation of dental practitioners and specialists; to redirect their attention towards a more inclusive system that lets healthcare professionals draw on the combined knowledge and resources in an attempt to improve disadvantaged communities like those with special needs, their caregivers and families (Waldman et al, 2001; DeMattei et al, 2012; Petrova et al, 2014; Dagli et al, 2017).

There is an increasing gap between the oral health needs and the utilisation of dental services among children with special health care needs, as is supported by various studies in the dental literature. The reasons and causes for these disparities should be the central theme and focus of dental researchers, administrators, and practitioners. Qualitative and mixed-methods studies can aid in gathering suitable data for the institution of systematic efforts to address them.

The decision to employ a concurrent data collection strategy for this mixed-methods study helped avoid wastage of resources and also helped streamline the dental registry system at the programme. Research studies undertaken with a clear view to enhance clinical practice should ideally stem from and be rooted in current methods employed within the healthcare industry. This helps identify their lacunae and distinguishes new areas of focus for improvement. Such studies, when evaluated properly, can then lead to solutions to backtrack and bring about course corrections in the functioning of the organisation as a whole.

Limitations

It must be kept in mind that since the NSPECC programme primarily caters to the children enrolled with the Block Education Office in Mangalore *taluk* (administrative district), the results may be more specific to the population of this region; however, it does not limit the study’s significance, mainly because such mixed-method studies are scarce in the dental literature.

CONCLUSION

In the current study setting, meeting the structural and financial barriers to dental services utilisation among the children with special health care needs did not cause the desired impact by increasing dental revisits or availing of treatments. Oral health needs among the children with special health care needs enrolled in the NSPECC programme remained high across the primary, secondary and tertiary treatment dimensions. Thus, it was observed that cognitive barriers may have a profound impact on the underutilisation of dental services among children with special healthcare needs and their caregivers, and consequently may require more intensive public health efforts on the part of dental practitioners, administrators and educators.

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Disability Inclusion and Global Development: A Preliminary Analysis of the United Nations Partnership on the Rights of Persons with Disabilities Programme within the context of the Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals

Holly Noel Wescott[1*], Malcolm MacLachlan[1,2], Hasheem Mannan[3,4]

1. Department of Psychology and Assisting Living and Learning (ALL) Institute, Maynooth University, Ireland
2. Olomouc University Social Health Institute, Palacky University Olomouc, Czech Republic.
3. FLAME University, India.
4. University College, Dublin, Ireland

ABSTRACT

Purpose: *This paper provides a preliminary snapshot of the proposed priorities approved by the United Nations programme designated to support the progressive realisation of the CRPD, the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) outlined by specific Convention Articles and, more broadly, the Sustainable Development Goals (SDGs).*

Method:A content analysis of project proposal summaries approved for funding by the UNPRPD was conducted against the CRPD and SDGs. A matrix of data was produced to draw links between proposed objectives and established international frameworks guiding global development.

Results:*This analysis provides two sets of information. First, a look at the distribution of rights identified in the initial project proposals and accepted by the UNPRPD, establishing a baseline of priorities and outstanding need. Second, it identifies issues that need to be addressed to ensure the advancement of all rights outlined in the CRPD and equitable achievement of the SDGs.*

Conclusion and Implications:*Disability inclusion is necessary to achieve the SDGs in an equitable manner by 2030, as well as implement the CRPD. The UNPRPD supports a diverse range of projects spanning many of the*

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[*] **Corresponding Author:** Holly Noel Wescott, Department of Psychology, Assisting Living and Learning (ALL) Institute, Maynooth University, Ireland. Email: holly.wescott2019@mumail.ie

Convention Articles and global goals; however, full participation and scope of disability inclusion requires programming in all areas of both instruments, and this has not yet been fully integrated in the UNPRPD funded project proposals.

Limitations: *This study was limited to the available UNPRPD project proposal summaries that were successful, and did not include all the proposals submitted for consideration. The proposals accepted for funding give insights into the disability inclusive development priorities chosen for project implementation by UN agencies.*

Key words: *capacity, international cooperation, monitoring and implementation, rights, UN agency*

INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (CRPD or the Convention) is an international treaty which identifies the rights of persons with disabilities, as well as the obligations of national governments to promote, protect and fulfil those rights.The CRPD has been ratified so far by 181countries.The CRPD is intended as a human rights instrument with an explicit social development dimension (United Nations, n.d.). Disability inclusion is a priority for development due to the extent of exclusion of people with disabilities globally and must be addressed as part of achieving "society for all," as declared in the 2030 Agenda for Sustainable Development (UN General Assembly, 2015). The United Nations Secretary-General, Antonio Guterres (United Nations Department of Economic and Social Affairs, 2018), highlighted the importance of disability inclusion in the global goals, stating "the Sustainable Development Goals can only be achieved with the full participation of everyone, including persons with disabilities." Disability inclusion is an essential part of realising the vision for 2030, making the CRPD a vital tool to support global progress.

Working towards a society for all, based on full citizenship of persons with disabilities, the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) is a joint United Nations initiative to advance the rights of persons with disabilities. Understanding the process and priorities of UNPRPD projects is essential to learn about and improve global efforts, as international development policy and programming continue to only partially address disability inclusion (MacLachlan & Swartz, 2009; Gartrell et al, 2016).

Background

Development projects and programmes implementing disability rights can take a variety of forms. One example is the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD). The UNPRPD aims to combine and optimise strengths from partnering entities, including United Nations agencies, local governments, civil society, and additional experts (United Nations Development Programme - UNDP, 2016). It does so by enabling structural changes that progressively fulfil disability rights and enhance capacity building of the individual partners, as well as collaboration between them. As of March 10, 2019, the UNPRPD Multi Donor Trust Fund has supported 39 country projects since its inception in December 2011 (UNDP, 2016) (see Table 1). The UNPRPD works to change normative structures within and across social systems, defined as "… the long-term underpinning conditions that shape social interactions" (UNDP, 2016). Country projects seek to reform the fundamental operations in social life, including actions, behaviours and perceptions that contain exclusionary norms, resource allocation and networks that work in tandem to frame individual experiences through legislative policy and cultural norms (UNDP, 2016). Two examples of structural change processes facilitated by the UNPRPD are briefly described here - one in Armenia and the other in South Africa.

In Armenia, the UN Country Team implemented a new national disability determination model, based on the International Classification of Functioning, Disability and Health or ICF (UNPRPD Technical Secretariat, 2018). This included the shift from medical assessments to a contextualised assessment of disability with social and environmental factors (in addition to the conventional medical assessment), determined with significant inputs from the individuals being assessed regarding their own experience of disability alongside a range of health professionals (UNPRPD Technical Secretariat, 2018). In this approach, clinicians are not the sole decision-makers regarding an individual's disability status; rather, a range of social experiences and environmental barriers are incorporated, reflecting a stronger rights-based model, and may include the presence of a representative from an Organisation of Persons with Disabilities (OPD) during the assessment. Disability determination in line with the Convention underpins the systems that follow disability status, such as accommodations or rights-based healthcare and education.

In South Africa, the UNPRPD programme triggered structural changes through synchronised state policy revisions to ensure the core guiding principles of CRPD were embedded (UNPRPD Technical Secretariat, 2016). Beyond addressing policy and legislative barriers, the project implemented a Disability Rights Monitoring and Evaluation Framework across government sectors (UNDP, 2016), solidifying the CRPD as a state norm. Thus national level reforms in the process of disability determination in Armenia and disability rights-based policy in South Africa strengthen equal opportunities for full citizenship of persons with disabilities, thus enabling protection, promotion and fulfilment of their rights as enshrined in CRPD and leaving no one behind in attainment of the 2030 Agenda for Sustainable Development.

Objective

For an overview of the relationship between CRPD Articles and the SDG goals addressed across the UNPRPD global programme so far, this paper presents content analyses of project summaries in terms of the CRPD and the Sustainable Development Goals. Such an analysis provides a preliminary snapshot of the CRPD Articles selected for funding by the UNPRPD in three rounds of projects and the SDGs addressed within the proposal objectives. It also provides an opportunity to reflect on the similarities and gaps found in priorities across proposals that were awarded funding.

METHOD

Table 1: UNPRPD Country Projects by Funding Round

Round 1	Round 2	Round 3
Costa Rica, Indonesia, Moldova, Mozambique, Occupied Palestinian territories, Pacific Island countries, South Africa, Togo, Tunisia, Ukraine, Vietnam	Armenia, Bolivia, China, Egypt, Ethiopia, India, Mexico, Sudan, Tajikistan, Uganda	Benin, Bhutan, Cambodia, Djibouti, Dominican Republic, The former Yugoslav Republic of Macedonia, Guatemala, Malawi, Morocco, Namibia, Nepal, Pakistan, Peru, Serbia, Timor-Leste, Uruguay, Zambia, Zimbabwe

Data Collection

The data for this study includes 36 of the 39 UNPRPD country project summaries to date, accessed from the UNPRPD Technical Secretariat. Five project summaries were not included in the data from the UNPRPD Technical Secretariat (Djibouti, Dominican Republic, Namibia, Nepal, and Vietnam); however two (Nepal and Vietnam) were located on the MPTF website (2019). Both sources of data were included in the study, leaving only three project summaries from funding rounds 1-3 excluded from this analysis. Each project summary contained 1-2 paragraphs giving context to disability in their respective countries, followed by a short overview of the project objectives. This study analysed only the project objectives and coded deductively based on CRPD Articles 5-33, as well as all 17 of the SDGs. United Nations agencies involved with each project were also listed alongside the summaries, and provided a supplemental analysis of agency participation across CRPD Articles 5-33.

The total number of project proposals submitted to the UN was not known in this data set, nor were the criteria on which projects were selected for funding or declined. While recognising this limitation, the study does not claim to assess the breadth of issues identified in the applications, but only the issues identified in those that were successfully funded over three cycles. This provides the opportunity to look at objectives supported by the UNPRPD programme in line with its stated intentions to "seek to enable structurally focused social action aimed at advancing disability rights, in keeping with the UN Convention on the Rights of Persons with Disabilities" (UNDP, 2016).The proposals approved for funding therefore give an insight into topics supported by the programme and, as this study shows, highlight concentrations of support in some areas outlined in the CRPD, but not all. The projects funded to date also provide evidence of attention to some SDGs, while others are currently not supported by projects selected by the UNPRPD. The authors of the current study acknowledge that the absence of or a low number of projects addressing particular Convention Articles or SDGs, does not necessarily reflect a lower priority for these. It may be that projects addressing such priorities were less well-designed or that the intention is to give these priorities more attention in subsequent programme cycles, or for other reasons. The following section outlines the protocol used to gain a deeper understanding of how the the stated intentions in the UNPRPD programme are delivered in the proposed objectives selected for project implementation.

Data Analysis

Preparation for analysis began with a general organisation of the relevant coding categories. Cross-cutting Articles 5-9 are also specific rights, and were included in this study to better understand the approach taken by the UNPRPD programme. In the case of Articles 5-9, the rights in question must have been direct programming targets rather than cross-cutting another CRPD right. Articles 5-9 were only counted in this study if the project summary addressed the right as a targeted intervention in programming, e.g., projects implementing the rights of children (Article 7) as opposed to the whole population of persons with disabilities, or systematic accessibility interventions (Article 9) rather than a principle cross-cutting substantive rights as a secondary outcome. In this way, projects that improve systems of education without a direct reference to how the proposal intends to implement the diverse rights of children with disabilities were only marked in Article 24 for the right to education. Although children are a primary recipient within the system of education, the subject for intervention was education.

Monitoring and implementation Articles 31-33 were also included in this study with a similar logic. States parties' obligations for progressive realisation of the CRPD have actionable items that align with the UNPRPD programme structure. Statistics and data collection, international cooperation (e.g., projects targeting ratification of the CRPD) and state monitoring and implementation, all involve actions eligible to be categorised in this study.

Articles 1- 4 were not included, as they are cross-cutting principles applied throughout the Convention, including: purpose, definitions, general principles and general obligations (CRPD, 2006). These provide the landscape for the Articles that follow, and are not specific targets for development. In other words, Articles 1- 4 are not mutually exclusive from the subsequent rights; rather, they are inherent to the specific rights used in this study to match the primary outcomes in project proposals. Furthermore, Articles beyond 33 involve procedures between States and the Committee to the CRPD, and final provisions (CRPD, 2006). The UNPRPD programme aims to address the Convention between duty bearers, rights holders, the UNCT and other experts (2016), limiting the scope of this analysis to Articles 5-33. While acknowledging that analysis of other articles in the CRPD may be instructive, it was beyond the scope of the current research.

The Convention on the Rights of People with Disabilities - CRPD

The UNPRPD country projects are written in the language of the CRPD, so the coding process resembled matching pairs. Articles were seen as whole coding categories, even when some project objectives only reference part of the Article components. For example, the country project in Armenia addresses Article 25 (right to health) by establishing a disability determination assessment to be implemented nationwide (UNPRPD Technical Secretariat, 2018). Reform of disability determination by medical professionals to a rights-based model addresses the right to health; however, it does not address the cost of services in Article 25(a) or location of service provision listed in Article 25(c). Alternatively, some project summaries had limited detail, as is the case of Togo stating health was targeted, with no additional information. In both of these summaries, Article 25 was marked on the data matrix. This categorical approach followed through the entire analysis, providing an assessment of manifest content in project summaries.

Data was organised in Microsoft Excel, by country project on the vertical axis and categories (CRPD Articles or SDGs) on the horizontal axis. Each item occupied a single cell, where an individual country project could be followed by row across all categorical columns from left to right. This format could also highlight the frequency of programming by Article or goal. For example, the UNPRPD as a global development programme can be seen to have substantial contribution to SDGs 10 and 17 (reduced inequalities and partnerships for the goals), with a substantial programmatic commitment within those categories. Each country was listed in order of funding round (round 1 countries in alphabetical order, followed by rounds 2 and 3), displaying the change in priorities over time. Each project summary was critically analysed for programming objectives, and individually placed in the corresponding categories.

The Sustainable Development Goals (SDGs)

The CRPD outlines the human rights to which people with disabilities are entitled, that are the same rights afforded to all people as they are rooted in the United Nations Universal Declaration of Human Rights (UNPRPD, 2016), nesting the Convention within a system of larger directives. There is synergy between these documents and the SDGs, as they all provide direction for global progress across populations. Disability inclusion and the SDGs are often discussed in terms of the disability-specific indicators that set the 2030 goals apart from the Millennium

Development Goals (MDGs), which had no direct mention of disability (United Nations, 2011). Disability development is still development, and this matrix steps outside the disability-specific lens and compares the UNPRPD programme to the systems it is embedded in. The cooperation between documents allowed for an additional content analysis of the same units (UNPRPD project objectives) against the SDGs.

The same procedures used to analyse the 36 UNPRPD project summaries with reference to the Articles of the CRPD were applied to coding based on the 17 SDGs. Project targets were screened with the United Nations General Assembly SDG resolution document (2015) to fully understand each goal against the project objectives. The same project objectives were coded to the 17 goals as whole categorical units, rather than to isolated targets and indicators. Formatting design remained the same, and were placed in a separate Microsoft Excel sheet.

Each CRPD Article or SDG was treated as an independent category for coding the project summaries. The Articles were then analysed according to type: cross-cutting principles and specific rights, substantive articles, and monitoring and evaluation based on the Convention framework. For analysis of the CRPD, basic addition and division were used to show the frequency and percentages of UNPRPD project targets in a specific Article or category of Articles by the total number of project targets. For example, the total number of project targets identified in the country summaries accepted for funding were 178. Based on that total, the data shows which type of CRPD Articles are more frequently addressed in the selected projects. Between the cross-cutting Articles 5-9, substantive Articles 10-30 and monitoring and evaluation Articles 31-33, the total number of project targets in each category are roughly similar. Furthermore, the number of project targets found in each category were divided by the number of Articles in each category. The 66 targets between 5 cross-cutting Articles versus 58 targets in 21 substantive Articles then throws light on the concentrations of development initiatives found in selected UNPRPD country projects.

Articles 10-30 accounted for 33% of the total data in 21 rights, with a particularly high concentration of data in 4 specific Articles. In this case, a percentage was also taken for the number of project targets in Articles 24-27 within substantive rights to discuss the notable frequency in these four topics.

The SDGs were treated as whole categories and grouped into clusters of data based on frequency in UNPRPD country project summaries (see Figure 3).

In general, UNPRPD project summaries were found in clusters of zero, few, moderate and high frequencies of data. These groups, particularly the SDGs not found in UNPRPD programming, are discussed in the following sections.

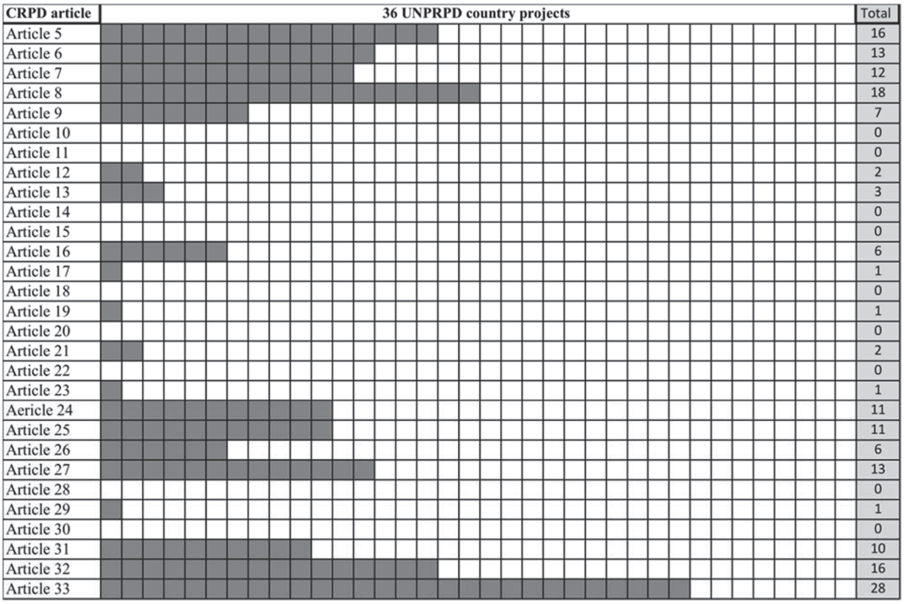
RESULTS

The projects supported by the UNPRPD are a vehicle for national disability development work aligned to one global framework, resulting in a range of contributions to development goals in both the CRPD and the SDGs. This section presents findings from the content analysis of the UNPRPD project summaries against the CRPD Articles 5-33 and SDGs. Importantly, the SDGs yet to be addressed in project proposals supported by the UNPRPD programme are identified. Finally, this section presents the UN agencies selected to participate in the proposed projects and the frequency of engagement between each specialised agency.

The CRPD

The results of the CRPD matrix show a strong concentration of work in the cross-cutting, monitoring and implementation Articles, and Articles 24-27 of the Convention. The 5 cross-cutting Articles accounted for 37% of the data points found in UNPRPD project summaries. 30% of the data accounted for three Articles (31-33) of the Convention for monitoring and implementation. Of the 29 CRPD Articles included in this study, 33% of project targets addressed the 21 substantive Articles. Furthermore, 71% of those targets in substantive Articles (33% of the total) were found in four specific rights (Articles 24-27). Additionally, many Articles of the Convention are not evident in the UNPRPD project summaries (see Table 2). The distribution of data (both data absence and concentrations) present a pattern of development activities approved for funding.

Figure 1: Frequency of CRPD Articles targeted by UNPRPD programming



CRPD article	36 UNPRPD country projects	Total
Article 5		16
Article 6		13
Article 7		12
Article 8		18
Article 9		7
Article 10		0
Article 11		0
Article 12		2
Article 13		3
Article 14		0
Article 15		0
Article 16		6
Article 17		1
Article 18		0
Article 19		1
Article 20		0
Article 21		2
Article 22		0
Article 23		1
Aericle 24		11
Article 25		11
Article 26		6
Article 27		13
Article 28		0
Article 29		1
Article 30		0
Article 31		10
Article 32		16
Article 33		28

Cross-cutting Articles 5-9

After categorising the data, a total of 66 project targets were located in CRPD Articles 5-9. The data found that 16 country projects (of the 36 in this study) target equality and non-discrimination as described in CRPD Article 5. Awareness-raising was the most frequent cross-cutting right targeted in 18 country projects. Both Articles were present in all three rounds of country projects. Article 6, addressing women with disabilities, was seen in 13 of the UNPRPD projects identified in funding rounds 1 and 3, without mention of Article 6 in the 10 country projects from round 2. Children with disabilities were targeted in 12 projects and found across all funding rounds. Accessibility was least prevalent, evidenced in 7 project summaries.

Monitoring and Implementation Articles 31-33

Monitoring and implementation of the Convention are a priority for UNPRPD programming based on the Strategic and Operational Framework (2016) to institutionalise a partnership between local governments and local experts (e.g., OPDs, civil society) to ensure the rights of persons with disabilities are realised with the support of the United Nations. The UNPRPD initiative is evidenced in the data, with 78% of country projects focusing on national implementation. Article 33(3) of the CRPD (2006) highlights the role of persons with disabilities and OPDs in national implementation and monitoring, and is prioritised in the UNPRPD projects aimed at building local capacity within OPDs and between these actors and government entities for progress and accountability.

International cooperation (Article 32) was targeted in 16 UNPRPD country projects, primarily in rounds 1 and 3. Round 2 had only one project focused on aligning the national frameworks to the CRPD. Many projects worked locally to develop a National Disability Strategy, but were not explicitly assessed against the international CRPD standards. A few projects also partnered with other international NGOs such as Humanity and Inclusion or other international or regional experts, resulting in a total of 44% of projects targeting Article 32.

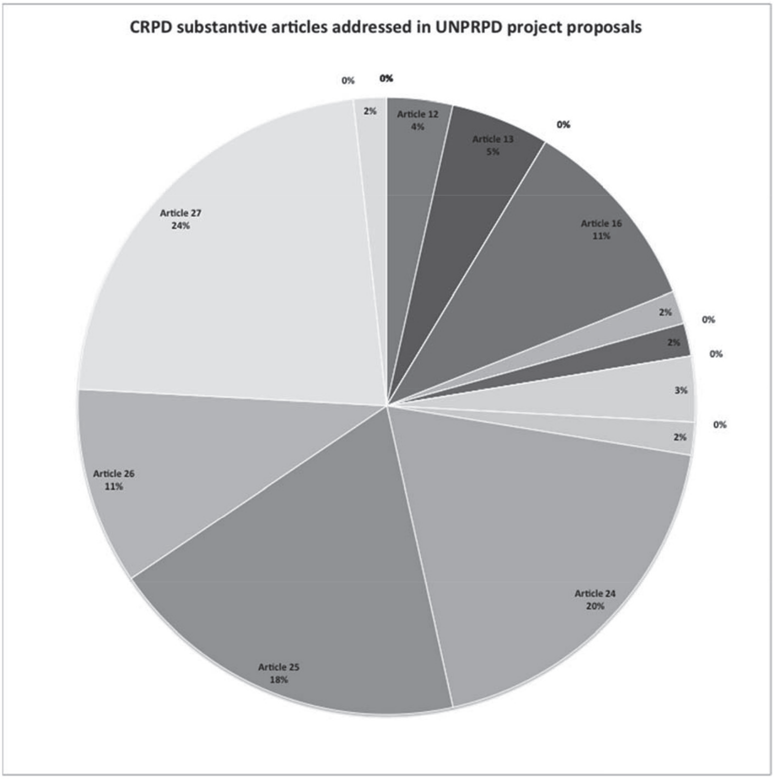
Finally, Article 31 recognises the importance of statistics and data collection to enable effective use of the Convention (CRPD, 2006). About 28% of UNPRPD country projects target data collection and improved capacity to generate and use disability-specific data in policies and programming.

Substantive Rights and Obligations

Substantive rights in the CRPD include both civil and political rights, as well as social and cultural rights specific to a disability context. Of the 58 substantive rights addressed, 71% of the data fell within 4 Articles. CRPD Articles 24-27 relate to education, health, rehabilitation and employment, and work. The next most frequent project objective fell under Article 16 - freedom from exploitation, violence and abuse. All 6 projects targeting violence were specifically aimed at reducing gender-based violence (GBV). These data were categorised in Article 16 rather than Article 6, as the interventions listed were specific to violence (gender-specific violence is articulated throughout Article 16), rather than women as bearers of a broad range of rights, including freedom from violence. As shown earlier (see Methods), this is an example of Article 6 as a cross-cutting principle as well as a specific right.

Figure 2 shows the percentages of CRPD substantive rights found in the approved UNPRPD project proposals. Of the 58 data points in Articles 10-30, Articles 16 and 24-27 are most frequently supported by the UNPRPD projects, and many Articles are not currently in programming.

Figure 2: Percentage of each Substantive Right found in CRPD Articles 10-30 from approved UNPRPD project proposal summaries



Nine CRPD Articles were not found in UNPRPD project proposals. All Articles not yet addressed in project proposals were substantive rights, covering a diverse range of topics including right to privacy, risk and humanitarian emergencies, and participation in cultural life, recreation, leisure and sport among others listed below in Table 2. Many of these rights lack available research but are however known barriers, such as adequate standard of living, to the inclusion of persons with disabilities. While the UNPRPD project summaries used for this study represent the starting point for various projects, identifying the rights that are recurrent and absent from United Nations programming provides a better understanding of which rights were supported for funding and which remain less supported or unsupported. Concentrations of rights supported by the UNPRPD across country contexts does not determine global priorities, though it is worth noting that the UNPRPD is one of the largest disability initiatives to progressvily implement the CRPD, and their selected priorities are located in a broader network of influence within international development.

Table 2: Articles absent from UNPRPD project proposal summaries

Articles absent from UNPRPD project summaries
Article 10: Right to life
Article 11: Situations of risk and humanitarian emergencies
Article 14: Liberty and security of person
Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment
Article 18: Liberty of movement and nationality
Article 20: Personal mobility
Article 22: Respect for privacy
Article 28: Adequate standard of living and social protection
Article 30: Participation in cultural life, recreation, leisure and sport

Sustainable Development Goals (SDGs)

The UNPRPD programme promotes several of the SDGs, with a strong emphasis on specific goals. The underlying premise of the UNPRPD programme is to engage new or strengthen existing partnerships, primarily between government entities and OPDs (UNDP, 2016). The data supports a partnership approach taken by the UNPRPD, evidenced by 22 country projects targeting interventions aligned with SDG 17. Capacity building among civil society and representative organisations of persons with disabilities for the purpose of partnership with government entities and decision-makers are prioritised among the country project summaries in all funding rounds, and found in SDG 17.18 regarding data, monitoring and accountability (UN General Assembly, 2015). Similarly, the capacity of government institutions to appropriately address the rights of persons with disabilities outlined in the CRPD were captured in SDG 16. It is worth noting that while the summaries did not discuss the capacity building and institutional strengthening of the UNCT, the participation of the United Nations teams within this UNPRPD partnership approach are likely affected by programming as well.

National legislation reviews were very common in the UNPRPD project summaries aimed at reducing existing structural barriers in policy and legislation for persons with disabilities. These data were categorised under SDG 10 : reduced inequalities. SDG 10.3 states, “Ensure equal opportunity and reduce inequalities of outcome, including by eliminating discriminatory laws, policies and practices and promoting appropriate legislation and action in this regard”

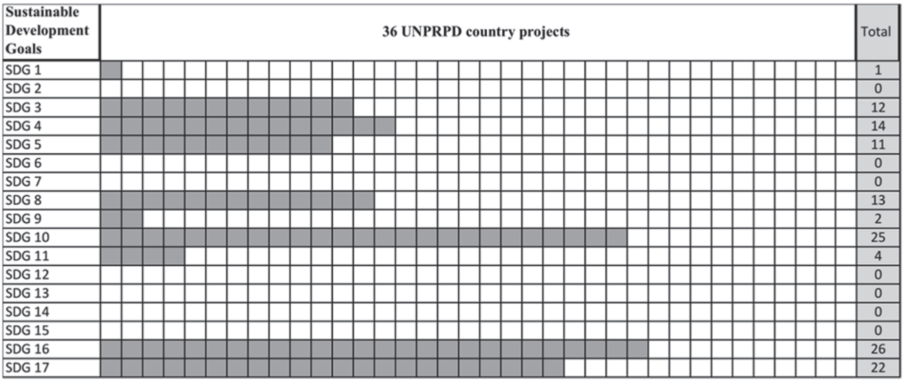
(UN General Assembly, 2015). Twenty-six country project summaries explicitly work to address legislative barriers. SDGs 10, 16 and 17 were the most frequently addressed goals in UNPRPD programming.

Goals addressing more concrete topics such as health, education, work and gender equality were evident in moderate frequency, much like the cross-referenced CRPD results. In particular, many of the participating United Nations agencies are focused on specialised topics, such as the International Labour Organisation (ILO) to decent work, World Health Organisation (WHO) to health and well-being, UN Women to gender equality, and UNICEF to education. Established technical expertise aligned with specific SDG goals were apparent in all three funding rounds of UNPRPD programming.

Few project proposals directly targeted SDG 1: poverty, SDG 9: industry, innovation and infrastructure, and SDG 11: sustainable cities and communities. Many of the goals in this data cluster are important for realising the rights in the CRPD, such as assistive technology, public spaces, and access and affordability of communities. With less than five UNPRPD country proposals addressing these goals in the initial summaries, additional research is needed to better understand current efforts.

Several SDGs were absent from UNPRPD country project summaries used for this study. Environmental goals are not represented, which provides reason to continue researching the connection between disability and their surrounding context beyond the built environment. Hunger and clean water and sanitation (SDGs 2 and 6) are not seen in approved proposals to date, despite the evidence available to link disability with the repercussions of disproportionate poverty affecting people with disabilities globally (World Health Organisation & World Bank, 2011). Furthermore, the goals absent from UNPRPD project summaries have a reinforcing relationship to the SDGs targeted with the lowest frequency (see Figure 3), including SDG 9 (industry, innovation and infrastructure), SDG 11 (sustainable cities and communities) and SDG 12 (responsible consumption and production), highlighting an opportunity to mainstream disability rights and inclusion throughout the SDGs. Figure 3 categorises the number of UNPRPD projects targeting various SDGs in programming.

Figure 3: Frequency of SDGs targeted by UNPRPD programming



Sustainable Development Goals	36 UNPRPD country projects	Total
SDG 1		1
SDG 2		0
SDG 3		12
SDG 4		14
SDG 5		11
SDG 6		0
SDG 7		0
SDG 8		13
SDG 9		2
SDG 10		25
SDG 11		4
SDG 12		0
SDG 13		0
SDG 14		0
SDG 15		0
SDG 16		26
SDG 17		22

Table 3: UNPRPD country project objectives by SDGs

Number of UNPRPD projects	SDGs represented
Few (1-5 data points)	SDG 1: No poverty SDG 9: Industry, Innovation and Infrastructure SDG 11: Sustainable cities and communities
Moderate (10-15 data points)	SDG 3: Good health and well-being SDG 4: Quality education SDG 5: Gender equality SDG 8: Decent work and economic growth
High (20-30 data points)	SDG 10: Reduced inequalities SDG 16: Peace, justice and strong institutions SDG 17: Partnerships for the goals
Zero projects targets	SDG 2: Zero hunger SDG 6: Clean water and sanitation SDG 7: Affordable and clean energy SDG 12: Responsible consumption and production SDG 13: Climate action SDG 14: Life below water SDG 15: Life on land

The Danish Institute for Human Rights (2018) has highlighted the value of examining the interaction between the Articles of the Convention and the SDGs.

Disability is referenced in multiple parts of the SDGs, specifically in the parts related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and the monitoring of the SDGs. Tebbutt et al (2016) have illustrated how Assistive Products are relevant to the equitable and inclusive achievement of each of the SDGs. Having noted that some SDGs are not addressed by approved UNPRPD project proposals, Table 4 provides some idea of local projects by the unmet global goals and corresponding CRPD Articles. The examples provided include persons with disabilities in addressing barriers, and offer a starting point to include new objectives to programming, both at the Convention level and global SDG framework.

Table 4: Disability Inclusion applied to SDGs absent from UNPRPD project proposal summaries

SDG 2: No hunger	CRPD Article 28: Adequate standard of living and social protection	*Application:* Persons with disabilities live in disproportionately high rates of poverty, and access to employment, communities and accommodation resources (e.g., personal care attendant) affecting food security and levels of nutrition (UNDESA, 2018). *Example:* As of 27 February 2019, the ADA National Network and Grassroots Gardens of Buffalo websites highlight universal design techniques in community gardens, promotion of inclusive public space, increased access to food, stress reduction and community engagement for persons with disabilities.
SDG 6: Clean water and sanitation	CRPD Article 28: Adequate standard of living and social protection Article 32: International cooperation	*Application:* Disability accessible latrines and clean water in public spaces will reduce environmental barriers that prevent individuals with disabilities from engaging in their communities, and increase awareness among community members without disabilities. *Example:* Development projects in Uganda and Zambia led by WaterAid initiated a community-driven programme for accessible latrines and sanitation, resulting in increased access to public spaces and community awareness, in addition to the development of an inclusive standard for local WaSH projects (Wapling & WaterAid, 2014).

SDG 7: Affordable and clean energy	CRPD Article 28: Adequate standard of living and social protection Article 32: International cooperation	*Application:* Exclusion from schools and public spaces, and increased rates of poverty, mean that households with an individual with a disability are more often lacking heat or have increased exposure to poor air quality from burning inefficient fuels indoors (UNDESA, 2018). *Example:* A solar-powered wheelchair has been designed and proposed in Bangladesh to promote an affordable alternative to power chairs for increased access to individuals with mobility disabilities, and low environmental impact (Sakib et al, 2015).
SDG 12: Responsible consumption and production	CRPD Article 9: Accessibility Article 21: Freedom of expression and opinion, and access to information Article 24: Education Article 27: Work and employment	*Application*: Individuals with disabilities face barriers to participating in market production, including skills and opportunity to engage in sustainable production. *Example*: An NGO in Serbia called UdruženjeNašaKuća, or Our House, recognises that individuals with developmental disabilities who lack legal capacity are left out of critical sectors including vocational training and employment. The organisation serves as a day programme to provide technical training in a variety of production skills such as making chocolate flavoured from fresh fruits and herbs from the gardens on side or eco-friendly cardboard bins and boxes and pressed paper for wedding invitations. Members of the organisation become part of an environmentally conscious approach to production, and skills training for meaningful participation in market activities (https://www.facebook.com/nasa.kuca/).
SDG 13: Climate action	CRPD Article 9: Accessibility Article: 10: Right to life	*Application:* Individuals with disabilities are at an increased risk during climate-related emergencies due to lack of standardised preparedness or evacuation strategies (Handicap International, 2015; UNDESA, 2018; Wolbring & Leopatra, 2012).

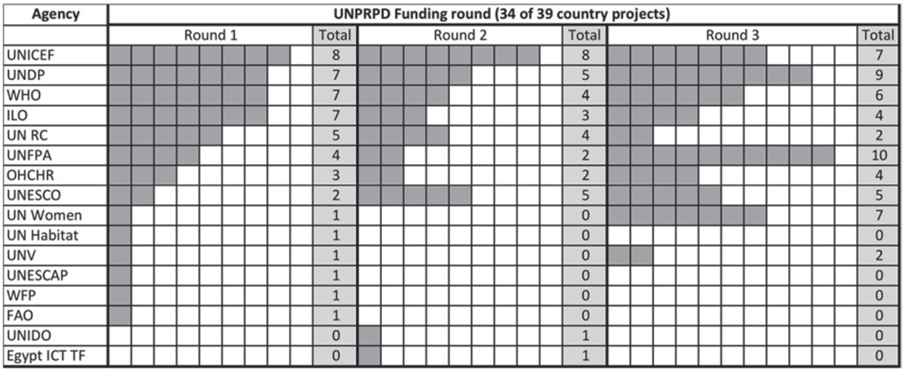
	Article 11: Situations of risk and humanitarian emergencies Article 21: Freedom of expression and opinion, and access to information Article 24: Education	*Example:* Malteser International and the Community Empowerment and Resilience Association (CERA) (2017) implemented visual early warning systems for deaf or hard of hearing individuals in Myanmar, increasing a sense of belonging within their local communities and reducing vulnerability in the event of a disaster.
SDG 14: Life below water		*Application:* Over three billion people depend on marine and coastal biodiversity for their livelihoods. Impacts of coastal pollution on childhood disabilities and adverse outcomes for pregnant women (Rahman et al, 2012). *Example:* Projects that aim to sustainably manage and protect marine and coastal ecosystems from pollution involving women with disabilities (recycling). Waste Aid project example - in The Gambia, to capture plastic waste in the coastal town, training in plastics recycling will be offered for women, young people and people with disabilities (Citation-https://resource.co/article/wasteaid-wins-funding-plastics-recycling-project-gambia-12958)

SDG 15: Life on land		While there are no explicit articles within the CRPD to address how SDGs 14 and 15 are relevant to the fundamental rights of persons with disabilities, disproportionate levels of poverty (WHO & World Bank, 2011), food insecurity (UNDESA, 2018), community reliance on agriculture and marine industries, and climate affects on disability (Groce et al, 2011; Wolbring & Leopatra, 2012) all link these SDGs to disability development. Farming for health (di Iacovo et al) and disability on farms (Mohan,1987; Whelan et al, 2009; Gómez-Marín et al, 2004; Field & Jones, 2006; Deboy et al, 2008) are of significance, thus a role for agencies like that of UN Environment Programme and International Fund for Agricultural Development do exist in future rounds of UNPRPD programming. *Example:* Green care farms in the United Kingdom are found to support individuals with learning disabilities in an accessible and holistic way, while promoting vocational skills and environmental awareness (Rotheram et al , 2017).

UN Agencies

Each project summary lists participating United Nations agencies, which were cross-matched with Articles 5-33 of the Convention. These agencies are seen to work together as “One UN” (UNDP, 2016); therefore each agency was tallied as participants on all targets evidenced in the project summary. Tasks may be delegated during implementation to respective agency specialisation; however this analysis looks at the country project as a unit, including all agencies enlisted to contribute. Additionally, the UN agencies were listed by funding round with the number of projects affiliated with each agency (see Figure 3) to see trends as the UNPRPD programme launches new project cycles. The analysis of UN agencies only includes the 34 country projects sent from the UNPRPD Technical Secretariat due to lack of available data for the remaining 5 country projects.

Figure 4: Frequency of UN agency affiliation in 34 UNPRPD Country Projects by Funding Round



Agency	UNPRPD Funding round (34 of 39 country projects)		
	Round 1 Total	Round 2 Total	Round 3 Total
UNICEF	8	8	7
UNDP	7	5	9
WHO	7	4	6
ILO	7	3	4
UN RC	5	4	2
UNFPA	4	2	10
OHCHR	3	2	4
UNESCO	2	5	5
UN Women	1	0	7
UN Habitat	1	0	0
UNV	1	0	2
UNESCAP	1	0	0
WFP	1	0	0
FAO	1	0	0
UNIDO	0	1	0
Egypt ICT TF	0	1	0

UNICEF was documented to participate in more Convention Articles than other agencies across the UNPRPD programme, followed by UNDP. Of the 178 total project targets, UNICEF is affiliated with 104, and UNDP is participating in 92. The next most affiliated agencies are UNFPA and WHO. The ILO, UNESCO, Office of the Resident Coordinator (UN RC), UN Women, and OHCHR were all moderately affiliated with projects, ranging from 42-62 of the 178 project targets. Disability development crosscuts fields of expertise and supports the partnership approach of the UNPRPD; however it is important to explore how agency specialisation interacts with disability-inclusive development. While the programme aims to support projects based on local need, many of the project objectives align with UN specialisations (also see Figure 2). Further research is recommended to better understand the relationship between UN agency specialisation and the priorities receiving funding from UN programmes. The remaining agencies were affiliated with 15 or less project targets, often involved with just 1-2 country projects.

UN agency participation changed across funding rounds. This was especially noticeable with UN Women, going from one project affiliation in round 1 to seven projects in round 3, and was not listed in any of the round 2 projects. This trend in UN Women supports the data from CRPD Article 16 focusing on GBV, found only in round 3. Additionally, the lack of environmental project targets aligns with the lack of UN agency affiliation with an environmental specialisation. Finally, OHCHR was affiliated with 9 country projects of the 34 available in this part of the study. As technical expertise guides various UNPRPD interventions, stronger representation from the agency specialised in human rights instruments may further support implementation of the Convention in more diverse ways.

DISCUSSION

Despite global consensus around disability exclusion and the wide-ranging barriers to social inclusion, not all rights and priorities outlined in the CRPD and SDGs have been fully embraced – so far - within the UNPRPD country proposals selected to launch projects. There are trends in projects accepted for funding by the UNPRPD, whereby certain rights and goals are heavily supported, and others are absent from all three funding rounds. The lack of environmental targets outlined in project proposals supported by the UNPRPD programme parallels the acknowledged lack of data and lack of focus around these issues, as also found in other types of reviews (The Danish Institute for Human Rights, 2018; UNDESA, 2018). Environmental sustainability cannot be done without people with disability, and disability rights cannot be realised without access to a healthy planet. Thus this research recommends future calls for proposals to address environmental aspects that respect, protect, and fulfil related CRPD rights and that are closely linked with SDGs.

The data from the funded applications from 39 country projects suggests that thus far they have not been inclusive of all rights or goals. Approximately two-thirds of proposals focused on legislative reviews, capacity building and partnerships proposed by individual UNCTs. Having more project proposals originating from outside the UNCT, or in closer collaboration with local actors, may enhance the diversity of applications.

It is important to consider where disability is positioned in international development, particularly from a large programme such as the UNPRPD. The evidence from project proposals shows a pattern (20-30 data points) that focuses on SDG 10: reduced inequalities, SDG 16: peace, justice and strong institutions, and SDG 17: partnerships for the goals. Future calls for project proposals could address CRPD Article 28, adequate standard of living and social protection, with a focus on SDG 2**:** zero hunger, SDG 6: clean water and sanitation, and SDG 7: affordable and clean energy. Further research on project trajectories over time will shed light on patterns that evolve. The programme has introduced the stronger presence of UN Women, incorporating gender as a priority in the most recent funding round. However, participation of OPDs in the development and implementation of the projects should also be enhanced. A recent survey carried out by International Disability Alliance (2020) indicates that among OPDs in 13 out of the 25 countries where UNPRPD projects were operational, 60% of them were aware of the UNPRPD and 100% of those who were aware of them were consulted on the projects only to 'some extent'.

This paper has sought to report disability inclusion in development programming within the UNPRPD programme. The programme has many laudable achievements and it is understandable that certain Articles and goals should predominate during earlier project cycles. In the next stages of the programme it is suggested that focus can be given to some additional and emergent issues. For instance, how is the experience of disability a driver to achieving the global goals and rights-based programming? How can incorporating disability into environmental development facilitate greater progress towards implementing the CRPD and achieving the SDGs? How can development practices innovate new approaches to achieving disability inclusion beyond the established scope of specialised agencies? Further research and reflection will continue to support the pursuit of these questions; however this assessment hopes to offer some insight from one approach to disability development seen in the UNPRPD programme.

CONCLUSION

Disability inclusion is necessary to achieve the United Nations SDGs and the implementation of the CRPD. The UNPRPD supports a diverse range of projects spanning many of the Convention Articles and global goals. Increasing the scope of the programme will allow it to address areas of both instruments. This broader scope could be a feature of future funding calls within the programme. Future research should continue exploring the progress of disability rights as a result of the UNPRPD country projects, with a view towards full implementation of the CRPD and achievement of the SDGs. Such research may include an assessment of country need against the project priorities selected; project outcomes and impact; the role and extent of participation between the United Nations agencies, government and civil society- particularly Organisations of Persons with Disabilities (OPDs); how the results form country projects inform the evolution of the UNPRPD programme; and the power dynamics involved in project planning, trajectories and outcomes.

Limitations

The authors stress that the UNPRPD country project summaries are not a comprehensive account of the work done in each country and only represent the proposed priorities accepted for support by the programme. The data set used for analysis reflects only what was made available to them; it did not include rejected project proposals, or the criteria on which selections were made. Additionally, the UNPRPD programme quite legitimately seeks to support project targets that address local needs (UNDP, 2016), which may not be captured in the CRPD Articles or SDGs, and so were not analysed in this study. Future research could include a similar analysis between the UNPRPD project objectives supported for implementaiton and the States Parties and alternative reports to the Committee on the Rights of Persons with Disabilities, list of issues and concluding observations. Such an analysis may provide further insight into the project selection process and the extent to which priorities are selected based on UN agency specialisation versus local need. The issuing of the call for project proposals only through UN channels may need to be reconsidered so that government and civil society are able to particiapte at the entry stage on an equal footing.

The project proposals used for this study were written and submitted before the inception phase and may not represent the objectives put into action. As projects were accepted and planning began between partnering entities, the stated objectives may have evolved. This limits the possible interpretation and meaning that can be derived from the project proposals. It may well be that projects continue to develop new objectives in subsequent funding rounds to build towards progressive realisation of the CRPD; that is not captured in the study results. Ongoing and detailed project summaries would provide new information to expand this analysis. Despite the acknowledged limitations of the data used in this study, it nonetheless serves as a preliminary snapshot from available information, to report on important development efforts underway to implement disability rights in diverse country contexts.

One important point to distinguish is the UNPRPD programme's stated goal of enabling the advancement of disability rights in line with the CRPD, and it does not claim to advance all rights evenly (UNDP, 2016). The project proposals all evidence the advancement of rights found in the CRPD, however they are concentrated by priority topics. The purpose of this research is to take a step back and look at the UNPRPD programme as one mechanism deployed to address the known barriers facing people with disability around the world, especially structural barriers. While the data used for this study cannot speak for the efficacy of actual project implementation, it does offer a critical analysis of the proposed objectives that got through to the funding stage. This reflection brings to light considerations for setting future objectives in disability development efforts, the procedures by which priorities are selected, and areas of disability rights that may benefit from more focused action.

Finally, while this paper seeks to report on the priorities set by different projects, there is awareness that these priorities occur within a deeper political context, power struggles within the UN, and broader political economy of international development efforts that impact the selected objectives for UNPRPD projects. Such topics are beyond the scope of the current paper, but are the focus of ongoing research (ALL Institute working paper, 2020).

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Employers' Attitudes and Hiring Intentions towards Persons with Disabilities in Hotels in India

Senthilkumaran Piramanayagam[1*], Partho Pratim Seal[2]

1. Professor, Welcomgroup Graduate School of Hotel Administration, Manipal Academy of Higher Education, Manipal, India

2. Assistant Professor, Welcomgroup Graduate School of Hotel Administration, Manipal Academy of Higher Education, Manipal, India

ABSTRACT

Purpose: *The hospitality industry is labour intensive. Currently, in India, hotels have a high employee attrition rate. This study aimed to explore the attitudes of hotel managers towards recruiting persons with disabilities as employees, a move which could benefit all concerned.*

Method*: A structured survey instrument was sent to 31 employers in star category hotels.*

Results: *Employers' attitudes have a significant influence on the recruitment of persons with disabilities. While the intention to hire persons with disabilities is positively associated with quality of work, loyalty, and dependability, it can also be negatively associated with lack of skill, work experience, poor time management and absenteeism.*

Conclusion*: It is concluded that employers hire person with disabilities to work in hotels as they are more reliable and loyal towards the organisation. This attitude from the side of employees with disabilities will also help to overcome the problem of high employee attrition that has a deleterious effect on profitability in the service industry.*

Limitation: *The data is collected from hotels in a single city, which may limit the generalisation of the findings.*

Key words: *employer, attitude, hotel, persons with disabilities, hiring intention, factor analysis*

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[*] **Corresponding Author:** Partho Seal, Assistant Professor, Welcomgroup Graduate School of Hotel Administration, Manipal Academy of Higher Education, Manipal, India. Email:partho.seal@gmail.com

INTRODUCTION

Tourism, a leading economic sector, contributes 10.4% of the world's GDP and 9.9 % of the total employment. In terms of employment generation, tourism directly contributes 5% and indirectly contributes 8.1% of total employment in India, and this is expected to rise by 2% per year (India Brand Equity Foundation, 2020). The hospitality industry is one of the most significant segments of the tourism industry (Hayes et al, 2009). Hospitality and tourism have a symbiotic relationship where the sustained success of one industry determines the sustainability of the other. The hospitality industry is labour intensive, where the success of the firm is determined by its employees, from top management to entry-level employees (Hayes et al, 2009).The memorable experience provided by a human being cannot be substituted by technology (Harkison, 2017). Currently, the hospitality industry in India faces a grave threat of high employee attrition (Datta, 2020). Compared to other service industries, employee attrition in the hospitality industry is significantly higher (Guchait et al, 2015; Datta, 2020) and can be as high as 40% (Sathyanarayanan, 2016). High employee turnover has a significant impact on the quality of service provided to the customers (Zhao et al, 2015; Datta, 2020). Important causes identified for labour shortage are an inadequate number of people willing to make a career in hospitality, perceived low financial compensation and high employee turnover (Hayes et al, 2009). Hayes and his colleagues (2009) concluded that hotels will continue to face human resource challenges for the foreseeable future until an innovative solution is obtained.

Finding skilled employees is an ongoing challenge for every hotel manager and a lot of time is spent in recruiting and training new employees. However, there is another pool of human resources known for loyalty and a long tenure of service with an organisation (Strindlund et al, 2018), yet it faces severe unemployment in the same context. A study in 2011 by the International Labour Organisation (ILO) concluded that out of about 70 million people with disability in India, a meagre 0.1 million are employed (Shenoy, 2011). The unemployment rate among persons with disabilities has many adverse cascading effects on their lives. High levels of poverty, inequity in salaries, poor access to quality education, and poor access to housing and sanitation further hinders them. Disability of an individual can lead to social isolation, negative image, negligence, inequity, discrimination in education, employment, healthcare, access to resources, transport and built infrastructure (Naami, 2011; World Health Organisation, 2011; Hoff, 2013). The noted economist Amartya Sen opines that poverty and disability are bidirectional, where disability tends to increase poverty and poverty escalates the risk of disability (Sen, 2015).

Employment is a critical factor that determines the quality of life of individuals with a disability. Persons with disabilities have been found as good in doing their work as people without disability (Hernandez et al, 2010). Yet, historically, persons with disabilities have never been given equal opportunities; they are discriminated against and stigmatised in their workplaces even after the enactment of the Disability Act by the governments in both developed and developing countries. Despite years of legislative and social efforts to include persons with disabilities as employees in an organisation, their presence remains very minimal, with even a decreasing trend (Burkhauser et al, 2012).

The attitudes of employers, the key stakeholders, have been identified as a significant determinant in the employment rate of persons with disabilities (Houtenville et al, 2012). Although there have been a few studies regarding recruitment, hiring and retaining of persons with disabilities in the hospitality field, a study by Hernandez et al (2010) revealed that persons with disabilities, as compared to people without disability, had similar ratings on job performance, and had a longer tenure in the job with similar supervision time. A study on Pizza Hut's "Job Plus Programme" with 4,000 participants, more than two-thirds of them persons with a disability, found that persons with disabilities had a turnover of less than 20% as compared to people without disability at 150% (Disabled World, 2009). On hiring persons with disabilities, Chicago Marriott had also experienced a lower turnover rate which came down to 32% as compared to an industry average of 50% (Laabs, 1994). While comparing the performance of employees in the hospitality industry, rated by their managers, persons with disabilities are found to be either equal to or better at doing their work than persons without disabilities (Ignamells et al, 1991). Employers from food service firms have also appreciated the role of persons with disabilities for their skills at work, dependability, cooperation, adaptability, low absenteeism, and low turnover (Chi et al, 2003). Employing persons with disabilities as a workforce leads to increased revenue as it attracts guests from diverse backgrounds and enhances corporate social responsibility (Kalargyrou et al, 2014). Research in the United States found that guests prefer those organisations which hire persons with disabilities as employees (Siperstein et al,2006).

While giving an overview of positive experiences and attitudes of employers on hiring employees with disabilities, this review also suggests that employers have negative attitudes towards persons with disabilities. Employers perceive that persons with disabilities lack in skill and job-related knowledge (Bruyere et al, 2006). Managers and administrators have been found to be biased against hiring persons with disabilities, as they fear that their supervisory time will increase and productivity is hampered (Hernandez et al, 2008). Employers' discomfort and unfamiliarity in managing issues related to disability are found to be other barriers for hiring persons with disabilities (Dixon et al, 2003). Gilbride et al (2003) found that employers are hesitant to recruit persons with disabilities as they lack awareness of the source of recruitment, knowledge of the selection process, and experience uncertainty related to the degree of comfort or assistance to be provided. Shaw et al (2014) and Strindlund et al (2018) found that a lack of accommodation strategies by the employer forms another barrier in recruiting persons with disabilities. Ebunenyi et al (2018) observed that the most critical determinant on employers' unwillingness to employ persons with disabilities is their perception that persons with disabilities are not productive and may be violent at the workplace. Employers in leisure and hospitality do have "aesthetic anxiety" as they believe that direct interaction between guests and persons with disabilities will make the guests uncomfortable (Colella et al, 2011; Madera et al, 2019). They have a negative apprehension that persons with disabilities may spoil the aesthetics of the hotel (Groschl, 2005).

It is observed that most of the earlier research work has been from the supply side, i.e., the perspectives of persons with disabilities, rather than from the demand side, i.e., the employers. Various researchers in other cultural contexts have studied the attitude of employers (Unger, 2002; Chan et al, 2010; Houtenville et al, 2012; Strindlund et al, 2018). However, the voice of the employer or the demand side is largely absent in the existing review of literature in the Indian context. It is of prime importance that various concerns of employers be addressed so as to increase the rate of employment of persons with disabilities. Unemployment among persons with disabilities and the high employee turnover in the hotel industry induces a paradox. Narrowing and counterbalancing this paradox will improve the success and profitability of the hospitality industry as well as the well-being of persons with disabilities.

Considering the high employee turnover in the hospitality industry and the severe unemployment rate among persons with disabilities in India, this study was undertaken to elicit information that could be relevant and significant in the Indian context.

Objective

The study aims to identify and analyse the managers/service providers' attitudes and intention to recruit persons with disabilities. The outcome of the study will open new avenues that might give an opportunity for developing innovative solutions to fill the paradoxical gap of high employee attrition in the hotel and severe unemployment among persons with disabilities.

METHOD

Study Setting

This study was carried out in early 2020 in Bengaluru, the capital city of Karnataka State. The city is an information technology hub, housing renowned national and international hotel chains.

Sample

The study targeted the managers of hotels that were star-rated, varying from three-star to five-star deluxe hotels. There are totally 39 star category hotels in Bengaluru, approved by the Hotel and Restaurant Classification and Approval Committee, India, and the Hotel Association of India (Federation of Hotel and Restaurant Association of India, 2020; Hotel Association of India). The study units were selected, adopting a cluster random sampling technique. The hotels are clustered based on their geographical location as South, West, North and East Bengaluru.

The managers responsible for recruitment were approached and requested to participate in this study. A total of 31 persons agreed while 5 hotel managers refused to participate. The response rate was 86%.

Data Collection

Data was collected between February and March 2020, using a validated structured questionnaire with a five-point Likert Scale. The external validity of the data collection instrument was verified by three academic and two research experts. Necessary modifications were made as per the suggestions of the experts, before submitting the Scale to the agency which had been funding the present study. After getting the funding agency's approval, data collection took place. Both descriptive and inferential data analysis were carried out to fulfil the aims of the study. SPSS Version 25 was used to analyse the data. Mean and standard deviation were used to describe the data. Explorative factor analysis was adopted to identify underlying dimensions of the recruiters' attitudes towards persons with disabilities.

Ethical Approval

The study was approved by the funding agency. Prior approval and verbal consent were taken from the hospitality recruiters who agreed to participate in the study.

RESULTS

Demographic Profile of the Respondents

The data collected for the study was analysed using descriptive statistics. The demographic profile of the respondents is given in Table 1.

Table 1: Demographic and Business Profile of the Respondents

Demographic Profile	Frequency	Percent	Demographic Profile	Frequency	Percent
Gender			**Employing Persons with Disabilities**		
Male	25	80.06	Yes	20	64.50
Female	6	18.52	No	11	35.50
Age			**Number of Persons with Disabilities in Hotel**		
Average	38		Average	1.91	
Minimum	28		Minimum	1	
Maximum	53		Maximum	5	
			Total	69	
Star Category			**Type of Disability**		
3 Star	16	51.62	Hearing Impaired	28	40.58
4 Star	4	12.90	Locomotor Disability	22	31.88
5 Star	6	19.35	Blind and Low Vision	13	18.84
5 Star Deluxe	5	16.13	Multiple Disability	6	8.70

Type of Ownership			**Level of Employment**		
Independent	10	32. 25	Entry	58	84.05
Chain	21	67.75	Supervisory	9	13.30
			Managerial	2	2.65
Number of Rooms			**Previous Work Experience of Employing Persons with Disabilities**		
Average	137.8		Yes	8	25.81
Minimum	35		No	23	74.19
Maximum	357				
Total Number of Employees					
Average	114.7				
Minimum	30				
Maximum	515				
Total	3556				

The sample consisted of 25 male and 6 female respondents, ranging in age from 28 to 53 years. Their average age was 38 years. Close to 65% of the respondents did not have any past work experience with persons with disabilities. More than half of the respondents belonged to three-star category hotels, while about 34% were from luxury hotels, both five and five-star deluxe hotels. About two-thirds of the respondents were from hotels that were part of a hotel chain, while one-third were from independent hotels. The average number of rooms in the sample hotels was 137.8 rooms. The availability of rooms in the sample units varied between a minimum of 35 and a maximum of 357 rooms. The number of persons employed in the hotels ranged from 30 to 515, while the average was 114 employees.

Almost half of the hotels were currently employing persons with disabilities. The total number of persons with disabilities employed in all the 31 hotels was 69. The number of persons with disabilities employed per hotel varied from 1 to 5. Among the employed persons with disabilities, the primary disability was hearing disability followed by locomotor, visual and multiple disabilities. More than three-fourths of the persons with disabilities were in entry-level jobs in the hotels, and only 7.4 % were employed at managerial level.

Employers' Attitudes towards Persons with Disabilities

The attitudes of recruiters towards employing persons with disabilities were elicited by making use of 18 statements. Existing literature has described the attitudes of employers as a major hindrance in the recruitment of persons with disabilities in star hotels. The descriptive statistics on employers' attitudes are presented in Table 2.

Table 2: Employers' Attitudes towards Persons with Disabilities

Sl. No	Statements related to Recruiters' Attitudes	Mean (Standard Deviation in bracket)
1.	Persons with disabilities are loyal to their organisation	3.91 (1.24)
2.	Persons with disabilities turn out work of higher quality	3.80 (1.04)
3.	Persons with disabilities are more reliable	3.94 (0.68)
4.	Persons with disabilities need less supervision	2.34 (0.76)
5.	Persons with disabilities are more productive than others	2.84 (0.93)
6.	Persons with disabilities generally have good work experience	3.26 (1.07)
7.	Persons with disabilities have a low level of absenteeism	2.31 (0.88)
8.	Persons with disabilities have poor time management*	3.78 (1.08)
9.	Persons with disabilities are less emotional than others	3.78(0.85)
10.	Persons with disabilities are generally superior in job-related skills	3.31 (0.87)
11.	Persons with disabilities are consistent in their performance	3.09 (0.96)
12.	Persons with disabilities display strange/unpredictable behaviour*	3.13 (1.09)
13.	Persons with disabilities never bring up excuses at work	3.87 (0.92)
14.	Persons with disabilities are easy to train for jobs	2.90 (1.06)
15.	Persons with disabilities make guests uncomfortable*	4.23 (0.90)
16.	Other employees are comfortable about working with persons with disabilities	2.48 (0.92)
17.	Employing persons with disabilities would increase business cost*	3.12 (1.11)
18.	Employing persons with disabilities brings in litigation*	2.37 (0.92)

* Negatively worded statements

The results in Table 2 reveal that for most of the attitude-related variables, the recruiters displayed a mix of both positive and negative attitudes towards persons with disabilities. The positive attitude towards employees with disability was in terms of the low level of absenteeism, quality of work, dependability and loyalty towards the organisation. The recruiters believed that employing persons with disabilities in hotels could make the guests uncomfortable. They also had negative attitudes towards persons with disabilities regarding various organisational aspects such as training, supervision, productivity, lack of work experience, relationship with co-workers and the possibility of litigation in employing persons with disabilities. However, the results also reveal the high variance in attitudes among the recruiters, as the standard deviation for many statements was more than 1.

Underlying Dimension of Employers' Attitudes

Exploratory Factor Analysis (EFA) was conducted using the principal component analysis to understand the principal dimensions within the variables that reflect the attitudes of the recruiters. The EFA yielded five factors : 'Workplace Discipline', 'Interpersonal Relationship', 'Workplace Behaviour', 'Quality and Loyalty', and 'Cost of employment'. The total variance explained by the five factors was about 74.06. The Eigen values of factors varied from 5.644 to 1.001. High Cronbach Alpha values, more than 0.7, indicate good reliability of the factors. During the EFA, two variables in attitude were removed. The statement "Persons with disabilities display strange/unpredictable behaviour" was removed for the low factor loading, which was less than the 0.5 cutoff. The statement "Persons with disabilities are less emotional than others" was removed to improve the reliability coefficient as the removal results increased the Cronbach alpha from 0.430 to 0.817 for the factor named 'Interpersonal Relationship'. The results of factor analysis, Eigen value, Cronbach Alpha and the variance explained are presented in Table 3.

Table 3: Results of EFA for Recruiters' Attitudes

Statements related to Recruiters' Attitudes	Factor Loading	Eigen Value	Cronbach Alpha	Variance Explained	Mean (SD)
Workplace Discipline	5.644		0.854	20.03	3.50 (0.84)

Persons with disabilities generally lack job skills	0.883				
Persons with disabilities lack work experience	0.841				
Persons with disabilities are prone to high absenteeism	0.705				
Persons with disabilities have poor time management	0.689				
Persons with disabilities are less productive than others	0.676				
Interpersonal Relationship		2.442	0.826	15.09	2.84 (1.02)
Persons with disabilities make guests uncomfortable	0.904				
Persons with disabilities make other employees uncomfortable	0.868				
Employing persons with disabilities brings in litigation	0.742				
Workplace Behaviour		1.521	0.817	14.95	3.27 0.816)
Persons with disabilities often bring up excuses at work	0.852				
Persons with disabilities need less supervision	0.733				
Persons with disabilities are inconsistent in their performance	-0.726				
Persons with disabilities are more emotional than others	0.653				

Quality and Loyalty		1.259	0.766	13.10	3.71 (0.66)
Persons with disabilities turn out work of higher quality	0.860				
Persons with disabilities are loyal to their organisation	0.754				
Persons with disabilities are more reliable	0.717				
Cost of employment		1.001	0.726	10.86	3.24 (0.93)
Employing persons with disabilities increases business cost	0.867				
Persons with disabilities are harder to train for jobs	0.765				

Hiring Intentions of Employers

The hiring intention is a behavioural construct that reflects affective behaviour of an individual which is the outcome of cognitive and affective feeling towards an object, individual and event (Robbins et al, 2013). The hiring intentions of the employers in star hotels were measured using 5 statements which reflect their positive and negative attitudes in recruiting persons with disabilities in their respective organisations. The descriptive statistics on employers' hiring intentions are presented in Table 4.

Table 4: Descriptive Statistics on Hiring Intentions

Sl. No	Statements related to Employers' Attitudes	Mean (Standard Deviation in bracket)
1.	I prefer to hire persons with disabilities over others if I get a chance	3.61 (1.11)
2.	High probability of hiring persons with disabilities in my organization	3.77 (1.20)
3.	I am interested in hiring persons with disabilities in my organization	3.68 (0.83)
4.	I recommend that others recruit persons with disabilities	3.48 (0.99)

5.	Within the coming 6 months, I plan to hire persons with disabilities	3.58 (0.99)
6.	Overall hiring intention	3.62 (0.95)

The descriptive statistics in Table 4 show that the employers in hospitality organisations have very moderate intentions towards recruiting persons with disabilities. The standard deviation reveals that there is a significant variation in employers' intentions in hiring persons with disabilities in the sampled hotels.

Effect of Employers' Attitudes on Hiring Intentions

The effect of employers' attitudes on their hiring intentions has been studied in previous research. There is contradicting evidence on the effect of attitude on hiring intention (Burke et al, 2013). However, the factors that influenced either the negative or positive intentions to hire persons with disabilities have not been studied. Using a multiple linear regression model, this study aimed to uncover the relationship between these two constructs. The mean factors evolved using EFA have been considered as independent variables, with the hiring intention as a dependent variable. Mean scores were calculated for each factor. The results of the regression analysis are presented in Table 5.

Table 5: Effect of Employers' Attitudes on Hiring Intentions

Variable	B	Standard Error	Beta	t value	P value
Intercept	2.205	0.482		4.574	0.000**
Workplace Discipline Issues	-0.306	0.103	-0.392	-2.965	0.007*
Workplace Behaviour	0.074	0.106	0.092	0.700	0.490
Cost of Hiring	-.0085	0.071	-0.120	-1.206	0.239
Interpersonal Relationship	-0.245	0.066	-0.380	-3.727	0.001**
Quality and Loyalty	0.881	0.166	0.893	5.308	0.000**

Dependent variable: Intention to hire persons with disabilities

* Denotes the significance at 5% and ** significance at 1%

The results of multiple regression disclose that employers' attitudes towards discipline-related issues, interpersonal concerns and quality and loyalty of persons with disabilities have a significant impact on hiring intentions. Attitudes related to workplace discipline and interpersonal concerns have statistically significant adverse effects on hiring intentions. The finding reveals that when employers have a negative attitude towards persons with disabilities in workplace discipline-related issues and interpersonal concerns, they have low intention to hire persons with disabilities. The adjusted R^2 value 0.743 shows that the estimated model has a good fit and the F ratio of ANOVA value 18.323 reflects that the independent variables in the model are good predictors of dependent variable ' hiring intention'.

DISCUSSION

The continued success and positive contribution of tourism to the Indian economy are determined by the sustained success of the hospitality industry in the country, as they share a symbiotic relationship with each other. However, for the last few years, the sustainability of the hospitality industry has been affected due to high employee attrition, which requires an innovative solution (Hayes et al, 2009). This research aimed to address the high employee turnover in hotels nowadays, by identifying an alternative workforce, namely, persons with disabilities who are currently facing unemployment. The results of the study also indicate the poor rate of employment, as a mere 69 persons with disabilities (out of 3556 employees), hardly representing 1.94%, are employed in the sampled hotels.

The finding implies that employers in hotels have both positive and negative attitudes towards persons with disabilities. The managers have a positive attitude towards persons with disabilities as they are very loyal to the organisation, more reliable and deliver better quality of work. The findings of this study are similar to the studies of Hernandez et al (2010) and Strindlund et al (2018), as the employers in the current research context also believe that persons with disabilities are more loyal and reliable to the organisation. However, in terms of absenteeism, the findings of the present study contradict the earlier studies.

Most of the respondents fear that the presence of persons with disabilities in hotels will make the guests uncomfortable and affect their business. The findings of the study are in line with studies by Bruyere et al (2006), Hernandez, et al (2008) and Colella et al (2011). Results of the current study reveal that respondents also have a similar attitude towards persons with disabilities. This phenomenon is attributed to "aesthetic anxiety" (Colella et al, 2011). Other issues on which the recruiters have negative attitudes are additional cost of training, extended supervision, lack of work experience, workplace litigation and poor time management.

The results obtained through multiple regression divulge that the employers' attitudes have a significant influence on their intention to recruit persons with disabilities in their organisations. Employers have low intentions when they believe that employing people with disability leads to workplace discipline and interpersonal issues and vice versa. They are open to recruiting persons with disabilities if the employees demonstrate quality work output, loyalty and are reliaable. The employers abstain from recruiting persons with disabilities for not possessing requisite skills necessary for the job, lacking work experience, for absenteeism, poor time management and productivity.

Implications

The major implication for employees with disability is to prove that they are capable of delivering high-quality job performances, are loyal to the organisation and are reliable. When they apply for a hotel job, they must convince the recruiters that they are adequately skilled, with appropriate experience, productivity, low levels of absenteeism in the past, and can effectively manage time and work. This research implies that recruiters must be aware that there is another pool of human resources consisting of those who are in no way inferior to other employees in terms of skill and competence. Institutions working with persons with disabilities must provide accurate information to employers on the cost of recruitment, training and supervision of these personnel, in order to increase the workplace representation of persons with disabilities. Recruiters should be educated to do away with their misperceptions and negative attitudes towards persons with disabilities. They must believe that hiring qualified workers with a disability will increase their organisations' diversity. It also helps the organisations to secure loyal, reliable employees who will have long service tenure.

Limitations

The data was collected from a single city, which limits the generalisation of the findings. Hotel-specific variables that influence employers' hiring intentions may not be included in the study; as there are minimal studies in the country, this affects the content validity of instruments used to collect the data. The moderating role of the type of hotel operation, past experience of recruiters who employ persons with disabilities and type of hotel ownership, have not been studied; these can be explored in future. The low sample size is another concern in adopting multiple regression as it may lead to the problem of overfitting and reproducibility. However, the sample size of more than 25 is adequate as sample units are not clustered (Jenkins et al, 2020).

Despite the limitations, this research work contributes valuable insights on narrowing down the factors that act as barriers in the recruitment of persons with disabilities by hotel managers. By addressing these barriers, recruiters can effectively reduce employee attrition while persons with disabilities will reduce their unemployment proactively.

CONCLUSION

The significant contribution of the study is multifold. The study provides evidence on employers' attitudes in recruiting persons with disabilities in India, an emerging economy and a culturally diverse one. The existing studies available are from developed economies, mostly from the western world. This study extends the possibilities for replication in different service sectors, where employee attrition is a major issue for sustainability. It is a step towards addressing the paradox of high employee attrition and severe unemployment in the same context. By adopting exploratory factor analysis, five specific positive and negative factors that determine employers' hiring intentions have been identified.

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Exploring the Use of Communication Supports Inventory- Children and Youth (CSI-CY) - to Identify Barriers and Facilitators in Implementing Augmentative and Alternative Communication in India: Preliminary Evidence from Two Case Reports

Dafiah PM[1*], Krishnendu Sreekumar[1], Vineetha Sara Philip[1,2]
1. All India Institute of Speech and Hearing, Manasagangothri, Mysore, Karnataka, India
2. National Institute of Speech and Hearing, Trivandrum, Kerala, India

ABSTRACT

Purpose: *Augmentative and Alternative Communication (AAC) systems are very often abandoned by the users and caregivers due to potential challenges in implementation. This study aimed at exploring the use of Communication Supports Inventory-Children and Youth (CSI-CY), based on the International Classification of Functioning, Disability, and Health-Children and Youth (ICF-CY), as a potential tool for identifying barriers and facilitators in AAC implementation in the southern part of India.*

Method: *The CSI-CY was administered to the parents of a child with cerebral palsy and a child with autism spectrum disorder, respectively. Environmental facilitators and barriers that affect communication were rated. A semi-structured interview was also conducted to identify additional barriers and facilitators as identified by parents.*

Results: *Barriers related to services and policies, people and assistive technology, were identified for both cases. Additionally, the semi-structured interview identified barriers related to myths, clinicians, child, AAC use, economy and society.*

Conclusion: *CSI-CY is a potential tool for clinicians to systematically identify and document barriers and facilitators to implement AAC. It can further assist them in setting goals and defining the necessary intervention for each child*

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[*] **Corresponding Author:** Dafiah PM, Speech Language Pathologist, All India Institute of Speech and Hearing, Manasagangothri, Mysore, Karnataka, India. Email: dafiahpm@gmail.com

with disability. Early use of AAC contributes to better therapeutic outcomes. Training should be given to professionals, special need educators and school teachers about different AACs and the appropriate techniques to be used. Counselling and evidence from earlier successful AAC interventions can dispel existing myths. Awareness programmes, group discussions and training on AAC can be done to eliminate barriers that may exist among rehabilitation professionals in India.

Key words: *AAC, Communication Supports Inventory- Children and Youth (CSI-CY), barriers, South India*

INTRODUCTION

Augmentative and Alternative Communication (AAC) includes methods and technologies used to compensate for an individual's reduced communication competence (Light, 1989), which can either be temporary or permanent (American Speech and Hearing Association, n.d.). It uses techniques and strategies to either augment or alternate speech, and can be as simple as a shrug of the shoulders or as complex as speech generating devices. AAC can provide the means for persons to interact with other members of the community independently and become integrated into society. Communicative competence through such interactions can increase confidence levels and feelings of acceptance among AAC users (Beck et al, 2000). AAC promotes independence and enhances educational opportunities (Johnston et al, 2004).

Among individuals with developmental delays, AAC offers significant benefits regarding enhancing communicative competence and promoting language development (Millar et al, 2006). However, when and how to use AAC is still subject to debate. Myths and misconceptions regarding the use of AAC appear to be still existent in and across many societies around the world (Cress & Marvin, 2003; Romski & Sevcik, 2005; Singh et al, 2020). Most of the speech-language pathologists (SLPs) or the caretakers of individuals with complex communication needs, usually postpone opting for AAC based on a "wait and see" strategy, until there is a considerable delay in verbal communication, and this can be detrimental to a child's speech and language development in the long term (Cress & Marvin, 2003). The misconceptions, both in AAC theory and practice, affect its clinical implementation and later result in abandonment of AAC. Other factors responsible for abandonment are: the lack of support from professionals, family members, or significant others; personal issues such as lack of motivation, lack of acceptability; the mismatch between the abilities of the individual and the features of the device; and technology-related issues such as difficulty in use and functionality of the device. In addition, lack of training among AAC users, communication partners and SLPs regarding AAC strategies, device programming and manipulation, lack of ongoing adjustments or fine-tuning of devices, and lack of opportunities to use AAC, are among other sets of hurdles (Johnson et al, 2006).

To reduce abandonment and enable successful use of AAC, assessment of barriers and facilitators is crucial. It should be a part of pre-therapy assessment and outcome measurement; however, existing AAC assessment tools such as the Test of Aided communication Symbol Performance or TASP (Bruno, 2011), or Augmentative and Alternative Communication profile (Kovach, 2009) do not include this as a part of their assessment protocol. The Communication Supports Inventory-Children and Youth (CSI-CY) is an instrument based on the International Classification of Functioning, Disability and Health-Children and Youth (ICF-CY), which helps in profiling the needs and strengths related to communication in an individual using AAC. It enables planning and documentation of individualised intervention goals for children and youth who use AAC. Even though CSI-CY is not an assessment tool, it aids in gathering information regarding communication limitations, restrictions in participation caused by the communication limitations, impairments in body functions that limit communication, and environmental factors that serve as barriers or facilitators for communication in a structured and organised pattern (Rowland et al, 2012). It characterises students who use AAC based on the following four categories which include (1) restrictions in participation caused by communication limitations, which is further divided into two subgroups: (a) school-related activities, and (b) interpersonal interaction and relationships; (2) communication limitations, with 7 subgroups which are: (a) receptive language and literacy, (b) expressive language and literacy, (c) functions of communication, (d) rules of social interaction in conversation, (e) augmentative and alternative communication - receptive strategies, (f) augmentative and alternative communication - expressive modes and strategies, (g) augmentative and alternative communication - motor access; (3) impairments in body functions that limit communication; (4) environmental factors that serve as barriers or facilitators for communication with four subcategories which are: (a) physical environment assistive technology,(b) assistive technology, (c) people, (d) services and policies.

Objective

It is important to identify, at an early stage, the potential barriers and facilitators in using AAC. This should be part of assessment, which will then enable clinicians to set goals in the initial phases of intervention and work towards better therapeutic outcomes. Hence, the current study aimed at exploring the use of CSI-CY as a tool in identifying barriers and facilitators in implementing AAC in a south-western state of India.

METHOD

Study Design

This study discusses the use of CSI-CY using two case studies which are described in detail below.

Case Report 1

The case under consideration will be discussed using the pseudonym 'Susan' to maintain anonymity.

Susan was a 6-and-a-half-year old girl when she was brought to the institute, for a detailed evaluation of her communication skills and for further treatment. She had already received a diagnosis of spastic triplegia and, apart from being given physiotherapy for a couple of years elsewhere, she had not received any other form of intervention or education as per parental reporting. Her language evaluation was done using the Receptive-Expressive Emergent Language Scale-2 or REELS-2 (Bzoch & League, 1991). It showed that Susan had a receptive language age-matched to a typically developing child of 4.5 - 5 years. However, her expressive language age was less than that of a 1-year-old typically developing child. This could be attributed to her minimal verbal repertoire and, possibly, because her primary mode of communication was with the use of gestures and pointing. Her oro-motor structures were adequate but lacked in function. Her tongue movements was restricted in its range of motion, and she had severe drooling. Her speech was limited to vocalisations.

After a comprehensive assessment, Susan received a diagnosis of spoken language disorder associated with cerebral palsy. She was then directly referred to the Augmentative and Alternative Communication intervention unit at the institute. A direct referral was made due to the following reasons: (a) There was an urgent need to find a potential communicative medium as the child exhibited frustration when unable to communicate her wants and needs to her mother through the use of gestures and pointing, (b) she had relatively intact language comprehension skills, and (c) no previous attempts had been made to improve speech, language or communication.

Case Report 2

The case under consideration will be discussed using the pseudonym 'Anna' to maintain anonymity.

Anna, a 5-and-a-half-year old girl, was brought to the institute for a detailed re-evaluation of her communication skills and for further treatment. She had undergone a speech and language evaluation at 2-and-a-half years of age, and her receptive and expressive language age, based on REELS-2, was 12 - 14 months. She had poor eye contact, attention, sitting behaviour and verbal imitation. Her peer group and social interaction were also found to be poor. She had difficulty comprehending simple commands and expressed herself largely by using gestures along with 2 or 3 true words. Her communicative intent was also found to be poor.

Anna was diagnosed as having autism spectrum disorder by a team of specialists consisting of a speech-language pathologist, a psychologist, and a neurologist. She received early intervention after this. At the time of discharge, after 1 year of intervention, her receptive language age on REELS was 27 - 30 months, while her expressive language age on REELS was 14 - 16 months. Her ability to give and maintain eye contact improved, along with motor and verbal imitation. She could comprehend simple auditory commands and recognised many common lexical items. Her expressive vocabulary improved to a set of 10 meaningful words. Her peer group interaction improved and she could engage in taking turns while playing.

Anna had received speech and language therapy for over 3 years at different institutes and hospitals in her home town. Eventually she was referred to the particular institute where the current study was conducted, in order to explore the possibility of using an alternate medium for communication as (a) she had not improved in verbal expressive skills even after 3 years of speech therapy, and (b) she was able to communicate only basic needs, and parents at times had difficulty in understanding her needs. A re-evaluation of language skills at 5.5 years, based on REELS-2, showed that Anna had a receptive language age equivalent to a 3-year-old typically developing child, while her expressive language age was equivalent to a 1-year-old typically developing child. She lacked communicative intent and often used a few functional words along with a few gestures (e.g., no, more), which she had gained during her early intervention period, to communicate basic needs.

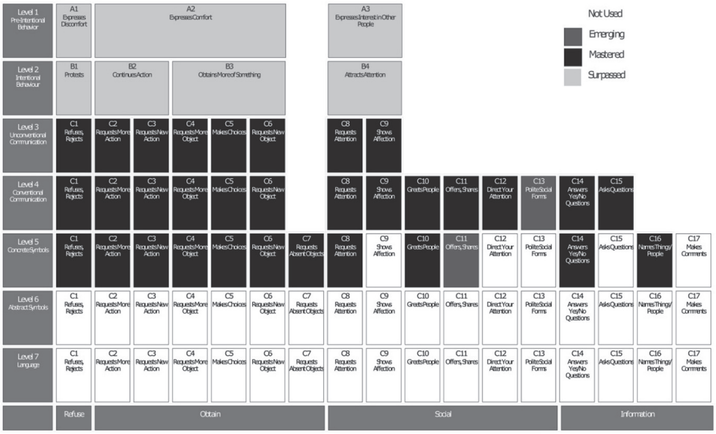
AAC Assessment and Intervention of Case 1 and Case 2

A baseline AAC assessment was carried out for both Susan and Anna, using Augmentative Communication Assessment Protocol for Symbolic Augmentative Systems (Gamel-McCormick & Dymond, 1994) and the Communication matrix (Rowland et al, 2010) as part of the routinely conducted AAC assessment protocol at the institute. The Augmentative Communication Assessment Protocol for Symbolic Augmentative Systems helps in identifying a child's expressive and receptive language skills, cognitive, motor, visual and auditory skills through a series of questions. It also allows for the collection of details on communication settings, probable content of communication, specific vocabulary to be used along with a list of communication partners, and the type of communication the child using AAC is expected to have with each of them. Tactile, visual, positional, interactional and communication preferences of students, along with any other preferences that might influence the use of an AAC system, can also be identified using the protocol. In addition, family and caregiver preferences for communication modes/ methods can also be obtained. The Communication matrix assessment tool is designed to evaluate any type of communicative behaviour, including different forms of AAC such as picture systems, electronic devices, sign language and 3-dimensional symbols, pre-symbolic communication such as gestures, body movements, sounds, eye gaze and facial expressions, as well as the typical forms of communication such as speech and writing (Rowland & Fried-Oken, 2010). It allows organisation of observed communication behaviour into 7 levels, such as pre-intentional behaviour (level 1), intentional behaviour (level 2), unconventional pre-symbolic communication (level 3), conventional pre-symbolic communication (level 4), concrete symbols (level 5), abstract symbols (level 6), and language (level 7). Thus, the AAC assessment tools used allowed a comprehensive evaluation of the child's language, sensory-motor and communication skills, communication needs, communication environment, communication partner skills, symbolic abilities using objects and Picture Communication Symbols (PCS) (Johnson, 1981), and feature matching.

The assessment sessions were successful in identifying the communication needs, environments and partners, along with the AAC devices, for both Susan and Anna.

The primary communication partner for Susan was her mother. Susan's mother was initially reluctant to use AAC, as she firmly believed that if her child used a device to communicate, it would restrict her ability to speak. She was counselled over several sessions and was enrolled for a trial AAC therapy session after obtaining informed consent to conform to the ethical guidelines of the institute. An iOS-based AAC application for communication, Avaz, was selected for the AAC intervention after feature matching and having 3 or 4 trial therapy sessions involving a communication book, 7-level communicator and the Avaz app. Susan preferred using Avaz to communicate during the trial sessions. She was provided AAC therapy for 45 minutes, once a week, for three months. As Susan's family could not afford the AAC system due to their low socio-economic background, she was provided with a communication book with the printed picture symbols, for use at home and at school (the other major communication environments). Communication partner training was provided to the mother during the intervention sessions and she was given the responsibility to train other family members. After an intervention period of three months, Susan was able to communicate her needs, ask and answer questions, greet others, protest, and express her feelings using Avaz. Her communication profile after three months of intervention is provided in Figure 1.

Figure 1: Communication Profile of Susan after three months of AAC Intervention



When improvements in communication became quite evident, Susan's mother was convinced that AAC would be beneficial for her child. She was even quite hopeful that along with AAC intervention, traditional speech-language therapy would enable Susan to start using speech for communication. Susan's mother also had concerns about AAC usage, such as getting her own device for home use, training other family members to use AAC, providing opportunities and training to use AAC at home, and using it in other social environments such as school. Thus, it became necessary to address the mother's concerns for further planning of intervention goals after the initial success with AAC.

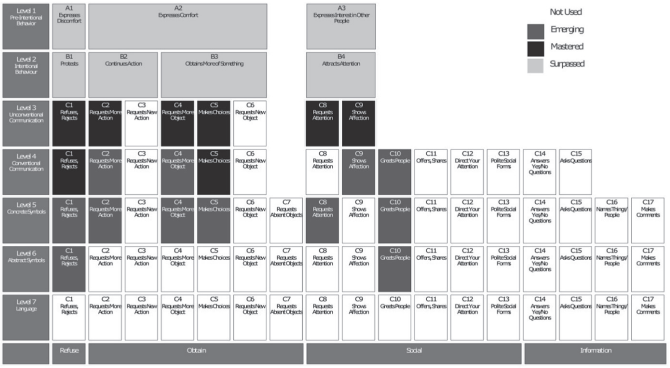
CSI-CY was administered to Susan's parents to systematically identify barriers and facilitators for using AAC in Susan's environment. In the CSI-CY, 28 environmental factors included were either rated as a barrier or facilitator, or as not applicable. In addition to CSI-CY, a semi-structured interview was conducted to obtain additional qualitative information on barriers and facilitators as percieved by the parents. The interview was audio-recorded, and was later transcribed and analysed by two of the primary authors.

Anna enrolled for AAC intervention after a baseline AAC assessment, and informed consent was obtained conforming to the ethical guidelines of the institute. Since she had already been introduced to a communication book using Picture Communication Symbols (PCS) by her parents before the AAC assessment, it was decided that she could be taught to communicate using the same symbols, utilising the underlying principle of Picture Exchange Communication System (PECS). Within the first month of her therapy, she could select and combine symbols to produce short sentences or phrases with minimal prompt. In a span of four months, she showed an improvement in her vocabulary, language, and communication skills. Her improvement in communication skills, as documented using the Communication matrix, is provided in Figure 2. With training, she was able to identify her communication partners, differentiate pictures in a picture array, navigate from one page to another while building a sentence, and point fingers at individual pictures during Sentence Strip exchange. She had achieved phases I to IV on PECS level; however, when the PECS book could no longer support her vocabulary needs, Anna was shifted to an iPad-based application, Avaz, following the guidelines provided by Pyramid Educational Consultants for transitioning from PECS to a speech-generating device. Refining her communication book based on her changing vocabulary needs was a tiresome and time-consuming process, especially for the parents. The parents did not have access to picture symbols and often had to wait for the clinician to provide them.

This prevented them from interacting with her on "here and now" incidents. A high-tech AAC system was chosen, not only based on her skills but also because the in-built digital library would enable parents as well as clinicians to easily include any vocabulary as and when the need arose during communication interactions. The economic capability of Anna's family to afford an iOS-based app was an added factor for selecting the same.

During the three-month intervention period, even though there was a steady growth in Anna's language skills, as evidenced by the increase in the receptive repertoire of words and ability to combine words to form simple phrases and sentences on her AAC system, her communicative attempts lacked spontaneity most of the time. Communication partner training was part of the intervention, wherein Anna's parents and a shadow teacher - a teaching assistant who supports an individual child with his/her special needs in the classroom (Malik, 2017) - were trained to provide aided language stimulation as well as various strategies to provide and fade prompts as and when required. It was noted and informed that her parents were unable to fade the verbal prompts that they used with her at home. This resulted in Anna waiting for some form of verbal confirmation before initiating communication using Avaz. As in the case of Susan's mother, Anna's parents also had concerns regarding how to provide her with opportunities to use AAC, acceptance of the device among other extended family members such as grandparents, and usage of the device in other social environments, especially in school. This triggered the need to identify barriers and facilitators for AAC use in Anna's environment. Hence CSI-CY and a semi-structured interview were used, and the same procedure used with Susan was followed to obtain information.

Figure 2: Communication Profile of Anna after three months of AAC Intervention



Not Used
▨ Emerging
■ Mastered
░ Surpassed

Level 1 Pre-Intentional Behavior	░ A1 Expresses Discomfort	░ A2 Expresses Comfort						░ A3 Expresses Interest in Other People									
Level 2 Intentional Behaviour	░ B1 Protests	░ B2 Continues Action		░ B3 Obtains More of Something				░ B4 Attracts Attention									
Level 3 Unconventional Communication	■ C1 Refuses, Rejects	■ C2 Requests More Action	C3 Requests New Action	■ C4 Requests More Object	■ C5 Makes Choices	C6 Requests New Object		■ C8 Requests Attention	■ C9 Shows Affection								
Level 4 Conventional Communication	■ C1 Refuses, Rejects	▨ C2 Requests More Action	C3 Requests New Action	▨ C4 Requests More Object	■ C5 Makes Choices	C6 Requests New Object		C8 Requests Attention	▨ C9 Shows Affection	▨ C10 Greets People	C11 Offers, Shares	C12 Direct Your Attention	C13 Polite Social Forms	C14 Answers Yes/No Questions	C15 Asks Questions		
Level 5 Concrete Symbols	▨ C1 Refuses, Rejects	▨ C2 Requests More Action	C3 Requests New Action	▨ C4 Requests More Object	▨ C5 Makes Choices	C6 Requests New Object	C7 Requests Absent Objects	▨ C8 Requests Attention	C9 Shows Affection	▨ C10 Greets People	C11 Offers, Shares	C12 Direct Your Attention	C13 Polite Social Forms	C14 Answers Yes/No Questions	C15 Asks Questions	C16 Names Things/ People	C17 Makes Comments
Level 6 Abstract Symbols	▨ C1 Refuses, Rejects	C2 Requests More Action	C3 Requests New Action	C4 Requests More Object	C5 Makes Choices	C6 Requests New Object	C7 Requests Absent Objects	C8 Requests Attention	C9 Shows Affection	▨ C10 Greets People	C11 Offers, Shares	C12 Direct Your Attention	C13 Polite Social Forms	C14 Answers Yes/No Questions	C15 Asks Questions	C16 Names Things/ People	C17 Makes Comments
Level 7 Language	C1 Refuses, Rejects	C2 Requests More Action	C3 Requests New Action	C4 Requests More Object	C5 Makes Choices	C6 Requests New Object	C7 Requests Absent Objects	C8 Requests Attention	C9 Shows Affection	C10 Greets People	C11 Offers, Shares	C12 Direct Your Attention	C13 Polite Social Forms	C14 Answers Yes/No Questions	C15 Asks Questions	C16 Names Things/ People	C17 Makes Comments
	Refuse	Obtain						Social						Information			

RESULTS

For both Susan and Anna, many common barriers were identified under the domains of assistive technology, services and policies, and people-related barriers (Table 1). In assistive technology, the first barrier identified was imposed by limitations towards using general products and technology for communication. Susan and Anna, as well as some of their immediate communication partners, were not skilled enough in using technological devices (computers and smartphones) that could support their communication skills. Another barrier identified for Susan was related to assistive products and technology for education (for the acquisition of knowledge, expertise, or skills). From anecdotal reports, it is worth noting that there is a dearth of learning apps or technology-related learning programmes to meet the educational needs of children with complex communication needs, belonging to diverse cultural and linguistic backgrounds within the country. The third barrier identified was the lack of assistive products and technology for mobility and transportation. It was noted that the special schools which Susan and Anna attended had neither any provision for wheelchairs nor any other assistive products for mobility and transportation or anything for communication or learning.

Table 1: Summary of the Barriers identified using CSI-CY

for Cases 1 and 2

CSI-CY Domains and Sub-domains	Case 1 (Susan)	Case 2 (Anna)
Physical Environment		
Sound intensity and/or sound quality	x	x
Light intensity or quality	x	x
The arrangement of physical space	x	x
Level of surrounding activity	x	x
Others	x	x
Assistive Technology		
Adapted or specially designed HIGH tech products/technology	x	x
Adapted or specially designed LOW tech products/ technology	x	x
General products and technology for communication	√	√

Assistive products and technology for education	√	√
Assistive products and technology for mobility and transportation	x	x
Assistive products and technology for generalised use in school	√	x
Others	x	x
People		
Providing physical support at school	x	x
Providing emotional support at school	√	√
Having skills needed to support communication in school	√	√
Providing physical support at home	x	x
Providing emotional support at home	x	x
Having skills needed to support communication at home	√	√
Others		
Services and Policies		
Special education services	√	√
Regular education services	√	√
School transportation services	√	√
School food services	√	√
School social services	√	√
Before- and after-school care services	√	√
School-based health services	√	√
Special education policies	√	√
Others	x	x

Note: '√' indicates the barrier identified; 'x' indicates that the particular domain was not a barrier

Lack of policies and services such as special education services, regular education services, school transportation services, school food services, school social services, before- and after-school care services, school-based health services and special education policies to accommodate AAC at school and other community areas, were identified as some of the significant environmental barriers. Moreover, their poor socio-economic status prevented Susan's parents from accessing private services requiring payment, which proved a barrier in implementing AAC for

Susan. People-related barriers such as lack of emotional support from teachers at school, and lack of skills among parents and educators to support communication at home and school, respectively, were also identified. In addition to CSI-CY, other barriers associated with the implementation of AAC, as identified through a semi-structured interview with caregivers (parents) of both children under consideration, are provided in Table 2.

Table 2: Summary of the Barriers identified in both Cases by using Semi-Structured Interview

Case 1 (Susan)		Case 2 (Anna)	
Myth-related Barriers	False beliefs that caregivers held about the use of AAC	**Clinician-related Barriers**	Late introduction of AAC after the failure of traditional speech-language therapy
Child-related Barriers	Motor impairment induced by triplegia	**Child-related Barriers**	The lack of spontaneity in using AAC
AAC use- related Barriers	Symbols used are not culturally adapted	**AAC use-related Barriers**	Symbols used are not culturally adapted
Economical Barriers	Poor socio-economic status	**Societal Attitudes**	Negative societal attitudes related to AAC use

DISCUSSION

The communication competence of an individual using AAC is decided by the intrinsic factors such as linguistic, operational, social, strategic, and psychosocial skills of that individual, as well as by extrinsic factors related to policy, practice, attitudes, knowledge, skill, and support systems from the environment (Light & McNaughton, 2014). Identifying the potential challenges or barriers in achieving communication competence by using AAC systematically, allows SLPs and early interventionists to set goals to overcome the challenges and obtain better intervention outcomes.

Some of the already identified and documented barriers in implementing AAC across literature include: (a) the misconception that AAC could limit the ability to learn speech (Light & Drager, 2007; Light & McNaughton, 2012; Huisman, 2014), (b) lack of knowledge and confidence to use the system by families depending on the support provided to them (Saito, 2007), (c) lack of adequate training for professionals in the area of AAC (Mukhopadhyay & Nwaogu, 2009; Light &

McNaughton, 2012; Beukelman & Mirenda, 2013; Huisman, 2014; Douglas, 2020), (d) lack of accessibility to service (Trembath et al, 2010; Light & McNaughton, 2012; Beukelman & Mirenda, 2013; Huisman, 2014; Donato et al, 2018), and (e) lack of funding (Trembath et al, 2010; Donato et al, 2018).

Need for Identifying Culturally Specific Barriers

Environmental factors that act as a barrier for one AAC user do not necessarily create the same impact on another individual belonging to the same cultural and linguistic background, more so when two individuals have different cultural backgrounds. India is a culturally diverse country and extensive exploration is required of environmental factors that may act as barriers in implementing AAC. Results from the aforementioned two case studies have clearly identified a number of barriers for implementation of AAC; these will be discussed in further detail.

Physical Environment

For any AAC intervention to be effective, the physical environment of the individual under consideration should be motivating and less distracting. The physical environment includes the arrangement of the physical space, quality, and intensity of environmental sound and light, and the level of surrounding activity. While AAC therapy for both the cases under consideration was carried out in a controlled environment, it proved to be less of a barrier. However, school environments were not found to be conducive to AAC use for both cases. Susan, who used a communication book in her classroom, was required to point to the picture symbols to communicate. This prevented her from interacting with her peers who were physically distant. For Anna, the physical environment at school was thought to be less conducive as the mainstream classrooms were not equipped to accommodate a child using a high-technology communication device. The speech generated from the device was often not heard above the background noise in the class. The physical distance between the mainstream teacher and the child often prevented one-to-one interactions. The novelty of using a device focused overwhelming attention on the child from her peers; this was another reason that made her hesitate to use it all the time.

Assistive Technology

In India, even though assistive technology is slowly gaining popularity, its inaccessibility and high cost is a major hindrance among the potential users

(Manjula, 2004). Many low technology AAC systems that include simple battery-operated devices (such as BIGmack, LITTLEmack communicators, iTalk 2 communicator, 7-level communication builder, GoTalk devices) as well as dedicated high-technology AAC devices (such as Tobii Dynavox's speech generating devices with eye tracking technology, Unity language system from Prentke Romich Company) are developed in western countries and have to be imported for use. Most of the popular and top-rated AAC applications (such as Proloquo2Go, TouchChat HD) are based on iOS operating system and can be found expensive by the end users. Lack of awareness regarding the AAC devices (for e.g., Voice output Communication Aid such as GUPSHUP and KATHAMALA), assistive switches (e.g., ADITI), and android-based AAC apps (Jellow, KAVI-PTS) developed and available in India, limits popularity and usage. Moreover, these devices are not always suitable for all the potential users who require AAC for communication.

Susan and Anna had difficulty in using general products and technology for communication, assistive products and technology for education, and for generalised use in school. This could be because of a lack of exposure and training to use general technology such as mobile phones and/or computers for communication. Parents' lack of awareness on this aspect, in both cases, along with financial issues in Susan's case, would have prevented the children from getting familiar with these products in general. Moreover, the availability of assistive products and technology for education and generalised use in schools are limited in both regular as well as special schools in India. Most of the special schools lack the infrastructure to provide an adequate number of products and technology for each child with a disability. The infrastructure and economic support required for implementing assistive technology is as relevant a concern as the inability to access whatever facilities are available in the country.

The inception of 'The Rights of Persons with Disabilities Act' (2016) and the 'Assistance to disabled persons scheme' - ADIP (2014) for purchase/fitting of aids and appliances, have marked the birth of policies and schemes favouring the use of AAC in India. It took more than two decades for the concept of AAC use to materialise at the level of policymaking in the country. Even so, such policies are a definite advantage for individuals with communication difficulties.

'The Revised Persons with Disability (RPWD) Act' in 2016 states that "the appropriate government and local authorities shall promote the use of appropriate augmentative and alternative modes including means and formats of communication, Braille and sign language to supplement the use of one's speech to fulfil the daily communication needs of persons with speech, communication or language disabilities and enable them to participate and contribute to their community and society" (The Gazette of India Extraordinary, 2016). Under the ADIP scheme, there are various communication supports, such as visual schedules, tactile books, and Android Tablets made available to individuals with different disabilities.

However, a large number of stakeholders are still unaware of such policies. Empowering parents and caregivers, as well as educating special educators and school managements on existing policies and the advantages of AAC, could be a preliminary step towards achieving the goal of removing barriers due to lack of accessibility to assistive technology. Moreover, the specifications of service providers or guidelines on available products in the country, which the individuals with disabilities might make use of, are not readily available. Experts in the field and/or rehabilitation institutions at the national level (in the area of AAC) need to be continually updated on available and appropriate technologies, and should contribute to providing reliable information about these to any individual with disability.

People

Communication partners play a vital role in making the individual with disability use and accept AAC. Communication partners range from immediate family members, school teachers and neighbours, to many others in the local community. According to the Circle of Communication partners (Blackstone, 1999), the most significant and frequent communication partners include family (spouse, siblings, children, grandparents), followed by friends, neighbours, colleagues or acquaintances in the community, professionals (such as doctors, rehabilitation professionals, teachers) and unfamiliar partners (such as taxi drivers, waiters at a restaurant, shopkeepers, etc.). The last category includes individuals who become communication partners incidentally, or when the individual is trying to accomplish certain tasks such as ordering food in a restaurant or calling a taxi (Blackstone, 1999).

In the case of a child with disability of school-going age, the most significant communication partners after the parents would be teachers or educators. In both the reported cases, lack of communication and emotional support by teachers at school was identified as a barrier towards the successful implementation of

AAC. The majority of the special educators in India are not trained to use AAC (Srinivasan et al, 2010), and hence, this might lead them to be less motivated towards working with a child who uses AAC. In order to encourage and motivate children to use AAC, teachers must be made aware of different AACs, as well as be equipped with strategies and techniques for their use. In Anna's case, this barrier was partially addressed by the presence of a shadow teacher (educational assistant) who used to be present in her classroom during school hours as well as during AAC therapy sessions.

Training all significant communication partners to use the child's AAC system is as important as training the child himself/ herself. In the case of both Susan and Anna, lack of training of caregivers was identified as a barrier for using AAC at home. However, caregivers of both the children were willing to learn about the AAC system of their child and to acquire strategies to teach language concepts and support them to communicate. They were allowed to manipulate the device and were even provided with the opportunity to teach concepts under guidance during the AAC intervention sessions. In India, a large number of children with special needs and their parents belong to the lower socio-economic stratum, which prevents them from being aware of or exposed to AAC systems. This will remain a barrier unless steps are taken by each AAC interventionist to integrate communication partner training into their intervention plan.

Policies and Services

Barriers related to services and policies were found to have an influence on the effective implementation of AAC for both Susan and Anna. The regular and special schools lack the option to facilitate the use of AAC, not only in classrooms but also in services related to transportation, canteen, or even before- and after-school care. For example, a person who serves the food or manages the transportation facility is neither accustomed nor patient enough to communicate with the child with a disability using AAC.

This barrier should and can be addressed by proposing and implementing new policies and schemes that provide opportunities for using AAC in conjunction with different provided services. For instance, by targeting spontaneity in communication during therapy sessions, Anna was helped to improve her communication competency. Children should be given opportunities to learn communication strategies by providing proper feedback and prompting the correct form of expected responses (Cress & Marvin, 2003).

It is also important for an AAC user to get accepted by individuals surrounding him or her to reinforce assertiveness in communication (Light & McNaughton, 2014). Moreover, solving barriers related to societal attitudes plays a vital role in successfully implementing AAC (Light & McNaughton, 2014; Moorcroft et al, 2018). In Anna's case, societal attitudes were solved to a large extent by counselling and allowing participation of extended family members (such as grandparents) in AAC therapy sessions and at home.

CSI-CY as a Potential Tool for Identifying Barriers in Implementing AAC

CSI-CY is a code set based on ICF-CY for profiling AAC related skills of school-aged children. This tool is developed in order to provide content and guidance for professionals to develop goals of individualised education plan (IEP) for children who use AAC (Rowland et al, 2012). Administering CSI-CY prior to the planning of AAC intervention and goals would help in better implementation of these services by trying to resolve the issues at the beginning. Barriers and facilitators tend to change as the child courses through his or her life, and CSI-CY can be used to track barriers during the course of the developmental age as well as to predict the prognosis of children using AAC.

CSI-CY was successful in identifying 13 and 12 barriers related to different aspects of AAC use for Susan and Anna, respectively, of which 12 were common to both of them. The tool essentially helps in identifying major barriers related to assistive technology, people, and services and policies. Seven among the 12 commonly identified barriers belonged to the category of services and policies. Administering CSI-CY to a larger population of children using AAC across different states in India would provide an insight into how services and policies are affecting the effective implementation of AAC. Data from such research studies can lay the foundation for improvising existing policies and services or for developing new ones. The barriers related to the policies for purchase and maintenance of AAC devices is a matter of serious concern which needs to be addressed immediately in order to prevent AAC abandonment by the current and potential users.

With the help of appropriate policies and services, the availability of technology and products for general communication, education, generalised use in school, mobility, and transportation, can be improved. A major portion of AAC devices and software are manufactured in the US and some in the UK, which necessitates importing them and hence makes them less accessible. A few Indian institutes have taken up the challenge of developing voice output communication aids, picture symbol software, and Android-based mobile as well as Tablet AAC applications for individuals with various communication disorders. Even then, the paucity of original research that adds positive evidence regarding the efficacy of these indigenous products in improving communication interactions, limits their popularity. Moreover, purchasing and maintaining these foreign-built products places a considerable economic burden on the parents or caregivers of children who use these devices. CSI-CY can be used as a tool to identify barriers related to 'adapted to or specially designed high/low tech products/technology developed for the purpose of improving communication' in different parts of the country. CSI-CY also points out the importance of identifying barriers related to the people, which include lack of emotional support at school, and lack of skills required to support communication using AAC at school as well as at home.

The present study has found that a semi-structured interview can prove to be beneficial in identifying additional barriers to the successful implementation of AAC. Nine additional barriers were identified using the semi-structured interview. Moreover, throughout the course of administering CSI-CY, the authors found that a cultural and linguistic adaptation of the tool is inevitable because the nature of the progress of AAC interventions in a culturally and linguistically diverse India is different from other developed countries. Furthermore, due to the lack of awareness about AAC services, the existence of myths and misconceptions, attitudinal barriers and lack of accessible assistive technology, specific services and policies specific to AAC, the tool requires to be adapted in order to have a better understanding of barriers towards AAC implementation in different parts of the country.

Limitations

Although the CSI-CY proved useful in identifying factors that served as barriers in implementing AAC and in classifying them under different sub-categories, there are however several limitations to this study. First, the findings of the study are based on two case studies and hence, it will be difficult to generalise the use of the tool to a larger population. Second, the CSI-CY was not culturally and linguistically adapted to be used for the population under study; instead, the required information was obtained by the researchers on translating the statements and questions. Adaptation would have ensured that the instrument was equivalent to the original tool to enable comparisons of responses across culturally and linguistically diverse populations.

CONCLUSION

Even though AAC has made advances in recent years and its effect on improving communication has been proven, there are still factors that inhibit individuals from using AACs and also prevent AAC users from taking full advantage of the system. Practitioners should be aware of these factors affecting the successful implementation of AAC and of possible solutions available. Professionals are required to have updated knowledge regarding current technologies, services, and policies that may help in overcoming many barriers.

The two case studies that were discussed provide evidence for using CSI-CY to identify barriers more systematically when gathering information related to the implementation of AAC. Even though in both cases CSI-CY was used after the initial intervention, it would have been helpful if it had been used before initiating the intervention. However, it may have to be used frequently as a part of a dynamic AAC assessment, as barriers and facilitators may change periodically. The findings of the study can help clinicians in two ways: (a) It assures beginners that barriers are a part of the implementation process of AAC and require to be documented and tackled systematically, and (b) CSI-CY can be used as a guidance tool.

Since AAC is a field with immense potential for research, future studies could look into culturally validating CSI-CY and administering it to a larger population to study the efficiency of the tool in identifying barriers in AAC implementation. As more research about barriers becomes available, professionals and policy-makers would be able to join hands to resolve these issues. Future research on overcoming barriers would empower service providers with the knowledge and skill to provide AAC to any individuals with a communication disorder so that they can achieve full participation in mainstream society.

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The Quality of Life and Associated Factors in Indonesian Meningioma Clients after Surgery: A Cross-Sectional Study

Amelia Ganefianty[1], Dewi Irawati[2], Debie Dahlia[2], I Made Kariasa[2], Agung Budi Sutiono[3]

1. Student of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia, Depok 16424, Indonesia
2. Department of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia, Depok, Indonesia
3. Department of Neurosurgery, Faculty of Medicine, Universitas Padjadjaran, Indonesia

ABSTRACT

Purpose: *The quality of life (QOL) of meningioma clients in Indonesia is poorly understood. This study aimed to investigate and examine the factors associated with the QOL of these meningioma clients after surgery, in order to help create an appropriate post-operative nursing intervention.*

Method: *This was a cross-sectional study. The QOL data was collected from a sample of 118 clients, using a EuroQol-5D-5L (EQ-5D-5L) questionnaire. Functional status, fatigue, illness perception and social support were assessed by the Barthel Index, FACIT-Fatigue Scale, Brief Illness Perception Questionnaire, and Medical Outcome Study Social Support Survey-6, respectively. Statistical analyses were conducted using the Chi-square test, Fisher's exact test, and logistic regression test.*

Results: *After surgery, more than half of the 118 clients reported " problems" in the EQ-5D dimensions of mobility (65%), self-care (57%), usual activities (70%), pain/discomfort (84%), and anxiety/depression (70%).The average postoperative EQ-5D index value (±SD) was 0.55 ± 0.26 while the median of EQ-VAS was 69.2 (IQR 40–90).Factors related to low QOL were age (p = 0.014), tumour grade (p = 0.0001), functional status (p = 0.0001), fatigue (p= 0.001), illness perception (p = 0.0001), and social support (p = 0.001). Multivariate analysis showed that the most dominant factor associated with QOL was functional status (OR 6.728; Confidence interval=95%; p=0.008).*

Conclusion and Implications:*There is a correlation between age, tumour grade, functional status, fatigue, illness perception, and social support with the*

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* **Corresponding Author:** Amelia Ganefianty, Student of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia, Depok 16424, Indonesia. Email:ganefianty@gmail.com

QOL of postoperative meningioma clients. The study recommends that these be included in their nursing assessment and an appropriate nursing rehabilitation programme be planned in order to improve their QOL.

Key words: *meningioma, client, nursing, quality of life, surgery*

INTRODUCTION

Meningioma is the most common primary intracranial tumour, constituting about one-third of all tumours that attack the central nervous system (Najafabadi et al, 2018). Meningiomas originating from arachnoid cap cells that grow on meninges can be found in the spinal cord and brain (Backer-Grøndahl et al, 2012), with an incidence rate of 8.9 per 100,000 persons (Batista et al, 2011; Najafabadi et al, 2017; Benz et al, 2018). About 90% of meningioma cases are benign and can cause symptoms in the form of seizures, visual disturbances, cognitive impairments, emotional disorders, and neuropathy (Najafabadi et al, 2017).

Meningioma can affect the physiological, psychological, and social domains of life. The neurological symptoms most often experienced by meningioma clients are headache, impaired vision, cognitive impairment, epilepsy, motor disorders, and speech disorders (Alkemade et al, 2012). That explains why the QOL of clients with postoperative meningioma shows worse results than a healthy population, both physically, cognitively, psychologically, and in social function (Najafabadi et al, 2018). Surgery is the main management of meningioma clients (McFaline-Figueroa & Lee, 2018). Nevertheless, in the management of clients with meningioma as a primary brain tumour, both surgery and further radiation therapy can aggressively reduce some domains in clients' QOL (Jalali & Dutta, 2012).

In Indonesia, at present, studies on the quality of life of meningioma clients after surgery are still limited in number (McAllister et al, 2017). A study on 65 Indonesians with several different types of brain tumours found that while there was improvement, many clients were still reporting problems about quality of life at 3 months post-discharge, highlighting the need for ongoing support and care to ensure the best possible outcomes (Ganefianty et al, 2019). However, there is no research that explains the factors related to their condition.

Factors related to the quality of life of meningioma clients need to be studied and managed comprehensively. Armed with this knowledge, nurses can determine appropriate nursing interventions, compile discharge planning programmes, and rehabilitate clients based on their needs. Assessment of the quality of life of meningioma clients is also very important because it can serve to recognise the initial changes in clinical conditions subjectively to meningioma clients, and their relationship to disease progression (Ooi & Mazlina, 2013). Further research on the quality of life of meningioma clients in Indonesia is urgently needed.

Objective

The purpose of this study was to identify the factors related to quality of life among clients with meningioma after surgery, in Indonesia.

METHOD

Study Sample

This cross-sectional study was carried out with a total of 118 clients who underwent meningioma surgery in the neurosurgery department of Hasan Sadikin Hospital, between January 2018 and January 2019.

Meningioma clients with integrated medical records, 3 months to 1 year after surgery, who were able to answer the questionnaires postoperatively and could give informed consent, were included in the study.

Measures

Demographic and Medical Variables - The sociodemographic variables assessed were gender and age, while medical variables consisted of the type of brain tumour. Imaging evaluation of brain tumours was carried out by CT scans or MRIs. Histological grading was performed according to the World Health Organisation (WHO) classification.

Quality of Life - Postoperative evaluation of surgical outcomes in terms of quality of life was performed using a EuroQol-5D-5L (EQ-5D-5L) questionnaire. It is a generic measure of health-related quality of life, widely used across many countries (Brooks & De Charro, 1996). In EQ-5D, five dimensions of HRQL are scored: mobility, self-care, usual activities, pain/discomfort and anxiety/depression, with 5 possible answers to each dimension, i.e., ‘no problem’, ‘slight problem’, ‘moderate problem’, ‘severe problem’, and ‘extreme problem’. These results on the state of health were transformed into a single index value based on a large survey in the Indonesian population (Purba et al, 2018). The EQ-5D index has a score of 0.865 for the worst state, and a score of 1 for full health. A Visual Analog Scale (EQ-VAS) was also used, forming the second part of the EuroQol questionnaire. For the Indonesian language, the corrected item-total correlation of all subscales was reported to be above 0.306. The test-retest reliability for all subscales was above 0.910.

Functional Status - The Barthel Index (BI) was used to assess functional status (Collin et al, 1988). Items were scored on the level of assistance required for an individual to perform activities of daily living. The Scale included 10 items, with each item scored from 0 - 3 based on the level of independence. Possible scores range from 0 - 19, with higher scores indicating more independence. A score of 19 is categorised as being independent; 12-18 as a mild dependence; 9-11 as a moderate dependence; 5-8 as severe dependence; and 0-4 as total dependence. For Indonesian clients, the BI has shown good reliability and validity. The corrected item-total correlation of all subscales was reported to be above 0.306 and the reliability test for all subscales was above 0.871.

Fatigue - FACIT-Fatigue Scale was used to measure the severity of fatigue (Al-shair et al, 2012). It has been established as a valid and reliable tool for assessing fatigue for neurology clients (Butt et al, 2013). The FACIT-Fatigue Scale is a 13-item client-reported measure of fatigue. Severity of fatigue symptoms is rated from 0 - 52. The calculation is performed using the FACIT-Fatigue subscale Scoring Guidelines (Version 4). The lower the score on the FACIT-Fatigue Scale, the more severe are the client's fatigue symptoms. The corrected item-total correlation of all subscales was reported to be above 0.306, and the reliability test for all subscales was above 0.902.

Illness Perception - Possible illness perception was measured by the Brief Illness Perception Questionnaire (Broadbent et al, 2015). The questionnaire has 9 items that use a 0 - 10 numeric Scale, has good data reliability and validity, and can be completed in a few minutes. Higher scores of BRIEF-IPQ reflect an individual's more negative perceptions about his/her illness. The corrected item-total correlation of all subscales was reported to be above 0.306, and the reliability test for all subscales was above 0.859.

Social Support - The social support was measured using the Medical Outcome Study Social Support Survey-6 , which contained 6 questions on a 1- 5 Likert scale (Holden et al, 2014). The MOS-SSS-6 is a good instrument for measuring social support in cancer clients (Singh et al, 2017). Answers are given scores of 1 for 'never', 2 for 'ever', 3 for 'sometimes', 4 for 'frequent', and 5 for 'very often'. The measurement results are stated in the total score, where the lowest score is 6 and the highest score is 30. It is stated that social support is good if the total score is ≥ 24 (Holden et al, 2014).The corrected item-total correlation of all subscales was reported to be above 0.306, and the reliability test for all subscales was above 0.909.

Statistical Analysis

Data was analysed using SPSS version 21.0. All data was summarised as means, standard deviations (SD), medians, and interquartile ranges (IQR) for continuous variables, and as frequencies and percentages for categorical variables. The associations between age, tumour grade, functional status, fatigue, illness perception, and social support were confirmed by the Chi-square test and Fisher's exact test. The logistic regression analyses were then conducted to identify the factors most related to the quality of life. The level of statistical significance was set at p-value< 0.05 (Polit & Beck, 2013).

Ethics Approval

This study was approved by the Ethics Committees of the Universitas Indonesia, Depok, Indonesia (Reference No. 01/UN2.F12.D/HKP.02.04/2019), and the Hasan Sadikin Hospital, Bandung, Indonesia (No. LB.02.01/X.2.2.2/4458/2019).

RESULTS

Client and Clinical Characteristics

Client and clinical characteristics are summarised in Table 1. The mean age at surgery was 45 years and there was a female predominance (80 %) among the clients in the sample. In 57 % of clients the tumour was diagnosed as Grade II meningioma and most had a mild functional dependence status based on the Barthel Index category (59.3%). Furthermore, more than half of the respondents experienced fatigue (72%) with negative illness perception (53.4%), and received poor social support(72.9%).The average EQ-5D index value (±SD)was 0.55 ± 0.26, while the median of EQ-VAS was 69.2 (IQR 40–90).

Table 1: Client and Clinical Characteristics (n = 118)

Characteristics	n (%)
Age (year), mean ±SD	45±12
Female (%)	94 (80%)
Histopathology (%)	
Grade I	39 (33.1%)
Grade II	67 (56.9%)
Grade III	12 (10.2)
Functional status (%)	
Independence	36 (30.5%)
Mild dependence	70 (59.3%)
Moderate dependence	7 (5.9%)
Severe dependence	3 (2.5%)
Total dependence	2 (1.7%)
Fatigue (%)	85 (72%)
Illness perception (negative)	63 (53.4%)
Social support (poor)	86 (72.9%)
EQ-5D Index, mean ± SD	0.55 ± 0.26
EQ-VAS (range)	69.2 (40–90)

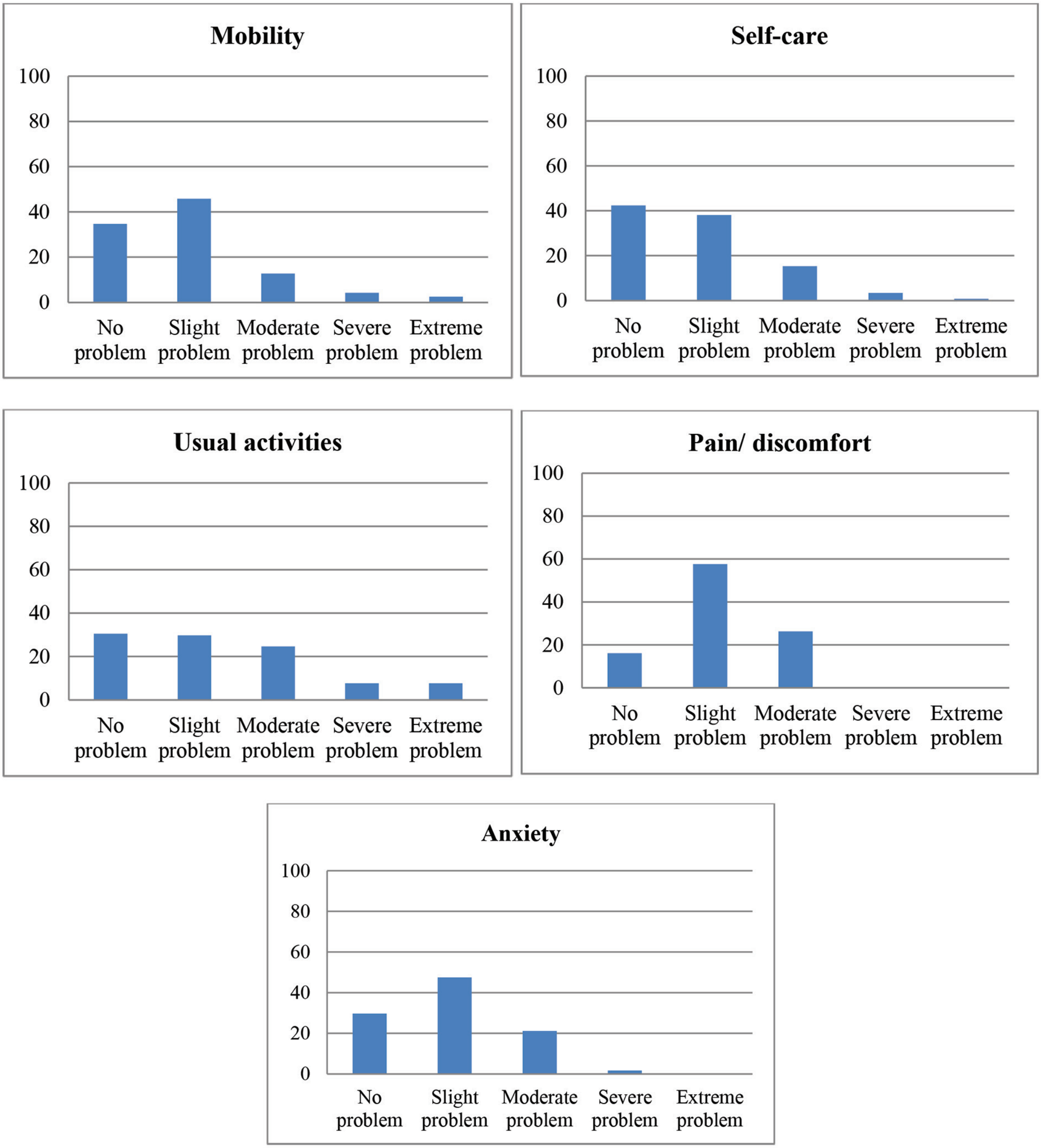
Dimensions of Quality of Life

After surgery, more than half of the 118 clients reported " problems" in the EQ-5D dimensions of mobility (65%), self-care (57%), usual activities (70%), pain/discomfort (84%), and anxiety/depression (70%). Additionally, a number of clients reported extreme problems with EQ-5D mobility (2.5%), self-care (0.8%), and usual activities (7.6%) (see Figure 1).

Factors related to Quality of Life

The bivariate analysis was conducted for QOL measured as dependent variables; age as sociodemographic variables, and tumour grade as medical variables, were associated with quality of life ($p < 0.05$, CI 95%). Determination of tumour grade in this study was carried out by looking at the histology results and the category of WHO-based meningioma grade from the client's medical record. In this study, clinical characteristics involve functional status, fatigue, illness perception, and social support. All of the clinical characteristics were related to the quality of life (p <0.05, CI 95%). The result of bivariate statistical analysis can be seen in Table 2.

Figure 1: Relative Distribution for each Dimension in EQ-5D-5L



Mobility

Self-care

Usual activities

Pain/ discomfort

Anxiety

Table 2: Correlations between Age, Tumour Grade, Functional Status, Fatigue, Illness Perception, Social Support, and Quality of Life (n=118)

Variable	P-value	OR (95% CI)
Age	0.014	0.108
Tumour grade	0.0001	0.162
Functional status	0.0001	12.667
Fatigue	0.001	4.373
Illness perception	0.0001	12.353
Social support	0.001	4.665

Regression analyses excluded age, tumour grade, and fatigue as influencing variables since there were no significant associations with QOL in multivariate analysis. Illness perception was entered in the first step, functional status in the second step, and social support in the third step. The results indicated that the most dominant factor associated with the quality of life of postoperative meningioma clients was functional status OR = 6.728 (95% CI = 1.655; 27.348). We obtain an OR for quality of life of meningioma patients of 6.728 for people who have good functional status. This means that the odds of quality of life of meningioma patients are 6.728 times as high for patients with good functional status (Table 3).

Table 3: Multivariate Statistical Test for Factors related to Quality of Life (n=118)

Variable	p-value	OR	95%CI Min	95% CI Max
Illness perception	0.003	5.874	1.819	18.962
Functional status	0.008	6.728	1.655	27.348
Social support	0.02	2.043	0.616	6.773

DISCUSSION

Quality of life can be influenced by several factors.The results indicated that more than half of the postoperative meningioma clients in this study experienced low quality of life. The average value of the EQ-5D index score is 0.555 with EQ-VAS of 69.32. The average value is lower as compared to the quality of life of the general population in Indonesia, because the index score for the general population is 0.86-0.91 with an average EQ-VAS of 79.39 (Purba et al, 2018). This is in line with other studies that explain that meningioma clients have a significantly decreased quality of life when compared with similar demographic groups (Benz et al, 2018). The index scores in this study are lower than those of meningioma clients in Norway, where the value is 0.73 - 0.76 (Drewes et al, 2016). This can occur because the determination of the index score in each country is different (Purba et al, 2018).

The current study indicated that most clients still experienced problems in the domains of mobilisation, self-care, usual activity, pain, and anxiety/ depression. Clients experience impaired mobilisation due to the effects of long-term suppression of tumour mass on hemispheric function in the brain (Capabianca et al, 2018). Besides, some meningioma clients in this study experienced a decrease in postoperative visual function due to the suppression of long-term meningioma in the optic nerve which regulates vision function. The decrease in visual function also results in impaired mobilisation. Clients in the study sample had difficulty in walking, moving, or ascending stairs and difficulty in carrying out daily activities, resulting in decreased quality of life.

The results of the study showed that the pain dimensions of quality of life were low because most of the clients experienced headaches. There are several mechanisms of headache that can occur in meningioma clients (Capabianca et al, 2018). First, headaches are caused by suppressing the tumour mass against the arteries and veins surrounding the meninges. Both relate to the inflammatory process. In this process, macrophages will produce cytokines (interleukin-1, ILG, alpha TNF, and NGT), neurons will produce ATP and protons, and mast cells will produce histamine, prostaglandin and serotonin. These substances will stimulate the release of vanilloid-1 receptors, neurokinin A, substance P, and calcitonin gene-related peptide (CGRP) which will stimulate the nocireceptor to cause pain. Furthermore, headaches can also be associated with cerebral oedema conditions. Other literature explains that despite surgery, 36% of meningioma clients can have headache complaints (Benz et al, 2018). In the current study, postoperative meningioma clients who experienced headaches had difficulty in carrying out daily activities. Some individuals also said that their rest periods were disturbed due to headaches.

Patients with meningiomas in the frontal lobes can experience symptoms in the form of impaired concentration, depression, and decreased motivation (Jordan et al, 2018). The results of this study are in line with other studies that found that about 30% of meningioma clients experience depression (Litofsky & Resnick, 2009). Meanwhile, the literature explains that when a person experiences depression, there will be an over-reactive state of the sympathetic nerve, adrenal cortical dysfunction, and inflammation that can underlie changes in the body's biology (Kumar & Nayak, 2017). Physiological changes that occur with depression made the postoperative meningioma clients in this study feel sad, thereby affecting their quality of life. In line with this, literature explains that depressive conditions in brain tumour clients are responsible for about 26% decrease in quality of life and 56% decrease in functional status abilities (Fox et al, 2007).These conditions caused a decrease in the quality of life of the postoperative meningioma clients in this study.

The mean age of respondents in the study sample was 45 years, which was lower than the average age of meningioma clients in other developing countries (Deltour et al, 2016; Drewes et al, 2016). In this study, older clients had poorer quality of life. These conditions can be analysed based on the results of previous studies on brain tumour clients in the same place, whereby younger clients experience an increase in their ability to mobilise, care and fulfil their daily needs, as compared to older clients, and this will affect clients' quality of life (Ganefianty et al, 2019). These results are in line with some existing literature. In several studies that have been conducted, age is considered to be one of the factors that affect the quality of life of meningioma clients (Miao et al, 2010; Tsay et al, 2012; Poon et al, 2014) .

Tumour grade is a factor related to the quality of life of postoperative meningioma clients. Signs and symptoms experienced by meningioma clients are highly dependent on the level of meningioma (Raizer, 2011). For example, if an individual has grade II meningioma (as per WHO) affecting the optic nerve, the clinical manifestation that occurs is loss of vision, even though surgery has been performed on the person (Alkemade et al, 2012). A systematic review explains that the grade of meningioma can affect the rate of recurrence among clients. Recurrence rates range from 0.00 to 2.36 per 100 people per year for WHO grade I meningiomas and 7.35 -11.46 per 100 people per year for WHO class II meningioma, which will certainly affect the quality of life of clients(Lam Shin Cheung et al, 2018).

Functional status and fatigue are physical factors related to the quality of life of meningioma clients (Bunevicius et al, 2014; Tankumpuan et al, 2015). In this study, functional status was the dominant factor associated with quality of life. This happens because clients who have functional dependence status will have problems in the domains of self-care and usual activities at various levels of quality of life. The worse the condition of the functional status, the greater will be the disturbances to the quality of life of meningioma clients. For example, clients who are dependent for mobilisation, eating, bathing, or dressing are considered to have a poorer quality of life than independent clients (Tsay et al, 2012). The same is true of fatigue. The results showed that higher levels of fatigue will further worsen the quality of life of meningioma clients (Tankumpuan et al, 2015).

Illness perception is also related to the quality of life. This is supported by the results of a meta-analysis study which explains that illness perception has an important role in causing symptoms of distress and emotional conditions that affect the physical health of cancer clients (Drewes et al, 2016; Krok & Telka, 2018). Social support has a relationship with quality of life because it has a positive impact on the body's immune system. A cross-sectional study that examined the relationship of social support with levels of lymphocytes and cytokines, involved 232 samples and the results concluded that there was a relationship between social support and the immune system, as samples that had low social support increased CD8 + CD57 + and TNF-◎ lymphocyte levels significantly (Copertaro et al, 2014).

Limitations

The findings of the present study have some limitations. Despite being a multicentre study, purposive sampling and the relatively small sample size limit the generalisability of the study. Also, almost all the clients were accompanied by their families when filling in the research questionnaire and the social support questionnaire. This could lead to bias when answering questions about social support.

CONCLUSION

Factors related to the clients' quality of life were age, tumour grade, functional status, fatigue, illness perception, and social support. Multivariate test results demonstrated that functional status factors are the dominant factors related to the quality of life of postoperative meningioma clients. Nursing assessment and discharge planning were carried out regarding factors related to the quality of life of postoperative meningioma clients.

The results of the current study can be referred to in the development of nursing assessments of meningioma clients based on predictors of quality of life which include age, tumour grade, functional status, fatigue, illness perception, and social support. Subsequently, nurses can take preventive measures against the quality of life problems that might occur in post-operative situations. In addition, the study findings can be used for developing a discharge planning programme and a neuro-restorative treatment unit that is intended for postoperative meningioma clients. The restoration unit can function as a unit to optimise client independence. Nurses should develop an appropriate nursing rehabilitation programme for the recovery of postoperative meningioma clients. A nursing rehabilitation programme, from 3 months to 1 year after surgery, is needed for meningioma clients.

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The authors declare there is no conflict of interest.

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Academic Outcomes and Coping Mechanisms of Children using Cochlear Implants in Mainstream Schools in Kerala, India

Anju George[1], Jeena Mary Joy[2*], Sita Sreekumar[3]

1. MASLP Student, Department of Audiology and Speech Language Pathology, National Institute of Speech and Hearing, India, Trivandrum, Kerala, India
2. Asst. Professor, Department of Audiology and Speech Language Pathology, National Institute of Speech and Hearing Trivandrum, Kerala, India
3. Sr. Lecturer, Department of Audiology and Speech Language Pathology, National Institute of Speech and Hearing, Trivandrum, Kerala, India

ABSTRACT

Purpose: *The aim of the present study was to understand the academic outcomes of children using cochlear implants in mainstream schools in Kerala, India and to explore the compensatory strategies used by them to overcome the difficulties faced in classrooms.*

Method: *Thirty-one children using cochlear implants who were attending first and second grades in mainstream schools, and their parents and teachers participated in the study. Teachers were asked to rate a questionnaire, "Teachers' Perceptions of Academic Outcomes", which consisted of five sections – oral comprehension, oral expression, reading, writing and mathematics. The performance of the children using cochlear implants was compared with the performance of typically hearing children in the class. The grades obtained in the previous examination were also used for the comparison. Information was collected regarding difficulties faced by the children inside the classroom and their strategies to overcome the challenges.*

Results: *The class teachers rated the performance of 71 % of these children as 'above average'. Though the academic outcomes were found to be good on the questionnaire and classroom tests, most of the children with cochlear implants faced various difficulties and had used different compensatory strategies to give their optimum performance in the classroom.*

Conclusion: *The study emphasizes the importance of having mid- and long-term follow-ups with children using cochlear implants, even after mainstreaming. It*

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[*] **Corresponding Author:** Jeena Mary Joy, Asst. Professor, Department of Audiology and Speech Language Pathology, National Institute of Speech and Hearing, Trivandrum, Kerala, India. Email: jeena@nish.ac.in

is necessary to orient and train teachers about the needs of these children and to implement support strategies in mainstream schools.

Key words: *children with cochlear implants, academic outcomes, teachers' perspectives, integrated school setting*

INTRODUCTION

A solid foundation in speech and language skills is an important pre-determiner for achieving good academic outcomes (Geers, 2003). Children with severe to profound hearing loss lag behind their typically hearing peers in the acquisition of auditory skills, oral language and speech skills because of their inability to hear speech sounds in their daily life (Zanjani et al, 2013). Hearing impairment may also lead to an inability to interpret speech sounds, and subsequent impairment in spoken language acquisition and literacy development. This affects the literacy acquisition and academic development of children with hearing loss and remains a challenge.

Since the 1980s, cochlear implantation has been an effective management option for individuals with severe to profound hearing loss. Children with cochlear implants (CIs) show significant improvement in speech perception, speech production, language, literacy development (Sarant et al, 2015) and cognitive abilities (Mosnier et al, 2014). Many studies report on the efficacy of CIs in terms of speech perception and production, language, and social development (Tobey et al, 2003; Farinetti et al, 2015; Lund, 2016).

Language Comprehension

Many studies have documented gains in language comprehension of children using CIs. A review of 12 articles comparing children with pre-lingual deafness who use hearing aids and children with CIs concluded that children using CIs achieved better results in speech perception and linguistic development than children using hearing aids (Bittencourt et al, 2012). Studies that compared language abilities of children using CIs with typically hearing children evidence that children with CIs performed within one standard deviation of the typically hearing children on measures of language comprehension (Spencer et al, 2003).

Expressive Language and Literacy

Spoken language competence is now possible for many children who receive

CIs along with appropriate habilitation (Geers et al, 2009). The rate of language development in children after implantation was found to be similar to that of children with typical hearing (Svirsky et al, 2000; Tomblin et al, 2005). Speech intelligibility was also found to be better in children using CIs as they produced significantly fewer phonetic and phonological errors when compared with children using hearing aids (Baudonck et al, 2010). However, some studies also report that children with CIs lag behind their typically hearing peers in several aspects such as expressive sentence formulation, lexical semantics and meta-phonological processing (Spencer et al, 2003; Schorr et al, 2008) and syntax (Geers et al, 2009).

Geers & Hayes (2011) have documented language-based factors necessary for successful literacy development which includes phonological processing skills, vocabulary knowledge, syntax and discourse skills. Children using CIs have been found to have significantly poorer phonemic awareness, which compromised their reading skills (Dashtelei et al, 2015).

Writing

Vocabulary knowledge, syntax, and phonological skills are important prerequisites for developing good writing skills, and children with hearing loss lack these skills (Marschark et al, 1994). Use of CIs has been shown to improve the writing skills of children with deafness. Children using CIs obtained above average scores for writing when compared with typically hearing children (Sarant et al, 2015), but used fewer words, had immature writing patterns (Spencer et al, 2003) and poorer spelling and expository writing skills (Geers et al, 2011).

Mathematics

Mathematics is known to be influenced by language skills. General verbal ability affects how children understand and reason with numbers, and phonological decoding is directly related to arithmetic performance as storing and retrieving numbers from memory is essential for solving mathematical problems (Vukovic & Lesaux, 2012). Studies reporting the mathematical abilities of children using CIs are scarce and the existing evidence is varied. Findings include a less than 10% performance gap between children using CIs and typically hearing children (Thoutenhoofd, 2006; Motasaddi-Zarandy et al, 2009) and, on the contrary, poorer mathematical skills than typically hearing children (Sarant et al, 2015) and low scores in both mathematics and geometric reasoning tasks (Edwards et al, 2013).

Most of the existing research studies on academic outcomes of children with CIs use standardised tools in the areas of oral language, reading, writing, and mathematics. Such standardised tools cannot be used in India because of differences in curriculum and language of instruction across different schools. Standardised tests can also be insensitive to small changes in performance (DuPaul et al, 1991). Teacher rating of students is more suited for use in India and may provide a more representative sample of academic achievement. A wider range of information can be obtained using a Teacher Perception Rating Scale, as teachers are able to directly observe student performance in a more comprehensive way based on academic content.

Cochlear Implant Programme in Kerala

The Kerala State Government has a fully funded cochlear implant project aimed at providing cochlear implantation for children between 1 - 3 years of age who meet specified income guidelines. The project started in 2012 and more than 900 children have received implants through the programme. The programme covers the cost of the CI, implantation surgery and auditory habilitation for 2 years. Approximately 70% of the children, who received implants between 2012 and 2014, attend mainstream schools which are government-funded state-run institutions.

Schooling System in Kerala

Kerala State has the highest literacy rate in India and education is given prime importance. There are private sector schools as well as public sector schools which differ in terms of the language of instruction (English vs. Malayalam), curriculum, and assessment methods. The private sector schools use an assessment scheme, where the children are assigned marks based on their performance in exams which are conducted periodically. On the other hand, the public sector schools use a grading system based on the child's performance in the exams (the marks scored in exams are converted into grades from A to E, which are specified based on the range of marks).

There is no evidence-based research on academic outcomes of children with CIs in the Indian context. It is imperative to study the academic outcomes of children using CIs in a developing country like India, as findings from developed countries cannot be generalised due to cultural and educational differences. The present study provides insight into academic areas of difficulty within the local context, and help to formulate appropriate remedial strategies and school support systems to assist children with CIs.

Objectives

The primary objective of this study was to answer the following questions:

- Do children using CIs perform on par with their peers in an integrated school environment, as perceived by their teachers?
- Is there agreement between their functional academic performance (teacher ratings) and their grades, which is the predominant scholastic assessment method in India?
- What are the challenges faced and the strategies used by children with CIs to cope with their listening and communication difficulties in the classroom?

METHOD

Participants

This study adopted a convenience sampling method. The list of all the children who had cochlear implantation done was obtained from various early intervention centres in five districts of Kerala. All those who met the inclusion criteria (children with no other disabilities and those who were given implants before five years of age) were included in the study.

A total of 31children using cochlear implants and their teachers and parents participated in the study. All the children (15 boys and 16 girls) were integrated into mainstream classrooms and were students in first and second grades across five districts in Kerala State. The language of instruction at school was Malayalam (for 15 children) and English (for 16 children). Audiological profiles of the children are provided in Table 1.

Table 1: Audiological Profile of the CI Users

	M (months)	SD (months)
Chronological age	90.16	8.2
Age of diagnosis	15.2	2.1
Age at hearing aid fitting	20.6	1.4
Age at implantation	44.8	9.3
Duration of implant use	45.3	7.5
Duration of intervention	38.06	11.1

Information about family income and parental education, which are contributing factors to student success, was collected through parental interviews. The average number of years of maternal education was 12.1 years, (range - 7 to 17 years), and the average monthly income was Rs.8383.8 (range -Rs.300 -100000).

Procedure

Development of the 'Teachers' Perception of Academic Outcomes' (TPAO) questionnaire was done to study the academic outcomes of children using cochlear implants. Item generation was done after a rigorous literature review and based on suggestions provided by several audiologists and speech language pathologists working in the area of rehabilitation. Studies focusing on various domains, namely language skills, literacy, reading, writing and academic skills of children using hearing aids and cochlear implants, were reviewed for item generation (Marschark et al, 2007; Sarant et al, 2015; Harris et al, 2017). The items were divided into five domains - oral comprehension, oral expression, mathematics, reading, and writing. Under each item, the possible difficulties and strategies that could be used by the teachers and students were also listed. The generated items were given to a linguist for item wording.

The selected items were reviewed for face and content validity by 5 Audiologists and Speech Language Pathologists (ASLP) with a Master's degree and more than 5 years of clinical experience. All the ASLPs were briefed about the aim and procedure of the study. They rated each item on a 5-point Likert Scale, based on the relevance of the item, appropriateness of language used, grammar, comprehensiveness, and appropriateness of the scaling used in the questionnaire. Only those items rated as relevant by 70% of the professionals were considered for the final questionnaire. Item reduction, sequencing, and modifications were done while keeping in mind suggestions from the experts. The final questionnaire consisted of 29 items that used a 5-point rating Scale (1 – Poor; 2 - Below average; 3- Average; 4- Above average; 5- Excellent) with a total possible score of 145.

Data Collection

The purpose of the study was explained to the participants and informed consent was obtained from the teachers and parents of children. Basic demographic details and audiological profile of the children were obtained through a parent interview by the first author.

TPAO was administered on the teachers by the first author using a face-to-face structured interview format. Teachers were asked to rate the performance of children with CIs on each item compared to hearing children in the same class. The teachers had taught their respective students as class-in-charge for more than six months. This ensured that they could give reliable information regarding their wards. The difficulties faced and the strategies used by children and/or the teachers to cope with the challenges were probed during the interview. Teachers were further asked to list out other difficulties or strategies used by the children or teachers, apart from the ones listed in the questionnaire. Additionally, marks obtained by the child for the previous class exams were also collected. To bring uniformity in the scoring system, the grades were converted back to the respective marks. The grades were assigned based on a range of scores; hence the median score of this range was considered as the student's marks.

The domain-specific scores and total score from TPAO were converted into a percent score for the ease of comparison with academic marks. The converted TPAO percent scores were categorised as poor (0 – 20%); below average (21-40%); average (41 – 60%); above average (61 -80%) and excellent (81 – 100%).

RESULTS

The results are presented in three domains: academic performance, agreement between TPAO scores and academic marks, and challenges and strategies used by children and their teachers.

Academic Performance

The means and standard deviations of the scores obtained by the children in each of the domains of TPAO are shown in Table 2. The results reveal that the mean performance score in each domain and the overall performance score is above average.

Table 2: Mean and Standard Deviation of the Domain-specific Scores

Domain	Mean (%)	SD
Oral comprehension	71.6	15.15
Oral expression	67.6	13.53
Reading	60.1	17.24
Writing	69.89	16.78

Mathematics	71.33	17.38
Overall	68.77	14.80

The percentage distribution of scores across the components of TPAO is shown in Table 3. The Table shows that most of the children are in the 'above average' category and only a small percentage of children fall in the 'below average' category.

Table 3: Distribution of TPAO Scores across the Subcategories of TPAO

Percent Score on TPAO	**Criteria**	**Percentage of Children**					
		Comprehension	Expression	Reading	Writing	Mathematics	Overall
0-20	Poor	-	-	-	-	-	-
21-40	Below average	-	3.2	9.6	3.2	3.2	-
41-60	Average	22.5	16.1	35.4	22.5	22.6	29
61-80	Above average	41.9	54.8	32.2	38.7	38.7	45.2
81-100	Excellent	35.4	25.8	22.5	35.4	35.5	25.8

Agreement between TPAO Scores and Academic Marks

The mean and standard deviations of TPAO scores and academic marks are shown in Table 4. The Spearman's rank correlation coefficient of 0.94 indicates a strong correlation between the academic marks/grades and TPAO scores.

Table 4: Mean and Standard Deviation of TPAO Scores and Academic Marks

	Mean (%)	**SD**	**Correlation Coefficient**
TPAO scores	68.77	14.80	.94[*]
Academic marks	71.07	17.99	

[*] Correlation is significant at the 0.01 level

On assessment of internal consistency, Cronbach's alpha of 0.97 was achieved, suggesting that the TPAO is a valid tool for assessing the functional academic performance of children using CIs.

Challenges and Strategies

The difficulties faced and the strategies used by children with cochlear implants in mainstream schools were compiled through the TPAO interview. The results are summarised in figures 1, 2 and 3.

Figure 1: Compensatory strategies used by teachers and children to facilitate oral comprehension

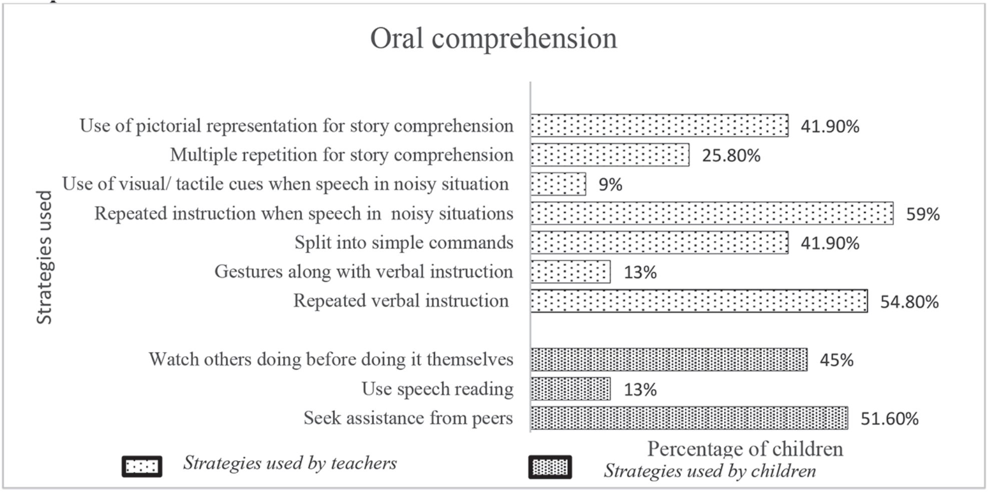


Figure 2: Compensatory strategies used by teachers and children to facilitate oral expression

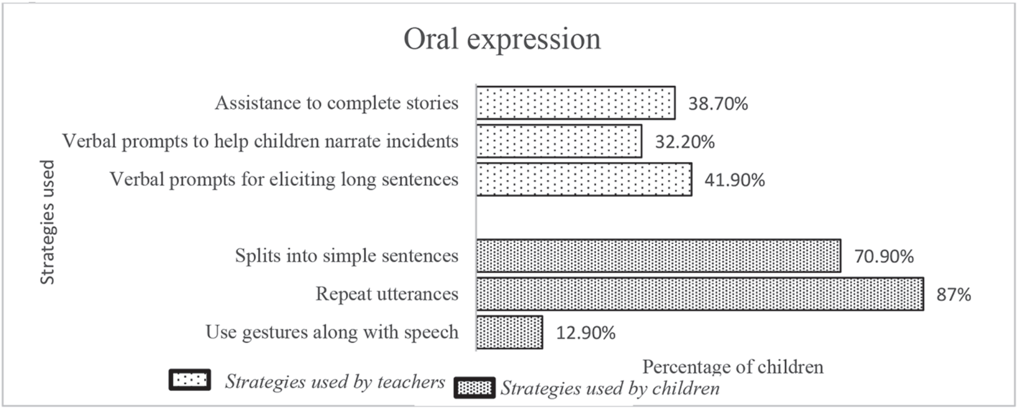
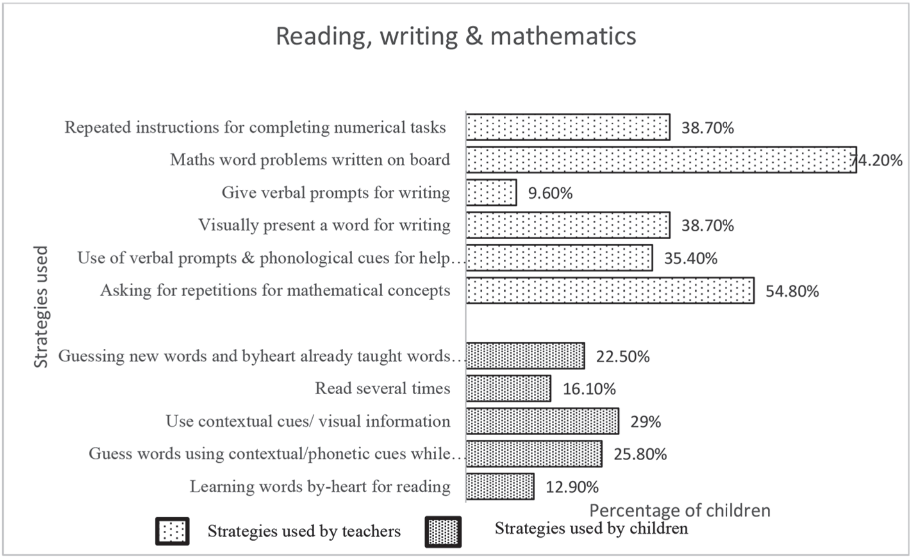


Figure 3: Compensatory strategies used by teachers and children to facilitate reading, writing and mathematics



Oral Comprehension

The mean score obtained for oral comprehension was 71.6 (SD = 15.15). Although 77.3% of children scored ‘above average’ or ‘excellent’, they faced various difficulties in the classroom situation. Only 29% of children were able to understand and organise tasks in response to complex instructions given in class, without any repetitions. Hence, 35.4 % of these children had difficulties following class content and lessons, and often missed concepts as they were not able to follow at the same pace as their peers. In order to overcome these problems and facilitate learning, both teachers and students used various compensatory strategies.

Strategies used by Teachers and Children

For 54.8% of the children, teachers repeated the verbal instructions and for 13% gestures or visual cues were also provided along with simple verbal instructions. Multi-step commands had to be split for 41.9% of children, 59% of children required repetitions and 9% required additional visual/tactile cues in noisy situations. Stories are the most important part of the academic curriculum for first and second grade children; however, 41.9% of children required pictorial representations to understand the whole story while 25.8% of children required multiple repetitions for story comprehension.

Children with CIs also used strategies to cope with their difficulty in following verbal instructions and lessons in the classroom. While 13% of children used speech reading to understand simple instructions, 51.6 % sought assistance from their peers to follow multi-step commands, and 45 % watched what others were doing before doing it themselves.

Oral Expression

The mean score obtained for oral expression was 67.6 (SD = 13.53). Children using CIs faced many difficulties in the classroom situation when conveying their ideas and expressing answers or stories verbally via complex sentence structures. Reduced intelligibility of speech was the major issue raised by most of the teachers. Only a few (13%) of the children had nearly acquired the articulatory skills that their peers had. Along with speech errors, several linguistic aspects were also noted, such as difficulty in constructing complex sentences and narrative skills. While 64.6% of children made syntactic errors in sentences, only 9.6% of children were able to retell a whole story or narrate an incident in correct sequential order.

Strategies used by Teachers and Children

Use of verbal prompts by teachers helped 41.9% of children to construct long sentences, 32.2% of children could narrate incidents with assistance and 38.7% could narrate entire stories. Gestures, along with speech, were used by 12.9% of children and repetition of utterances was necessary for 87% of children to make themselves understood to the listener. About 70.9% of the children had to shorten their sentences to make their ideas clear.

Reading

Teachers reported that 67.7% of children took a longer time to read than their peers and 9.6% of children skipped letters or words when trying to increase the speed of reading. Children using CIs faced severe difficulties in decoding. While 74.1% of children correctly identified all sounds, only 19.3% were able to correctly blend these sounds to form words. Around 29% of children made various errors like omission and substitution of sounds while reading. Since decoding was affected among most of the children, they were not able to read and understand new words. Reading fluency was also affected. Only 29.1% of children could read words with ease, whereas 70.9% took a lot of time moving from one sound to the other, which often reduced fluency.

Strategies used by Teachers and Children

Verbal prompts and phonological cues were necessary for 35% of children to decode and read words. Rather than phonetically decoding words, 12.9% of children memorised words and 25.8% of children guessed the words using contextual or phonetic cues. Contextual cues or pictorial representations were used by 29% of children for comprehending what was read, and multiple readings were required by 16.1 % of children.

Writing

The mean score obtained for writing was 69.8 (SD = 16.78). Children using CIs faced several difficulties although they obtained good scores. While 74.1% of children were able to copy words/sentences without mistakes, 80.6% of children could identify and use upper and lower case letters; however, 25.8% of children had difficulty in following rules for using upper and lower cases. One of the children exhibited the same errors in spoken and written language. Most of the children used proper spacing (74.1%) and good alignment (54.8%) while writing. Although 51.6% of children were able to write at the same pace as their peers, only a few (19.3%) were able to write words without spelling errors. Errors like letter omission (45.1%) and substitution of letters with similar sounding letters (38.7%) were observed by the teachers, while 6.4% of children did not attempt to write new words. About 29% of children were able to construct sentences and use subject-verb order in the right way while writing sentences, but teachers reported that 12.9% of children made incorrect use of tenses while writing and 3.2% included unnecessary morphemes when constructing sentences by themselves.

Strategies used by Teachers and Children

For 38.7% of children to write at the same pace as that of their peers, visual representation of the words was necessary rather than spelling them out. When verbal prompts were given by the teachers, 9.6% of children could write new words.

Children made wild guesses when writing new words (22.5%), while some of them memorised words and wrote words they had already been taught for written tasks. This helped them to score high in first and second grades, despite poor phonological segmentation.

Mathematics

The mean score obtained for mathematics was 71.3 (SD = 17.38). Children with CIs had several difficulties in mathematics and both teachers and children used certain strategies to cope with them. According to the teachers, 41.9% of children were able to complete numerical tasks with the same accuracy and speed as that of their peers. Pre-mathematical skills were reported to be good in these children as 90.3% of them were able to identify basic size differences and 87% knew all basic shapes.

Children using CIs had difficulties in certain aspects of mathematical tasks. Grasping numerical comparison was difficult for 32.2% of children, 35.4% had difficulty with simple addition and subtraction, whereas 25.8% were able to do verbally instructed mathematical problems. They found word problems difficult, as 51.6% of them had difficulty in converting word problems to numerical figures. The difficulty was predominantly due to lack of comprehension of the written instructions. About 29% often had confusion with numerical terminologies which were synonymously used, such as “add,” “plus,” and “combine.”

Strategies used by Teachers and Children

Numerical operations had to be written on the black/whiteboard for 74.2% of children and repeated instructions were required for 38.7% of children to complete their task.

Multiple repetitions were the only strategy used by children (54.8%) in order to generalise the mathematical concepts.

DISCUSSION

In the present study, teachers perceived that 71% of the children were performing above average in all academic domains. Teachers’ assessments of the children with CIs correlated well with their academic grading in exams. This indicated that teachers were aware of their students’ strengths and weaknesses and were contributing to help them cope in the classroom, even though they had no formal training to manage children with hearing impairments in a regular classroom. Furthermore, the good performance by the children can be attributed to their younger age at implantation, duration of auditory verbal therapy and incessant support from the parents and teachers.

Although performance on academic tasks was perceived to be good, children as well as teachers had to use several coping mechanisms and strategies to overcome the challenges in a real-world classroom setting. The need to use coping mechanisms can be due to both extrinsic and intrinsic factors. Extrinsic factors include environmental factors that limit the child’s participation in classroom activities, such as classroom acoustics, seating, and class size. Intrinsic factors include limitations imposed on the child due to the hearing impairment, such as deficient speech perception and language skills, decoding deficits and poor phonological processing skills(Transler & Gombert, 2001; James et al, 2005; Blamey et al, 2006; James et al, 2008, 2009).

An optimal listening environment is critical for young learners and the challenge of speech recognition in noise aggravates with hearing impairment. Many classrooms in India have an average size of 35 or more students, and the mean occupied noise levels in these classrooms have been reported to be 62.1dBA and 65.6dBC, with mean unamplified teacher speech to noise ratio of 10.6dB and estimated reverberation time > 2.6 seconds (double the duration of accepted standards) (Sundaravadhanan et al, 2017). Additionally, most of the classrooms do not use any noise reduction strategies like carpeting or curtains. Despite these extrinsic challenges, it is noteworthy that children and teachers in this study used self-developed strategies to compensate for the lack of any explicit training.

Oral Comprehension and Expression

Oral comprehension and expression is regarded as the most important predictor for academic success (Desjardin et al, 2009; Geers et al, 2009; Von Muenster & Baker, 2014). The use of CIs considerably improves speech perception and production which eventually makes oral language development easier for children with severe to profound deafness (Svirsky et al, 2000; Geers et al, 2009; Bittencourt et al, 2012). Despite good oral comprehension, most of the children and their teachers in this study had to use several compensatory strategies to overcome the intrinsic and extrinsic challenges. The speech intelligibility and the syntactic quality of linguistic output were perceived to be limited in these children. One major factor contributing to these finding in oral comprehension and expression could be the age at implantation. The mean age at implantation for the children in this study was 44 (±9.3) months. Moreover, it is also speculated that these children use predominantly visual rather than auditory modality for language processing, and hence miss out on essential segmental cues for speech and language production. These findings are corroborated by studies which have shown that inflectional morphology and sentence comprehension are poorer in late implanted children compared to early implanted children (Lopez-Higes et al, 2015). It may be beneficial to work on generalisation of auditory and language-based tasks in a noisy environment during the early intervention programme, in order to increase success in noisy school classrooms.

Reading, Writing and Mathematics

The different types of difficulties perceived by the teachers for reading and writing can be directly attributed to the limitations in phonological processing abilities, morphosyntax, vocabulary knowledge and integration of auditory and visual inputs (Vermeulen et al, 2007; Weiss et al, 2013; Dashtelei et al, 2015). Mathematics is often explained using complex verbal descriptions (Nunes & Moreno, 2002) and analogical reasoning is a significant prerequisite for achieving good mathematical skills. Language measures have been found to be significant predictors of verbal analogical reasoning (Edwards et al, 2010). Thus it is assumed that the limitations in mathematical skills of children using CIs arose due to the lack of understanding of the complex language used in mathematics and from language deficiencies leading to hampered verbal analogical reasoning.

Implications

Children with CIs may need additional accommodations and support to reach their full potential. The type and frequency of services needed will vary across children and time. It may be beneficial to organise programmes to train and orient teachers regarding the needs of children with CIs and what they can do to optimise learning in the classroom. Professionals involved in the rehabilitation of children with CIs should support mainstream teachers to implement the above strategies in classrooms. They should also be educated about the importance of classroom acoustics, environmental modifications and the use of assistive listening devices like FM systems for better speech perception in noisy classroom settings.

In addition to teacher training, students with hearing impairments should be provided with preferential seating close to the teacher and away from sources of noise in the room. Low-tech options for minimising classroom noise should be considered in order to improve the signal-to-noise ratio in the room. Where possible, FM systems should be utilised to overcome the challenges of noise and distance so that children are better able to hear the teacher.

Regular follow-ups should be planned to assess higher language abilities and academic development as children grow older. Children who face little or no challenge in the lower grades may have problems as their curriculum becomes more challenging. Academic performance can also vary according to individual factors. Therefore, it is essential for the professionals involved in aural rehabilitation to monitor each child on a regular basis. Active communication is required between audiologists, teachers and parents of children with CIs to know their challenges and take corrective measures.

CONCLUSION

The basis for all the difficulties faced in the academic development of children using CIs is their inability to acquire adequate auditory, speech and language skills. In a developing country like India where cochlear implant programmes are in their infancy, future goals need to be targeted on developing and stabilising the use of auditory verbal intervention strategies and outcome assessments. School-based support systems for children who are mainstreamed should be implemented to enhance the middle and long-term outcomes of children with CIs.

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Training of Mid-Level Rehabilitation Workers for Community-Based Rehabilitation Programmes

Ritu Ghosh[1*], Vennila Palanivelu[1], Emma Tebbutt[1], Sunil Deepak[2]

1. Mobility India, Rehabilitation Research and Training Centre, Bengaluru, India
2. Independent Consultant, Advisor AIFO/ Italy, and ex-head of North-East Regional Office of Mobility India

ABSTRACT

Purpose: *There is a lack of trained rehabilitation professionals, especially in the small towns and rural areas of low and middle income countries. In India, a cadre of mid-level rehabilitation workers, the Rehabilitation Therapy Assistants (RTAs), are being trained by Mobility India, a Non-Governmental Organisation (NGO). This paper aims to assess impact of their training and experiences after the training.*

Method: *Data were collected from 3 different initiatives connected with the trained RTAs: an impact assessment of their training; interviews with RTAs during an evaluation; and a survey of 188 RTAs trained between 2002 and 2019.*

Results: *RTAs were shown to have good skills to provide rehabilitation interventions in the field and are appreciated by clients and other stakeholders. Most of the RTAs work for NGOs in CBR programmes, and in private hospitals and clinics. There does not seem to be a role for them in government services in most countries. The number of trained RTAs remains small in spite of the large needs. This may be due to lack of an accreditation system for RTAs and the low priority given to rehabilitation services in general in some countries.*

Conclusions: *The results provide useful information to strengthen RTA training courses. Training RTAs to provide rehabilitation services in smaller towns and rural areas of low and middle income countries can have a good impact through CBR programmes. However, this impact remains circumscribed to small areas where NGOs are active. Changes are needed in health systems for the inclusion of mid-level rehabilitation workers in primary health care services.*

Keywords: *disability, rehabilitation, mid-level rehabilitation workers, CBR, training, Rehabiltation Therapy Assistants*

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[*] **Corresponding Author:** Ritu Ghosh, Academics Director, Mobility India, Rehabilitation Research and Training Centre, 1st & 1st 'A' Cross, J.P. Nagar, 2nd Phase, Bengaluru 560 078, Karnataka, India. Email: ritugm@mobility-india.org

INTRODUCTION

The World Report (World Bank & World Health Organisation, 2011) estimated that more than a billion people have some form of disability and took note that there is a global lack of rehabilitation professionals. It suggested that "Mid-level training programmes can be a first step to address gaps in rehabilitation personnel in low and middle income countries or to compensate for difficulties in recruiting higher level professionals in high income countries."

The First Expert Committee on Medical Rehabilitation of WHO had taken note that there were not enough qualified lecturing staff to train physiotherapists and occupational therapists in the low and middle income countries (WHO, 1958).

Now, sixty years later, apart from the big cities in the low and middle income countries, the number of rehabilitation personnel remains insufficient to answer the needs, especially in rural areas. A project by the World Confederation of Physical Therapists (WCPT) has provided evidence of variations in numbers of physical therapists across the world, in which the estimates of the ratio of physical therapists to populations range from a high of 1:354 people in Finland, to a low of 1:530,375 in Malawi (WCPT, 2014).

While low and middle income countries have fewer rehabilitation professionals, another challenge is that they are mostly based in the large towns. For example, a study in Vietnam showed that more than 80% of the rehabilitation professionals were employed in big cities and urban centres (Hai & Nhan, 1995). The World Report on Disability also found bigger unmet needs for rehabilitation professionals in rural areas than in urban parts of different countries (World Bank & WHO, 2011).

A WHO study (Anand & Fan, 2016) on the distribution of health workers in India underlined the wide variations in the ratio physiotherapists to population among different states and between urban and rural areas. These surveys count physiotherapists among "other health workers" and do not provide precise data. Studies have reported that there are around 50,000 trained physiotherapists (PTs) in India, which would mean 1 physiotherapist for about 20, 000 people (Sahu & Bharati, 2014).

CBR and Mid-Level Rehabilitation Workers

In 1969, the International Society for Rehabilitation of the Disabled (later renamed Rehabilitation International) took note of the lack of the rehabilitation professionals, more so in low and middle income countries and suggested the preparation of a new type of personnel (Helander, 2007).

The need for mid-level rehabilitation workers was also raised with the introduction of the Community-based Rehabilitation (CBR) approach by the WHO in the early 1980s (Helander et al, 1989). The joint Position Paper on CBR did emphasise the need for referral rehabilitation services through primary health care centres (PHCs): "The health sector needs to make serious efforts to ensure that rehabilitation is part of PHC" (ILO, UNESCO & WHO, 2004).

Over the past decades, the CBR approach has been adopted in a large number of countries. A survey in 29 African countries showed that in many countries CBR was adopted as the national rehabilitation strategy (WHO, 2004). According to the CBR Guidelines (WHO, 2010), there were CBR programmes in more than 90 countries in the world.

There is ample evidence about the effectiveness of CBR for people with disabilities in low- and middle-income countries (Iemmi et al, 2015). Through CBR, the needs of people with disabilities can be met within their environment, with the involvement of family members and the community where the use of highly trained health professionals is ineffective in addressing the magnitude of the problem (Thomas & Thomas, 2003).

However, the lack of rehabilitation professionals continues to be an issue in CBR implementation. The absence of medical rehabilitation reduces the effectiveness of CBR (Nganwa et al, 2013). Without specific rehabilitation personnel, CBR becomes a nice philosophy without having any practical meaning for people with disabilities (Cornielje et al, 2013).

With the wider implementation of CBR programmes, the issue of mid-level rehabilitation workers continues to be raised (Finkenflugel & Rule, 2008; Vuuren & Aldersey, 2018). A systematic review on the role of alternative cadres of rehabilitation personnel in CBR had concluded with a plea for the creation of new cadres of alternative health workers for its implementation (Mannan et al, 2012).

Training of Rehabilitation Therapy Assistants

CBR projects were initiated in various countries in the early 1980s and training of mid-level workers was piloted in South Africa by early 1990 in response to the need to develop community rehabilitation care. It was reported that the training course for a new cadre of mid-level CBR workers or community rehabilitation facilitators (CRF) was introduced in South Africa in 1990. These CRF were trained for two years in community development, which also included social and physical rehabilitation. Trained CRF were registered with the Occupational Therapy Board of Health Professional Council of South Africa, provided professional status and had the opportunity to be employed as therapy assistants within a government set up (Rule et al., 2006, p.274, 275). A similar approach was adopted for mid-level rehabilitation workers from Guyana, where the training of Rehabilitation Therapy Assistants (RTA) was initiated in 1997. The Ministry of Health "created a new category of intermediate level rehabilitation professionals, the rehabilitation assistants, who receive training for 18 months and whose training curriculum contains elements of physiotherapy, occupational therapy and speech therapy" (Deepak, 2007).

When Mobility India started RTA training in 2001-02, it was the only institution in India to offer such a course. Since then, according to a recent report from the Rehabilitation Council of India (RCI, 2019), there are 3 more institutions engaged in providing RTA training courses in the country. In 2007, Nepal started a training programme for rehabilitation assistants, as a basic level technical workforce in the field of physiotherapy and rehabilitation (Council for Technical Education and Vocational Training - CTEVT, 2014).

However, RTAs have a longer history in high income countries where there are intermediate- level rehabilitation professionals such as rehabilitation assistants, who work under the supervision of senior rehabilitation professionals. For example, in the UK, the rehabilitation assistants are junior multidisciplinary grade persons who combine elements from nursing, occupational therapy, physiotherapy and speech and language therapy (Knight et al, 2013). In Canada, they are also referred to as Rehabilitation Assistants (RAs) or Occupational Therapy Assistants (OTAs), and need to a complete a 2-year long diploma course (National Physical Assistants' Assembly - NPAA, 2009).

In Queensland (Australia), the Community Rehabilitation Assistant Workforce Project (CRAWP) was started to answer the needs of a growing ageing population, as workforce shortages, advancing technology and increasing consumer expectations required new models for delivery of healthcare services (Queensland Health, 2008). They also provided additional training to existing rehabilitation professionals, to support the community rehabilitation programme (Knight et al, 2008).

To sum up, over the past 4 decades the CBR approach has been adopted by a large number of low and middle income countries but they lack sufficient numbers of trained rehabilitation personnel. For this, two solutions have been proposed: 1) providing support through PHCs and 2) training a new cadre of mid-level rehabilitation professionals. A recent technical paper by the World Health Organisation (WHO, 2018) again advocates for the inclusion of rehabilitation workers in PHCs, while accepting that most low and middle income countries function with limited resources. For example, in the PHC services in India, rehabilitative and palliative care services are not included (Anant et al, 2016).

While many high and a few low and middle income countries, such as Guyana, India and Nepal, are training RTAs as a mid-level cadre of rehabilitation personnel, there are hardly any published studies regarding this new cadre of personnel from low and middle-income countries and their role in CBR programmes.

Accreditation and Professional Bodies for Rehabilitation Therapy Assistants

Introduction of a new cadre of workers in the health services requires an adequate accreditation system as well as a definition of policies regarding recruitment and career opportunities of the new workers, along with availability of financial resources to cover the additional costs of employing this new cadre. A study from Uganda found that lack of a proper accreditation system for a new category of nursing staff, lack of policies regarding their roles and lack of budget allocation had a negative impact on the introduction of this new cadre of nursing staff (Matua et al, 2013).

An accreditation system also leads to the development of a professional association along with standardisation of roles, competences and training content and duration. While high income countries have accreditation systems for RTAs, none could be identified in any low and middle income countries. Only one professional body of RTAs was identified in Canada, where the rehabilitation assistants organised themselves and were organising an annual national assembly with regular meetings and annual conferences (NPAA, 2009).

Training of Rehabilitation Therapy Assistants at Mobility India

Mobility India is an Indian NGO based in Bangalore, with more than 25 years of experience working with grassroots organisations in community-level programmes. In 2002-03, Mobility India started a one-year training course for mid-level rehabilitation workers designated as Rehabilitation Therapy Assistants

(RTAs), focused on teaching physiotherapy and occupational therapy skills for paediatric and adult conditions common in low-income countries. This training is recognised by the Rehabilitation Council of India (RCI) since 2004.

While planning the training, 3 settings were identified where RTAs might work: 1) in rehabilitation institutions; 2) in community outreach programmes; and 3) in CBR programmes. It was expected that the RTAs' work would be guided and supervised by rehabilitation professionals in rehabilitation institutions and in outreach programmes. However, it was felt that in CBR settings, especially in rural areas, where other rehabilitation professionals were scarce the RTAs would be working independently (Mobility India, 2014).

Overall, between 2002 and 2019, a total of 188 RTAs were trained at the Rehabilitation Research and Training Centre, including 141 persons from India and 47 persons from 11 other countries. During 2013-14, Mobility India was involved in the implementation of a USAID funded project for strengthening the rehabilitation interventions of institutions and rehabilitation professionals in conflict-affected areas in 8 states of east and north-east India. As a part of this project, 19 additional RTAs were trained in 2013-14, taking the total number of students that year to twenty-seven.

Aim

This paper aims to assess impact of training of RTAs and their experiences after the training, in order to elicit information about the importance and challenges of the introduction of this cadre of mid-level rehabilitation worker; and to strengthen and improve the on-going RTA training programme at Mobility India.

METHOD

The study brings together information from three separate evaluation initiatives related to RTAs trained at Mobility India. The methodology of each evaluation is presented separately in the chronological order it was carried out.

a) Methodology of Impact Assessment of 10 years of RTA Training

This assessment was carried out in 2014. It involved interviews with 26 RTAs – 18 from India (working with 9 different organisations) and 8 from Nepal (working with 4 different organisations). The participants were selected through purposive sampling to ensure inclusion of persons working in different geographical and clinical contexts and having a minimum of 1 year of field work experience after the completion of training.

An assessment tool developed by the International Society of Prosthetics and Orthotics (ISPO) was adapted for this purpose, using the RTA training programme competencies as a framework. A mixed-methods (qualitative and quantitative) approach was used to gain a broader understanding of the settings in which the RTAs worked and the challenges they faced. This questionnaire was pilot tested on 2 RTAs.

A written questionnaire was sent to the selected RTAs by email to be filled in. It focused on the following 7 elements of RTAs' work – (i) compiling and updating of clinical records, (ii) carrying out clinical assessment focusing on activities and participation in line with the International Classification of Functioning, Disability and Health (ICF, 2001), (iii) implementation of suitable rehabilitation interventions, (iv) setting up of functional goals with the clients, and their follow-up, (v) teamwork, networking and referral skills, (vi) communication skills, and (vii) professional ethics and development.

This phase was followed by interviews by a study team, composed of one external evaluator supported by two RTA trainers, in 13 different locations in India and Nepal. Five languages (including English) were used during the interviews. The interviews were used to clarify and expand on the answers given in the questionnaire. The additional information was added as notes to the questionnaires. Five (5) clinical records maintained by each RTA were reviewed and the RTAs were asked to demonstrate rehabilitation interventions which they used in their daily work. Each RTA was scored on his/her skills. An assessment framework with three-point rating scale was developed and used based on competencies expected to be achieved after one year of training. All members of the visiting team scored the RTA, basing their scores on all of the data collected throughout the visit, plus general observations during the visit. Scores were compared and for any scores that significantly differed, the team discussed and agreed a score.

In addition, semi-structured interviews with 23 clients or their families receiving services from the RTAs, were conducted to understand their perceptions regarding the quality of services provided by the RTAs. These interviews also touched on any changes in activities and participation of the clients following the interventions based on the ICF. These were audio-recorded and later transcribed.

Finally, the supervisors of the RTAs were sent a questionnaire by email, regarding the RTAs' competencies, and were asked to send it back on completion, in an unmarked envelope. Supervisors were assured that their responses would be kept confidential.

b) Methodology of Evaluation of the USAID Funded Project

The objective of the USAID funded project of Mobility India was to strengthen rehabilitation services in conflict-affected areas in the north-east of India. It involved different non-governmental organisations as local partners. During 2013-14, the project provided scholarships for 19 persons to attend RTA training at Mobility India.

During this project, 3 handbooks on rehabilitation interventions used for RTA training were revised and re-published in English. At the same time, they were also translated and published in 2 regional languages. After the training, each RTA was given a copy of the handbook in their preferred language.

In 2015, an external evaluation of this project was carried out by visiting 7 partner organisations in 5 states. Semi-structured interviews with 6 RTAs were conducted by 2 external consultants. These interviews covered 3 areas: 1) their experience during the one-year RTA training course in Bangalore; 2) their work-related satisfaction, and; 3) the challenges they faced in their daily work. They were also asked about the usefulness of the RTA training handbooks. No one from Mobility India was present during these interviews.

Some of the discussions between the authors and the two external evaluators, as well as the findings from their report related to RTA interviews, are presented in the result section.

c) Methodology of the General Survey among all RTA Graduates

In January 2020, a general survey was carried out through social media, telephone and/or email by Mobility India personnel. An attempt was made to contact all the 188 persons from India and students from the other 10 countries who had completed RTA training at Mobility India between 2002 and 2019.

The main objective of the survey was to understand their present area of work, their employers and whether they had completed other training courses after the RTA training.

RESULTS

This section begins with a description of the results of the general survey of all the RTAs, which provide a broad overview about their work after the completion of RTA training. This is followed by the findings from the impact assessment of RTA training in India and Nepal. Finally, the information collected through the RTA interviews, in the external evaluation of the USAID project in the north-east of India, is presented.

a) General Survey among all RTA Graduates of the training provided by Mobility India

A total of 188 students completed the RTA training between 2002 and 2019. They consisted of 119 women and 69 men. Among them, 20.7% (39 students -15 male and 24 female) were persons with disabilities. Out of the 188 students, 80.3% (151 persons - 98 females and 53 males) responded

The average number of students in the RTA training course each year is 11, while the median value is 8 students. The number of new students admitted each year varied from as few as 2 persons in 2010-11 to as many as 27 in 2013-14. There were some operational reasons for these variations. For example, during 2013-14 the relatively high number of students was due to additional scholarships provided by a USAID funded project. Table 1 presents the annual number of new students.

Table 1: Number of RTA Students each Academic Year at Mobility India

Academic Year	No. of students	Academic Year	No. of students
2002-03	8	2011-12	7
2003-04	10	2012-13	8
2004-05	17	2013-14	27
2005-06	16	2014-15	12
2006-07	15	2015-16	16
2007-08	7	2016-17	9
2008-09	11	2017-18	8
2009-10	8	2018-19	7
2010-11	2		

Geographical Representation of RTA Students

The 188 RTA students came from 12 countries, including India. While the students from India, Nepal and Sri Lanka were both male and female, those from the other countries were either all male or all female.

Of the 119 female students, 93 (78.1%) were from India while 26 (21.9%) came from 8 other countries i.e. Angola, Bangladesh, Ethiopia, Myanmar, Nepal, Sri Lanka, Tajikistan and Yemen.

Of the 69 male students, 48 (69.6%) were from India while 21 (30.4%) had come from 5 other countries i.e. Nepal, Nigeria, North Korea, Somalia and Sri Lanka.

Employment Situation of Female RTAs

Of the 119 female RTAs, 98 persons (82.3%) responded during the survey. Among the remaining 21 persons, 4 (3.4%) had passed away (3 from India and 1 from another country), while 17 (14.3%) could not be contacted. Of those contacted, 58 (48.7%) were working in the disability sector but 40 persons (33.6%) had changed their area of work. Table 2 presents an overview of their work-situation as of January 2020.

Table 2: Survey Results for Female RTAs: Area of Work

Country	Total RTAs	Died	No Contact	Working in Disability	Not Working in Disability
India	93	3 (3.2%)	15 (1.1%)	40 (43.1%)	35 (37.6%)
Other	26	1 (3.8%)	2 (7.7%)	18 (69.3%)	5 (19.2%)
Total	119	4 (3.4%)	17 (14.3%)	58 (48.7%)	40 (33.6%)

Of the 58 persons working in the field of disability, 39 (67.2%) worked in CBR programmes for national or international NGOs. Among the 35 who were no longer working in disability, 14 were now housewives who had stopped working after getting married and all of them were from India.

The data shows that a much higher percentage of women from outside India were engaged in disability- related work as compared to graduates from India. This difference is partly due to the fact that the Indian women stopped working after their marriage. In any case, Fisher's test shows that the difference between the two groups is statistically not significant (two-tailed P value is 0.0511).

Employment Situation of Male RTAs

Of the 69 male RTAs, 53 (76.8%) responded. Among the remaining 16 persons, 1 from India (1.4%) had died while the other 15 (21.8%) could not be contacted. Among the 53 persons who were contacted, 41 (59.4%) were working in the disability sector while the other 12 persons (17.4%) had changed their area of work. Table 3 presents an overview of their work situation as of January 2020.

Table 3: Survey Results for Male RTAs: Area of Work

Country	Total RTAs	Died	No Contact	Working in Disability	Not Working in Disability
India	48	1 (2%)	6 (12.5%)	33 (68.8%)	8 (16.7%)
Other	21	0	9 (42.8%)	8 (38.1%)	4 (19.1%)
Total	69	1 (1.4%)	15 (21.8%)	41 (59.4%)	12 (17.4%)

Of the 41 persons working in the field of disability, 28 (68.3%) worked in CBR programmes either with national or international NGOs.

Among the male RTAs, the percentage of persons still working in the field of disability was much higher in India as compared to those from other countries. However, Fisher's test shows that the difference between the two groups is statistically not significant (two-tailed P value is 0.4337).

Subsequent Higher Education among RTAs

Among all the contacted persons, a total of 26 (17.2%) gained additional educational qualifications after the RTA training.

Of the 98 females who were contacted, 13 (13.3%) obtained additional educational qualifications i.e. 6 in disability-related areas (including 4 who did training in special needs education), 3 in other areas of healthcare and 2 in other general areas.

Of the 53 males who were contacted, 13 (24.5%) obtained additional educational qualifications i.e. 11 in disability-related areas (including 6 who did training in special needs education) and 2 in other areas of healthcare.

Registration with Professional Associations

None of the countries to which the students belonged had a specific professional association for the RTAs, and none of the 151 graduates were registered with any such body. However, 41% of the RTA students from India, working in the disability sector, were registered with the Rehabilitation Council of India, which recognises their professional qualification.

Employment of RTAs

Among the 99 RTAs (58 female, 41 male) who were active in the disability sector, 76 (76%) were employed in community programmes run by NGOs and governments, 14 (14%) were employed in hospitals/clinics, while the remaining 9 (9%) did not specify the type of employers they were working for.

RTAs from only 2 countries (Tajikistan and Sri Lanka), without any additional qualifications, were employed in Government services. In all the remaining countries, including India, the only persons working in Government services were those who had completed additional training courses such as a Bachelor's or a Master's degree in special needs education.

b) Impact Assessment of 10 Years of RTA Training

A total of 26 persons who had completed RTA training at Mobility India were selected through purposive sampling, to ensure geographical representation from different parts and organisations in India and Nepal. They included 18 women (69%) and 8 men (31%), with an average age of 32 years. While 18 of them (69%) were from India, 8 were (31%) from Nepal.

In the sample, 19 RTAs (73%) had been working for 5-10 years while 7 (27%) had work experience of less than 5 years. As many as 21 RTAs (81%) were still working for the organisation which had sent them to the RTA training.

All of them had first filled in a questionnaire, and were later interviewed to assess their knowledge, practical rehabilitation skills and clinical record-keeping.

Professional Practice, Work Settings and Caseloads

While 24 RTAs were working for non-governmental organisations (NGOs), 1 person worked in a private clinic and 1 person had set up her own social enterprise engaged in training women with disabilities. While 23 of them (88%) were engaged in clinical work related to rehabilitation in CBR programmes or referral clinics, 3 (12%) had managerial roles.

Among the 23 RTAs engaged in clinical work, the majority (20 persons) worked alongside other rehabilitation professionals such as physiotherapists, occupational therapists, prosthetic and/or orthotic technicians, as well as with CBR workers, special educators, nurses, doctors and counsellors.

The RTAs provided interventions to an average of 29 clients during a 43-hour working week. They worked with persons who had a wide range of conditions including cerebral palsy, stroke, post-poliomyelitis, spinal injury, intellectual disability, clubfoot and amputations. Only one person reported a specialisation in a single condition (spinal injury). During their work, the RTAs also made referrals to diverse specialised services, among which the most common referrals were those to orthopaedic and neurology departments of secondary hospitals.

RTAs were asked about the interventions most commonly provided to the clients. For them, the most common goal of intervention was to improve activities of daily living. Muscle-strengthening, increasing the range of movement/stretching and developmental exercises were also frequently mentioned. The most observed interventions were impairment-related stretching and strengthening during practical demonstrations and in clinical records.

At the same time, the RTAs reported carrying out diverse activities across the five domains of the CBR matrix, which were interestingly not documented in the clinical records. For example, the RTAs described participation in the following activities: a monthly puppet show to educate women on antenatal care; supporting women who were victims of domestic violence to seek protection and justice through the legal system; referral to vocational training programmes; working with parents and schools to ensure that children with disabilities attend school; fabrication of developmental aids; and, organising cultural events for children with disabilities.

Overall, the rehabilitation skills of the RTAs were at par with or above the expected levels. As a cohort, their strengths were in networking and making referrals, teamwork and communication with clients. The interviews revealed two weak points i.e. lack of confidence in direct communication with other professionals, especially those with higher-level qualifications, and inadequate documentation of their interventions, as seen from assessing the clinical records. Difficulties of communication with other professionals seemed linked with hierarchies at the workplace and perceived lack of status. Documentation of re-assessment of clients, goal-setting and intervention planning were either absent or were often impairment-focused only, and lacked information regarding activity and participation.

Clinical Supervision Support at the Workplace

Of the 23 persons engaged in clinical work, 20 RTAs (86.9%) had a designated clinical supervisor and 3 (13.1%) were supervised by a non-clinical manager or director. Their supervising professionals included physiotherapists, speech and language therapists, nurses, special educators, and occupational therapists.

Twenty-one RTAs (80.7%) also supervised other persons, including physiotherapy and RTA students, volunteers, CBR workers, social mobilisers and special educators. They all reported being able to seek advice on complex cases, and gave examples of seeking advice from doctors, physiotherapists, occupational therapists and prosthetic/orthotic professionals, among others. Thus, the majority of the RTAs were part of a supportive network and were not left to fend for themselves.

Professional Development Plans

None of the RTAs had a formal professional development plan. When asked, 25 of the 26 RTAs reported that they needed more professional development opportunities, including training, to improve their clinical skills. The expressed needs were broad and included areas such as applying course work, improving documentation skills, getting experience in other development sectors, and learning skills about specific disabling conditions.

After the completion of RTA training, about 50% of them had participated in some formal learning activity, including physical or correspondence courses. Several RTAs cited high cost as a barrier to accessing formal learning opportunities. Only 5 of them reported that they had taken part in research activities within their organisation.

Almost all the RTAs from Nepal raised the issue of lack of official recognition for their training and its negative impact on their employment opportunities.

Feedback from the Supervisors

Overall, there was very positive feedback from supervisors regarding the work of RTAs in various areas including networking, teamwork, professionalism and communication skills. Of the 25 supervisors, 24 (96%) said that the skills learned during the RTA training had fully prepared them for working in the disability sector, while 16 of them (64%) said that they would recommend the RTA training to other organisations.

Feedback from Clients

The overall feedback from the 23 service-users and/or their families was positive.

The open-ended questions enabled investigators to gather qualitative data regarding the experience of clients with their RTAs. For example, one service user said:

> *"She plays with the children and treats us with respect. She speaks in a friendly way. She comes every week even when we are sick."*

Another service user described her experience:

> *"He teaches me and my family members on how to carry out the therapy techniques. He has very good attitude and communication skills. He has a good smile."*

Yet another service user shared his experience:

> *"We were frightened to go for surgery. He (the RTA) persuaded us that it was the right thing to do. He explained about exercises after surgery and if we don't do those exercises, it will go back to the same condition and the surgery will be a waste."*

According to the clients, most RTAs have made them aware of different local community-, medical -and education - services and, in some cases, assisted them in gaining access to these.

A few gaps also emerged from the feedback of clients. For example, the majority of clients felt that the RTAs did not help them to better understand their rights. One service user explained,

> *"She has only explained to me about the ID card but not about any other services."*

Approximately 50% of the clients did not have a proper understanding of their disabling condition. Other areas for improvement included ensuring that clients understand the services available to them and providing information about the prevention of complications. Overall, there was poor awareness of prognosis among the clients.

Almost all the clients (22 out of 23) reported improvements in functioning at the activity and/or participation levels, following the interventions of the RTAs. For example, a young woman explained that she had enrolled in a vocational training programme and subsequently gained full-time employment as a bookkeeper. Parents of a child with cerebral palsy explained that he had learned how to dress and wash himself and, after provision of a wheelchair, started attending school, moving independently within the community and had even competed in a National Para-Olympic sports event.

c) Findings from RTAs during External Evaluation of the USAID Project

The USAID project had provided scholarships for 19 persons from the north-eastern part of India to attend the RTA training course in Bangalore during 2013-14. During the external evaluation carried out in 2015, six of those RTAs were interviewed by 2 external consultants, without any staff member of Mobility India being present.

The interviews confirmed the findings of the RTA assessment carried out one year earlier and showed that all the 6 RTAs were engaged in providing clinical rehabilitation support to persons with disabilities referred by the CBR workers from the field. They also took part in supervision and training of CBR workers and participated in field activities related to other domains of the CBR matrix. Discussions with their employers showed that they were satisfied with the work of RTAs.

The opinions of the 6 RTAs were sought regarding the 3 new handbooks prepared by Mobility India for the RTA training during the USAID project. They felt that the books were relevant to the needs of RTAs in the field, and the language was simple and easy to understand. According to them, the different types of disabilities and the related interventions were explained in such a way that they could be used as a reference text at the community level to provide advice and interventions for persons with disabilities. They felt that having the handbooks in the local languages greatly facilitated their usefulness.

One of the RTAs described her situation:

> *"The scholarship for becoming RTA was a good opportunity for me, because my family did not have money to send me for any training. I like the work I do, and I am very happy when families recognise and appreciate my work. However, RTA is not like a physiotherapist. I can't work in a hospital, I can only work with NGOs."*

They also provided important feedback regarding some of the limitations of the RTA training. The most important challenge they had experienced during training was with regard to the limited opportunities for practical training. Practising hands-on skills on persons with different disabling conditions was difficult and limited as there were many students. Thus, RTA students were often told to practise on each other, which did not give them the experience gained from practising on persons with different disabling conditions.

Another challenge was that the RTA training was focused on clinical skills related to rehabilitation, while in the NGOs where they worked they were asked to carry out additional activities related to CBR such as organising self-help groups, for which they had received no or limited training.

A third challenge was related to the sustainability of their roles. During their training and the subsequent placement in the NGO, they had received a 'trainee stipend' from the USAID project budget. However, many of the NGOs did not have sufficient funds to continue to provide similar amounts as salaries to them after the project-funding ended.

The evaluation report concluded that "RTAs serve an important function in CBR settings. They assess persons with disabilities, set treatment goals, counsel families, select and carry out appropriate interventions, recommend home adaptations, and facilitate the utilisation of local resources for the integration of persons with disabilities in education, work and community. More than 90% of these RTA trainees come from rural settings where they are the first (and often only) resource available for families of persons with disabilities."

DISCUSSION

The three investigations into the roles and challenges of RTAs trained at Mobility India together provide complementary information that can be useful for improving and strengthening the current RTA training courses. At the same time, they point to the complexities and challenges of introducing a new cadre of mid-level rehabilitation workers into the healthcare systems of countries where community rehabilitation services have a low priority.

Apart from the general survey, for which students from different countries were contacted, the other 2 investigations focused only on students from India and Nepal. Thus, the findings from this exercise and the following discussion refer mainly to India and, to a lesser extent, to Nepal.

Role of RTAs in CBR Programmes

All the 3 investigations confirmed the importance of RTA training courses in preparing a cadre of workers capable of supporting CBR programmes, specifically through provision of clinical rehabilitation services and identifying needs for referral support. Globally, almost 68% of the contacted RTAs were working in CBR programmes.

Information for Improving RTA Training

Collecting qualitative information from different stakeholders – RTAs, their clinical supervisors and clients - provided an opportunity to understand the needs in the field and modify the RTA training programme so that it would respond better to those needs expressed by various stakeholders.

An analysis of the collected information raised issues in 2 kinds of training needs i.e. (i) training needs related to clinical rehabilitation competencies, including documentation and record-keeping; and (ii) training needs related to working within different domains of the CBR matrix.

With respect to the clinical rehabilitation competencies, an important step taken by Mobility India was the preparation of 3 handbooks in local languages, which helped the RTA students to learn better and to use those handbooks for reference whenever they encountered certain specific conditions in the field. Coming from different parts of India and the world, for most of them English was a second or third language, while most of the RTA training was in English. Thus, having easy-to-understand learning materials in their local languages became a significant facilitating factor for these students.

Mobility India has also designed a trainer's guide to being used in conjunction with the handbook, that is to be used by trainers of RTA students. This guide is meant to help new lecturing staff to develop their teaching skills, and it also guides trainers on how to assist students to understand the practical issues they will encounter when working in the field.

The issue of strengthening rehabilitation competencies was raised both by RTAs working in clinical services in hospitals and clinics, as well as by persons engaged in CBR programmes. However, since the RTA training is a one-year certificate course and cannot be compared to a Bachelor's degree course in physiotherapy or occupational therapy, there may have been some unrealistic expectations regarding the graduates, both from the employers as well as from the students.

Another area of weakness was related to goal setting and selecting and providing interventions which improve activities and participation in line with the ICF, as activities of RTAs often focused on impairments only. This bias is probably related to the short duration of the training course, new lecturing staff being less familiar in practising the ICF model, along with limited experience in ICF-based goalsetting and interventions.

The second area of training needs,related to working within different domains of the CBR matrix, poses different challenges because it is a wide area encompassing education, livelihood, social participation and empowerment. For example, the interviews with the clients highlighted and contextualised areas for improvement in the RTA training in providing information about rights, entitlements and different specialised services. Whether a module on these aspects can be added to the RTA training curriculum needs to be explored.

The discussions about the lack of rehabilitation professionals in low and middle income countries and the need for introducing mid-level rehabilitation workers to support community rehabilitation programmes, focus mainly on the needs for clinical rehabilitation. The RTA training course under Mobility India focuses on clinical skills. Such a focus works well for RTAs who find work in hospitals or clinics, where they are placed alongside other rehabilitation and health professionals. On the other hand, CBR programmes which employ the mid-level rehabilitation workers are looking for persons who may have broader and additional skills in different domains of the CBR matrix.

These two groups of persons who come for RTA training –those who are going to work in clinical rehabilitation in clinics and centres, and those who are going to work in multi-sectoral CBR programmes - have many common learning areas, but they also have some specific learning needs, which can and should be made more explicit at the beginning of the RTA training. While maintaining the focus on clinical skills, RTA training can also consider the possibility of additional learning on holistic understanding of the CBR matrix.

The external evaluation of the USAID project revealed the concerns of the RTA students in getting sufficient opportunities for practising clinical skills. It is likely that the sudden increase in the number of RTA students during 2013-14 (there were 27 students compared to the average of 11 students per year), might have created this difficulty. Thus, the trainers at Mobility India need to consider the optimum number of students who can receive adequate opportunities for practical training along with sufficient exposure to working with people with disabilities and their families.

Lack of Professional Development of RTAs

Though the RTA training course is recognised by RCI in India, only about 17% of the students did follow additional training. This low level of professional development among RTAs is probably linked to their origins from rural areas and the fact that they come from resource-poor families.

The issue of financial constraints faced by NGOs working in rural areas was also highlighted in the evaluation of the USAID funded project. Findings showed that NGOs employing graduates did not have sufficient resources to pay for these RTAs once project funds were finished.

Another reason for the low professional development of RTAs might be lack of proficiency in English, which is also related to their resource-poor family backgrounds. Most professional training courses in India, including the RTA training course, are offered in English. To help persons from rural areas, they are given additional English lessons during the RTA training courses, and the trainers from Mobility India provide some extra lessons in their regional languages. However, this may not be sufficient to increase their English proficiency and subsequently, this may hamper their learning.

Limited Number of RTA Students

As shown from the literature review, there is a lack of rehabilitation professionals in smaller towns and rural areas of low and middle income countries. According to a news report from 2017, India had about 1 physiotherapist for 10,000 people. Since most of them live in bigger cities, the actual ratio would be much worse in smaller towns and rural areas. Although a larger number of RTA students from India might have been expected to be trained, yet the annual number of students has been very small over the past 2 decades. This could be linked to their lack of access to government jobs.

RCI registration entitles RTAs to practise as rehabilitation professionals/personnel in any part of India. However, it does not allow them to apply for the roles of rehabilitation professionals in Government hospitals; this requires a degree in physiotherapy or occupational therapy. In fact, the survey showed that the only Indian RTA students working in Government services were those who had gained additional qualifications such as a Bachelor’s degree in special education. All the remaining RTA students without additional qualifications were working in CBR programmes or in private hospitals and clinics.

India has had pilot disability programmes in some districts where these RTAs can be employed. However, these are limited to a few areas and have not been expanded. This situation can be contrasted with Guyana, which has a total population of less than 1 million persons. There, an RTA training course of 18-months duration was started in 1997 and, on average, there are 20 students in each course. These trained RTAs easily find employment in Government service, as mid-level rehabilitation workers are a recognised cadre within health services at regional and provincial levels (Maison Halls, 2019). Thus, to convince policy makers that RTAs can play a meaningful and much needed role in addressing the rehabilitation needs of people with disabilities, serious and robust advocacy and lobbying directed at relevant government ministries is needed for the expansion of disability programmes and services within and under the responsibility of primary health care services in rural areas.

Difficulties of Introducing the Cadre of Mid-Level Rehabilitation Workers

The health systems of most low- and middle-income countries do not have a specific cadre of mid-level rehabilitation workers at PHC and community levels. This can be partly explained by the increased privatisation and the budget cuts for health services over the past couple of decades across different countries. At the same time, as shown by the repeated calls from the World Health Organisation for the inclusion of rehabilitation services in the primary healthcare services, it also denotes the low priority given to rehabilitation services. At the same time, one notices that global stakeholders including rehabilitation professional bodies are promoting rehabilitation in universal health coverage but with a strong emphasis on the involvement of therapeutic professions at secondary and tertiary health care levels, with limited attention for primary and community care levels.

Limitations

Bringing together the findings from 3 different initiatives, carried out in different time periods with different objectives can be seen as a limitation. One study, looking at different aspects of RTA training and employment after the training, probably would be more comprehensive.

Though the impact assessment among 26 RTAs was carried out by an external consultant, she was accompanied by two of the trainers of the RTA course who helped in translation and information collection. This might have created a bias in the collection of information and thus in the findings.

Another limitation was that the majority of the 26 RTAs involved in the impact assessment were working as members of rehabilitation teams that included other rehabilitation professionals. This made it difficult to assess whether some of the outcomes reported by the clients were due to the interventions of the RTAs or of the other team members. However, the issue of attribution is always a challenge when doing impact studies, but we are confident that the RTAs at least had a contribution in the positive outcomes that were noticed.

CONCLUSION

Different international reports and policy documents lament the lack of rehabilitation services in the primary health care system, especially in rural areas of low-and middle-income countries. Many of them have suggested the introduction of the cadre of mid-level rehabilitation workers. This study shows that with one year of training, this cadre of workers, the Rehabilitation Therapy Assistants, can play a useful role in CBR programmes in areas where no or few other trained workforce is available for the provision of rehabilitation services.

However, training this cadre of rehabilitation workers without appropriate changes in health systems, such as an accreditation system, the inclusion and recognition of the cadre within civil services structure and career opportunities for this cadre, does not resolve issues related to the lack of rehabilitation professionals. While RTAs in some high income countries are recognised and are part of the healthcare system, this is missing in most low and middle income countries. For example, although the RTAs are registered in India, there is no provision for mid-level rehabilitation workers within the national health system in India. As long as no priority is given to rehabilitation services in the health systems, and in spite of the existence of RTA training courses, such training programmes can only provide trained workers to work in CBR programmes of NGOs and their numbers, coverage and impact will remain limited.

The global calls for mid-level rehabilitation workers and the introduction of rehabilitation services as a part of primary health care services are constantly repeated. “The Guide for Action – Rehabilitation in Health Systems” launched by the WHO in 2019 as a part of the Rehabilitation 2030 action plan, again calls for the integration of rehabilitation in the primary health care (WHO, 2019). The RTA training courses of Mobility India provide knowledge and skills to mid-level rehabilitation workers through the NGOs running CBR programmes in areas which lack other alternatives. Such training courses can reach and benefit many more persons only if there are changes in the health systems and greater priority given for the rehabilitation services.

Mobility India’s RTA training programme provides insight into the training of mid-level rehabilitation workers and their role in primary health care services. Others may learn from it and contribute to the further development of this cadre and as such, can draw lessons for the expansion and scaleing up of this much needed cadre for ensuring access to rehabilitation services, especially in rural and underserved areas.

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LETTER TO EDITOR

Dear Editor,

Role of the Speech Therapist in Management of Autism Spectrum Disorder in the COVID-19 pandemic era

The COVID-19 pandemic has proved to be a challenging period for most families of individuals with Autistic Spectrum Disorder (ASD). ASD is a complex neurodevelopmental condition that encompasses changes in social communication, social interaction, and behavioural patterns (APA, 2013). During the COVID-19 pandemic, restrictive measures that have been implemented to contain the spread of the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) may affect the routine of people with ASD and consequently cause adverse outcomes including anxiety, stress, anger attacks, regression in behaviour development, hyperactivity and difficulty in adapting to new routines in the home environment (Eshraghi et al, 2020; Smile, 2020). The current scenario has also modified the provision of services to this population and their families (Smile, 2020). These changes include absence of multidisciplinary therapies, and decreased time in classrooms due to school closures (Narzisi, 2020; Smile, 2020).

With reduced health and education supports, there may be an increase in the frequency and severity of behaviours in individuals with ASD (Colizzi et al, 2020). A recent study showed that 94% of families reported a significant increase in home care, of whom 41% described more frequent and intense behaviour (Colizzi et al, 2020). In one sense, the COVID-19 pandemic has offered opportunities for reflection on autism and how to address and treat these individuals' mental health conditions during long periods of routine interruption.

At the time of writing this manuscript, SARS-CoV-2 had infected more than 3 million people and resulted in more than 100,000 deaths in Brazil, making the country the newest epicentre of the disease. In this context, telemedicine has played an important role in providing remote services to people during the COVID-19 pandemic (BRASIL, 2020a). The use of remote technologies provides fast communication without displacements and agglomerations, and ensures that health care is continuously provided, reducing the risks of SARS-CoV-2 spread (Lurie and Carr, 2018; Caetano et al, 2020).

For people with ASD, remote care can be an effective way to improve the accessibility of consultations by a multi-professional team. It has been shown that the telemedicine approach increases the sense of competence, improves social communication skills, and there is an adherence to the intervention by the parents (Narzisi, 2020). This approach requires intense one-on-one supervision by highly trained professionals (Baharav and Reiser, 2010). However, telemedicine can be restricted to a smaller number of individuals with autism, especially among families with better socioeconomic conditions and people with a less severe form of ASD. Speech therapists play a major role in the management of this complex condition because of the high demand for treating language problems and speech disorders among people with ASD. In the current scenario, speech therapists can work remotely by monitoring the treatments already planned, and ensuring technical training for family members to improve language and communication skills of people with ASD (Patterson et al, 2012).

The speech therapy should be based mainly on communicative strategies, either by gestures, signs, or electronic devices (Mandak and Light, 2018). The goal is to help the person with ASD to communicate in a more useful and functional way. The use of technology for speech therapy in autism can be effective in developing verbal, non-verbal and social communication skills, but the strategies implemented need to be individual, including accurate and confident information for family members (Defense-Netrval and Fernandes, 2016). In addition, there is evidence that continued therapy using an online platform does not appear to harm the results achieved from traditional therapy.

Communication using expressions and gestures favours the professional-client relationship and is essential for adherence to treatment. However, the use of personal protective equipment (PPE) seems to be an additional challenge for speech therapists because of the difficulty in communicating through facial expressions and gestures. In addition, the use of facemasks reduces the acoustic transmission and impairs lip reading (CNN, 2020).

Another challenge is related to the difficulty of using masks or face covering for people with ASD. Although these are important measures in reducing the risk of SARS-CoV-2 transmission (CDC, 2020), people with ASD may not adapt to them. For this reason, a recent Federal law dispenses with the obligatory use of facemasks for people with disabilities, intellectual or sensory impairment, including people with ASD (BRASIL, 2020b).

Speech therapists must be prepared for the proper management of people with ASD, especially during and after the COVID-19 pandemic. Additionally, in the post-pandemic period, changes and innovations must persist, in addition to face-to-face care options for autistic clients who have failed to adapt to remote care. Clients must be selected according to an order of priority, indication and established criteria. All procedures must be performed safely and with the use of appropriate PPE. On the other hand, distance treatment measures should be encouraged until the population is vaccinated. Finally, speech therapists must ensure the necessary support for individuals with autism and their families, especially during and after the COVID-19 pandemic, through adaptations in their clinical approach, such as the remote monitoring of routine care. Studies on the consequences on behaviour and communication resulting from COVID-19 are needed among people with ASD.

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Brenda Carla Lima Araujo[*]
Thales Rafael Correia de Melo Lima
Vanessa Tavares de Gois-Santos
Victor Santana Santos
Rosana Carla do Nascimento Givigi
Paulo Ricardo Martins-Filho

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[*] **Corresponding Author:** Brenda Carla Lima Araujo Email: brendaaraujo@yahoo.com.br

NLR - until No Leprosy Remains is a Dutch non-profit organization committed to a world without leprosy and its consequences. It tries to achieve this by supporting health authorities in countries where leprosy is prevalent. NLR promotes the independent social and economic functioning of leprosy patients and their families. By supporting scientific research NLR wants to improve the effectiveness of leprosy control.

NLR is a member of the International Federation of Anti Leprosy Associations (ILEP). NLR supports national health authorities in over twenty countries with endemic leprosy problems, collaborates with international partners in leprosy control, and works professionally and efficiently.

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The Liliane Foundation contributes to a world that is open to everyone and in which poor children with disabilities can develop and use their talents. The foundation collaborates with local partners in Africa, Asia and Latin America to raise awareness of the 'exclusion' of these children and to remove the barriers that they suffer because their environment is not set up to allow their participation.

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