

Occupational therapy needs of adolescents and young adults with cerebral palsy in Zimbabwe: caregivers' perspectives

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Abstract

Objectives: To determine occupational therapy needs of adolescents and young adults with cerebral palsy living in an urban setting, to identify participation levels in activities of daily living and social activities, to identify factors influencing participation and to determine the contribution of occupational therapy in participating in these activities.

Design: Descriptive cross-sectional

Setting: Community rehabilitation outreach points in Epworth, Mufakose, Glenview, Dzivarasekwa, Mabvuku and Norton.

Participants: Thirty-five randomly selected primary caregivers of adolescents and young adults with cerebral palsy.

Data analysis: Data collected on the questionnaires was analysed using SPSS/16.0 for frequencies and means.

Results: Fourteen (41%) of the adolescents and young adults were independent in self-care activities such as toileting, grooming, dressing, mobility and bathing. Twenty-one (59%) were totally dependent or needed some assistance in performing activities of daily living. Factors reported to influence participation included upper and lower limb contractures, lack of transport, financial constraints and a difficult home environment. Occupational therapy needs of adolescents and young adults as reported by their caregivers included further training in activities of daily living (74%), home adaptations (66%), vocational skills training (20%) and provision of appropriate assistive devices (6%).

Conclusion: In light of these findings performance areas that still needed occupational therapy interventions included activities of daily living, vocational skills training, use of assistive devices and home adaptations. Therefore adolescents and young adults with cerebral palsy living in Zimbabwe still have functional performance deficits that can be addressed by provision of follow-up community occupational therapy interventions.

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Introduction

Technological advances in health care services have dramatically improved survival rates for children with developmental disabilities¹ including cerebral palsy. As a result, the population of adolescents and adults with chronic disability is growing.² Majority of these adolescents and young adults with cerebral palsy live at home with their families.²

Cerebral palsy is often associated with a variety of neuromuscular and musculoskeletal impairments and abnormalities of speech, vision and intellect.^{3,4} These impairments can affect all aspects of a person's development interfering with normal function throughout life.³ The limitations in activity due to cerebral palsy require ongoing intensive rehabilitation including occupational therapy.⁵

Occupational therapy helps individuals with cerebral palsy to overcome deficits in performing activities of daily living.^{6,7} Whilst independent functioning is a key issue for adolescents transitioning into adulthood, children with multiple handicaps often regress in their functional ability as they progress from adolescence to young adulthood.^{8,9} This might be due to decreased exposure to the activities to be performed and decreased social support.¹⁰

The ultimate goal of occupational therapy management for patients with cerebral palsy is to enable such patients to engage and participate in meaningful occupations.¹¹ In Zimbabwe, people with cerebral palsy receive occupational therapy services from the time a diagnosis is established. Services provided include; screening and diagnosis, assessment and therapeutic intervention, disability awareness and advocacy, promoting child participation and child rights, networking with relevant stakeholders and teaching and training caregivers on child handling. Currently occupational therapy services are hospital based and there are no follow-up occupational therapy programmes for adolescents and adults with cerebral palsy in the community. It is therefore not known whether this ultimate goal of occupational therapy is being achieved.

In this article a report is given on the findings of a descriptive cross-sectional study that was carried out in Harare, Zimbabwe to determine the occupational therapy needs of adolescents and young adults with cerebral palsy living in an urban setting. Since primary caregivers are the most knowledgeable about the health and needs of the people they care for structured interviews were conducted with the caregivers. Study objectives were to identify participation levels in basic activities of daily living and social activities, to identify factors influencing participation and to determine the contribution of occupational therapy in participating in these activities.¹²

For the purposes of the research, an adolescent was defined as anyone aged between 12 years and 17 years old and a young adult was anyone aged between 18

years and 25 years old. Activities of daily living (ADLs) in occupational therapy are defined as basic tasks that people undertake routinely in their everyday life such as eating, bathing, toileting, cleaning and cooking.¹³

Materials and Methods

A descriptive cross-sectional research was conducted at six urban community outreach points in Harare and Norton. All adolescents and young adults with cerebral palsy aged between 12 years and 25 years old who were registered for the community outreach programme at Harare Central Hospital Children's Rehabilitation Unit were listed. Forty names were randomly selected from the list. The caregivers of the selected children who were older than 18 years old and who were willing to participate were then considered as study participants. These participants responded to an interviewer-administered questionnaire which was translated into a local language (Shona). Information on occupational therapy needs, level of participation in basic activities of daily living and the way occupational therapy intervention had contributed to the enhancement of function was collected from the caregivers. Data collection was completed in 6 weeks. Three community outreach points were visited per week interviewing at least 2 participants per visit.

The questionnaire was reviewed by four occupational therapists for content validation. A pre-test was done to determine the participants understanding of the questions and also to evaluate whether the instrument collected enough data to address study objectives. Modifications to the instrument were made based on the feedback from participants in the pre-test.

Ethics

Permission was sought from Harare Central Hospital Children's Rehabilitation Unit. Ethical approval was sought from the Harare Central Hospital Ethics Committee, the Joint University of Zimbabwe Research and Ethics Committee and from the Medical Research Council of Zimbabwe. Participation was on a voluntary basis and the participants had the right to withdraw from the study whenever they wanted to without any repercussions. Confidentiality was maintained throughout the research.

Data analysis

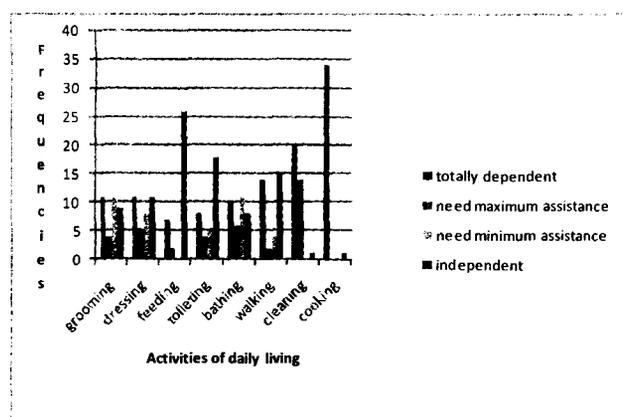
Data collected from the participants during the interviews was analysed using Microsoft Excel and the Statistical Package for Social Sciences (SPSS) Version 16.0. Quantitative data was analysed for frequencies and means. Qualitative data was analysed thematically and the frequencies for the themes were then expressed quantitatively.

Results

Thirty-five participants agreed to participate in the research giving a response rate of 87.5%. The mean age of caregivers was 37 (\pm 6.3) years. Thirty-three (94%) of the caregivers were females and two were males. Twenty-eight (80%) were married, three were divorced and 4 (11%) were widowed. Thirty-two (91%) of the caregivers were unemployed and three were self-employed as vendors. All the 35 caregivers interviewed lived in the urban areas. Eighteen (51%) of the caregivers rented houses and 17 (49%) owned the houses they were living in. Twenty-eight (80%) of the caregivers were the biological parents, while 7 (20%) of them were grandparents, aunts or extended family members of the patients.

With regard to participation in activities, the caregivers reported that the majority of the adolescents and young adults were independent in most basic activities of daily living such as feeding (74%), toileting (51%), walking (43%), dressing (31%) and bathing (23%) (Figure I).

Figure I: Levels of participation in activities of daily living by adolescents and young adults with cerebral palsy as reported by caregivers.



Only one adolescent was reported as able to participate in cleaning and cooking activities. Twenty (57%) were reported by their caregivers to be totally dependent on their caregiver for cleaning, cooking (97%) and walking (40%). Eight (23%) were reported to be totally dependent in toileting and 7 (20%) were dependent in feeding. Four (11%) needed maximum assistance in grooming, toileting and dressing, two needed maximum assistance in feeding and walking, 6 (17%) in bathing, and 14 (40%) in cleaning. Eleven (31%) of the adolescents and young adults needed minimum assistance in grooming, 8 (23%) in dressing, 5 (14%) in toileting as well as walking and four (11%) in bathing.

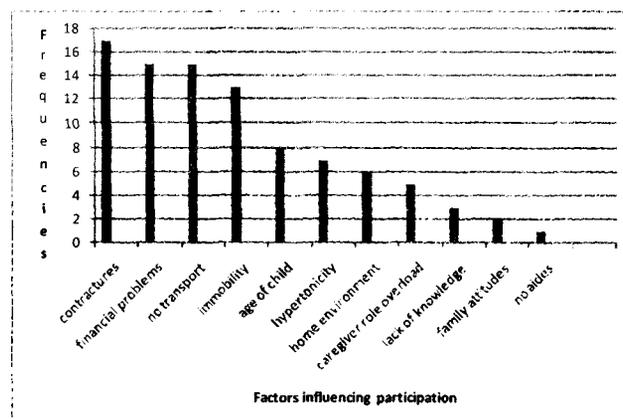
Participation in social and school related activities by the adolescents and young adults with cerebral palsy as reported by caregivers.

Only 10 (29%) of the adolescents and young adults

were reported to be involved in church activities. Twenty-five (71%) did not participate in any church activities at all. Reasons given for not participating in church activities were that the caregivers did not have transport to and from church. In the case of those who had wheelchairs, these were not collapsible and the operators of the public commuter omnibus require an extra payment for a wheelchair which makes travelling by public transport more expensive. Of the 25 (71%) who attended school, 6 (24%) attended mainstream schools and 19 (76%) attended special schools. Ten (29%) did not go to school due to the severity of their disabilities. Four (11%) of the adolescents and young adults participated in athletics, another 4 (11%) in music and one in soccer.

Twenty-three (66%) of the adolescents and young adults were able to communicate verbally. The most restricting factors to participating in activities as reported by 26 (74%) of the caregivers were contractures of both lower and upper limbs (Figure II).

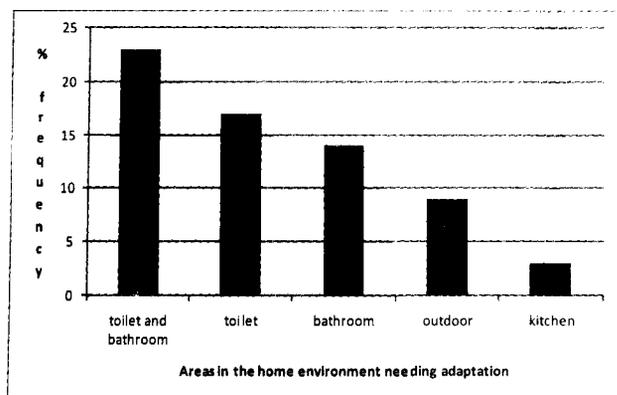
Figure II: Factors influencing participation in activities of daily living by adolescents and young adults with cerebral palsy as reported by caregivers.



Another 26 (74%) caregivers reported that they could not afford to pay for transport due to financial hardships and this made attending social functions difficult. Twenty-one (60%) of the adolescents and young adults also did not have aides and assistive devices that were needed for them to be able to participate in daily activities. Family attitude was the least reported limiting factor to participation in daily activities. The caregiver's role overload, social problems, age of child, home environment, community environment and lack of knowledge on how to facilitate participation in the activities were also reported as factors contributing to non-participation in daily activities. Some of the attitudes mentioned by caregivers included discrimination and neglect of the child by other family members.

Twenty-three (66%) adolescents and young adults, needed adaptations to their home environment and 12 (34%) did not need any adaptations (Figure III).

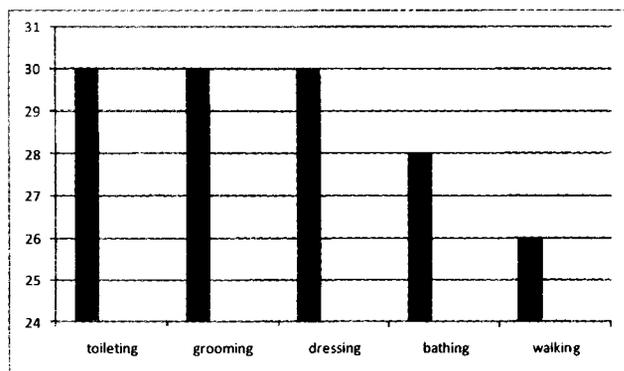
Figure III: Areas in the home environment needing adaptation to enhance participation in activities of daily living as reported by caregivers.



Eight (23%) of them needed adaptations of both toilet and bathroom while 6 (17%) needed adaptations to the toilet, five (14%) needed bathroom adaptations only, three needed outdoor adaptations and one needed kitchen adaptations to enhance participation.

Twenty-one (60%) of caregivers of adolescents and young adults reported that they had greatly benefited from training in activities of daily living (Figure IV).

Figure IV. Contribution of occupational therapy to participation in activities of daily living by adolescents and young adults with cerebral palsy as reported by caregivers.



Feeding was reported by 83% of the caregivers, toileting by 80%, grooming and bathing by 77%, dressing 74% and walking by 60%. Five (14%) of the caregivers reported that they had not benefited at all from attending therapy as the adolescents they took care of were still dependent on them in their day-to-day functioning. Thirty-two (91%) of the caregivers reported that caregiver education and physical exercises were most helpful.

Performance areas requiring further occupational therapy intervention as reported by caregivers.

Twenty-six of the caregivers (74%) reported that their children needed more intervention in order to achieve maximum independence in participating in activities of

daily living Twenty-four (69%) still needed assistance in the area of education and school placement. Seven (20%) were looking forward to vocational training in basic work skills. Fifteen (43%) needed assistive devices and could not function without them, while 4 (11%) needed assistive devices but could function at a minimum level without them. Sixteen (46%) did not need any assistive devices at all. Thirteen adolescents and young adults (37%) used wheelchairs, three used plate guards and two used walking frames. One used an adapted shoe and walking stick.

Discussion

The majority of caregivers were married females who were not formally employed. In most African societies including Zimbabwe, care-giving is seen as a social role that is shaped by gender.¹⁴⁻¹⁶ Therefore, women are seen as natural caregivers and some mothers might sacrifice some of their meaningful occupations to devote all their time to care-giving. It is taken for granted that mothers, wives, grandmothers and sisters have to take care of those in need.¹⁶ If a child is born with a disability, the child would require more attention and special care hence the role of a caregiver is of utmost importance in bringing up children born with cerebral palsy or any other disability.¹⁷

Most of the caregivers reported that those adolescents and young adults who had received occupational therapy services generally improved in their participation in activities of daily living. This was consistent with other researchers who reported that occupational therapy contributed to self-care promotion, independent mobility and improved function.^{3,8,18} In addition, the treatment of neuromuscular and musculoskeletal problems through physical exercise and the use of neuro-developmental techniques also helped to improve function.¹⁸⁻²¹

In this research, occupational therapy services also included caregiver education and the majority of caregivers reported that they had benefited from caregiver training. Palisano⁸ concluded that better functional outcomes were achieved when occupational therapy interventions also focused on caregiver support, education and capacity building. Therefore, in light of findings by Palisano the success of occupational therapy interventions in this research may also be attributed to caregiver support and education.

Very few adolescents and young adults were involved in social activities despite their ability to communicate. Shikako reports that children and youths with cerebral palsy experience difficulties in communication which therefore hinder their participation in social activities.¹⁹ However unlike in Shikako's research, findings in the current research showed that communication is not a major barrier to social participation. Adolescents and young adults with cerebral palsy in Zimbabwe are unable to participate in social activities due to financial constraints resulting in the caregivers not being able to

afford to pay for transport to travel for social activities and functions. Other factors reported by caregivers in Zimbabwe as limiting participation include, non-availability of equipment, caregiver role overload, social problems, the home environment which is not adapted to meet the needs of an individual with cerebral palsy and a lack of knowledge by the caregiver on how to facilitate participation. These factors compared with findings by other researchers^{19-20,23-24} who also reported psychosocial pressure, inadequate public services and limited disability awareness programmes and age as some of the factors limiting participation in activities by adolescents and young adults with cerebral palsy. Law suggests that such factors impact greatly on the overall function of an individual with cerebral palsy and result in disruption of participation in life situations, particularly in social and community-based activities.^{18,20}

The few adolescents and young adults who were involved in social activities participated in athletics, music, in outdoor play and soccer. The small number of adolescents and young adults participating in social activities suggests that adolescents and young adults with cerebral palsy were involved in few social activities and these activities tended to be less physically active, with fewer social engagements.^{8,20-21} Those who attended to mainstream schools participated mostly in academic-related activities like computers while those who attended to special schools were better in athletics, music and soccer than those in mainstream schools. This could be a result of exposure to different activities in the different school settings.

Whilst several restricting factors were reported by the caregivers as contributing to reduced participation in activities of daily living, having contractures was reported as the most limiting factor. The researchers observed that in general, rehabilitation services in Zimbabwe, including occupational therapy tend to focus more on young children with cerebral palsy rather than on adolescents and young adults. Since there are currently no follow-up community visits being conducted for these adolescents and young adults with cerebral palsy, it is possible that these contractures might have developed during the period when there is reduced support from the occupational therapists. Lack of community follow-up coupled with transport challenges were also mentioned as factors that might limit access to occupational therapy facilities, strongly indicating the need for consistent community occupational therapy services for adolescents and young adults with cerebral palsy.

The researchers have also observed that most caregivers carry their children on their backs when bringing them for therapy either at the community outreach points or to the occupational therapy departments in hospitals. However as the child gets older carrying them on one's back becomes increasingly difficult especially if the child also has contractures. In addition, public transport operators in Zimbabwe are still not willing to carry people on

wheelchairs as the wheelchair takes up more space in the commuter omnibus. All these factors contribute to caregivers not being able to continuously access the support services that they need as each stage of development brings with it new challenges.

The majority of the caregivers reported that they needed home adaptations. Research by Hemmingsson *et al.*²⁵ demonstrated that environmental factors may be a barrier to participation in meaningful activities, it is important to note that most of the rehabilitation services for children with cerebral palsy services are currently provided free of charge²⁶ for children under five years of age in Zimbabwe. Once the children are over five years they may still access basic rehabilitation services free of charge but are expected to pay for other services such as home adaptations. Given that some caregivers reported financial constraints as limiting their access to required occupational therapy services, this may mean that some of the caregivers cannot afford to pay for home adaptations. Home adaptations might also be very difficult to recommend for those who stay in rented accommodation as some of these adaptations might be permanent.

In the research, about half of the adolescents and young adults were reported to use assistive devices including wheelchairs, walking frames, adapted shoes and plate guards. A small number used a combination of these aides and assistive devices. However most of them did not have proper assistive devices such as age appropriate wheelchairs and walking frames specifically designed for them to function well and this in turn limited participation in some activities.

In Zimbabwe, there are currently no occupational therapists working in vocational training centres. As such not much is being done by occupational therapists to assist these adolescents and young adults with vocational skills training yet it was reported as an unmet occupational therapy need. Vocational skills training however, will be more feasible for very few of these adolescents and young adults who had no contractures and had appropriate assistive devices, who could communicate and were ambulatory. However for the rest with contractures as the most limiting factor to participation, this might be difficult.

Though most of the caregivers reported that the occupational therapy interventions had improved the level of functioning for the adolescents on young adults they cared for, more occupational therapy interventions were still needed. Performance areas that still needed occupational therapy interventions included instrumental activities of daily living, vocational skills training use of assistive devices and home adaptations and modifications both indoors and outdoors. In light of the findings from the research, adolescents and young adults still have functional performance deficits that can be addressed by community occupational therapy interventions.

Recommendations

Occupational therapists in Zimbabwe should provide follow-up community interventions. Occupational therapists should focus on the unique treatment needs of each adolescent or young adult with cerebral palsy to help in improve his or her quality of life and independence in functioning.

Occupational therapists in Zimbabwe with the assistance of relevant ministries should set up vocational skills training centres as vocational skills training is an important aspect of therapy. Occupational therapists should provide appropriate assistive devices based on individual assessments to adolescents and young adults with cerebral palsy to improve functional independence and participation in activities.

Limitations

The study was only conducted in an urban setting therefore results cannot be generalised to a rural setting. The sample size of 35 participants was not based on minimum sample size calculation and was drawn from only one province .Therefore it was not representative of all caregivers of adolescents and young adults with cerebral palsy in Zimbabwe.

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