DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Formerly Asia Pacific Disability Rehabilitation Journal

Volume 31 ■ No. 2 ■ 2020

Contents

EDITORIAL

GUEST EDITORIAL

ORIGINAL RESEARCH

REVIEWS

BRIEF REPORTS

Published by

Liliane Fonds
open de wereld voor een kind met een handicap

Supported by

NLR

Liliane Fonds
open de wereld voor een kind met een handicap

Website: www.dcidj.org

National Printing Press
580, K.R. Garden, Koramangala, Bangalore - 560 095, India.
Tel : 91-80-25710658 Email: nppbangalore@gmail.com

DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Formerly Asia Pacific Disability Rehabilitation Journal

CONTENTS

Volume 31 ■ No. 2 ■ 2020

EDITORIAL

GUEST EDITORIAL

ORIGINAL RESEARCH

REVIEWS

BRIEF REPORTS

Editorial

The Covid-19 pandemic is still affecting the lives of many people in the world and there is no continent – probably except for Antarctica – which is not affected by it. Many countries are facing a second wave and the impact of the pandemic on the quality of life of large groups of people is enormous; this is particularly true for those people living in low- and middle-income countries. The consequences of policies and strategies to curtail the pandemic are mostly felt by vulnerable groups of people such as people with disabilities. The Covid-2019 pandemic will mean that many more families will fall into extreme poverty. The most recent SDG report predicts that the global gains in reducing, for instance, child labour are likely to be reversed for the first time in 20 years[1]. While at this moment we won't be able to oversee all the consequences of the Covid-2019 pandemic, it becomes increasingly clear that this pandemic is having a major impact on individuals, families, communities, countries.

Amid this crisis, we need to be vigilant not to lose hope. We should not give up on working towards a better and more egalitarian world. One may wonder what the role of research is in creating that better world. What we learn these days is that mankind may have increasingly been thinking that with new scientific insights and technology, we would be, more than ever before, capable of controlling events in this world. However, this crisis tells us that we are often not in control and even when we think that we are in control, we aren’t. At the same time, it is evident that these days we are confronted with much fake news and criticism on research and its role in political decision-making and policy changes. It is the sheer facts that need to be well-explained to the public to create a solid understanding of the crisis and the measures that need to be taken to curb the crisis. At the same time, this global disaster should bring with it genuine attention for human suffering. Yet, the draconic actions such as lockdowns as a response to this public health crisis could very well mean that the cure would be worse than the ailment.

I invite you to share your ideas; your experiences and your research about the relationship between Covid-19 and disability and submit papers, reviews and letters to the editorial team. If you haven’t started yet, with writing down your observations; studying what is happening at the interface of Covid-19 and disability, I urge you to start with doing so and share your experiences.

---

[1] United Nations. (2020). *The sustainable development goals report 2020.* New York: United Nations Department of Economic and Social Affairs. Retrieved 2020, from Sustainable Development Goals: https://unstats.un.org/sdgs/

With the above call and reviewing the content of this 2nd issue of this year, I am challenging you at least 2 times in this journal. I sincerely hope that you will respond to these calls. With your support, we can continue making this a relevant journal that serves practitioners, researchers and policymakers.

At the end of this editorial, I would like to show my appreciation for the excellent collaboration that has taken place among a large number of people, making the migration of the DCID journal possible from the VU University Press in the Netherlands to Ubiquity Press in the United Kingdom. Thanks to the great help of Arjan de Rooij and Peter Vos of the VU University on one hand, but also the team in India on the other hand as well as Kim Brands of the Liliane Foundation, this was made possible without too many challenges. I am also pleased that we have found a new home for the journal with Ubiquity Press and hope that we will work together for many years. The loyal readers of the journal will notice the new layout; a new logo which, hopefully, will last for an equal number of years as the old one that has been used for 30 years.

Stay well; stay healthy and take care!

Huib Cornielje
Editor-in-Chief

GUEST EDITORIAL

Essential Standards for CBR Field Workers

Annemarie Gindorfer[1], Huib Cornielje[2*]

1. Guest Editor; Consultant, Light for the World
2. Editor-in-Chief; Disability, CBR & Inclusive Development Journal

In recent years there have been many changes in the field of community-based rehabilitation (CBR). In the early years of CBR development there was a strong medical focus on the rehabilitation opportunities for people with disability. However, CBR gradually evolved into a strong community based approach that supported families, adults and especially children with disabilities through practical home based rehabilitation activities – in reality often provided by the caregivers - that helped them to cope with daily life. Besides the practical rehabilitation activities, field workers supported the inclusion of people with disabilities in all aspects of life e.g. lobbying for inclusion in schools; raising awareness about disability in the community; lobbying for access to important service and ensuring that people with disabilities could participate in livelihood opportunities or gain employment. This approach which started already to evolve in the eighties of the last century, is now often referred to as the social and/ or rights model. For us this approach of working together with families and people with disabilities in the community, addressing rehabilitation needs, promoting participation and social inclusion is fundamental to CBR and thus the work and activities done by CBR field workers.

However, recent developments and changes, for example the move from CBR into community based inclusive development (CBID) or the Rehab2030 Action Plan of the WHO both seem to take the focus away from the extremely important grassroots work of the CBR field worker and as such seem to deny the importance of home-based services for people with disabilities. Various recent studies and reports from field visits by different NGOs working in the field of disability and rehabilitation, show that within the CBID approach many field workers talk about inclusion, disability rights, community mobilisation and advocacy, but

---

[*] **Corresponding Author:** Huib Cornielje, Editor-in-Chief, DCIDJ. Email: editor.dcid@gmail.com

lack the most elementary rehabilitation skills necessary to support children and adults, and coach families in order to improve functioning and quality of life. Some advocates of the CBID movement deny the importance of rehabilitation as a complementary but fundamental condition in achieving inclusion and seek inclusion especially in the form of mobilising communities. We, however, are convinced that these two aspects cannot be separated nor contrasted; both are important. Yet, the average person with a disability wishes to have access to high quality rehabilitation and assistive devices; precisely something that often is not available, accessible or affordable in many low- and middle- income countries. Not recognising such rehabilitation as of vital importance to those who have no access to such services is a violation of human rights. One could argue that the current WHO approach will fill the gap that is left with moving from CBR into CBID but given that the WHO approach apparently seems to focus largely on professional rehabilitation services we need to be on the alert. The shift from CBR to CBID is in our opinion a risky endeavour which may result in a shift from offering essential rehabilitation services at the community and household level to those who otherwise have nothing else then to rely on a community development approach focusing on mainstreaming which in practice will mean 'away-streaming'.

The newly widely embraced CBID approach mainly promotes the rights of people with disabilities and inclusion in community development, but it lacks attention to the practical rehabilitation skills that CBR field workers need to master in order to achieve disability inclusion and participation of people with disabilities in all sectors of society.

The Rehab2030 Plan of Action aims at improving accessibility to rehabilitation services for all people, not just people with disabilities. However, the reality in low- and even middle- income countries shows that essential rehabilitation services are only available in bigger cities and not in small towns, villages, or remote areas. Besides, many people cannot afford these services even if they can access them. In many low- and middle- income countries the numbers of professional rehabilitation staff such as physiotherapists, occupational therapists, or speech therapists are not sufficient at all to serve the rehabilitation needs of the entire population. Moreover, some rehabilitation professionals like social workers, psychologists, or CBR field workers are not even considered to be part of the core team of rehabilitation professionals. Even when the numbers of rehabilitation staff needed to deliver rehabilitation services are available, many people still would not be in a position to access the services because of eco-social factors such as poverty, geography. In order to reach them we seriously need to invest in supporting and further developing community level rehabilitation services. Some may argue that this is not a long-term solution and we better invest in ensuring that enough rehabilitation professionals will be trained according to western models. We, however, feel that a western solution may not be the answer; we also feel that it is inhumane and not respecting fundamental human rights to not ensure short term solutions for those living on the fringes of society. As such we rather see but one solution and that is to seriously invest in the promotion and development of rehabilitation at the community level. Whatever name one wishes to give to such a model is not a concern to us. Our concern is simple and simply the right of people with disabilities living in remote and under-resourced areas to also have access to essential rehabilitation services; our concern is not the position of rehabilitation professionals nor those of the minority of people with disabilities – usually the elite - who already have the luxury of making use of quality rehabilitation services. Our concern is simple and simply about the right for life for everyone.

In our view, it is high time to professionalise and recognise CBR field workers as an essential and valuable core member of a comprehensive rehabilitation team in low- and middle-income countries. In doing so, many CBR field workers, who are often people with disabilities, or mothers of a child with a disability, we are bringing valuable personal experience of disability into comprehensive rehabilitation, who – if receiving proper training in rehabilitation – are well able to address the needs of people with disabilities.

It is time to recognise the indispensable role of CBR workers in delivering rehabilitation services in low- and middle-income countries. They play a vital role in both community development as well as the work they do with families. It is in our view high time that CBR field workers receive a robust training followed by a proper career path, a decent salary and be part of existing health and/or social service personnel. They should be recognised by governments and NGOs as a valuable para-professionals in the delivery of rehabilitation services in the community.

We propose to develop a global CBR training curriculum based on core and essential skills a field worker needs in order to prepare him/her for their important tasks in the community. We propose – based on numerous evaluations of CBR programmes - a 1-year diploma/certificate training that offers people the opportunity to start a career working in rehabilitation at the community level. The minimum training CBR field workers need is 3 months spread over one year in which theoretical training is alternately followed by practicals in the field. The Essential Standards study done by Enablement during 2017-2018 clearly shows the core skills which CBR field workers need to have in order to offer practical rehabilitation activities in the community for people with disabilities and to train and coach families to support people with disabilities. The CBR curriculum should be based on group- based learning, practical assignments and learning from the implementation of CBR activities and thus gaining practical rehabilitation skills. CBR training should be clearly linked to the realities of the community.

CBR field workers can be the link between the new approaches focusing on community mobilisation (CBID) and the operationalisation of the Rehab2030 action plan of the WHO and as such play a vital role in making sure that really no one is left behind.

A CBR programme requires CBR fieldworkers with practical rehabilitation skills, and skills to collaborate and network with different organisations and various sectors. They need to be aware of the network of resources and services available within their area of work. CBR fieldworkers most of all need to be agents of change and problem solvers. Such a role will ensure that persons with disabilities and their families are empowered to make the changes needed in their lives and enabled to come into contact with the right mainstream resources, or at times with special services that are required.

A training curriculum for CBR fieldworkers should be related to the five CBR pillars and an additional to 2 other pillars: i.e. condition specific knowledge and management. The essential standards study (ref. 2018) showed a gap in training topics relates to the livelihood, social and education domain and these naturally received also the least attention in day-to-day activities of the fieldworkers. Yet, these domains are of large importance to people with disabilities and their families. Various studies show that there is a strong link between poverty and disability, and it is thus evident that this area of work requires attention. The social domain may seem of less importance (e.g. because of the attention for culture and arts as well as recreation, leisure and sports) however, this is also the domain that deals with issues of religion (culture), relationships and justice: aspects that so often refer to essential concerns such as discrimination, stigma as well as rights and righteousness. Awareness raising is regarded as a priority issue and closely linked to above mentioned issues.

We invite you to respond to this editorial; an editorial which for some of the readers may be common sense; for others it may be provocative; some may agree; others will disagree. We hope to get your views – not so much on terminology - but far more on principles; on what is needed on ground; not so much on grand philosophies and theories but far more on the reality of daily life in so many countries of this world. By promoting a recognised CBR career path we hope that many dedicated CBR workers will receive the adequate training and support that they need to create an inclusive society for all. CBR field workers can play a vital role in linking new developments and approaches about mainstreaming disabilities to practical rehabilitation activities in the community, making sure that really no one is left behind. Please submit your articles, best practices, reviews, opinion papers etc as we wish to publish next year a special on this subject.

ORIGINAL RESEARCH

Effects of Biofeedback and Task-Oriented Intervention on Balance Confidence and its Relationship with Social Participation among Stroke Survivors

Elumalai Pachiappan*

ABSTRACT

Purpose: *The study aimed to compare the effects of balance training on balance confidence and its relationship with social participation among clients with stroke.*

Method: *A pre- and post- experimental group design was used. Stroke survivors who met the inclusion criteria were consecutively assigned to two groups (task-oriented and biofeedback). Participants in the task-oriented group received task-oriented activities for 20 minutes and the biofeedback group received intervention in correckta (equipment used for balance training) for 20 minutes, along with conventional occupational therapy - 5 sessions per week, for 12 weeks. Balance Confidence Scale was used for measuring balance confidence, and Frenchay Activities Index (FAI) was used to measure social participation. Statistical calculations were performed with SPSS version 16.0 package. Statistical tests were carried out with the level of significance set at* $p \leq 0.05$.

Results: *The findings suggest that both the biofeedback and task-oriented groups showed significant improvement in balance confidence and there was no statistically significant difference between the groups. There was a moderate to good relationship between balance confidence and social participation.*

Conclusions and Implications: *There is evidence that many stroke survivors have low balance confidence. Therapists should assess the balance confidence of their clients and encourage them to participate in these beneficial interventions.*

---

* **Corresponding Author:** Lecturer, Occupational Therapy, Composite Regional Centre (CRC), National Institute for Empowerment of Persons with Intellectual Disability (NIEPID), Kanupuru Bit-2, Chavatapalem (post), Venkatachalam (mandal), SPSR Nellore District, A.P. India. Email: pachaime@gmail.com

Key words: *stroke, balance confidence, confidence, social participation, biofeedback, task- oriented, correckta*

INTRODUCTION

Stroke is the third leading cause of death and the leading cause of adult disability around the world (Strong et al, 2007; Feigin et al, 2009). The WHO defines stroke as an "acute neurological dysfunction of vascular origin with sudden or at least rapid occurrence of symptoms and signs corresponding to involvement of focal areas in the brain; further, the symptoms should last 24 hours or longer" (Aho et al, 1980). In India the incidence of stroke during the past decade was between 136 and 220 per 100000 (Banerjee et al, 2001; Saha et al, 2003; Gourie-Devi et al, 2004).

Balance impairment is a significant challenge after stroke because the number of falls can be as high as five per year in the first year post-lesion (Nyberg and Gustafson, 1995). These falls can further lead to pathological events (e.g., hip fractures), and additional declines in function and disability status (Grisso et al, 1991). Balance problems have been implicated in the poor recovery of activities of daily living (ADL) and mobility (Loewen & Anderson, 1990; Kwakkel et al, 1996; Lofgren et al, 1998). Diverse mechanisms are involved in determining individual causes of balance impairment. Decreased muscle strength, range of motion, abnormal muscle tone, motor coordination, sensory organisation, cognition, and multisensory integration can contribute to balance disturbances at different levels (Wing et al, 1993; Chen et al,2002; Bonan et al, 2004).

In addition to physical parameters, psychological measures such as balance confidence (i.e., the level of confidence that a person has in performing mobility tasks without losing balance or becoming unsteady) may also influence walking capacity among individuals with chronic stroke (Salbach et al, 2006). Many stroke survivors do not go out of the house as much as they would like to, and this has deleterious effects on their quality of life. Some reasons for poor outdoor mobility are potentially remediable, including the lack of confidence and inadequate information on transport options, aids, appliances or adaptations to the home (Logan et al, 2004). The belief in one's capabilities to organise and execute the skills required to produce given attainments is referred to as perceived self-efficacy (Bandura, 1977). Therefore balance confidence can be viewed as self-efficacious belief in one's capabilities to maintain balance while performing selected specific activities that commonly challenge balance.

Objective

The objective of this study is to compare the effects of biofeedback and task-oriented interventions on balance confidence and to find their relationship with social participation among persons affected by stroke.

METHOD

Participants

A total of 30 clients affected by were selected from Swami Vivekanand National Institute of Rehabilitation Training and Research Bhuvaneshwar (SVNIRTAR) and consecutively assigned to the task-oriented and biofeedback groups (15 participants each).

Inclusion criteria:

- Those who had a first attack of stroke,
- Age range below 65 years,
- Able to walk unaided or with minimal support, and
- No cognitive deficits.

MMSE was used to rule out cognitive deficit (more than 25 in MMSE).

Exclusion criteria:

- Hemiplegia due to other conditions,
- Those with previous injury to lower extremity, and
- Those with associated neurological problems.

Informed consent was obtained from the clients after explaining the treatment programme to them.

Outcome Measures

Balance Confidence Scale (BCS)

The Balance Confidence Scale (BCS) is a 22-item scale; each item is rated from 0% (no confidence) to 100% (complete confidence). Elderly respondents are asked to rate their confidence on whether they will lose their balance or become unsteady in the course of daily activities. Experts validated the content of BCS. Construct

Validity of BCS is established ($P<0.001$). BCS has high test – retest reliability ($R=0.93$, $P<0.001$), high internal consistency

($a=0.97$) and reliability on phone (($R=0.96.<0.001$).

The Frenchay Activities Index (FAI)

The Frenchay Activities Index (FAI) has been used in many studies. It has had its factor structure analysed on several occasions (Bond et al, 1992). The FAI contains 15 items or activities that can be separated into 3 subscales: domestic chores, leisure/work, and outdoor activities. The frequency with which each item or activity is undertaken over the past 3 - 6 months (depending on the nature of the activity) is assigned a score of 1 – 4, where a score of 1 = lowest level of activity. The Scale provides a summed score from 15 - 54.

Procedure

Balance Confidence Scale (BCS) was used to assess the balance confidence levels, along with FAI to assess social participation. After the pre-test, the therapy was begun. Participants in the task-oriented group received task-oriented activities and those in the biofeedback group received intervention in correckta (equipment used for balance training) for 20 minutes, along with conventional occupational therapy over 5 sessions a week for 12 weeks.

For the task-oriented group, intervention consisted of the following activities:

Warm-ups, step-ups, kicking ball, floor ladder and obstacle course, stand up and walk, walk and carry, and climbing stairs.

For the biofeedback group, intervention consisted of the following activities:

Exercises for balance, for posture, for asymmetries, distribution of loads, and guided or random objectives.

Before starting exercise in correckta the participants were asked to follow the guidelines and given an explanation about the activities. The exercises were carried out in a calm environment, without bright lights and disturbing noises.

RESULTS

The Test parameters were compared before and after therapy. Statistical calculations were performed with SPSS version 16.0 package, with the level of significance set at p≤0.05. The raw scores of pre- intervention and post- intervention of both outcome measures were added and summed up for final scores. As this was a 2-tailed non- parametric study, the changes in the two outcome measures within the biofeedback and task- oriented groups were analysed using Wilcoxon Signed Rank Test. Mann–Whitney U Test was performed to find the significance between the groups. Spearman Rank Correlation test was used for analysis of the relationship between balance confidence and social participation.

Table 1: Descriptive Statistics of Outcome Measures

Outcome Measure	**Mean test score(Group) Biofeedback (N = 15)**		**Mean test score(Group) Task-oriented (N = 15)**	
	Pre-test	**Post-test**	**Pre-test**	**Post-test**
Balance Confidence Scale	21.6	53.2	22.33	55
Frenchay Activity Index	5.46	20.6	5.6	21.6

Table 2: Results of Wilcoxon Signed Rank Test for Balance Confidence Scale within the Groups

Groups	**Mean diff.**	**z**	**P (2-tailed)**
BIOFEEDBACK	31.600	-3.408	0.001
TASK-ORIENTED	32.667	-3.412	0.001

The results of Balance Confidence Scale in Table 2 show there was significant improvement in both the biofeedback group and task-oriented group, with P values of 0.001 and 0.001 respectively.

Graph 1: Mean Score changes in the Balance Confidence Scale of both the Biofeedback and Task-oriented Groups

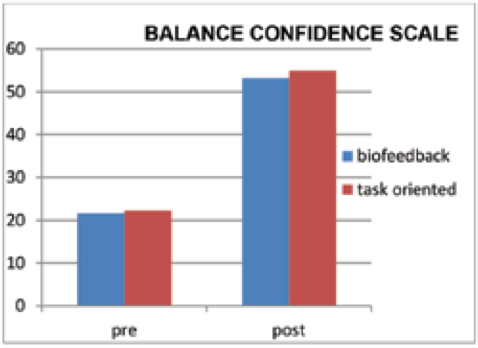


Table 3: Results of Wilcoxon Signed Rank Test for Frenchay Activity Index within the Groups

Groups	Mean Diff.	z	P (2-tailed)
BIOFEEDBACK	15.133	-3.410	0.001
TASK-ORIENTED	16.000	-3.419	0.001

The results of Frenchay Activity Index in Table 3 show there was significant improvement in both the biofeedback group and task-oriented group, with P values of 0.001 and 0.001 respectively.

Graph 2: Mean Score changes in the Frenchay Activity Index of both the Biofeedback and Task-oriented Groups

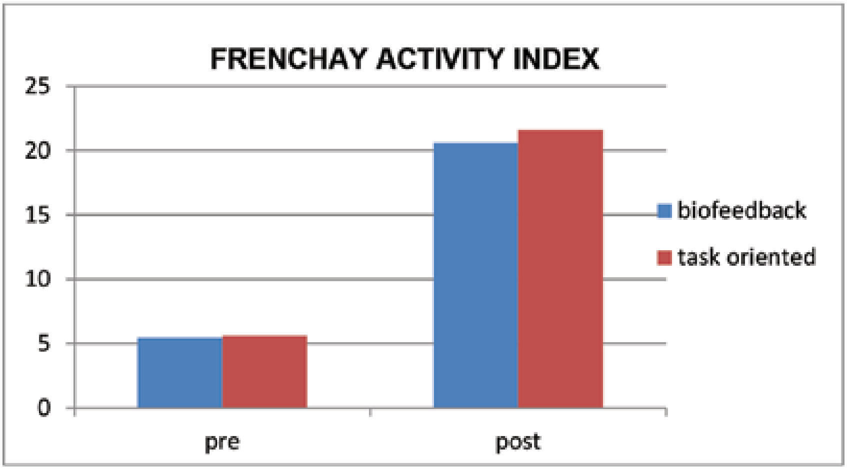


Table 4: Mann-Whitney U tests - Results between the Groups

Outcome Measures	Mean Diff.	z	P(2-tailed)
Balance Confidence Scale	1.800	- 0 .457	0.653
Frenchay Activity Index	1.000	-0.437	0.683

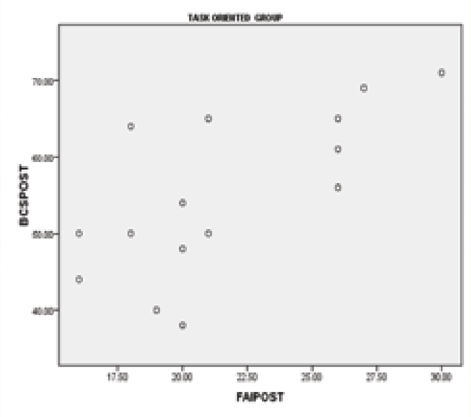
The task-oriented group showed slightly higher scores than the biofeedback group in both the outcome measures but it was not statistically significant, as shown by the results of Mann- Whitney U test at P values of 0.653 and 0.683 respectively.

Table 5: Spearman Rank Correlation tests - Results for the Relationship between Balance Confidence and Social Participation for Biofeedback and Task-oriented Groups

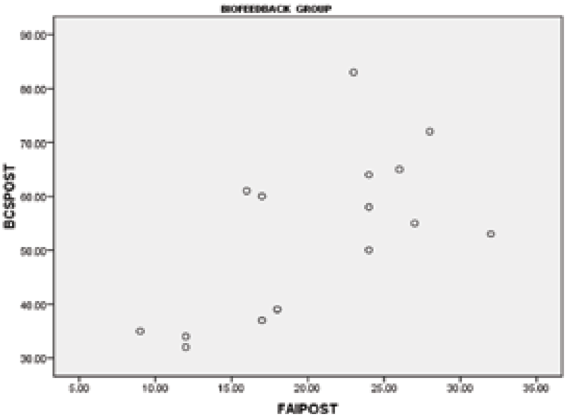
Group	Spearman Rank Correlation (r)	Level of significance (2- tailed)
BIOFEEDBACK	0.566	0.002
TASK-ORIENTED	0.684	0.005

Both the groups showed a moderate to good relationship between balance confidence and social participation.

Graph 3: Scatter Diagram showing the Relationship between Balance Confidence and Social Participation in the Task-oriented Group



Graph 4: Scatter Diagram showing the Relationship between Balance Confidence and Social Participation in the Biofeedback Group



DISCUSSION

The findings of the study suggest that both the biofeedback and task-oriented groups showed significant improvement in balance confidence, and there was no statistically significant difference between the groups as shown by scores. Before the intervention, the pre-scores on the Balance Confidence Scale showed that all the clients had lower balance confidence. The pre-test mean balance confidence level was 21.6% for the biofeedback group and 22.33% for the task-oriented group. However, post-intervention, both the groups showed significant improvements in the outcome measure. The task-oriented group showed a higher score in the outcome measure but it was not statistically significant when compared to the biofeedback group. The mean balance confidence level was 53.2% for the biofeedback group and 55% for the task-oriented group.

The task-oriented group showed significant improvement in balance confidence. The finding of the study is consistent with previous studies on rehabilitation (Marigold et al, 2005; Salbach et al, 2005). Task-oriented walking retraining enhances balance self-efficacy in community-dwelling individuals with chronic stroke (Salbach et al, 2005). The task-oriented progressive resistance strength training programme could improve lower extremity muscle strength in individuals with chronic stroke and could carry over into improvement in functional abilities (Yang et al, 2006).

The study found positive effects of visual feedback-based balance training on clients with stroke. They were able to benefit from the visual feedback exercise programme focused on balance control. The motor learning theory has emphasised the role of feedback in learning motor tasks, and earlier studies have shown the importance of vision in learning to produce effective postural responses (Clark & Rose, 2001; Hu & Woollacott 1994; Nichols, 1997). This study supports the notion that enhanced use of visual feedback for balance training can facilitate the learning of balance skills. Visual feedback training improves dynamic balance in stroke clients and there is also significant improvement in self-care abilities (Chen et al, 2002).

There is a moderate to good relationship between balance confidence and social participation, as shown in Table 6. Spearman Rank Correlation r value is 0.566 for the biofeedback group and 0.684 for the task-oriented group. Balance self-efficacy is an independent predictor of satisfaction with community reintegration in older adults with chronic stroke. Improving balance self-efficacy may be instrumental in enhancing community reintegration in this population (Pang et al, 2007).

Enhancing balance self-efficacy in addition to functional walking capacity may lead to greater improvement, primarily in perceived health status and physical function (Salbach et al, 2006).

CONCLUSION

This study provides evidence that many stroke clients have low balance confidence. However, the results of the study suggest that participants in both the groups (biofeedback and task-oriented interventions) showed significant improvement in balance confidence. There is a moderate to good relationship between balance confidence and social participation. Occupational therapists are encouraged to assess the balance confidence of their clients and those with low confidence should be advised to participate in these beneficial interventions. In addition, occupational therapists should consider incorporating activities and exercises that physically challenge the balance of their clients, in order to maximise their occupational performance.

REFERENCES

Aho K, Harmseni P, Hatano S, Marquardsen J , Smirnov VE, Strasser T (1980). Cerebrovascular disease in the community: Results of a WHO collaborative study. Bulletin of the World Health Organization; 58: 113-30.

Bandura A (1977). Self-efficacy: Toward a unifying theory of behavioural change. Psychological Review; 84(2): 191-215 https://doi.org/10.1037/0033-295X.84.2.191 PMCid:PMC4010856

Banerjee TK, Mukherjee CS, Sarkhel A (2001). Stroke in the urban population of Calcutta -- An epidemiological study. Neuroepidemiology; 20(3): 201-207 https://doi.org/10.1159/000054788 PMid:11490167

Bonan IV, Colle FM, Guichard JP, Vicaut E, Eisenfisz M, Huy PTB, Yelnik AP (2004). Reliance on visual information after stroke. Part I: Balance on dynamic posturography. Archives of Physical Medicine and Rehabilitation; 85(2): 268-273. https://doi.org/10.1016/j.apmr.2003.06.017 PMid:14966712

Bond MJ, Harris RD, Smith DS, Clark MS (1992). An examination of the factor structure of the Frenchay Activities Index. Disability and Rehabilitation; 14(1): 27-29. https://doi.org/10.3109/09638289209166423 PMid:1586756

Chen IC, Cheng PT, Chen CL, Chen SC, Chung CY, Yeh TH (2002). Effects of balance training on hemiplegic stroke patients. Chang Gung Medical Journal; 25(9): 583-590.

Clark S, Rose DJ (2001). Evaluation of dynamic balance among community-dwelling older adult fallers: A generalizability study of the limits of stability test. Archives of Physical Medicine and Rehabilitation; 82(4): 468-74. https://doi.org/10.1053/apmr.2001.21859 PMid:11295006

Feigin VL, Lawes CMM, Bennett DA, Barker-Collo SL, Parag V (2009). Worldwide stroke incidence and early case fatality reported in 56 population-based studies: A systematic review. Lancet Neurology; 8(4): 355-369 https://doi.org/10.1016/S1474-4422(09)70025-0

Gourie-Devi M, Gururaj G, Satishchandra P, Subbakrishna DK (2004). Prevalence of neurological disorders in Bangalore, India: A community-based study with comparison between urban and rural areas. Neuroepidemiology; 23(6): 261-268 https://doi.org/10.1159/000080090 PMid:15297791

Grisso JA , Kelsey JL, Strom BL, Chiu GY, Maislin G, O'Brien LA, Hoffman S, Kaplan F (1991). Risk factors for falls as a cause of hip fracture in women. The New England Journal of Medicine; 324(19): 1326-1331. https://doi.org/10.1056/NEJM199105093241905 PMid:2017229

Hu MH, Woollacott MH (1994). Multisensory training of standing balance in older adults: I. Postural stability and one-leg stance balance. Journal Gerontology; 49(2): M52-M61. https://doi.org/10.1093/geronj/49.2.M52 PMid:8126353

Kwakkel G, Wagenaar RC, Kollen BJ, Lankhorst GJ (1996). Predicting disability in stroke -- A critical review of the literature. Age Ageing; 25(6): 479-489. https://doi.org/10.1093/ageing/25.6.479 PMid:9003886

Loewen SC, Anderson BA (1990). Predictors of stroke outcome using objective measurement scales. Stroke; 21(1): 78-81. https://doi.org/10.1161/01.STR.21.1.78 PMid:2300994

Löfgren B, Nyberg L, Osterlind PO, Gustafson Y (1998). In-patient rehabilitation after stroke: Outcome and factors associated with improvement. Disability and Rehabilitation; 20(2): 55-61. https://doi.org/10.3109/09638289809166054 PMid:9494038

Logan PA, Gladman JRF, Avery A, Walker MF, Dyas J, Groom L (2004). Randomised controlled trial of an occupational therapy intervention to increase outdoor mobility after stroke. BMJ; 329(7479): 1372-1375. https://doi.org/10.1136/bmj.38264.679560.8F PMid:15564229 PMCid:PMC535450

Marigold DS, Eng JJ, Dawson AS, Inglis JT, Harris JE, Gylfadóttir S (2005). Exercise leads to faster postural reflexes, improved balance and mobility, and fewer falls in older persons with chronic stroke. J Am Geriatr Soc.; 53(3): 416-423. https://doi.org/10.1111/j.1532-5415.2005.53158.x PMid:15743283 PMCid:PMC3226796

Nichols DS (1997). Balance retraining after stroke using force platform biofeedback. Physical Therapy; 77(5): 553-558. https://doi.org/10.1093/ptj/77.5.553 PMid:9149764

Nyberg L, Gustafson Y (1995). Patient falls in stroke rehabilitation. A challenge to rehabilitation strategies. Stroke; 26(5): 838-842 https://doi.org/10.1161/01.STR.26.5.838 PMid:7740577

Pang MY, Eng JJ, Miller WC (2007). Determinants of satisfaction with community reintegration in older adults with chronic stroke: role of balance self-efficacy. Physical Therapy; 87(3): 282-291. https://doi.org/10.2522/ptj.20060142 PMid:17284545

Saha SP, Bhattacharya S, Das SK, Maity B, Roy T, Raut DK (2003). Epidemiological study of neurological disorders in a rural population of Eastern India. Journal of Indian Medical Association; 101(5): 299-304

Salbach NM, Mayo NE, Robichaud-Ekstrand S, Hanley JA, Richards CL, Wood-Dauphinee S (2005). The effect of a task-oriented walking intervention on improving balance self-efficacy poststroke: A randomized, controlled trial [published correction appears in J Am Geriatr Soc. 2005 Aug; 53(8): 1450]. J Am Geriatr Soc; 53(4): 576-582. https://doi.org/10.1111/j.1532-5415.2005.53203.x PMid:15817001

Salbach NM, Mayo NE, Robichaud-Ekstrand S, Hanley JA, Richards CL, Wood-Dauphinee S (2006). Balance self-efficacy and its relevance to physical function and perceived health status after stroke. Archives of Physical Medicine and Rehabilitation; 87(3): 364-370. https://doi.org/10.1016/j.apmr.2005.11.017 PMid:16500170

Strong K, Mathers C, Bonita R (2007). Preventing stroke: Saving lives around the world. Lancet Neurology; 6(2): 182-187. https://doi.org/10.1016/S1474-4422(07)70031-5

Wing AM, Allison S, Jenner JR (1993). Retaining and retraining balance after stroke. Baillieres Clinical Neurology; 2(1): 87-120.

Yang YR, Wang RY, Lin KH, Chu MY, Chan RC (2006). Task-oriented progressive resistance strength training improves muscle strength and functional performance in individuals with stroke. Clinical Rehabilitation; 20(10): 860-870. https://doi.org/10.1177/0269215506070701 PMid:17008338

Physical Activity of Community- Dwelling Elderly Population in Gujarat, India: A Cross-Sectional Study

Samira Sirajulhak Patel[1*], Nalina Gupta[2], Lata Parmar[3]

1. PG student, College of Physiotherapy, Sumandeep Vidyapeeth Deemed to be University, Gujarat, India
2. Associate Professor, College of Physiotherapy, Sumandeep Vidyapeeth Deemed to be University, Gujarat, India
3. Principal & Professor, College of Physiotherapy, Sumandeep Vidyapeeth Deemed to be University, Gujarat, India

ABSTRACT

Purpose: *While ageing is an inevitable phenomenon of life, physical activity is important for healthy ageing. Compared to the other age groups, older adults throughout the world have the lowest rate of participation in recommended levels of physical activity. This study aimed to investigate the physical activity status of the community-dwelling elderly population in Gujarat, India.*

Method: *This was a cross-sectional study. A door-to-door survey was conducted among selected communities near Vadodara in Gujarat. Based on the inclusion criteria (age≥60years, MMSE-≥24), 347 elderly persons were included in the study. Data was collected using the Global Physical Activity Questionnaire (GPAQ), and analysed using descriptive statistics.*

Results: *Among the 347 older adults (mean age 67.43±7.46 years) who participated in the study, 159 were male and 188 were female. While 125 participants (36%) were physically active at levels recommended by the World Health Organisation, 222(64%) were physically inactive.*

Conclusion*: Only 36% of the participants were physically active as per WHO recommendations. The men were more physically active than the women in the study sample. This study implies that there is a need to create an awareness regarding the importance of physical activity for healthy aging.*

Key words*: healthy ageing, WHO, physical activity, community- dwelling elderly*

---

* **Corresponding Author:** Dr. Nalina Gupta Associate Professor, College of Physiotherapy, Sumandeep Vidyapeeth Deemed-to-be-University, Vadodara, Gujarat, India.
Email: nals235@yahoo.co.in

INTRODUCTION

The World Health Organisation (WHO) defines physical activity (PA) as ‘any bodily movement produced by skeletal muscles that requires energy expenditure', such as working, playing, carrying out household chores, travelling, and engaging in recreational activities. For older adults the recommended duration of physical activity is a minimum of 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity aerobic activity or their equivalent combination per week (WHO, 2010).

Evidence suggests that participating in regular moderate-intensity physical activity, e.g., walking, cycling and light sports, as well as light-intensity activity, e.g., easy walking (<4.5 km/h), has significant benefits for health (The Department of Health, Australian Government, 2019). Physical activity helps to avoid the risk of injury and falls, improves health-related quality of life, reduces depression, reduces sedentary activities, gives a feeling of being in good health, improves cognitive function, mood, self-esteem, general mental health, short or long-term memory, and sleep (Warburton, 2017). It also decreases the risk of cardiovascular disease, hypertension, diabetes mellitus, lung disease, bone disease, and cancer (Warburton, 2017).

Physical inactivity is more common among women, elderly people and rich countries (Gamage, 2019).Compared to all age groups throughout the world, older adults have the lowest rate of participation in recommended physical activity (WHO, 2010). A study by Musich (2017) found that only 12% of adults aged 75 years and older were involved in 30 minutes of moderate physical activity for five days or more per week.

Older adults with visual impairment, hearing impairment, musculoskeletal disease, and incontinence have a lower level of physical activity than their peers without these conditions (Bryan, 2011). Participation in physical activity is influenced by many factors such as age, gender, education, lack of time, self-efficacy, barriers to exercise, social support from friends and peers, social support from spouse/family, access to facilities, hilly terrain, enjoyable scenery, neighbourhood safety, and various internal and external barriers (Trost, 2002; Schutzer, 2004).

Increasing PA among elderly persons has become an international priority (WHO, 2015). In India there is a lack of studies based on physical activity in connection with healthy ageing.

Objective

The objective of this study was to focus on the physical activity status of community-dwelling elderly individuals, and its association with gender and occupation.

METHOD

Study Design

This was a cross-sectional study with men and women above 60 years of age, from selected communities near Vadodara in Gujarat, India.

Study Sample

The Sarpanch and Primary Health Centres of selected villages were approached for permission to conduct the study. After obtaining permission from both, a door-to-door survey was undertaken. The purpose of the study was explained to elderly persons, 60 years of age or older, whom the researcher encountered. Those who were willing to participate were asked to sign a written informed consent form. After this, they were given an information sheet with more details about the study.

In accordance with the inclusion criteria of having a Mini Mental State Examination (MMSE) score ≥24, the recruited elderly persons were screened using a physiotherapy assessment form including a Mini-Mental State Examination (MMSE) (Creavin et al, 2016). Male and female subjects, above 60 years of age, with MMSE≥24 and willing to participate, were included in the study.

Sample size was calculated as 347 $(n = \frac{Z^2\, P\,(1-P)}{d^2},)$

Where Z= statistic for the level of confidence at 95% confidence interval Z=1.96,

P= Expected prevalence of proportion at 67% P=0.67, and

d= Precision at 0.05.

Data Collection

Three hundred and fifty one (n=351) elderly persons from the Bhadalpur and Waghodia communities were approached at their door-steps, out of which four persons declined to participate in the study. The remaining 347 participants were screened for inclusion criteria and the data was collected using the Global Physical Activity Questionnaire (GPAQ). This questionnaire was developed by the WHO to assess the frequency and intensity of physical activity in different settings. It collects information on physical activity participation in three domains (settings), namely, activity at work, travel to and from places, and recreational activities as well as sedentary behaviour. Screening and administering a questionnaire required approximately an hour to collect the data from a single participant. On an average, data was collected from 2-3 participants per day for five days in a week.

Data Analysis

All statistical analysis was performed using Statistical Package for Social Sciences version (SPSS 25). Descriptive statistics including mean, standard deviations, and standard error were computed for all variables.

Ethics Approval

The study was approved by the Sumandeep Vidyapeeth Institutional Ethical Committee (SVIEC/ON/PHYS/BNMPT17/D18007). Data collection started after obtaining the SVIEC approval.

RESULTS

Although 351 community-dwelling elderly individuals were screened, there were only 347 participants in the study. Four individuals declined due to prior commitments. The predominantly female participants numbered 188 or 54%, while the male participants were 159 in number or 46%. They were all from Bahadalpur and Waghodia areas, and the mean age was 67.43±7.46 years. The pattern of physical activity of all the participants, according to the four domains of the WHO questionnaire, is shown in Table 1.

Table 1: Pattern of Physical Activities in a typical week among Community-dwelling Elderly People (N=347)

Pattern of Physical Activities	**N (%)**	**Mean MET- minute**
Activity at work		
Vigorous intensity	07(2%)	3300
Moderate intensity	41(12%)	357.55

Travel to and from places	264(76)	737.84
Recreational activities Vigorous intensity Moderate intensity	 0 2(0.9)	 0 150
Sedentary behaviour(min)	347(100%)	326.94
Total activities in MET-minutes		
MET Score < 600 (Physically Inactive)	222(64%)	1892.34
MET Score ≥ 600 (Physically Active)	125(36%)	2822.56
Total population	347	1201.09

Based on the GPAQ, the study population can be divided into 2 two groups. Those with <600 MET score are classified as physically inactive and those with ≥600 MET score are categorised as physically active. Demographic characteristics of physically active and physically inactive groups are shown in Table 2.

Table 2: Demographic Characteristics of both Groups (N=347)

Demographic Variables	**Active Group N (%) 125 (36)**	**Inactive Group N (%) 222 (64)**	**Total N(%) 347(100)**
Gender			
Male	90(72)	69(31)	159(46)
Female	35(28)	153(69)	188(54)
Age Group			
60-69 years	96(77)	144(65)	240(69)
70-79 years	20(16)	50(23)	70(20)
80-89 years	09(7)	25(11)	34(10)
90-99 years	00	3(1)	3(1)
Body Mass Index (BMI)			
Underweight	11(9)	17(8)	29(8)
Normal	71(57)	94(42)	165(48)
Overweight	23(18)	51(23)	72(21)
Obese	20(16)	60(27)	80(23)

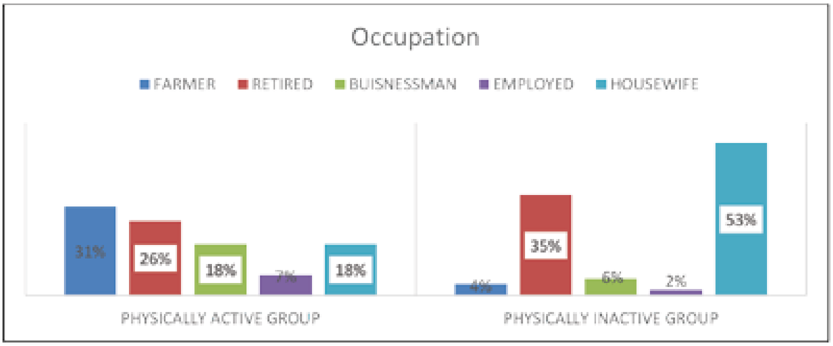
Occupation			
Retired	32(26)	78(35)	110(32)
Farmer	39(31)	08(4)	47(13)
Businessman	22(18)	13(6)	35(10)
Employed	09(7)	05(2)	14(4)
Housewife	23(18)	118(53)	141(41)
Education			
Illiterate	16(13)	38(17)	54(15)
Primary school	41(33)	91(41)	132(38)
Secondary school	49(39)	72(32)	121(35)
College	19(15)	21(10)	40(12)

The data of the present study did not fall under normal distributions such as the Shapiro-Wilk normality test with significant result of p-value <0.05. Therefore, non-parametric chi-square test and Spearman's correlation coefficient test were used for significant association among various variables. These are shown in Table 3 and Figure 1.

Table 3: Association of GPAQ with Gender and Occupation (N=347)

	VARIABLE	CHI-SQUARE VALUE	CORRELATION COEFFICIENT	P-VALUE
GPAQ	GENDER	53.937	0.394^{**}	<0.01
	OCCUPATION	86.816	0.331^{**}	<0.001

Figure 1: Global Physical Activity Questionnaire (GPAQ) on different Occupations (N=347)



DISCUSSION

This study was an attempt to learn about the physical activity levels of the community-dwelling elderly population. Only 36% of the individuals in the study sample were physically active according to WHO- recommended levels. As per WHO recommendations, inclusive of the activity for purposes of work, transport and leisure throughout a week, an adult should perform at least 150 minutes of moderate-intensity physical activity or 75 minutes of vigorous-intensity physical activity, or an equivalent combination of moderate and vigorous-intensity physical activity, achieving at least 600 MET-minutes (WHO, 2010).

Literature on the subject, has pointed - for quite some years already- to the decline in the physical activity of the elderly population across the globe. In the USA, Centres for Disease Control and Prevention (CDC) reported that 26.9% of adults aged 65–74 years and 35.3% aged ≥75 were found to be physically inactive (Kruger, 2007). In the UK, the Health Survey for England reported that 50% of adults aged 65-74 years and 74% aged 75 years or older were found to be physically inactive (Trinh, 2008). In one of the studies done in Canada by the National Advisory Council on Ageing (NACA) in 2006, it was reported that 62% of adults aged 65 years and older were physically inactive (Rotermann, 2006). Similar to their findings, in the present study, 42% of adults aged 60-69 years and 22% of adults aged 70 years and older (in total 64% of adults above 60 years of age) were found to be physically inactive when assessed with the Global Physical Activity Questionnaire (GPAQ). One of the possible reasons for inactivity among the elderly population, as stated in the literature, is that physical activity is not being given much importance by the elderly as compared to the medication (Shaheen, 2016).

A study by De et al (2018) on the elderly population in an urban slum area of West Bengal in India, reported that 24% of the participants were involved in physical activity of vigorous intensity, 36% in physical activity of moderate intensity. For 19.8%, physical activity took the form of travel to and from places, 5.6% were involved in vigorous recreational activities, 17.9% in moderate level of recreational activity, and only 3% of the participants were inactive, as assessed by the GPAQ Scale. However, by using the same questionnaire, the current study found only 2% carried out vigorous physical activity, 9.4% performed moderate-intensity physical activity at their workplace, 76% experienced physical activity in the form of travel to and from places, 0.6% had recreational activities of moderate-intensity, and 12% were inactive. De et al (2018) suggested that the much higher proportion of physically active/highly active elderly individuals in their West Bengal study could be due to the poor socio-economic status of the participants from the slum area.

In the United States, Conn et al (2002) found that only 12% of adults aged 75 years and older were engaged in 30 minutes of moderate physical activity for 5 days or more per week while 65% reported no physical activity.Approximately 40% - 80% of the older adults do not meet the recommended physical activity standards, according to the finding of a systematic review by Notthoff et al (2017). In the present study, only 0.6% of participants aged 75 years and older were engaged in 60 minutes of moderate physical activity for 3 days or more per week, 0.3% of adults were engaged in vigorous physical activity on a regular basis, 11% were involved in moving to and from a place, and 4% of participants were totally inactive.

According toWarburton (2006), in Canada walking is reported to be the most popular physical activity among adults aged 65 years and older, with 65% of older adults opting to walk. However, in the present study, only 51% of the participants in the same age group of 65 years and above, did 30-60 minutes of walking in a day per week, in the form of exercise, transportation (to shops and market), for leisure or for daily activity. The elderly population is the most sedentary population, even when one considers walking which is the most popular and accessible activity for them (Notthoff et al, 2017). In the present study, only 12% of the elderly population was involved in activity of moderate intensity, and only 2% undertook high-intensity activity in the form of occupational pursuits like farming, handling cattle, pottery, cutting wood, tailoring, and working as house help and in the construction sector.

Statistically significant association of physical activity with gender and occupation was found in the present study. Gender is an important factor that influences the physical activity levels of the older population. One of the studies (McPhee, 2016) reported that women were more inactive as they had lower levels of education and income, fewer were married, and a greater number was living alone. In addition, women perceiving their health to be worse, were more likely to have barriers to physical activity, and indicated lower self-efficacy for physical activity than men (Humpel, 2002). In the US population, 26% of men and 12% of women were engaged in regular physical activity or exercise for at least 30 minutes a day, 5 times a week. There were similar findings in the present study, with 26% of males and 10% of females engaged in walking for 30 minutes a day, 6-7 days a week.

In the current study, the information regarding daily chores of the elderly population were also taken in order to understand their daily schedule. The majority of female participants were housewives who engaged in household chores like cooking, sweeping, mopping the floor, washing clothes and utensils, taking care of grandchildren and family members, reading religious books, watching TV serials, chanting *mantras* (prayers) and chatting with friends. They were also walking for 10-20 minutes, 3-7 days per week, but they were not involved in any activities of moderate or high-intensity and were sedentary for longer periods of time - approximately 337 minutes per day. They preferred to use vehicles for transportation. In most of the studies included in a systematic review, men were found to be more physically active as compared to women. In addition, men were found to be more involved in vigorous physical activities - work-related, transportation or sports-related activities and leisure-time physical activities. In contrast, women were more physically active when it involved household chores/gardening (Notthoff et al, 2017).

Occupation also had a positive association with physical activity. Those who were employed and engaged in occupational activities had higher physical activity levels and were less sedentary. Though employment may not have a strong association with physical activity (Notthoff, 2017), in the present study the female participants were found to be more inactive than the male participants. The majority of the elderly male participants were involved in occupational activities like farming, handling cattle, pottery, wood cutting, tailoring, and labouring in the fields for their livelihood, and the majority of the female participants were engaged in household chores. Older adults are the most sedentary age group, spending 65%-80% of their waking time in sedentary behaviour (Rathi, 2017)

Physical disabilities and chronic diseases which increase with advancing age restrict elderly people's participation in daily activities, social engagements, and leisure activities, making them feel sad, socially isolated, frustrated and dissatisfied with life. They feel they are a burden to their family and have poor quality of life (Singh et al, 2009). In the current study, information regarding their co-morbidities such as hypertension, diabetes etc. was obtained during the physiotherapy assessment and was analysed with respect to their physical activity. The information regarding co-morbidities which was asked during the physiotherapy assessment revealed that, among the 222 inactive participants, 133(69%) had hypertension, 44(20%) had diabetes and 174(78%) had musculo-skeletal conditions. Among the 125 active participants, 40(32%) had hypertension, 13(10%) had diabetes and 61(49%) had musculo-skeletal conditions. Physical activity reduces the risk of cardio-vascular disease, osteoporosis, improves cognitive functioning and overall well-being (Notthoff et al, 2017).

CONCLUSION

In the current study, the majority of the participants (64%) were physically inactive when measured against the recommendations of the WHO. The female participants were found to be more physically inactive than the male population. This study implies that there is a need to create awareness among the general public regarding the importance of physical activity for healthy aging. More specifically, focused health promotion strategies and interventions should be directed at the elderly population. While the government has an important role to play in educating the society, the physiotherapy profession in particular can play a role in lobbying for the necessary public health interventions and at the same time on a small scale start with the dissemination of information to the elderly population and encourage them to take part in activities which stimulate physical activity and which can be set up by physiotherapists.

References

Barnett A, Cerin E, Zhang C, Sit C, Johnston J, Cheung M, Lee R (2016). Associations between the neighbourhood environment characteristics and physical activity in older adults with specific types of chronic conditions: The ALECS cross-sectional study. International Journal of Behavioural Nutrition and Physical Activity; 13(1): 1-13. https://doi.org/10.1186/s12966-016-0377-7 PMid:27105954 PMCid:PMC5477845

Bryan S, Katzmarzyk P (2011). The association between meeting physical activity guidelines and chronic diseases among Canadian adults. Journal of Physical Activity and Health; 8(1): 10-17. https://doi.org/10.1123/jpah.8.1.10 PMid:21297180

Cadilhac D, Cumming T, Sheppard L, Pearce D, Carter R, Magnus A (2011). The economic benefits of reducing physical inactivity: An Australian example. International Journal of Behavioral Nutrition and Physical Activity; 8(1): 99. https://doi.org/10.1186/1479-5868-8-99 PMid:21943093 PMCid:PMC3192710

Conn V, Minor M, Burks K, Rantz M, Pomeroy S (2003). Integrative review of physical activity intervention research with ageing adults. Journal of the American Geriatrics Society; 51(8): 1159-1168. https://doi.org/10.1046/j.1532-5415.2003.51365.x PMid:12890083

Creavin ST, Wisniewski S, Noel-Storr AH, Trevelyan CM, Hampton T, Rayment D, et al (2016). Mini-Mental State Examination (MMSE) for the detection of dementia in clinically unevaluated people aged 65 and over in community and primary care populations (Review). Cochrane Database of Systematic Reviews; 1: 1-3.

Department of Health (2019). Publications [online]. Available at: https://www.health.gov.au/internet/main/publishing.nsf/Content/health-publicat.htm.

De S, Roy R, Mitra K, Das D, Dan A (2018). Physical activities and quality of life among elderly population in urban slum of Bardhaman Municipality, West Bengal. Journal of Dental and Medical Sciences (IOSR-JDMS); 17(12): 67-73.

Galloway M, Jokl P (2000). Ageing successfully: The importance of physical activity in maintaining health and function. Journal of the American Academy of Orthopaedic Surgeons; 8(1): 37-44. https://doi.org/10.5435/00124635-200001000-00004 PMid:10666651

Gamage N, Rathnayake N, Alwis G (2019). Prevalence and associated risk factors of falls among rural community-dwelling older people: A cross-sectional study from Southern Sri Lanka. Current Gerontology and Geriatrics Research; 2019: 1-10. https://doi.org/10.1155/2019/2370796 PMid:31275369 PMCid:PMC6558626

Humpel N (2002). Environmental factors associated with adults' participation in physical activity: A review. American Journal of Preventive Medicine; 22(3): 188-199. https://doi.org/10.1016/S0749-3797(01)00426-3

Kruger J, Carlson S, David Buchner D (2007). How active are older Americans? Centres for Disease Control and Prevention; 4(3): 1-12

McPhee J, French D, Jackson D, Nazroo J, Pendleton N, Degens H (2016). Physical activity in older age: Perspectives for healthy ageing and frailty. Biogerontology; 17(3): 567-580. https://doi.org/10.1007/s10522-016-9641-0 PMid:26936444 PMCid:PMC4889622

Musich S, Wang S, Hawkins K, Greame C (2017). The frequency and health benefits of physical activity for older adults. Population Health Management; 20(3): 199-207. https://doi.org/10.1089/pop.2016.0071 PMid:27623484 PMCid:PMC5488312

Nelson M, Rajeski W, Bilar M, Rejeski W, Blair S, Duncan P, Judge J, King A, Macera C, Castaneda-Sceppa C (2007). Physical activity and public health in older adults. Medicine & Science in Sports & Exercise; 39(8): 1435-1445. https://doi.org/10.1123/jpah.4.4.496

Notthoff N, Reisch P, Gerstorf D (2017). Individual characteristics and physical activity in older adults: A systematic review. Gerontology; 63: 443-459. https://doi.org/10.1159/000475558 PMid:28675889

Rathi H, Matthu S (2017). Quality of life in elderly population - A survey. Journal of Frontiers in Cognitive Psychology; 2(2): 33-37.

Rotermann M (2006). Seniors health care use. In: Statistics Canada. How healthy are Canadians. Annual report 2005. Ottava: Statistics Canada. [online]. Available at: https://www.peelregion.ca/health/health-status-report/seniors-health-report/pdfs/2006-seniors-hsr.pdf

Schutzer K (2004). Barriers and motivations to exercise in older adults. Preventive Medicine; 39(5): 1056-1061. https://doi.org/10.1016/j.ypmed.2004.04.003 PMid:15475041

Shaheen M, Puri S, Tandon N (2016). Physical activity measurement in elderly: The Indian scenario. Journal of Physical Activity research; 1(1): 9-14.

Singh A, Misra N (2009). Loneliness, depression and sociability in old age. Ind Psychiatry J; 18(1): 51-55.Trinh O, Nguyen N, Dibley M, Phongsavan P, Bauman A (2008). The prevalence and correlates of physical inactivity among adults in Ho Chi Minh City. BMC Public Health; 8(1): 1-11 https://doi.org/10.4103/0972-6748.57861 PMid:21234164 PMCid:PMC3016701

Trost S, Owen N, Bauman A, Sallis J, BrownW (2002). Correlates of adults participation in physical activity: Review and update. Medicine & Science in Sports & Exercise; 34(12): 1996-2001. https://doi.org/10.1097/00005768-200212000-00020 PMid:12471307

Warburton D (2006). Health benefits of physical activity: The evidence. Canadian Medical Association Journal; 174(6): 801-809. https://doi.org/10.1503/cmaj.051351 PMid:16534088 PMCid:PMC1402378

World Health Organisation (2010). Global recommendations on physical activity for health [online]. Available at: https://www.who.int/dietphysicalactivity/factsheet_recommendations/en/

World Health Organisation (2015). Ageing and health. Available at: https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1

World Health Organisation (2019). Physical activity and adults [online]. Available at: https://www.who.int/dietphysicalactivity/factsheet_adults/en/

Teachers' Attitudes towards Inclusion of Blind or Partially-Sighted Students in Secondary Schools in Nigeria

Paul M Ajuwon[1*], George Chitiyo[2], Liziana N Onuigbo[3], Adaka T Ahon[4], James E Olayi[5]

1. Dept of Counselling, Leadership & Special Education, Missouri State University, Springfield, Missouri, USA
2. Dept of Curriculum & Instruction, Tennessee Technological University, Cookeville, Tennessee, USA
3. Dept of Educational Foundations, University of Nigeria, Nsukka, Enugu State, Nigeria
4. Dept of Special Needs Education, Federal University, Lafia, Nasarawa State, Nigeria
5. Dept of Special Education, University of Calabar, Calabar, Cross River State, Nigeria

ABSTRACT

Purpose: *This study investigated the attitudes of secondary school teachers towards students with blindness or partial sight in selected states in Nigeria.*

Method: *The authors utilised the modified version of a previous instrument to collect data from 306 secondary school teachers in Nigeria. Six basic questions were established to address: respondents' attitudes towards inclusion; training acquired related to teaching; knowledge pertaining to policy and legislation; confidence levels to teach students with disabilities.; impact of geographical location; and differences in attitudes by the variables of subject(s) taught, school level taught, and years of teaching experience.*

Results: *Attitudes of participants were mixed but were generally positive. The level of training was low, with teachers showing limited knowledge of policy and legislation. A little over a quarter (27%) of them lacked confidence in teaching. There were differences in attitudes related to the geographical location of respondents. Those who taught at the senior secondary school level tended to have higher attitude scores on average than their counterparts at the junior secondary school level.*

Conclusion and Limitations: *This study used self-report measures, although observations and interviews could be additional ways to evaluate the attitudes of participants throughout the country. Moreover, in-service programmes may need to be implemented to increase teachers' knowledge base and expand their experiences in line with established policies and legislation.*

---

[*] **Corresponding Author:** Paul M Ajuwon, Department of Counselling, Leadership & Special Education, Missouri State University, 901 S. National Avenue, Springfield, MO 65897, USA. Email:paulajuwon@missouristate.edu

Key words: *inclusive education, secondary schools, perceptions of practitioners, visual impairment, disabilities, Nigeria, Africa*

INTRODUCTION

In Nigeria, unlike in high-income countries, students with blindness or partial sight (also known as visual impairment) have generally been educated in regular secondary schools — a process popularly known as "inclusion" (UNESCO, 2009). Inclusion implies that students with disabilities will receive quality education among classmates without disabilities who are of a similar age. Therefore, the inclusive process is now seen as a strategy to ensure education for all learners (UNESCO, 1994; Ainscow & Miles, 2009). Inclusionists contend that in an inclusive education setting, the curricula, instructional methods, assessment techniques and documentations need to be adjusted. Thus, teachers are expected to provide students with disabilities with equitable support to enable them to fully participate physically, socially and academically with their peers without disability (United Nations, 2006; UNESCO, 2009; Forber-Pratt & Lyew, 2019).

In Nigeria today, frontline teachers, school administrators, organisations of persons with and without disabilities, parents, and politicians, among others, continue to examine the ramifications of this education practice (Ajuwon, 2008; Adaka, 2013; Olayi, 2016). In furtherance of this philosophy, the Nigerian government has been a signatory to a number of major international treaties that seek to promote inclusion. These include: the Salamanca Statement and Framework for Action on Special Needs Education (UNESCO, 1994), the Dakar Framework for Action (United Nations, 2000), and the Convention on the Rights of Persons with Disabilities (United Nations, 2006).

The Federal Republic of Nigeria has initiated four landmark policies in the past five years. These include: the National Policy on Education (2014), the National Policy on Special Needs Education in Nigeria (2015), the National Policy on Inclusive Education in Nigeria (2017), and the Discrimination against Persons with Disabilities (Prohibition) Act (2019). These international treaties and domestic policies emphasise, among other ideas, the implementation of inclusive education within community schools for students with special needs, including those with blindness or partial sight.

As inclusion of students with blindness and partial sight into community-based schools becomes a reality within junior and senior secondary schools, it has become imperative to evaluate the attitudes, knowledge, roles and responsibilities of teachers. Implementing inclusionary services in an effective manner remains a challenge, even in high-income countries. In most societies today, teachers are known to be powerful agents of change, and they are gradually being seen as vital stakeholders in the implementation of inclusive programmes. However, limited empirical research exists to document the efficacy of the practice of including students who are blind or partially-sighted into Nigeria's secondary schools.

Objective

This study aims to explore teachers' knowledge, attitudes, confidence level of teaching children with diverse needs, and roles in the inclusion process. This is an important initiative, given the numerous secondary schools that now accommodate such learners. In addition, there are state and national pressures to include students with visual impairments in community schools. Therefore it is important to acquire knowledge and gain an understanding of the attitudes, roles and responsibilities of these teachers towards learners who are visually impaired. Such an understanding would provide evidence for needed reform in pre-service and in-service special needs education training that would ultimately enhance teaching and learning in junior secondary school (JSS) and senior secondary school (SSS) levels in the country.

Research Questions

To guide the analyses of project data, the authors formulated the following research questions:

1. What are teachers' attitudes towards including students who are blind or partially-sighted in their classrooms?
2. How much training have teachers received regarding teaching these students?
3. How knowledgeable are teachers regarding policy and legislation on these students?
4. How confident are teachers in educating these students?
5. How do teachers' attitudes towards including students with blindness or partial sight in their classrooms vary by geographic location?

6. How do teachers' attitudes towards including such learners in their classrooms vary by: (a) subject(s) taught, (b) school level taught, (c) education level, and (d) years of teaching?

METHOD

Participants

The participants comprised mainly general education teachers employed in junior and senior secondary schools in 10 states and the Federal Capital Territory Abuja (FCTA). After all the data screening procedures were completed, the sample consisted of 306 participants. The distribution of teachers by gender, school level taught, education level, and years of experience is given in Table 1.

Procedure

As a starting point for the investigation, the lead author modified the instrument used in Zimbabwe by Mushoriwa (2001). While the Zimbabwe study focused on the attitudes of teachers towards including children who are blind in regular classrooms, the current research assessed the attitudes of regular secondary school teachers toward inclusion. The instrument comprised three sections. Section 1 consists of items that asked for participants' basic demographic information, including gender, age, highest educational qualification, subject(s) and class level(s) taught, name of school (which was used to determine the state in which the participant was employed), and length of years of teaching. There were questions on whether respondents and their immediate family members had a disability, and the type of disability. In addition, the authors wanted to ascertain how much training participants had in teaching students who are blind or partially-sighted, how they rated their knowledge of policy and legislation related to their students, and their perceptions of their overall level of confidence in teaching these students. The 14 items in the second section of the instrument evaluated the attitudes towards students who are blind or partially-sighted. The last section of the questionnaire elicited additional respondents' comments that were not included in the two previous sections.

Data Collection

About 400 copies of the questionnaire in ink print format and another 100 copies in Braille format, making a total of 500 copies, were distributed in the second half of

2017. Reminder phone calls, text and/or email messages were sent to the Nigerian Association of Exceptional Children (NAEC) and the Nigerian Association of Special Education Teachers (NASET) at two- and four-month intervals of the six-month survey period. In all, 321 (64.2%) completed questionnaires (52 in Braille format, and 240 in ink print format) were returned to the lead author for data entry and analyses, using SPSS version 24.

Ethics Approval

After obtaining approval from the Institutional Review Board (IRB) of Missouri State University, U.S.A., the major special education organisations in Nigeria were notified on the goals and objectives of the project, and their help was solicited to distribute the questionnaires and collect them after completion.

RESULTS

The distribution of participants by key demographic variables is shown in Table 1. The sample consisted of 306 participants, of whom 46% (*n* = 141) were male and 53.9% (*n* = 165) were female. Of the 296 teachers who indicated their place of employment, 58% (*n* = 173) taught at the junior secondary school (JSS) level and 42% (*n* = 123) taught at the senior secondary school (SSS) level. Most of the teachers at both the JSS and SSS levels had between one and five years of teaching experience.

Table 1: Distribution of Participants by Demographic Variables

	JSS Level	**SSS Level**	**Total**
Education Level			
NCE	39.3% (69)	18.7% (23)	31.3% (92)
BED/Bachelors/HND	46.8% (81)	58.5% (72)	51.7% (153)
Masters/PGDE/PhD	13.3% (23)	22.8% (28)	17.2% (51)
Total	100% (173)	100% (123)	100% (296)
Gender			
Male	41.2% (73)	52.8%	46.0% (139)
Female	58.8% (104)	47.2% (59)	54.0% (163)
Total	100% (173)	100 (125)	100 (302)
Years of Experience			
1-5	43.5% (74)	42.6% (52)	43.2% (126)
6-10	22.9% (39)	18.9% (23)	21.2% (62)

11-15	12.4% (21)	15.6% (19)	13.7% (40)
16-20	11.8% (20)	10.7% (13)	11.3% (33)
21-35	9.4% (16)	12.3% (15)	10.6% (31)
Total	100.0% (170)	100.0% (122)	100.0% (292)

Teachers' Attitudes towards Including Students with Visual Impairments in their Classrooms

The first research question sought to ascertain teachers' attitudes towards including students with visual impairments in their classrooms. The survey instrument had 14 items (shown in Figures 1 and 2) which respondents were asked to rate on a 5-point Likert scale. The majority of respondents consistently agreed with each of the positively worded statements, and smaller percentages of the teachers agreed with the negatively worded items.

Figure 1: Percentage of Teachers in Agreement with each Statement about Attitudes towards Including Students with Visual Impairment

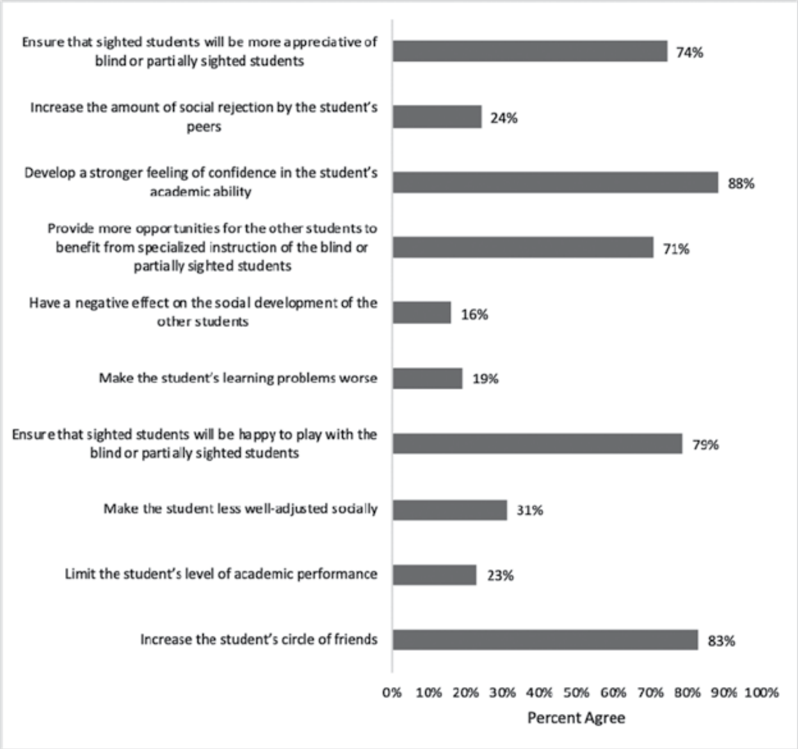


Figure 2: Percentage of Respondents in Agreement with each Statement regarding Regular Teachers' Preparedness to Educate Students with Visual Impairment

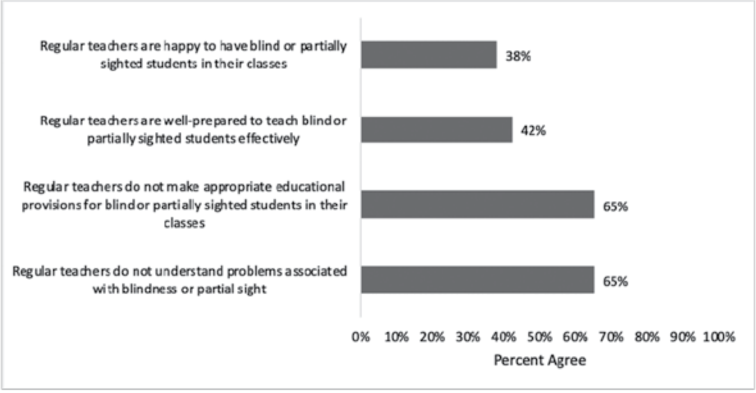


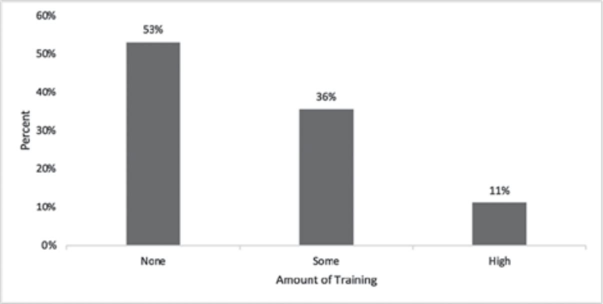
Figure 2 shows responses regarding regular teachers' preparedness to include students with visual impairments in their classrooms. The percentages of positive responses were generally low:

- 38% of teachers indicated that regular education teachers are happy to have students who are blind or partially-sighted in their classes,
- 42% indicated that regular education teachers are well prepared to teach students who are blind or partially-sighted,
- 65% indicated that regular education teachers do not make appropriate educational provisions for blind or partially-sighted students in their classes,
- 65% indicated that regular teachers do not understand problems associated with blindness or partial sightedness.

Training regarding Teaching Students who are Blind or Partially-Sighted

The second research question sought to ascertain how much training participants had received related to teaching students who are blind or partially-sighted. As illustrated in Figure 3, more than half (53%) had received no training, 36% had received some training, and 11% indicated a "high" amount of training.

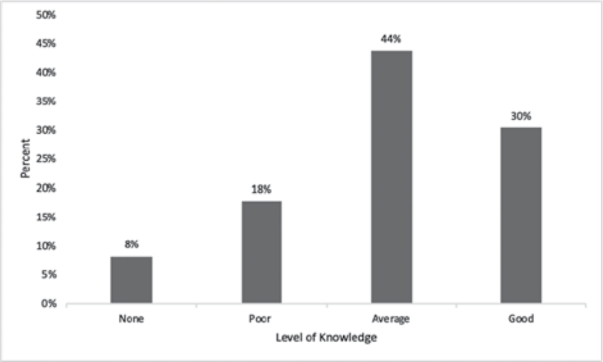
Figure 3: Amount of Training Received



Knowledge of Policy and Legislation

Regarding knowledge of policy and legislation pertaining to students with visual impairments, less than one-third of the participants (30%) indicated having a good amount of knowledge, and slightly less than half (44%) had average knowledge. Some of them (8%) had no knowledge at all, and 18% had poor knowledge. This distribution is shown in Figure 4.

Figure 4: Distribution of Teachers by Level of Knowledge of Policy and Legislation



Level of Confidence in Teaching Students with Visual Impairments

Figure 5 presents the distribution of responses to the study's third research question, about participants' level of confidence in teaching students with visual impairments. Slightly over one- third (38%) of the teachers expressed high (25%) and very high (10%) levels of confidence in teaching students with visual impairments. About 27% had low or very low confidence.

Figure 5: Level of Confidence in Teaching Students who are Blind or Partially-Sighted

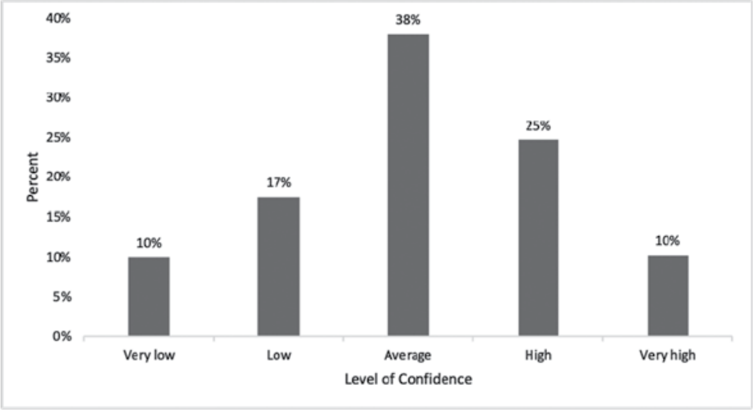
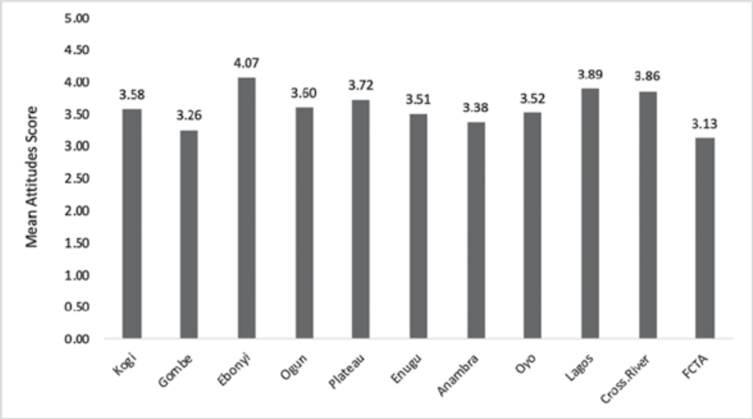


Figure 6: Mean Attitude Score of Teachers teaching Visually Impaired Students (by State)



Attitudes of Teachers by State

Figure 6 shows the mean attitudes of the teachers who teach students with visual impairments in 10 different states and FCTA. From the Figure, it is evident that the mean for Ebonyi is generally higher than for all other states, and that for FCTA is the lowest among the 11 jurisdictions. A one-way analysis of variance was conducted to assess whether these attitudes were significantly different across the various states. The results revealed statistically significant differences in mean attitudes [F (10,295) = 7.801, $p< .05$] among some pairs of states. Tukey's post hoc test showed that mean attitudes for Ebonyi state (M_{EB} = 4.07) were significantly higher ($p < .05$) than for Kogi M_{KO} = 3; Gombe M_{GO} = 3.26; Ogun M_{OG} = 3.60; Enugu M_{EN} = 3.51; Anambra M_{AN} = 3.38; Oyo M_{GY} = 3.52; and, FCTA M_{FC} = 3.13.

Other differences in means ($p < .05$) were between Gombe and Lagos ($M_{GO} = 3.26$, $M_{LA} = 3.89$), Gombe and Cross River ($M_{GO} = 3.26$, $M_{CR} = 3.86$); Ogun and FCTA [($M_{OG} = 3.6019$, $M_{FC} = 3.13$); Plateau and FCTA ($M_{PL} = 3.72$, $M_{FC} = 3.13$); Anambra and Lagos ($M_{AN} = 3.38$, $M_{LA} = 3.89$); Anambra and Cross River ($M_{AN} = 3.38$, $M_{CR} = 3.86$); Lagos and FCTA ($M_{LA} = 3.89$, $M_{FC} = 3.13$); and lastly, Cross River and FCTA ($M_{CR} = 3.86$, $M_{FC} = 3.13$).

Testing for Differences in Attitudes

An average attitude score was computed using all 14 items presented in Figures 1 and 2. The mean attitude score was $M = 3.57$, with a standard deviation of .49, a minimum score of 1.93 and a maximum of 4.79. A four-way analysis of variance was conducted to test for differences in attitudes using the independent variables of school level taught, years of teaching, education level, and subject taught. The main effect of the school level taught was statistically significant [$F(1,276) = 5.95$, $p < .05$]. Teachers who taught at the SSS had a higher adjusted mean ($\mathrm{M}_{\mathrm{SSS}} = 3.66$) than those who taught at the JSS level ($\mathrm{M}_{\mathrm{JSS}} = 3.52$), controlling for the other variables.

Regarding education level, the mean for NCE ($\mathrm{M}_{\mathrm{NCE}} = 3.69$) was higher than that for teachers with Bachelor's degrees/HND ($\mathrm{M}_{\mathrm{Bach}} = 3.63$) and advanced degrees ($\mathrm{M}_{\mathrm{ADV}} = 3.44$). Although, the omnibus F statistic showed significance for this variable [$F\ (2,276) = 3.925$, $p < .05$], Tukey's post hoc test only showed a **near significant** difference between the NCE and advanced degrees (Masters/PGDE/PhD) ($p = .079$). The mean differences among the other pairs were not significant. The main effects of years of teaching ($F\ (4,276) = 1.614$, $p > .05$) and subject taught ($F\ (2,276) = 2.665$, $p > .05$) were both not statistically significant.

In summary, attitudes among teachers were mixed, but generally pointed in the positive direction. The level of training among teachers working with students with visual impairments was low. Teachers had limited knowledge of policy and legislation regarding students with visual impairments. Ideally, all teachers should have minimally an "average" amount of knowledge regarding students with disabilities. A little over a quarter (27%) of them were not confident about teaching students who are blind or partially-sighted.

There were differences in attitudes among some states, with Ebonyi having the highest mean attitude score and FCTA having the lowest. The range of mean scores was thus .91. Holding other factors constant, mean attitudes did not differ due to years of teaching or subject taught.

Teachers who taught at the SSS tended to have better, more positive attitudes towards blind and partically sighted students on average than those who taught at the JSS level. No meaningful conclusion can be made about differences in education level when controlling for subject taught, years of teaching, and school level taught.

DISCUSSION

It is important to investigate the attitudes of classroom teachers towards the practice of inclusion because attitudes have the potential to impact the educational outcomes of learners with and without disabilities. Clearly, for this paradigm of education to be effective, all educators must be fully involved in the conceptualisation and implementation of inclusion (Snyder, 1999).

Educators in various countries are now expected to rise to the challenge of an increasingly diverse classroom culture (Peterson & Beloin, 1992), adjust their teaching strategies to accommodate varying learning styles, and be psychologically and pedagogically prepared to assume the dynamic role of an inclusive educator (Hunter-Johnson et al, 2014). Having recognised the fact that teachers are the primary agents in the implementation of the curriculum in inclusive classrooms, there is need to consider how their attitudes will influence their behaviour towards, and their acceptance of, students with disabilities. Besides, the attitudes of teachers instructing students with disabilities may have some bearing on the success of inclusive educational programmes (Van Reusen et al, 2001; Boyle et al, 2013).

Based on the pattern of responses, the study data indicated that teachers' attitudes towards inclusion of students were generally positive; however, several teachers still displayed some negative feelings. This finding is supported by previous studies which show teachers' positive attitudes towards inclusion of students with disabilities (York et al, 1992; Ward et al, 1994; Villa et al, 1996; Avramidis et al, 2000). Conversely, other studies have shown teachers' negative attitudes towards students with disabilities in inclusive settings (Larrivee & Cook, 1979; Gersten et al, 1988; Coates, 1989; Semmel et al, 1991; Jelagat & Ondigi, 2017). The generally positive trend found in the current study showed that the teachers in Nigeria have a fairly sound understanding that inclusion has both social and academic benefits, not only to the students with disabilities, but also to students without disabilities. This improvement in attitudes may be attributed to recent in-service training for teachers. When teachers acquire information and knowledge, there is a tendency that they will develop positive attitudes.

Although some of the teachers have been exposed to some form of training, it is possible that many have not received the training specifically tailored to teaching students who are blind or partially-sighted. This fact is corroborated by a Cameroonian study (Mngo & Mngo, 2018) which showed a serious shortage of trained specialists required to work with students with disabilities in inclusive settings. This may suggest that inclusion of students with visual impairments could be fraught with challenges because teachers must acquire specialised and unique competencies to teach students who are blind or partially-sighted.

In spite of the mandate given to teacher training institutions to introduce into their curriculum Elements of Special Education, a large number of teachers have not received the appropriate training on how to teach students with visual impairments. This may be because the mandate is yet to be implemented in some tertiary institutions, resulting in some of their teacher candidates graduating without the requisite knowledge and skills. It is also possible that the visual impairment emphasis in the course on Elements of Special Education is insufficient to inculcate adequate knowledge and skills that will enable trainees to teach effectively. In order to alleviate these challenges, the National Teachers Institute (NTI) under the Millennium Development Goals (MDGs) incorporated Special Education Needs and Disabilities (SEND) training into their annual programme in 2012 (National Teachers Institute, 2012). However, it is likely that many of the currently employed teachers might not have had the opportunity to participate in the training programmes. Those that reported "high" amounts of training would most likely be teachers who specifically studied Special Education.

With regard to knowledge of policy and legislation, 44% of respondents stated that they had "average" knowledge, 30% had "good", and 18% had "poor", while 8% had "none". Based on this data, it is evident that many teachers possess limited knowledge of policy and legislation related to inclusive education. This finding is not surprising considering that many teachers, especially in Nigeria, are concerned that including students with blindness or low vision would lower school standards because these students would be unable to pass national examinations. Anecdotal evidence suggests that this is a real concern among administrators and teachers because adequate funding options are often unavailable to sustain inclusionary programmes in community-based schools. In other words, teachers usually view policies and legislation as documents that only influence the government, while their responsibility as teachers is only to teach the academic components in the curriculum. This attitude towards policies and legislation could explain the current findings illustrated in the project data.

The data indicated that slightly over a quarter (27%) of the participants lacked confidence to teach students who are blind or partially-sighted. By implication, the majority of teachers (73%) are confident about teaching such students. This might seem in contrast to a previous study conducted by Ajuwon (2012) which showed that teachers were less confident in managing behaviours of students with special needs, including those with visual impairments. The high level of confidence seen in the current investigation could be attributed to the mandatory course on Introduction to Special Education in all tertiary institutions. This course provides a platform for teacher trainees to acquire the knowledge, information and skills that will increase their confidence in the classroom. Such training could have provided teachers with ample knowledge of the characteristics and behaviours of students with visual impairment, as well as some strategies they could apply in inclusive classrooms. This underscores the need for continuous professional training of teachers, since training will no doubt equip them with the necessary skills. Given the importance of professional development training, it will behove the authorities to streamline the selection of candidates for such training in order to guarantee that as many teachers as possible are given the opportunity to participate in the process.

The finding on the attitudes of teachers based on geographical location showed that there were differences in attitudes amongst some states, with Ebonyi having the highest mean attitude score and FCTA having the lowest score. This is an unexpected outcome, given that FCTA is a cosmopolitan city with a considerable number of educated and heterogeneous citizens from various parts of the country. One might have expected that the very high levels of educational and social attainment of the people in FCTA would translate into a more positive attitude. In comparison, people in Ebonyi state are known to be communally oriented, accommodating and favourably disposed towards persons in the general community. It is conceivable that such open-mindedness could have also influenced the teachers' attitudes towards including students with disabilities in their community schools.

Respondents at the senior secondary schools tended to have attitudes that were more positive, compared to those who taught at the JSS level. This finding is in consonance with previous studies conducted by Leyser et al (1994) who found that senior high school teachers displayed significantly more positive attitudes towards integration than did junior high school and elementary school teachers. However, this finding contradicts the assumption of Salvia and Munson (1986) who concluded that as children's age increased, teacher attitudes became less positive to integration.

The lack of significant findings on years of teaching experience is at variance with the finding on educational level taught by the teachers. This is congruent with another study conducted by Dukmak (2013), which showed that teachers' years of experience had no influence on their attitudes towards inclusion. This is in contrast to the findings of Offor and Akinlosotu (2017), which revealed that the years of teaching experience had significant influence on teachers' attitudes towards students with special needs in secondary schools.

Limitations

This study is not without some limitations. First, the reliance on self-report measures in investigating teachers' attitudes in inclusive classrooms may have limited validity. Although self-reports are very relevant due to the obvious relationship between beliefs and actions, observations and interviews may serve as additional sources of information that researchers can rely on to measure the attitudes of teachers. Observing teachers' behaviours and reactions to students in inclusive classrooms could provide a better understanding of their attitudes. Future research should go beyond using only self-report questionnaires and employ other measures.

One other limitation is the generalisation of the findings pertaining to the respondents who were drawn from 10 of the 36 states, as well as the Federal Capital Territory of Abuja. A larger sample comprising teachers from all the 36 states would provide a better representation of Nigerian teachers, especially as inclusion of students with visual impairment is implemented throughout the country.

CONCLUSION

The purpose of this study was to examine the attitudes of teachers towards the inclusion of students who are blind or partially-sighted in regular secondary schools in Nigeria. There were differences in the attitudes of teachers towards inclusion of learners with visual impairment. While some teachers showed negative attitudes, many demonstrated positive attitudes. Because training has an influence on the attitudes of teachers as well as on their level of confidence in teaching students who are blind or partially-sighted, the government should implement practical measures to train more teachers, and provide adequate resources and greater incentives for participants.

RECOMMENDATIONS AND IMPLICATIONS

From their personal and professional perspectives, the authors believe that an inclusive system of education can only evolve if ordinary schools within the communities become truly inclusive, that is, if they become better at meeting the academic, social, physical and societal needs of diverse learners, including those with blindness or partial sight. This implies putting in place the necessary structures and systems, including dedicated teachers and administrators, an effective peer support system, sustained professional development for all the stakeholders, and a robust budgetary allocation annually for implementing and monitoring programmes. Already, Nigeria's newest legislation - Discrimination Against Persons with Disabilities (Prohibition) Act (2018) -affirms two salient points in support of this notion, namely: "A person with disability shall have unfettered right to education without discrimination in any form", and, "All public schools, whether primary, secondary or tertiary shall be run to be inclusive or accessible to persons with disabilities". This legislation further attests to the need for policy-makers to move from rhetoric to action, so as to create a rights-based environment for all learners in their neighbourhood schools.

The authors stress that the practice of successful inclusion must transcend government policy; hence, the need for a concerted effort for its practical implementation at all levels. This will require more professional development opportunities and the creation of awareness amongst the stakeholders. Teachers must be cognisant of policies and legislation to allow for proper implementation of inclusive programmes and services. Failure to do this will make it difficult to achieve equity and justice for learners with and without disabilities.

Higher institutions that offer courses related to Introduction to Special Education must ensure that all candidates acquire the fundamental skills needed to teach students who are blind or partially-sighted. Based on the identified needs of participants in this project, it will be necessary to diversify the visual impairment component of the introductory course on Special Education to include such specialised topics as Braille reading and writing, orientation and mobility, and assistive technology applications. Furthermore, and to maximise outcomes, the introductory course should be mandatory for all novice teachers.

Teachers are central to the successful implementation of inclusive education, and their attitudes towards the inclusion process must be evaluated periodically. It is known that teacher attitudes and beliefs can affect the learning environment and will somehow determine whether students with disabilities will be socially accepted, or academically successful. The teachers' attitudes will determine the inclusivity of any child. Teachers' attitudes will also affect the other students and how they perceive inclusive practices, hence the need for all teachers to cultivate positive attitudes.

Lack of adequately trained teachers has been perceived as one of the major challenges that inclusion of students with disabilities face (Mngo & Mngo, 2018). The absence of proper training of teachers would negatively affect inclusive education. It may adversely influence school learning outcomes and the available educational opportunities for all students. In addition, inadequate training of teachers will result in diminished confidence in their ability to teach students with visual impairment and undermine their adjustment process.

ACKNOWLEDGEMENT

This study was not funded by any agency. The authors declare that they have no competing interests.

REFERENCES

Adaka TA (2013). Inclusive education: The Nigerian attempt. In C. Sunal & K. Mutua (eds.): Influences of educational policy on teaching and learning. Charlotte: IAP Information Age Publishing.

Ainscow M, Miles S (2009). Developing inclusive education systems: How can we move policies forward? La educación inclusiva: de la exclusión a la plena participación de todo el alumnado; 167-170.

Ajuwon PM (2008). Inclusive education for students with disabilities in Nigeria: Benefits, challenges, and policy implications. International Journal of Special Education; 23(3): 11-16

Ajuwon PM (2012). Making inclusive education work in Nigeria: Evaluation of special educators' attitudes. Disabilities Studies Quarterly; 32(2). Available at: https://dsq-sds.org/article/view/3198. https://doi.org/10.18061/dsq.v32i2.3198

Avramidis E, Bayliss P, Burden R (2000). A survey into mainstream teachers' attitudes towards the inclusion of children with special educational needs in the ordinary school in one local educational authority. Educational Psychology; 20(2): 193-213. https://doi.org/10.1080/713663717

Bender WN, Vail CO, Scott K (1995). Teachers' attitudes toward increased mainstreaming: Implementing effective instruction for students with learning disabilities. Journal of Learning Disabilities; 28(2): 87-94. https://doi.org/10.1177/002221949502800203. PMid:7884302

Bennett T, Deluca D, Bruns D (1997). Putting inclusion into practice: Perspectives of teachers and parents. Exceptional children; 64(1): 115-131. https://doi.org/10.1177/001440299706400108

Boyle C, Topping K, Jindal-Snape D (2013). Teachers' attitudes towards inclusion in high schools. Teachers and Teaching; 19(5): 527-542. https://doi.org/10.1080/13540602.2013.827361

Coates RD (1989). The regular education initiative and opinions of regular classroom teachers. Journal of Learning Disabilities; 22: 532-536. https://doi.org/10.1177/002221948902200902 PMid:2530295

Dukmak SJ (2013). Classroom teachers' attitude towards including students with disabilities in the regular classroom in the United Emirates. The Journal of Human Resource and Adult Learning; 9(1): 26-39

Federal Ministry of Education (2015). National Policy on Special Needs Education in Nigeria. Abuja, Nigeria.

Federal Ministry of Education (2017). National Policy on Inclusive Education in Nigeria. Abuja, Nigeria.

Federal Republic of Nigeria (2014). National Policy on Education, 6th edition. Lagos, Nigeria. NERDC Press.

Federal Republic of Nigeria (2019). Discrimination against Persons with Disabilities (Prohibition) Act 2018. Official gazette No. 10. Lagos 21st January, 2019. 106: A97-122.

Forber-Pratt AJ, Lyew DA (2019). A model case: Specialized group home for girls with disabilities in India. Child and Adolescent Social Work Journal; 1-13. https://doi.org/10.1007/s10560-019-00633-8

Gersten R, Walker H, Darch C (1988). Relationships between teachers' effectiveness and their tolerance for handicapped students. Exceptional Children; 54: 433-438. https://doi.org/10.1177/001440298805400506 PMid:2963747

Hunter-Johnson Y, Newton NGL, Cambridge-Johnson J (2014). What does teachers' perception have to do with inclusive education: A Bahamian context. International Journal of Special Education; 29(1): 143-157.

Jelagat KJ, Ondigi SR (2017). Influence of socio-cultural factors on inclusive education among students and teachers in Nairobi integrated educational programme. Kenya IOSR Journal of Research & Method in Education (IOSR-JRME) e-ISSN: 2320-7388, p-ISSN: 2320-737X 7, (I), Ver. II (Jan. - Feb. 2017): 49-55. https://doi.org/10.9790/7388-0701024955

Larrivee B, Cook L (1979). Mainstreaming: A study of variables affecting teacher attitudes. Journal of Special Education; 13: 315-324. https://doi.org/10.1177/002246697901300310

Leyser Y, Kapperman G, Keller R (1994). Teacher attitudes toward mainstreaming: A cross-cultural study in six nations. European Journal of Special Needs Education; 9: 1-15. https://doi.org/10.1080/0885625940090101

Mngo ZY, Mngo AY (2018). Teachers' perceptions of inclusion in a pilot inclusive education program: Implications for instructional leadership. Hindawi Education Research International; 2018: 1-13. https://doi.org/10.1155/2018/3524879

Mushoriwa T (2001). A study of the attitudes of primary school teachers in Harare towards the inclusion of blind children in regular classes. British Journal of Special Education; 28(3).

https://doi.org/10.1111/1467-8527.00214

National Teachers Institute (2012). Special educational needs and disabilities (SEND) in Nigeria: Manual of special educational needs and disabilities (SEND). Lagos, Nigeria: Axiom Learning Solutions, Ltd.

Offor DI, Akinlosotu NT (2017). Teachers' attitude towards special needs students in secondary schools in North senatorial district of Edo State, Nigeria. Journal of Education and Practice; 8(4): 6-12.

Olayi JE (2016). Inclusive education and its impact on the society and students who are blind and visually impaired: A survey of Nigeria. A Ph.D. thesis submitted to the Institute of Special Education, Faculty of Education, Palacky University, Olomouc, Czech Republic. Unpublished.

Peterson M, Beloin KS (1992). Teaching the inclusive teacher: Restructuring the mainstreaming course in teacher education. Teacher Education and Special Education; 21(4): 306-318. https://doi.org/10.1177/088840649802100406

Salvia J, Munson S (1986). Attitudes of regular education teachers toward mainstreaming mildly handicapped students. In MEISEL, C. J. (Ed.): Mainstreaming Handicapped Children: Outcomes, Controversies, and New Directions. London: Lawrence Erlbaum: 111-128.

Semmel M, Abernathy T, Butera G, Lesar S (1991). Teacher perceptions of the regular education initiative. Exceptional Children; 57: 9-22. https://doi.org/10.1177/001440299105800102. PMid:1954974

Snyder RF (1999). Inclusion: A qualitative study of in-service general education teachers' attitudes and concerns. Education; 120(1): 173-182.

United Nations (2000). The Dakar Framework for Action. Retrieved from: https://sustainabledevelopment.un.org/content/documents/1681Dakar%20Framework%20for%20Action.pdf

United Nations (2006). Convention on the Rights of Persons with Disabilities. Retrieved from: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

UNESCO (1994). Salamanca statement and framework for action on special needs education. World Conference on Special Needs Education: Access and Quality. Paris, France. 5.43.

UNESCO (2009). Policy guidelines on inclusion in education. Retrieved from: http://unesdoc.unesco.org/images/0017/001778/177849e.pdf

Van Reusen AK, Shoho AR, Barker KS (2000). High school teacher attitudes toward inclusion. High School Journal; 84: 2

Villa BA, Thousand JS, Meyers H, Navin A (1996). Teacher and administrator perceptions of heterogeneous education. Exceptional Children; 63: 29-45. https://doi.org/10.1177/001440299606300103

Ward J, Center Y, Bochner S (1994). A question of attitudes: Integrating children with disabilities into regular classrooms? British Journal of Special Education; 21: 34-39. https://doi.org/10.1111/j.1467-8578.1994.tb00081.x

York J, Vandercook T, MacDonald C, Hiese-Neff C, Caughey E (1992). Feedback about integrating middle-school students with severe disabilities in general education classes. Exceptional Children; 58: 244-258. https://doi.org/10.1177/001440299105800307. PMid:1839896

Life Accomplishment, Social Functioning and Participation of South-Eastern Nigerians with Lower Limb Amputation

Christopher Olusanjo Akosile[1], Christian Arinze Okonkwo[1*], Fatai Adesina Maruf[1], Emmanuel Chiebuka Okoye[1]

1. Medical Rehabilitation Department, Faculty of Health Sciences and Technology, College of Health Sciences, Nnamdi Azikiwe University, Nnewi Campus, Nigeria.

ABSTRACT

Purpose: *For a better understanding of the possible impact of impairments and disabilities on the life of individuals with lower limb amputation,it is important to explore the levels of Life Accomplishment (LA), Social Functioning and Participation (SFP) among them.The present study, set in South-Eastern Nigeria, aimed to study these levels and the influence of selected clinical and demographic variables on these constructs.*

Method: *This cross-sectional survey involved 60 individuals with lower limb amputation (46 unilateral, 14 bilateral) recruited from all the five South-Eastern Nigerian States. The Social Functioning Questionnaire (SFQ), Participation Scale and Life Habit Questionnaire were used for measuring levels of social functioning, social participation and life accomplishment, respectively. Data was analysed using descriptive statistics of frequency count, percentages, mean and standard deviation. Mann-Whitney U and Kruskal-Wallis tests were used to test the hypotheses. Alpha level was set at 0.05.*

Results: *Most of the participants (51.7%-58.3%) had low levels of social functioning across SFQ domains. Most of them (61.7%) had severe participation restrictions, and they all had reduced life accomplishments. Participants with bilateral amputation had poorer levels of social functioning (P<0.0001), participation restriction (P<0.0001), and life habits accomplishment (P<0.0001) than their counterparts with unilateral amputation. Individuals with below-knee amputation had significantly better levels of social functioning (P<0.0001) and participation (P<0.0001) than those with above-knee amputation. Participants with prosthetic mobility aids had significantly better levels of social functioning*

---

[*] **Corresponding Author:** Christian Arinze Okonkwo, Lecturer, Department of Medical Rehabilitation, Faculty of Health Sciences and Technology, College of Health Sciences, Nnamdi Azikiwe University, Nnewi Campus, Anambra State, Nigeria.
Email: ach.okonkwo@unizik.edu.ng

(P<0.0001) and participation (P<0.0001) than those with no prosthetic mobility aids. There was no significant difference in the levels of social functioning and participation between male and female participants, but female participants had statistically significant (P<0.0001) higher scores in nine out of twelve life habit domains than their male counterparts.

***Conclusion and Implications**: Low social functioning, severe participation restrictions, and reduced life accomplishments were prevalent among individuals with lower limb amputation, particularly amongthose with bilateral and above-knee amputations.*

There is a need to routinely evaluate the studied constructs among individuals with lower limb amputation. The provision of prosthetic aids may help to improve their levels of life accomplishment, social functioning and participation.

***Keywords**: life accomplishment, social functioning, participation, lower limb amputation*

INTRODUCTION

Amputation, the surgical removal of a part or whole of a limb (Walter et al, 2003), is an acquired condition that results in the loss of a limb or part thereof usually from injury, disease or surgery (Walter et al, 2003). The procedure is performed when arterial reconstruction surgery has failed or is not technically possible, and when the state of the limb is such that it cannot function well. It can be described as a salvage procedure embarked upon usually when reconstructive or restorative procedures are not achievable (Ogunlade et al, 2002).

Walters et al (2003) reported 200-500 million as the global figure for all amputations, with approximately 70,000 of these in the United States of America. Amputations due to vascular causes such as peripheral vascular disease (PVD), diabetes mellitus (DM) or chronic venous insufficiency (CVI) account for 82% of all lower extremity amputations in industrialised nations such as the United States of America (Dillingham et al, 2002). It is estimated that 25-27 in every 100,000 of the German population have undergone amputation (Moysidis et al, 2011). Non-industrialised nations generally have a higher incidence of amputation due to a higher rate of war, trauma, less developed medical systems, and the deplorable state of roads (Dillingham et al, 2002). Thanni and Tade (2007) reported 10 per 100,000 as the estimated prevalence of extremity amputation in Nigeria, with 70-90% involving one of the lower limbs. It was reported that 101 lower-limb amputations were performed at the University College Hospital Ibadan in the Oyo State of Nigeria over 5 years (average of 20 amputations per year) and the majority (70.3%) of the individuals were males (Ogunlade et al, 2002). Similar male preponderance has been reported in studies from different parts of Nigeria (Yakubu et al, 1996; Olaogun and Lamidi, 2005; Ndukwe and Muoneme, 2015).

Persons with amputations may experience a wide range of activity limitations and participation restrictions (World Health Organisation, 2001).Typical activity limitations and participation restrictions for persons with lower extremity amputation relate, but are not restricted, to self-care activities and mobility (Kohler et al, 2009). Amputation thus leads to an unlimited burden of care on the individual, family, and society,bearing in mind the significance of the lower limbs for weight-bearing and walking (Kohler et al, 2009). Amputation also affects the ability of the person to return to and maintain work, maintain social functioning, participate in social activities, and to the overall quality of life (Kohler et al, 2009).

Social functioning defines an individual's interactions with their environment and the ability to fulfill their role within such environments as work, social activities, and relationships with partners and family (Bosc, 2000). This implies involvement at the individual level with his/her environment. Environmental factors such as barriers in the community related to physical/structural environments, as well as certain clinical and demographic factors such as sex difference, amputation type, amputation level, and ambulatory category may restrict functioning in normal social roles for individuals with lower limb amputation (IWLLA) (Kohler et al, 2009). A study from Nigeria found sexand prosthetic use to be the only variables associated with a social relationship in individuals with lower limb amputation (Adegoke et al, 2012).

Social participation is described as the right for meaningful involvement in decision-making about health, policy and planning, care and treatment, and the well-being of self and the community (Fredricks and Eccles, 2006). This implies the involvement of the individual at the community level. The concept of social participation has been extensively used in the health and social care literature (Jette et al, 2003). Participation, believed to contribute to health and well-being,became a central concept of several policy articles and is considered as the most relevant outcome (Fredricks and Eccles, 2006).Several authors consider social participation as an indicator of health, well-being, and positive social behaviours (Koster et al, 2008), yet the researchers found hardly any study available for referencing social participation among individuals with lower limb amputation.

According to the International Network on Disability Creation Process (INDCP, 1998), the accomplishment of life habits is the ability to successfully execute daily activities and social roles that ensure the survival and development of a person in society throughout his or her life. The accomplishment of life habits is not only determined by one's identity, choices, impairments to organs, abilities and disabilities, but also by the interaction of one's social activities. It is all about the quality of a person's social functioning and social participation (INDCP, 1998). There is a bidirectional link between life accomplishment, social functioning, and participation. The improved social functioning level has been reported to lead to quality participation and vice versa, which eventually allows life tasks to be accomplished with ease (Noreau et al, 2004), yet the researchers found hardly any study available for reference on the influence of the constructs among individuals with lower limb amputation.

Previous studies have shown that individuals with amputation suffer from poor health-related quality of life (Harness and Pinzur, 2001; Hammarlund et al, 2011; Karami et al, 2012; Rahimi etal, 2012) and have recommended comprehensive social assessment and activity participation as needful for a better quality of life among individuals with limb amputation (Nunes et al, 2012). Barnett et al (2013) reported that individuals with amputation had poor physical health following discharge from hospital, and needed improvement in overall quality of life post-discharge. In Nigeria, a recent study that investigated quality of life of individuals with unilateral lower limb amputation reported that male individuals with amputation had higher scores in the domain of social relations and overall health, and individuals with prosthesis scored higher in physical, psychological, environmental domains and overall health (Adegoke et al, 2012). The study was however clinic-based; therefore the authors recommended a community-based study amongst individuals with amputation.

Objective

While information on quality of life among individuals with amputation exists, little is known about their levels of life accomplishment, social functioning and participation. This study was therefore designed to evaluate the levels of life accomplishment, social functioning and participation among individuals with lower limb amputation,as well as the influence of selected clinical/demographic variables on the constructs.

METHOD

Study Participants

The study focused on 60 participants with lower limb amputation, who could speak and understand the English language and had no other co-morbid health conditions such as hearing or vision problems. Snowball sampling technique was utilised in recruiting the participants through the records of the Joint National Association of Persons with Disability (JONAPWD) in Abakaliki, Awka, Enugu, Owerri, and Umuahia, and the National Orthopaedic Hospital Enugu. Some of the participants were traced to their respective place of residence through the contact address in their medical and Associations' records.They were also contactedwith the help of some of the initial participants who were reached at their Associations' meeting points at the designated meeting centres (Awka, Enugu, Abakiliki, Owerri, and Umuahia).

Data Collection

The participants' demographic data and details such as the type of amputation, level of amputation and ambulation category, were collected and recorded. The Social Functioning Questionnaire (Clifford and Isobel, 2001)was first administered to the participants, followed by the Participation Scale (Carlijn et al, 2010), and the Life Habits Questionnaire (Fougeyrollas et al 2001).

The Social Functioning Questionnairewas designed to enable a detailed assessment of an individual's social functioning for both rehabilitation and research purposes. It is divided into 5 sections, each containing 8 items to be completed for each person: Self-care Skills, Domestic Skills, Community Skills, Social Skills, and Responsibility (Clifford and Isobel, 2001). Also, there are 10 'Index Items' which are asterisked and can be used to derive a global measure of social functioning (Clifford and Isobel, 2001). Each item of the instrument has tasks that are ranked 1- 4 (1= when the respondent encounters major problems performing the task; 2= when the respondent needs frequent prompting or help; 3= when the respondent needs occasional prompting or help; and, 4=when the respondent performs the task independently). The questionnaire is scored by summing the items, for which a rating has been made in each section, and dividing that total score by the number of items completed (Clifford and Isobel, 2001). However, social functioning profiling was given as follows: scores of 1-1.4 represent a very poor level; scores of 1.5-2.3 representa poor level;scores of 2.4-3.1

represent a low level; scores of 3.2-3.7 representa moderate level; and, scores of 3.8-4.0 representa high level of social functioning. Tyrer et al (2005)revealed that the Social Functioning Questionnaire demonstrated good test-retest reliability with r=0.8. The inter-rater reliability and the construct validity of the instrument were also good, with r = 0.7 and 0.8 respectively (Tyrer et al, 2005).

The Participation Scale (version 6) is an 18-item interview-based instrument designed to assess the level of social participation. The Scale allows quantification of social participation restrictions experienced by people affected by leprosy, disability, or other stigmatised conditions. The Participation Scale covers 8 of the 9 major life domains defined in the International Classification of Functioning, Disability, and Health (ICF), published by the WHO in 2001. The domains of participation include Learning and applying Knowledge (sharing skills and knowledge, solving problems, etc.), Communication (conversation, expressing needs and ideas, participating in discussions, etc.), Mobility (use of public transport, visiting public places, walking, ability to move about, etc.), Self-Care (washing, grooming, nutrition, hygiene, clothes, and appearance), Domestic Life (household tasks, assisting others, etc.), Interpersonal Interactions (relationships, etc.), Major Life Areas (work, education, employment, economic life, etc.), and,Community, Social and Civic (community life, recreation, leisure, religion, political life) (World Health Organisation, 2001). The Participation Scale can be administered, on average, in less than 20 minutes. Most questions ask the participant to compare himself or herself with an actual or hypothetical 'peer', someone who would be similar to him/her in all aspects, except for the disease or disability. The participant is asked whether he or she perceives the level of participation to be the same or less than that of their peer(s). If the participant indicates a potential problem, he or she is asked how big the problem is to him/her and indicate this on a 4-point scale with the following possible scores giving more weight by given a score 5 when some indicates a problem as a large one (1='no problem', 2='small problem', 3='medium problem', 5= 'large problem'). The questionnaire is scored by summing the items for which a rating has been made. A score of 0-12 implies no significant participation restriction, 13-22 implies mild restriction, 23-32 implies moderate restriction, 33-52 implies severe restriction, and, 53-90 implies extreme restriction (World Health Organisation, 2001). Carlijn etal (2010) reported the psychometric properties of the Social Participation Scale as follows: validity=0.92, test-retest reliability=0.83, inter-tester reliability=0.80. The Scale has been validated for use with people affected by leprosy, people with spinal cord injuries, polio, and other disabilities (World Health Organisation, 2001).

The Life Habits Questionnaire (version 3) assesses the level of life accomplishment. This version of the questionnaire was developed by Fougeyrollas et al (2001). It contains 12 domains including nutrition, fitness, personal care, communication, housing, mobility, responsibilities, interpersonal relationship, community life, education, employment, and recreation. Each of the domains contains life habittasks that directly relate to it. Within each life habit task, the respondent is asked to indicate how he/she accomplishes the task. It is scored in this format:9= no difficulty, no assistance;8= no difficulty, but with an assistive device; 7= with difficulty, no assistance; 6=with difficulty, assistive device; 5= no difficulty, human assistance; 4=no difficulty, assistive device, and human assistance; 3=with difficulty, human assistance; 2=with difficulty, assistive device, and human assistance; 1= accomplished by proxy; 0=not accomplished, not applicable. The total score in each domain is generated by the addition of the indicated difficulty level and type of assistance. When the total score is further multiplied by 10, it gives the numerator. Multiplication of the number of items in each domain by 9 gives the denominator (Fougeyrollas et al, 2001). The weighted score, which is the score of judgement, is finally arrived at by dividing the denominator by the numerator. A weighted score of less than 9 implies reduced life habits (Fougeyrollas et al, 2001). The instrument has excellent convergent validity (r=90), excellent discriminant validity (0.90), and test-retest reliability was also noted to be excellent (r=0.95) (Johannes etal, 2004).

The questionnaires were used as interviews. One of the researchers explained the questions simply and clearly to the participants. Participants' scores on each item of the questionnaires were obtained and recorded.

Data Analysis

The data obtained was coded in Microsoft Excel, summarised using the Statistical Package for Social Sciences (SPSS) version 16, and subsequently analysed using descriptive statistics of frequency, percentages, mean and standard deviation. Inferential statistics of the Mann-Whitney U test were used to compare levels of social functioning and participation between participants with unilateral and bilateral amputation, male and female participants, participants with above- and below- knee amputation, and also to compare life habit domains between participants with unilateral and bilateral amputation, and male and female participants. Kruskal-Wallis test was used to compare participants' levels of social functioning and participation across ambulation statuses. P-value was set at 0.05.

Ethics Approval

Before the commencement of the study, ethics approval was obtained from the institutional review boards of the National Orthopaedics Hospital Enugu and Enugu State University Teaching Hospital. The researchers explained the protocolto the participants. They were made to understand that their participation in the study would be voluntary and that they were free to withdraw at any time. Those who gave their informed consent by thumb-printing or signing the consent form were included in the study.

RESULTS

There were 60 individuals (49 males, 11 females) with lower limb amputation in this study. The socio-demographic and clinical profile of the participants revealed that the majority (60%) were less than 40 years of age, had unilateral amputation (76.7%), and were using non-prosthetic mobility aids (75%). Most of the participants were still single and had not received more than primary level education.

Individuals with above-knee amputation were almost similar in proportion to those with below-knee amputation (Table 1).

Table 1: Participants' Socio-demographic and Clinical Variables

Variable	**Frequency (N)**	**Percentage (%)**
Age (yrs)		
18-28	16	26.7
29-39	20	33.3
40-50	18	30.0
51+	6	10.0
Amputation Type		
Unilateral	46	76.7
Bilateral	14	23.3
Sex		
Male	49	81.7
Female	11	18.3
Marital Status		
Married	24	40.0

Single	36	60.0
Amputation Level		
Above knee	32	53.3
Below knee	28	46.7
Ambulation Category		
Prosthesis	15	25.0
Crutches	31	51.7
Wheelchair	14	23.3
Educational Status		
Primary	44	73.3
Secondary	16	26.7

The majority of the study participants ranked their levels of social functioning as either low (51.7-58.3%) or poor (23.3-25.0%) in all social functioning domains. All the participants also ranked themselves as having severe to extreme restrictions in social participation (Table 2).

Table 2: Participants' Levels of Social Functioning and Participation

Variable	**Levels**			
	High N (%)	Moderate N (%)	Low N (%)	Poor N (%)
SF Self-care	2(3.3%)	9(15.0%)	35(58.3%)	14(23.3%)
SF Domestic Skill	14(23.3%)	0(0%)	31(51.7%)	15(25.0%)
SF Community Skill	15(25.0%)	0(0%)	31(51.7%)	14(23.3%)
SF Social Skill	15(25.0%)	0(0%)	31(51.7)	14(23.3%)
SF Responsibility	15(25.0%)	0(0%)	31(51.7%)	14(23.3%)
Social Participation	Mild Restriction	Moderate Restriction	Severe Restriction	Extreme Restriction
	0(0%)	0(0%)	37(61.7%)	23(38.3%)

Key: SF =Social Functioning; N=Frequency; %=Percentage

All the participants had reduced life accomplishment (Table 3).

Table 3: Participants' Level of Life Accomplishment

Variable	**Mean ± SD**	**Levels** Normal LA N (%)	Reduced LA N (%)
LH Nutrition	6.16 ± 1.96	0 (0%)	60 (100%)
LH Fitness	6.21 ± 1.97	0 (0%)	60 (100%)
LH Personal Care	6.14 ± 1.93	0 (0%)	60 (100%)
LH Communication	6.20 ± 0.19	0 (0%)	60 (100%)
LH Housing	6.61 ± 0.19	0 (0%)	60 (100%)
LH Mobility	6.56 ± 3.75	0 (0%)	60 (100%)
LH Responsibility	6.16 ± 2.00	0 (0%)	60 (100%)
LH Interpersonal Relationship	6.15 ± 1.98	0 (0%)	60 (100%)
LH Community Life	6.19 ± 2.00	0 (0%)	60 (100%)
LH Education	6.16 ± 2.01	0 (0%)	60 (100%)
LH Employment	6.16 ± 1.98	0 (0%)	60 (100%)
LH Recreation	6.17 ± 1.98	0 (0%)	60 (100%)

Key: LH=Life Habit; LA=Life Accomplishment; SD=Standard Deviation

Participants with bilateral amputations had significantly poorer social functioning in all social functioning domains and more extreme participation restrictions compared to those with unilateral amputation (Table 4).

Table 4: Comparison of Levels of Social Functioning and Participation between Participants with Unilateral and Bilateral Amputation

Variable	Amp Type	Levels				Mean Rank	U	P
		High N (%)	Moderate N (%)	Low N (%)	Poor N (%)			
SF Self-care	Unilateral	2(4.3%)	9(19.6%)	35(76.1%)	0(0%)	37.50	0.000	<0.0001*
	Bilateral	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
SF Domestic Skill	Unilateral	14(30.4%)	0(0%)	31(67.4%)	1(2.2%)	37.50	0.000	<0.0001*
	Bilateral	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
SF Community Skill	Unilateral	15(32.6%)	0(0%)	31(67.4%)	0(0%)	37.50	0.000	<0.0001*
	Bilateral	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
SF Social Skill	Unilateral	15(32.6%)	0(0%)	31(67.4)	0(0%)	37.50	0.000	<0.0001*
	Bilateral	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
SF Responsibility	Unilateral	15(32.6%)	0(0%)	31(67.4%)	0(0%)	37.50	0.000	<0.0001*
	Bilateral	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
Social Participation		Mild Restriction	Moderate Restriction	Severe Restriction	Extreme Restriction			
	Unilateral	0(0%)	0(0%)	37(80.4%)	9(19.6%)	23.50	0.000	<0.0001*
	Bilateral	0(0%)	0(0%)	0(0%)	14(100%)	53.50		

Key:*=Significant at P<0.05; SF=Social Functioning; AmpType=Amputation Type; N=Frequency; %=Percentage

There was no significant difference in levels of social functioning and participation between male and female participants except in the social functioning self-care domain (Table 5).

Table 5: Comparison of Levels of Social Functioning and Participation between Male and Female Participants

Variable	Sex	Levels				Mean Rank	U	P
		High N (%)	Moderate N (%)	Low N (%)	Poor N (%)			
SF Self-care	Male	0(0%)	9(18.4%)	26(53.1%)	14(28.6%)	27.39	117.000	0.002*
	Female	2(18.2%)	0(0%)	9(81.8%)	0(0%)	44.36		
SF Domestic Skill	Male	12(24.5%)	0(0%)	22(44.9%)	15(30.6%)	29.65	228.000	0.386
	Female	2(18.2%)	0(0%)	9(81.8%)	0(0%)	34.27		
SF Community Skill	Male	13(26.5%)	0(0%)	22(44.9%)	14(28.6%)	29.67	229.000	0.397
	Female	2(18.2%)	0(0%)	9(81.8%)	0(0%)	34.18		
SF Social Skill	Male	13(26.5%)	0(0%)	22(44.9%)	14(28.6%)	29.67	229.000	0.397
	Female	2(18.2%)	0(0%)	9(81.8%)	0(0%)	34.18		
SF Responsibility	Male	13(26.5%)	0(0%)	22(44.9%)	14(28.6%)	29.67	229.000	0.397
	Female	2(18.2%)	0(0%)	9(81.8%)	0(0%)	34.18		
Social Participation		Mild Restriction	Moderate Restriction	Severe Restriction	Extreme Restriction			
	Male	0(0%)	0(0%)	31(63.3%)	18(36.7%)	30.76	250.000	0.809
	Female	0(0%)	0(0%)	6(54.5%)	5(45.5%)	29.36		

Key:*=Significant at P<0.05; SF=Social Functioning; N=Frequency; %=Percentage

Participants with above-knee amputation had significantly poorer social functioning and participation compared to those with below-knee amputation (Table 6).

Table 6: Comparing Levels of Social Functioning and Participation between Participants with Above-knee (AKA) and Below-knee (BKA) Amputations

Variable	Amp Level	Levels				Mean Rank	U	P
		High N (%)	Moderate N (%)	Low N (%)	Poor N (%)			
SF Self- care	AKA	1(3.1%)	2(6.2%)	15(46.9%)	14(43.8%)	22.97	207.000	<0.0001*
	BKA	1(3.6%)	7(25.0%)	20(71.4%)	0(0%)	39.11		
SF Domestic skill	AKA	4(12.5%)	0(0%)	13(40.6%)	15(46.9%)	23.59	227.000	<0.0001*
	BKA	10(35.7%)	0(0%)	18(64.3%)	0(0%)	38.39		
SF Community Skill	AKA	5(15.6%)	0(0%)	13(40.6%)	14(43.8%)	23.75	232.000	<0.0001*
	BKA	10(35.7%)	0(0%)	18(64.3%)	0(0%)	38.21		
SF Social skill	AKA	5(15.6%)	0(0%)	13(40.6%)	14(43.8%)	23.75	232.000	<0.0001*
	BKA	10(35.7%)	0(0%)	18(64.3%)	0(0%)	38.21		
SF Responsibility	AKA	5(15.6%)	0(0%)	13(40.6%)	14(43.8%)	23.75	232.000	<0.0001*
	BKA	10(35.7%)	0(0%)	18(64.3%)	0(0%)	38.21		
Social Participation		Mild Restriction	Moderate Restriction	Severe Restriction	Extreme Restriction			
	AKA	0(0%)	0(0%)	14(43.8%)	18(56.2%)	23.50	230.000	<0.0001*
	BKA	0(0%)	0(0%)	23(82.1%)	5(17.9%)	53.50		

Key: *=Significant at P<0.05; N=Frequency; SF=Social Functioning; %=Percentage; AKA=Above Knee Amputation;BKA=Below Knee Amputation; AmpLevel=Amputation Level

Wheelchair-users had significantly poorer social functioning and participation compared to those with crutches and prostheses. Participants with crutches had significantly poorer social functioning and participation compared to those with prosthetic mobility aids (Table 7).

Table 7: Comparison of Levels of Social Functioning and Participation in Different Ambulation Categories of the Participants

Variable	Ambulation Categories	Levels				Mean Rank	K	P
		High N (%)	Moderate N (%)	Low N (%)	Poor N (%)			
SFSelf- care	Prosthesis	2(13.3%)	9(60.0%)	4(26.7%)	0(0%)	53.00	53.213	<0.0001*
	Crutches	0(0%)	0(0%)	31(100%)	0(0%)	30.00		
	Wheelchair	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
SF Domestic Skill	Prosthesis	14(93.3%)	0(0%)	0(0%)	1(6.7%)	53.00	58.794	<0.0001*
	Crutches	0(0%)	0(0%)	31(100%)	0(0%)	30.00		
	Wheelchair	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
SF Community Skill	Prosthesis	15(100%)	0(0%)	0(0%)	0(0%)	53.00	59.000	<0.0001*
	Crutches	0(0%)	0(0%)	31(100%)	0(0%)	30.00		
	Wheelchair	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
SF Social Skill	Prosthesis	15(100%)	0(0%)	0(0%)	0(0%)	53.00	59.000	<0.0001*
	Crutches	0(0%)	0(0%)	31(100%)	0(0%)	30.00		
	Wheelchair	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
SF Responsibility	Prosthesis	15(100%)	0(0%)	0(0%)	0(0%)	53.00	58.822	<0.0001*
	Crutches	0(0%)	0(0%)	31(100%)	0(0%)	30.00		
	Wheelchair	0(0%)	0(0%)	0(0%)	14(100%)	7.50		
Social Participation		Mild Restriction	Moderate Restriction	Severe Restriction	Extreme Restriction			
	Prosthesis	0(0%)	0(0%)	13(86.7%)	2(13.3%)	73.00	79.000	<0.0001*
	Crutches	0(0%)	0(0%)	24(77.4%)	7(22.6%)	52.00		
	Wheelchair	0(0%)	0(0%)	0(0%)	14(100.0%)	13.00		

Key:*=Significant at P<0.05;SF=Social Functioning;N=Frequency;%=Percentage

Those with bilateral amputation had significantly poorer scores in all life habit domains than those with unilateral amputation (Table 8).

Table 8: Comparison of Life Habit (LH) Domains between Participants with Unilateral and Bilateral Amputation

Variable	Amputation Type	Mean Rank	U	P
LH Nutrition	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Fitness	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Personal Care	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Communication	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Housing	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Mobility	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Responsibility	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Interpersonal Relationship	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Community Life	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Education	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Employment	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		
LH Recreation	Unilateral	37.50	0.000	<0.0001*
	Bilateral	7.50		

Key: *=Significant at P<0.05; LH=Life Habit; SD=Standard Deviation

Female participants had higher scores in all life habit domains compared to the male participants (Table 9).

Table 9: Comparison of Life Habit (LH) Domains between Male and Female Participants

Variable	Sex	Mean Rank	U	P
LH Nutrition	Male	28.52	172.500	0.059
	Female	39.32		
LH Fitness	Male	28.73	183.000	0.078
	Female	38.36		
LH Personal Care	Male	28.59	176.000	0.057
	Female	39.00		
LH Communication	Male	27.50	122.500	0.003*
	Female	43.86		
LH Housing	Male	27.59	127.000	0.004*
	Female	43.45		
LH Mobility	Male	27.48	121.500	0.002*
	Female	43.95		
LH Responsibility	Male	27.83	138.500	0.008*
	Female	42.41		
LH Interpersonal Relationship	Male	27.73	134.000	0.009*
	Female	42.82		
LH Community Life	Male	28.01	147.500	0.013*
	Female	41.59		
LH Education	Male	28.00	147.000	0.011*
	Female	41.64		
LH Employment	Male	27.59	127.000	0.004*
	Female	43.45		
LH Recreation	Male	27.82	138.000	0.007*
	Female	42.45		

Key: LH=Life Habit; SD=Standard Deviation; *=Significant at $P<0.05$

DISCUSSION

Participants' Socio-demographic and Clinical Profile

This study explored the levels of life accomplishment, social functioning and participation among individuals with lower limb amputation. Sixty individuals (49 males, 11 females) with lower limb amputation participated in the study (Table 1). This suggests that male individuals were more exposed to conditions capable of causing lower limb amputation. The higher proportion of men in this study is in line with the report of previous studies that lower limb amputations are more common among males than females (Thompson et al, 1991; Yakubu et al, 1996; Ogunlade et al, 2002; Olaogun and Lamide, 2005; Da Silva et al, 2011; Adegoke et al, 2012; Ndukwe and Muoneme, 2015), and that males are more exposed to traumatic events than females (Dillingham et al, 2002; Ndukwe and Muoneme, 2015). Adegoke et al (2012) have reported that traumatic amputations in Nigeria occur mainly from road traffic accidents. There has been a public outcry by various non-governmental organisations and sister agencies for the government to fast-track efforts to rehabilitate worn-out roads in order to curtail road traffic accidents. Federal Road Safety staff have been regularly deployed at major roads across the country to warn careless and reckless road users about imminent traumatic accidents. The majority (60%) of the participants were less than 40 years of age (Table 1). This implies that conditions that led to the amputation may have occurred at an early adult age. This is consistent with a previous assertion by Dillingham et al (2002) that trauma was the major cause of amputation and most individuals with amputation were involved in traumatic incidents in early adulthood. Also, the majority of the participants (60%) were single (Table 1), implying that individuals with amputation were not ready to engage in marital life. This may be because options for achieving financial independence, usually a matter for consideration when getting married, are limited by the impact or burden of losing a limb.

The majority of the participants (73.3%) had not received more than primary level education (Table 1), suggesting low literacy levels among them. This could be attributed to the fact that most primary school leavers in South-Eastern Nigeria prefer to learn a trade rather than enrol themselves for post-primary education. Also, a good number of the participants may have joined the Joint National Association of Persons with Disability mainly to find help.

The majority of the participants (76.7%) had unilateral amputation (Table 1). This reflects the prevalent trend in amputation. It is consistent with anearlier Nigerian study by Ndukwe and Muoneme (2015) which opined that unilateral amputation is more common than bilateral amputation.

Participants' Levels of Social Functioning and Participation

The majority of the study participants ranked their levels of functioning as either low or poor in all the social functioning domains (Table 2). All the participants also felt that they experienced severe to extreme restrictions in social participation (Table 2). This implies their need for help to carry out self-care activities (such as changing clothes, washing hands, shaving, and toileting), domestic skills (such as cleaning of rooms and preparing meals), community skills (such as shopping and use of public facilities), social skills (such as making conversation with residents and engaging in leisure activities) and responsibility (over matters such as personal possessions, medications, and self-financing). This finding is consistent with the finding of an earlier work by Pinzur et al (2008) which reported the low social functioning among individuals with amputation. Better social functioning however, has been reported among individuals with lower limb amputation which was facilitated by sporting competitions (Fiorilli et al, 2013;Pezzin et al, 2013).

The findings of this study demonstrated that significant differences existed in the levels of social functioning and its domains, and also in participation, between participants with unilateral and bilateral amputation (Table 4), above and below-knee amputation (Table 6), and ambulation categories (Table 7). The finding of significantly poorer levels of social functioning and extreme levels of participation restriction among participants with bilateral lower limb amputation than among their unilateral counterparts is in line with a previous assertion by Asano et al (2008), which suggested that the likelihood of social activity decreases with increasing disability. Moreover, bearing in mind their extent of disability, individuals with bilateral amputation are reported to be likely to live a more dependent lifestyle than those with unilateral amputation, thereby limiting their ability for active functioning, participation in the society, and overall quality of life (Rahimi et al, 2012).

There was no significant difference in levels of social functioning and participation between male and female participants except in the social functioning self-care domain (Table 5). This implies that female participants may need less help in doing self-care activities (washing, grooming, nutrition, hygiene, clothing, and appearance) than their male counterparts. Adegoke et al (2012) found significantly higher scores by male participants in social relationships and overall quality of life. The fact that the two studies have similar sex spread seems to suggest that,apart from other factors,gender may have significantly affected the level of social functioning and degree of participation restriction among individuals with amputation. The finding of significantly poorer levels of social functioning and a similar degree of participation restriction among participants with above-knee amputation compared to participants with below-knee amputation(Table 6) suggests that the presence of the knee joint may have given an edge to the below-knee amputation groupin the matter of social functioning and participation. This is similar to the findings of a previous study by Harness and Pinzur (2001) which revealed that participants with transtibial amputation had better social functioning. Cox et al (2011) also found that individuals with below-knee amputation had better social functioning and participation, with overall quality of life, than those with above-knee amputation. This may be explained by an assertion of Seymour (2002) that the more proximal the amputation, more energy is demanded from the cardiovascular and pulmonary systems, and the less can the energy demand be satisfied for functional and social activities. Moreover, the absence of a functional knee joint amongthe above-knee amputation group may also be a contributing factor to their functional limitation because the presence of the knee joint in individuals with amputation was reported to improve stability and enhance function (Andrysek et al, 2016). It was found that there was a significantly better level of social functioning and participation among individuals using prosthetic mobility aids compared to their counterparts with non-prosthetic mobility aids (Table 7).While prosthetic users could move easily around their homes and in the community, non-prosthetic users - particularly those using wheelchairs - may find the environment as an obstacle to social participation. Ephriam et al (2006) had reported that perception of environmental barriers is very prevalent among individuals with amputation, especially among those with non-prosthetic mobility aids. This outcome also agrees with the finding of significantly better quality of life among participants with prosthesis in a previous study by Adegoke et al (2012). Similarly, the use of prosthesis was reported as a predictor of better quality of life in an earlier study by Asano et al (2008). Barnett et al (2013) also reported that the use of prosthesis improved overall quality of life of individuals with amputation while decreasing fall efficacy. Zidarov et al (2009) similarly reported that the use of prosthetic mobility aids significantly improved function. Individuals with prosthetic mobility aids may have expended less energy for mobility than their counterparts with non-prosthetic mobility aids.

Participants' Levels of Life Accomplishment

This study revealed that all the participants had reduced life accomplishments (Table 3). This suggests that the impact of lower limb amputation on life habit accomplishments may negatively affect quality of life. It calls for detailed attention to be paid to community rehabilitation and reintegration for individuals with lower limb amputation. The finding of generally reduced life accomplishments in this study differs from the finding of Zidarov et al (2009) in Canadaabout improved life accomplishment among individuals with lower limb amputation. The difference may be attributed to the fact that Canadahas a more organised economy than Nigeria, even to the extent of entrenching the rights of persons with disability, and as such may be operating a better community rehabilitation and reintegration facility for individuals with lower limb amputation. Also, reduction in life habit scores that was observed among the majority of the participants, supports the findings of a previous study by Noreau et al (2004) which established that participation restrictions hinder the accomplishment of life habits, and suggested that assessment of life habits may help to estimate the level of participation. The finding of significantly higher scores in all life habit domains among participants with unilateral amputation as compared to those with bilateral amputation (Table 8) implies that while those with unilateral amputation occasionally encountered difficulty in task accomplishments with no assistance, those with bilateral amputation often encountered difficulty in the same task accomplishment in spite of significant human assistance. This seems to buttress the assertion by the World Health Organisation (2001) that increased activity limitation leads to decreased task performance, and thus restricts activity participation.

There are statistically significant lower scores by male participants,as compared to their female counterparts, in the life habit communication, housing, mobility, responsibility, interpersonal relationship, community life, and education, employment, and recreation domains (Table 9). This may suggest that females were more likely to cope with a disability than males. However, bilateral amputation (suggestive of higher density) could also be the reason for lower life accomplishment among the men. Cox et al (2011) also found females with lower limb amputation to have significantly higher scores than males in quality of life domains. Gallagher and MacLachlan (2004) did not find any significant sex difference in quality of life domains, while Da Silva et al (2011) found no correlation between sex and quality of life among individuals with lower limb amputation. Male participants also had lower scores in life habit domains of nutrition, fitness, and personal care but it was not statistically significant.

There is, therefore, the need for the establishment of centres that render comprehensive rehabilitation services (involving all experts) and support to individuals with lower limb amputation in Nigeria to help them accomplish their routine tasks with ease, and subsequently reduce their suffering. Reinforcement of their available capabilities, compensation for their disabilities during rehabilitation, reduction of obstacles due to prejudice, addressing lack of resources or assistance, addressing accessibility within the home and other social environments, are all steps which may improve their level of life accomplishment and overall quality of life.

Limitations

The exclusion of individuals with lower limb amputation who could not speak and understand the English language was a limitation to the study. Since the study was purely community-based, it excluded individuals with lower limb amputation at the hospital inpatient and rehabilitation centres and clinics. This affected the sample size. Another limitation was the absence of gender-matched controls for the constructs; hence the findings of this study may not be generalised.

CONCLUSION

Reduced life accomplishment, low social functioning, and severe participation restrictions are prevalent among individuals with lower limb amputation, and more particularly among those with bilateral and above-knee amputations. Female participants have significantly better accomplishments across nearly all domains than their male counterparts. It is therefore recommended that clinicians involved in the rehabilitation of individuals with amputation should routinely evaluate their levels of life accomplishment, social functioning, and participation, and also devise appropriate interventions to address their needs in these areas. Healthcare professionals involved in the care of people with amputations, and organisations such as JONAPWD and other Disabled People's Organisations (DPOs) for individuals with lowerlimb amputation should jointly advocate for prosthetic aids to be made accessible and easily affordable for individuals with amputation. The government and its agencies can help accomplish this by allocating sufficient budget and providing subsidies or donations. Non-governmental organisations may also partner with JONAPWD and other DPOs to help with the provision of prosthesis.

The study has provided information,hitherto unavailable, on the levels of life accomplishment, social functioning and participation among individuals with lower limb amputation in the South-Eastern Nigerian States. The findings of prevalent low social functioning, severe participation restriction and reduced life accomplishments, particularly among those with bilateral and above-knee amputations, may help to highlight the need for clinicians involved in amputation rehabilitation to routinely investigate these constructs. It may also help them in the development of their management plans for this client group. This could improve the situation of individuals with lower limb amputation in terms of the studied constructs and overall quality of life. Consequently they may be enabled to contribute more meaningfully to their communities and society at large. The study also revealed the need to put policies in place that would make prosthetic aids readily accessible and easily affordable.

REFERENCES

Adegoke BAO, Adeolu OK, Akosile CO,Alao LO (2012). Quality of life of Nigerians with unilateral lower limb amputation. Journal of Disability, CBR and Inclusive Development; 23(4): 192. https://doi.org/10.5463/dcid.v23i4.192

Andrysek J, Wright FV, Rotter K, Garcia D, Valdebenito R, Mitchell CA, Rozbaczylo C, Cubillos R (2016). Long-term clinical evaluation of the automatic stance-phase lock-controlled prosthetic knee joint in young adults with unilateral above-knee amputation. Journal of Disability Rehabilitation; 4(2): 1-7. https://doi.org/10.3109/17483107.2016.1173730 PMid:27376843

Asano M, Rushton P, Miller WC, Deathe BA (2008). Predictors of quality of life among individuals who have a lower limb amputation. ProsthetOrthot International Journal; 32(2): 231-43. https://doi.org/10.1080/03093640802024955 PMid:18569891

Barnett CT, Vanicek N, Polman RC (2013). Temporal adaptations in generic and population-specific quality of life and fall efficacy in men with recent lower-limb amputations. Journal of Rehabilitation Development; 50(3): 437-48. https://doi.org/10.1682/JRRD.2011.10.0205 PMid:23881768

Bosc M (2000). Assessment of social functioning in depression. Comprehensive Psychiatry; 41(1): 63:69 https://doi.org/10.1016/S0010-440X(00)90133-0

Carlijn HV, Annique RP, Luikje VD, Albert K, Vera PMS, Johonna MA, Visser M, Marcel WM (2010). Reproducibility of three self-report participation measures: The ICF measure of participation, the activity screener, the participation scale. Journal of Rehabilitation Medicine; 42: 752-757. https://doi.org/10.2340/16501977-0589 PMid:20809057

Clifford P, Isobel M (2001). Social functioning questionnaire: A modification of the adaptive functioning scale developed by Tilly Latimer-Sayer and Isobel Morris. International Journal of Social Psychiatry; 51(3): 265-275.

Cox PS, Williams SK, Weaver SR (2011). Life after lower extremity amputation in diabetes. The West Indian Medical Journal; 60(5): 536-540.

Cutson TM, Bongiorni D, Michael JW, Kockersberger G (1994). Early management of elderly dysvascular below-knee amputees. Journal of Prosthetics and Orthotics; 6(3): 62-66.

Da Silva R, Rizzo JG, Gutierres FPJ, Ramos V, Deans S (2011). Physical activity and quality of life of amputees in southern Brazil. Journal of Prosthet Orthotics International; 35(4): 432-8. https://doi.org/10.1177/0309364611425093 PMid:22042373

Dillingham TR, Pezzin LE, Mackenzie EJ (2002). Limb amputation and limb deficiency: Epidemiology and recent trends in the United States. Archives of Physical Medicine and Rehabilitation; 95(8): 875-883. https://doi.org/10.1097/00007611-200295080-00019 PMid:12190225

Ephraim PL, MacKenzie EJ, Wegener ST, Dillingham TR, Pezzin LE (2006). Environmental barriers experienced by amputees: The Craig Hospital inventory of environmental factors-short form. Archives of Physical Medicine and Rehabilitation; 87(3): 328-33. https://doi.org/10.1016/j.apmr.2005.11.010 PMid:16500165

Fiorilli G, Iuliano E, Aquino G, Battaglia C, Giombini A, Calcagno G, di Cagno A (2013). Mental health and social participation skills of wheelchair basketball players: A controlled study. Research in Developmental Disability; 34(11): 3679-85 https://doi.org/10.1016/j.ridd.2013.08.023 PMid:24012595

Fougeyrollas P, Noreau L, St-Machel G (2001). LIFE habit questionnaire: Short version 3. Journal of Rehabilitation; 3(6): 177-182.

Fredricks JA, Eccles JS (2006). Is extracurricular participation associated with beneficial outcomes? Concurrent and longi¬tudinal relations. Journal of Developmental Psychology; 42(4): 698-713. https://doi.org/10.1037/0012-1649.42.4.698 PMid:16802902

Gallagher PA, MacLachlan M (2004).The Trinity amputation and prosthesis experience scales and quality of life in people with lower limb amputation. Archives of Physical Medicine and Rehabilitation; 85: 730-736. https://doi.org/10.1016/j.apmr.2003.07.009 PMid:15129396

Hammarlund CS, Carlström M, Melchior R, Persson BM (2011). Prevalence of back pain, its effect on functional ability and health-related quality of life in lower limb amputees secondary to trauma or tumor: A comparison across three levels of amputation. Journal of Prosthet and Orthotics International; 35(1): 97-105. https://doi.org/10.1177/0309364610389357 PMid:21515895

Harness N, Pinzur MS (2001). Health-related quality of life in patients with transtibial amputation. Journal of Clinical Orthopaedics and Related Research; (383): 204-7. https://doi.org/10.1097/00003086-200102000-00023 PMid:11210955

International Network on Disability Creation Process (1998). What is LIFE-H? [online]. Available at https://ripph.qc.ca/en/documents/life-h/what-is-life-h/ [Accessed on 3 Mar 2015]

Jette AM, Haley SM,Kooyoomjian JT (2003). Are the ICF activity and participation dimensions distinct? Journal of Rehabilitation Medicine; 35(3): 145-149. https://doi.org/10.1080/16501970310010501 PMid:12809198

Karami G, Ahmadi Kh, Nejati V, Masumi M (2012). The better mental component of quality of life in an amputee. Iran Journal of Public Health; 41(7): 53-8.

Kohler F, Cieza A, Stucki G (2009). Developing core sets for persons following amputation based on the International Classification of Functioning, Disability and Health as a way to specify functioning. Journal of Prosthetic Orthotics International; 33(2): 117-129.

Koster M, Nakken H, Pijl SJ, van Houten EJ, Lutje HC (2008). Assessing social participation of pupils with special needs in inclusive education: The construction of a teacher questionnaire. Education Research Evaluation; 14(5): 395-409. https://doi.org/10.1080/13803610802337657

Moysidis T, Nowack T, Eickmeyer F, Waldhausen P, Brunken A, Hochlenert D (2011). Trends in amputations in people with hospital admissions for peripheral arterial disease in Germany. European Journal of Vascular Medicine; 40(4): 289-95. https://doi.org/10.1024/0301-1526/a000117 PMid:21780052

Ndukwe UC,Muoneneme CA (2015). Prevalence and pattern of extremity amputation in a tertiary Hospital in Nnewi, Southeast Nigeria. Tropical Journal of Medical Research; 18(2): 104-105. https://doi.org/10.4103/1119-0388.158405

Noreau L, Desrosiers J, Robichard L, Fougeyrollas P, Rochette A, Viscogliosi C (2004). Measurement of life habits of an adult. Journal of Disability Rehabilitation; 26(6): 346-52. https://doi.org/10.1080/09638280410001658649 PMid:15204486

Nunes MA, de Barros N Jr, Miranda F Jr, Baptista-Silva JC (2012). Common mental disorders in patients undergoing lower limb amputation: A population-based sample. World Journal of Surgery; 36(5): 1011-5. https://doi.org/10.1007/s00268-012-1493-4 PMid:22362046

Ogunlade SO, Alonge TO, Omololu BO, Gana JY, Salawu SA (2003). Major limb amputation in Ibadan. African Journal of Medical Science; 31: 333-336.

Olaogun MOB, Lamidi ER (2005). Appraisal of lower limb amputations and some rehabilitation problems of amputees. Journal of Royal College of Surgeons; 41: 102-104.

Pezzin LE, Padalik SE, Dillingham TR (2013). Effect of post-acute rehabilitation setting on mental and emotional health among persons with vascular amputations. Journal of Physical Medicine and Rehabilitation; 5(7): 583-90. https://doi.org/10.1016/j.pmrj.2013.01.009 PMid:23490724

Pinzur MS, Beck J, Himes R,Callaci J (2008). Health-related quality of life following distal tibiofibular bone-bridging in transtibial amputation. Journal of Bone and Joint Surgery;90(12): 2682-7. https://doi.org/10.2106/JBJS.G.01593 PMid:19047714 PMCid:PMC3076214

Radcliffe B (1998). Concept of social functioning in man. South African Journal of Social Anthropology; 124-47.

Rahimi A, Mousavi B, Soroush M, Masumi M, Montazeri A (2012). Pain and health-related quality of life in war veterans with bilateral lower limb Amputations. Trauma Monthly; 17(2): 282-6. https://doi.org/10.5812/traumamon.5135 PMid:24350107 PMCid:PMC3860634

Seymour R (2002). Prosthetics and Orthotics: Lower limb and spinal. Lippincott Williams &Wilkins: 485.

Thanni LO,Tade AO (2007). Extremity amputation in Nigeria - A review of indications and mortality. Vascular surgery; 5(4): 213-7. https://doi.org/10.1016/S1479-666X(07)80006-0

Thomson A, Skinner A, Piercy J (1991). Tidy's Physiotherapy (12th Ed) Oxford, UK. Butterworth and Heinemann: 260-273.

Tyrer P, Nur U, Crawford M, Karlsen S, McLean C, Rao B, Johnsn T (2005). The social functioning questionnaire: A rapid and robust measure of perceived functioning. The International Journal of Social Psychiatry; 51(3): 265-75. https://doi.org/10.1177/0020764005057391

Walter S, Burgess EM, Romemo RC, Zettle JH (2003). The management of lower extremity amputations. Veterans Administration Report 106. Government Printing Press, New York, USA.

World Health Organisation (2001). International classification of function disability and health. Available at www.who.int/classification/icf/en.[Accessed on 26 Nov 2014]

Yakubu Am, Muhammak I, Mabogunje OA (1996). Major limb amputation in adults, Zaria, Nigeria. Journal of Royal College of Surgeons; 41: 102-104

Zidarov D, Swaine B, Gauthier-Gagnon C (2009). Life habits and prosthetic profile of persons with lower-limb amputation during rehabilitation and at 3-month follow-up. Archives of Physical Medicine and Rehabilitation; 90(11): 1953-9. https://doi.org/10.1016/j.apmr.2009.06.011 PMid:19887223

Menstrual Hygiene Management: Challenges and Coping Strategies for Adolescents with Disabilities in the Kumasi Metro of Ghana

Acheampong Enoch*[1], Alberta Nadutey[1], Barbara Fosua Afful[1], Reindolf Anokye[2]

1. Department of Health Promotion & Disability Studies, Kwame Nkrumah University of Science & Technology, Kumasi, Ghana

2. School of Medical and Health Sciences, Edith Cowan University, Joondalup, WA, Australia

ABSTRACT

Purpose: *Effective menstrual hygiene management is vital to the health, well-being, dignity, empowerment, mobility and productivity of girls and women. This study was conducted to ascertain menstrual hygiene management challenges and coping strategies of adolescents with disabilities in the Kumasi Metro of Ghana.*

Method*: An exploratory study design with qualitative approach was employed to select 18 participants. Data was collected through in-depth interviews and focus group discussions, and then transcribed and categorised into specific themes.*

Results: *Females with visual impairment had difficulty in maintaining good menstrual hygiene because of problems in detecting menstrual blood, inability to fix sanitary pads appropriately and wash underwear properly, and anxiety and stress from not knowing whether their period has started. The problems of those with physical impairment were related to inaccessible washrooms, long hours of being seated on the part of wheelchair-users, and difficulty in fixing sanitary pads for those with upper limb impairment. For those with hearing impairment, the main challenge was the communication barrier between them and their significant others whenever they needed help.*

Conclusion: *There are common challenges faced by all girls across the globe with regard to menstrual hygiene management. Adolescent females with disability however face additional challenges with regard to MHM. Those with physical disability encounter accessibility challenges, while the main challenge for the deaf and those with speech problems is communication. The visually impaired live in anxiety due to fear of staining their clothes.*

---

* **Corresponding Author:** Acheampong Enoch, Lecturer, Department of Health Promotion & Disability Studies, Kwame Nkrumah University of Science & Technology, Kumasi, Ghana. Email: caposterl@yahoo.com

Key words: *menstrual hygiene, adolescents with disability, Kumasi Metro, challenges and coping strategies*

INTRODUCTION

The issue of menstruation, especially menarche, is a life-changing event for girls stepping into womanhood. Effective menstrual hygiene is vital to the health, well-being, dignity, empowerment, mobility and productivity of women and girls (Environmental Health Group, 2016). It is an important part of basic hygiene, sanitation and reproductive health services to which every woman and girl has a right (Water Supply and Sanitation Collaborative Council, 2015). From adolescence until menopause, reproductive health and menstrual hygiene management become important aspects in the life of a female. If attention is paid to these needs of adolescent girls, it will lay a good foundation for their physical and mental well-being and their ability to cope with the heavy demand of reproductive health later in life (Muntunda, 2013).

An adolescent female with disability will have the same menstrual hygiene needs as other adolescent girls, but will need more knowledge and information since she may face additional challenges. Physical challenges, communication challenges, sensory challenges and caregiver challenges are notable challenges with respect to practising hygienic menstruation among female adolescents with disabilities (Beckeljauw, 2004).

Across the world, many cultures have beliefs or myths relating to menstruation. There are almost always social norms or unwritten rules and practices about managing menstruation and interacting with menstruating women. Girls are viewed as having reached "maturity"; therefore many are married off (Guerry, 2013). Most cultures have secret codes and practices around managing periods, of which some are helpful but others have potentially harmful implications. In some cases, girls are forced to have sexual intercourse with a 'Fisi' (traditional doctor) in order to initiate them sexually; a ritual that can have a negative impact on their 'sexual maturity'. These beliefs and practices often lead girls to feel isolated and stigmatised, as well as discourage them from participating in school and other social events and religious activities while menstruating (House et al, 2012).

Myths surround the burning of used products as it is thought to cause cancer or infertility, and dietary restrictions, are widespread (Guerry, 2013). In the western part of Uganda, where the cultural norm is to keep menstruation a secret, cattle owners do not let menstruating women attend to their cows, for fear that the milk may turn bloody (Ten, 2007).

Even though menstruation is a natural process, in most parts of the world it links up with cultural beliefs and taboos and is rarely talked about. The taboo surrounding Menstrual Hygiene Management (MHM) is present across the world, and prevents women from speaking out about these issues (WaterAid, 2009). In societies where disability is considered inferior, these restrictions only perpetuate inequality.

The issue has also been largely neglected by the Water Sanitation Hygiene (WASH) sector and other sectors focussing on reproductive health and education. As a result, the practical challenges of menstrual hygiene are made even more difficult by socio-economic, cultural and physical factors (WaterAid, 2009). Research from other countries has found that women and girls, who cannot stand or see, often have to sit on dirty latrine seats to change their pads or clothes (House et al, 2012). Some of them lack resources to buy sanitary pads and are also unable to wash their used materials themselves. Visually impaired women find it difficult to know when their period starts. A large gap exists in the area of communication on menstruation for the visual and hearing impaired women (United Nations, 2013). Another report by Rodriguez (2013) on menstrual management for adolescent girls with disabilities reiterated that adolescents with disabilities may have more difficulties with puberty and menses, with major challenges related to menstrual irregularities, hygiene, behavioural issues as well as sexuality, pregnancy and abuse. Cyclic behavioural changes such as tantrums, crying spells, self-injurious behaviour, and catamenial Epilepsy (pattern of seizure clustering related to menstrual cycle) have also been reported as challenges faced by adolescents with disabilities (Quint, 2008).

Menstrual pain (abdominal pain), a commonly reported problem experienced by adolescents globally, can be extra challenging to adolescents with disability (Muntunda, 2013; Munda, 2014; Blessing, 2016). They face the challenge of being unable to communicate discomfort or pain (Rodriguez, 2013).

In Ghana, menstruation is a verbal taboo (not allowed to be discussed within the family setting and not supposed to let any other person see one's menstrual blood) based on cultural and religious beliefs, norms and myths. Up to 48% and 90% of girls felt shame about menstruation in urban and peri-urban/rural areas respectively (Montgomery, 2012). Preliminary findings of a study conducted in Zabzugu and North Dayi districts as part of the UNICEF led Water, Sanitation and Hygiene in Schools for Girls (WinS4Girls) programme showed that girls are increasingly finding it difficult to attend school when they are menstruating (UNICEF, 2012).

Menstrual hygiene management as a globally emerging issue and its implications for the dignity, health and safety of women is increasingly well-documented. However, in Ghana, there is very little evidence of such documentation despite the development of Conventions and linked actions, such as the platform for action developed at the United Nation Fourth World Conference on Women which reaffirmed that all human rights – civil, cultural, economic, political and social, and the right to development - are universal, indivisible, interdependent and interrelated as expressed in the Vienna Declaration. Both the Declaration of the Rights of the Child (Article 31) and the Convention on the Rights of the Child (Article 11) guarantee children's rights and uphold the principle of non-discrimination on the grounds of gender. Even though various Conventions and action plans elaborate on women's sexual and reproductive rights, they however do not explicitly name menstruation as one of the most stigmatised, silent and socially constructed challenges that plague developed and developing countries like Ghana. In Ghana however, the conception and design of sanitation and hygiene facilities completely ignore this very real need of women and girls to manage menstruation. Such conditions put girls in a disadvantaged position and perpetuate gender inequality further.

Objective

Against this background, the current study was conducted in the Kumasi Metro to ascertain the experiences of menstrual hygiene management among adolescents with disabilities. The focus of the study was mainly on the challenges encountered and the coping strategies they have developed to manage the challenges.

METHOD

Setting

The study was conducted in the Kumasi Metropolis of Ghana, located in the forest zone and covering a total land area of 254 square kilometers (25,415 hectares), with about 2.4% of the population having disability (Ghana Statistical Service, 2010).

Design

An exploratory design with qualitative approach was used to investigate the challenges faced by adolescents with disability in managing their menstruation..

Sample

A sample size of 18 female adolescents with disability was purposively selected. Participants were identified through a two-step process, beginning with consultation of 'key informants' who included Disabled Peoples' Organisations (DPOs), and leaders of the church of Christ Deaf Ministry at Bomso. The key informants identified female adolescents with disability. The second step in the process involved confirming eligibility, which was determined by disability type and age. The inclusion criteria were age (12 - 19 years) and disability type (6 each from the three main impairment groups - visual, hearing and physical). Participants were then purposively selected based on the set inclusion criteria.

Data Collection

Data was collected through in-depth face-to-face interviews, with the use of an interview guide. Two female research assistants were engaged in the data collection exercise. Both were fluent in the Ghanaian sign language. The research assistants were given two weeks training in qualitative research data gathering, with special focus on conducting interviews and focus group discussions. The interviewers had no familial relationship with participants and did not know any of them prior to data collection. Non-participants were not present during data collection to avoid the possibility of influencing responses.

The interviews were conducted at the home of each participant. Each interview session lasted for an average of 45 minutes. Interviews were tape-recorded and field notes were taken during interviews. The interview was structured to cover the following areas: individual challenges in terms of managing menstrual experiences, restrictions placed on them by their culture, and coping strategies used to manage the challenges.

In addition, 3 focus group discussions (FGDs) were conducted with the 18 females with disability who had been interviewed. Each group consisted of 6 members. The focus group discussions were held in a rented community centre which was an enclosed room. The use of focus group discussions helped in getting additional information, as individual participants were more willing to give information in relation to their challenges in the presence of their peers who had similar experiences. Video-recording was employed during the interaction with the hearing impaired.

Data Analysis

Data was transcribed, edited and categorised into themes. Three analysts, with each blinded to the work of the others, did the analysis. Their work was compared later, to resolve possible overlaps and inconsistencies. The themes that emerged have been presented as the findings of the study, supported by quotations. Simple frequencies and percentages have been used to present the demographic characteristics of respondents.

Ethical Issues

The study process was explained to the Committee on Human Research, Publication and Ethics at the Kwame Nkrumah University of Science and Technology-Kumasi, Ghana, and approval was obtained. Verbal consent of participation was sought from caregivers of the adolescents with disability who were below 18 years of age. Participants were informed about the purpose of the study and were assured that refusal to take part would not lead to denial of services provided by any public institution within their locality. They were told they could decline to answer questions that they considered too personal. Participation was voluntary and no form of inducement was offered. Responses of those who participated in the study have been kept anonymous.

RESULTS

The findings are grouped under challenges that are generally faced by girls and women during menstruation, irrespective of whether they have disability or not, followed by challenges faced by the three main disability groups.

Demographic Characteristics of Respondents

Table 1: Demographic Characteristics of Respondents

Variables	Frequency	Percentage (%)
Age Group of Participants		
12-15 years	7	39
16-19 years	11	61

Religion		
Christian	14	78
Muslim	4	22
Educational Background		
Primary School	3	17
Junior High School	9	50
Senior High School	6	33
Type of Disability		
Visual	6	33.33
Hearing	6	33.33
Physical	6	33.33
Duration of Disability		
Below 10 years	3	16.7
Above 10 years	15	83.3

Source: Field work, 2018

From Table 1, it can be observed that majority of the participants (7) were between 16 -17 years of age, 3 of them were between 12-13 years of age, and 4 were between 14 -15 years and 18-19 years respectively. A total of 14 participants were Christians while 4 were Muslims. In terms of educational background, 3 were in Primary School, 9 were in Junior High School and 6 were in Senior High School. With regard to the disability type, among the 6 with visual impairment 1 was partially sighted, 1 had low vision and 4 were totally blind. Among those with hearing impairment, there were 2 each in the categories of mild, severe and profound impairment and they were all deaf. Among those with physical impairment, 2 were wheelchair- users, 2 had problems with their upper limbs, and the remaining 2 had problems with their lower limbs.

Challenges faced by women and girls in general

Several challenges that affected all the disability groups were identified. These challenges were mainly related to the restrictions that are placed on females during menstruation, which are influenced by culture, traditions and myths surrounding the subject, and faced by all women and girls. These restrictions have been presented under sub-themes such as social and religion, food and recreation restrictions.

Social and Religious Restrictions

It was evident from the study that majority of the adolescents with disability face challenges that are related to restrictions pertaining to the general female population when they are menstruating: they do not have the right to fast, pray or enter holy places. They are also restricted from being in the company of boys or men.

The majority are not supposed to cook, especially for an elderly person, priest or native doctor, because of the perception that menstruation affects the palms too and that the hands are dirty.

*"........I do not pray, go to the mosque or touch or read the Quran, and not allowed to sit on the mat for praying" (*Visually impaired adolescent, focus group discussion).

".......You don't sit on the mat with those who have not menstruated, you don't hold the Quran until you are done, you don't pray too…….because they said it is "haram"… Haram means bad omen" (Mobility impaired respondent, focus group discussion).

Food Restrictions

The girls are also subjected to food restrictions. Certain foods are not consumed during menstruation. It is believed that sweet foods like sugar, toffees and oranges will increase blood flow.

Recreation Restrictions

During menstruation, most of them are restricted from playing with boys for fear that they will become pregnant. The majority do not run, jump or play with friends for fear that they will stain their clothing.

Sources of the Restrictions

From the interviews and focus group discussions several myths were revealed. The people believed that: menstrual blood can be used for rituals, which can make one become barren; it is a sickness; it can cause fibroids; you are not a woman if you do not menstruate; you are unclean, so you do not cook for people; if someone sees your blood, it will stop and you will fall sick; when you are forty and you menstruate you will die; you do not enter the chief's palace, because the chief will not like it; the Gods hate menstruation.

"....If a dog takes your used pad and leaves it at the shrine, it can be used for a charm which can affect you or you can become barren so I burn mine" (Hearing impaired participant, individual interview).

"......if someone sees your blood it will stop flowing and you will become sick so I don't just throw it away, wrap it in toilet roll before I dispose it off" (Physically impaired participant, individual interview).

Challenges faced by the Visually Impaired

The study found certain challenges that were peculiar to the visually impaired adolescents. The challenges are presented here under specific sub-themes.

Difficulty in detecting Menstrual Blood

The visually impaired cannot see or detect when their menstrual period begins. In order to prevent staining, they have to prepare ahead of time by using sanitary pads even when they are not menstruating. This creates discomfort and is a major challenge for the girls. The economic burden that comes with having to buy more pads and waste them cannot be understated.

"……..I do not know whether blood is flowing or not, so I sometimes have to fix sanitary pad even when I am not menstruating to avoid embarrassment" (Focus group respondent).

"……Can you imagine the discomfort one goes through when you have fixed pad on you even when you are not in your menses? This indeed is a problem for me" (Focus group respondent).

Difficulty in fixing Sanitary Pads

The visually impaired also find it difficult to know whether the pad is properly fixed in the right place. They sometimes have to depend on other people to check on their behalf. This compromises their privacy and causes shame. The trauma of allowing someone else to see them naked, in order to help fix the sanitary pad, is a serious challenge for the visually impaired adolescents during menstruation.

"…….to be sure that my pad is well fixed, my senior sister usually does the inspection for me before I step out of the house. I am usually not comfortable when she is doing the inspection as she sees my private part but I have no option than to allow her" (Individual interview).

Anxiety and Emotional Stress

They lamented that they always had to be alert to the possibility that their clothes could be stained. Since they could not see, they had to rely on their mates to prompt them. Being caught unawares is a challenge. The girls realise the problem has occurred only when their pants become wet. This makes them feel anxious and uneasy especially when their period is due.

"…….I always feel uncertain anytime I move out of the house as I will not be able to detect whether my menstruation has started or not. I am always thinking about it, which makes me feel very uneasy among my friends" (Individual interview).

*"……Am always worried that I will stain myself, especially on days that I feel my pad is not well positioned (*Individual interview).

Maintaining good Menstrual Hygiene

Another challenge the visually impaired adolescents faced was their inability to determine whether their clothes or underwear were washed properly. This serves as a challenge in maintaining good hygiene levels.

"……because of my condition I cannot tell if my underwear is neatly washed or not" (Focus group discussion).

Challenges faced by the Physically Impaired

There were certain challenges that the physically impaired faced as far as managing and maintaining menstrual hygiene. The specific challenges have been presented as sub-themes in this section.

Inaccessible Washrooms

One common challenge that the physically impaired (wheelchair- users) faced was the inaccessible nature of the washrooms. Girls with mobility challenges have to abandon their wheelchair to access washrooms. The problem is further compounded by the washrooms being unclean. Bathing usually involves getting off the wheelchair and sitting on the floor, which becomes more challenging during menstruation.

"………Using the bathroom becomes difficult for me, the place will be dirty and you would have no choice than to use it like that as you can't go in with the wheelchair" (Physically impaired participant).

Long Hours of being Seated

The long hours of sitting add to the discomfort. Adolescents who use wheelchairs are almost always confined to their device as they are unable to stand. Remaining seated all the time causes them more discomfort during menstruation.

"………I basically have to sit in the wheelchair for long hours and it gets really uncomfortable when I am flowing" (Physically impaired participant).

Inability to fix Sanitary Pads

Those with upper limb limitations find it difficult to fix pads and ensure they stay in place, hence they may have to depend on others for help.

"……….I have to get help in fixing my pad because one of my arms is not functioning. I can manage at times but in extreme cases of pain I have to fall on someone to help me" (Physically impaired participant).

Challenges faced by the Hearing Impaired

The major challenge of the hearing impaired is communication. They revealed that they prefer to discuss issues with their deaf friends because most of the people with hearing cannot use sign language. Communication becomes difficult in consequence, and caregivers do not understand their pain and their feelings. They also raised concerns that anything they share with people with hearing might be disclosed to their hearing friends.

"………*My mother cannot sign and I find it difficult to explain myself"* (Hearing impaired adolescent).

Coping Strategies

Due to the unique challenges faced by adolescent females during menstruation, they have developed their own strategies to cope with minimal inconvenience during those days.

Almost all those who complained of pain take painkillers for relief. Paracetamol and Efpac are the commonly used painkillers. The few who do not take painkillers endure the pain and cry. Another strategy is to have enough rest or sleep to relieve the pain. Most of the visually impaired adolescents seemed to keep track of their menstrual cycle calendar so as to be prepared, although they did not find this strategy absolutely reliable.

"……..*I take a painkiller to ease the pain. I get it from my mother or the housemistress when I am in school"* (Hearing impaired participant).

"……..*I mostly do not know what to do. I mostly cry a lot sometimes till I fall asleep"* (Physically impaired participant).

"………*I keep track of my calendar so that I don't get caught unaware*" (Visually impaired participant).

DISCUSSION

The challenges that all three impairment groups face in common are menstrual pain, mood swings, weakness and tiredness, and lack of sanitary material. These are challenges commonly faced by other girls across the globe, as studies have reported (Muntunda, 2013; Munda, 2014; Blessing, 2016). The findings also confirm results from six studies (Carlson, 2002; Ditchfield and Burns, 2004; Rodgers et al, 2006; Cho et al, 2008; Mason and Cunningham, 2008) which reported that 22.2% to 90.9% of the study participants complained of abnormal pain during menstruation, mood swings and lack of sanitary materials. Lack of sanitary materials is the result of delay in supplying them on the part of caregivers. As a result the girls have to borrow from friends, especially when in school, or use the toilet roll as a substitute, which may not be hygienic. This is in line with the report by Ibaishwa and Achakpa (2016) in Nigeria that women with disability face problems when it comes to maintaining proper menstrual hygiene. Adolescents with disability face additional challenges apart from those that they have in common with their counterparts without disability. The study revealed that girls with mobility impairments face accessibility challenges. Washrooms are generally constructed to be used by every member of the house but individual needs are not taken into account, making it more challenging for young girls with disability. The narrow entrances usually are not able to accommodate the passage and free movement of wheelchairs. This problem is compounded if the washrooms are dirty and the wheelchair-users are forced to sit on the floor. This can predispose them to other health problems that may be associated with unhygienic menstrual practices. Sometimes those with upper and lower limb disabilities as well as balance challenges have to forgo privacy and ask for help, especially when menstrual pains are severe.

Difficulty faced by families in communicating with children who are deaf and those with speech limitations was the major challenge for the hearing impaired.

This means that sending messages and getting feedback from caregivers hindered discussion on issues of menstruation. This could partly explain why Ghanaian parenting is described as cool and non-conversational (Scott, 2013). The deaf face a major limitation with regard to obtaining information as most of the caregivers are sign language illiterates. The girls may feel they are not understood and will be more reluctant to talk to their caregivers.

The visually impaired face the challenge of being anxious all the time. The findings of Rodgers and his colleagues (2006) that 50% of girls with disabilities could not detect blood stains in their clothes during menstruation is similar to the findings of this study wherein all the visually impaired adolescents could not detect whether they had stained themselves or not. Their common problem was the inability to see when the menstrual flow begins and ends, as well as whether they have stained themselves. There is great embarrassment when individuals have to be prompted that there is staining because they cannot see for themselves. The act of secrecy surrounding the phenomenon can also prevent adolescent girls from asking for help openly. Paracetamol and Efpac were the painkillers generally used by adolescents to manage their menstrual pains. However, they could not indicate how effective these painkillers were.

CONCLUSION

There are common challenges faced by all girls across the globe with regard to menstrual hygiene management. Adolescent females with disability however face additional challenges with regard to MHM. Those with physical disability encounter accessibility challenges, while the main challenge for the deaf and those with speech problems is communication. The visually impaired live in anxiety due to fear of staining their clothes.

Recommendation

The Ministry of Health should extend reproductive health programmes to include persons with disability so that they and their parents, who are key informants to children, receive accurate information about menstruation and other issues relating to reproductive health. The Ministry of Gender and Social Protection should collaborate with relevant stakeholders to ensure that the conception and design of sanitary facilities and hygiene materials embrace the menstrual needs of women and girls, especially those with disabilities.

REFERENCES

Backeljauw PF, Rose SR, Lawson M (2004). Clinical management of menstruation in adolescent females with developmental delay. The Endocrinologist; 14(2): 87-92. https://doi.org/10.1097/01.ten.0000123566.01901.e7

Blessing E (2016). Menstrual hygiene management among basic school girls in Legon, Accra. MPH: University of Ghana.

Carlson G (2002). Supporting the health and wellbeing of people with intellectual disability and high support needs through networking and resource development. Australian Occupational Therapy Journal; 49: 37-43. https://doi.org/10.1046/j.0045-0766.2002.00285.x

Chou Y, Lu Z (2012). Caring for a daughter with intellectual disability in managing menstruation: Mother's perspective. Journal of Intellectual and Developmental Disability; 37: 1-10. https://doi.org/10.1111/j.1365-2788.2012.01624.x PMid:22998422

Ditchfield H, Burns J (2004). Understanding our bodies, understanding ourselves: The menstrual cycle, mental health and women with learning disabilities. Tizard Learning Disability Review; 9: 24-32. https://doi.org/10.1108/13595474200400035

Environmental Health Group (2016). Why does menstrual hygiene matter? Available at: htt://ehg.ishtm.ac.uk/menstrual hygiene. [Accessed on: 20 Feb 2017]

Ghana Statistical Service (2010). Population and Housing Census (PHC) manual. Accra Ghana.

Guerry E (2013). An assessment of menstrual hygiene practices and absenteeism in Western Uganda - A dissertation submitted in partial fulfillment of the requirements for the degree of Master of Public Health.

House S, Mahon T, Cavill S (2012). Menstrual hygiene matters: A resource for improving menstrual hygiene around the world. Available at: www.wateraid.org/mhm [Accessed on 27 Mar 2018].

Ibaishwa RL, Achakpa P (2016). Menstrual hygiene management amongst marginalised physically challenged women and adolescent girls in 10 states of Nigeria. Water Supply and Sanitation Collaborative Council.

Mason L, Cunningham C (2008). An exploration of issues around menstruation for women with Down syndrome and their carers. Journal of Applied Research in Intellectual Disabilities; 21: 257-267. https://doi.org/10.1111/j.1468-3148.2007.00406.x

Montgomery P, Ryus CR, Dolan CS, Dopson S, Scott LM (2012). Sanitary pad interventions for girls' education in Ghana: A pilot study. PloS one; 7(10): 48-74. https://doi.org/10.1371/journal.pone.0048274 PMid:23118968 PMCid:PMC3485220

Munda NN (2014). An assessment of hygiene knowledge and practices: A case study of Choto informal settlement in Katima Mulilo. Doctoral dissertation.

Mutunda A (2013). Factors impacting on the menstrual hygiene among school-going adolescent girls in Mongu District, Zambia. Available at: http://akros.com/downloads/papers/mutunda-study.pdf [Accessed on 27 Feb 2017].

Quint EH (2008). Menstrual issues in adolescents with physical and developmental disabilities. Annals of the New York Academy of Sciences; 1(135): 230-236 https://doi.org/10.1196/annals.1429.020 PMid:18574229

Rodgers J, Lipscombe J (2005). The nature and extent of help given to women with intellectual disabilities to manage menstruation. Journal of Intellectual & Developmental Disability; 45-52. https://doi.org/10.1080/13668250500033094

Rodrigues A (2013). Menstrual manipulation for adolescents with disabilities. Available at: https://www.macpeds.com/documents/menstrualmanipulationpresentation.pdf. [Accessed on 20 Apr 2018]

Scott A, Ejikeme CS, Clottey EN, Thomas JG (2013). Obesity in sub-Saharan Africa: development of an ecological theoretical framework. Health Promotion International; 28(1): 4-16. [Accessed on 17 Feb 2018]. https://doi.org/10.1093/heapro/das038. PMid:22933446

Ten VTA (2007). Menstrual hygiene: A neglected condition for the achievement of several millennium development goals, Europe External Policy Advisors

United Nations Children's Fund - UNICEF (2012). WASH in schools for girls: Voices from the field. Advocacy and capacity building for menstrual hygiene management through WASH in schools programmes.

WaterAid (2009). Is menstrual hygiene and management an issue for adolescent girls? A comparative study of four schools in different settings of Nepal. Water Aid in Nepal. Available at: http://www.indiahabitat.org/qefl/link/Practices/wa_nep_mhm_rep_march2009.pdf [Accessed on 27 Mar 2018].

Water Supply and Sanitation Collaborative Council (2013). Celebrating womanhood. Menstrual hygiene management, Highlights report. Available at www.wsscc.org/sites/default/files/content/Research_article_files/mhm_8_march_highli 29 ghts_report.pdf [Accessed on14 Sep 2017].

Water Supply and Sanitation Collaborative Council -WSSCC/UN-WOMEN (2015). Menstrual hygiene management: Behaviour and practices in the Kedougou region, Senegal. Available at: http://wsscc.org/2015/03/09/menstrual-hygiene-management-wssccun-women-studies-on-behaviour-and-practices-in-senegal-and-cameroon/ [Accessed on 2 Sep 2018]

REVIEWS

A Bibliometric Review of Executive Function as Cognitive Endophenotypes in Parents of Children with Neurodevelopmental Disorders

Kamlam Gopalkrishnan Iyer[1*], Venkatesan Srinivasan[2]

1. PhD Scholar, Department of Studies (DOS) in Psychology, University of Mysore, Mysore, India

2. Head of Clinical Psychology Department, All India Institute of Speech and Hearing, Manasagangotri, Mysore, India

ABSTRACT

Purpose: *The main aim of this study was to review whether first-degree relatives (parents) and their children with neurodevelopmental disorders (NDD) are cognitive endophenotypes in executive functioning.*

Method: *A survey design was employed from May 2018 to January 2019, using an online and offline database of national and international ISSN Journals and ISBN books.*

Results: *A bibliometric analysis was conducted on 19 of the 63 reviewed studies. A PRISMA Flow diagram and Harvest Plot have been used to depict the results of the analysis*

Conclusion and Implications: *Delineation of executive functions (EF) as cognitive endophenotypes of NDD is, first of all, useful in exploring the genetic basis of these disorders; secondly, for identifying which cognitive traits may be important to it; and thirdly, to initiate and promote better educational practices and cognitive remediation. With a disclaimer that this analysis is only as inclusive as possible in the field of endophenotypes in NDD, limitations in the various studies have been identified, along with future suggestions for research.*

Key words: *genetic, Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), working memory, inhibition, cognitive flexibility*

---

* **Corresponding Author**: Kamlam Gopalkrishnan Iyer, PhD Scholar, DOS in Psychology, University of Mysore, Mysore, Karnataka, India. Email: iyerkamlam@gmail.com

INTRODUCTION

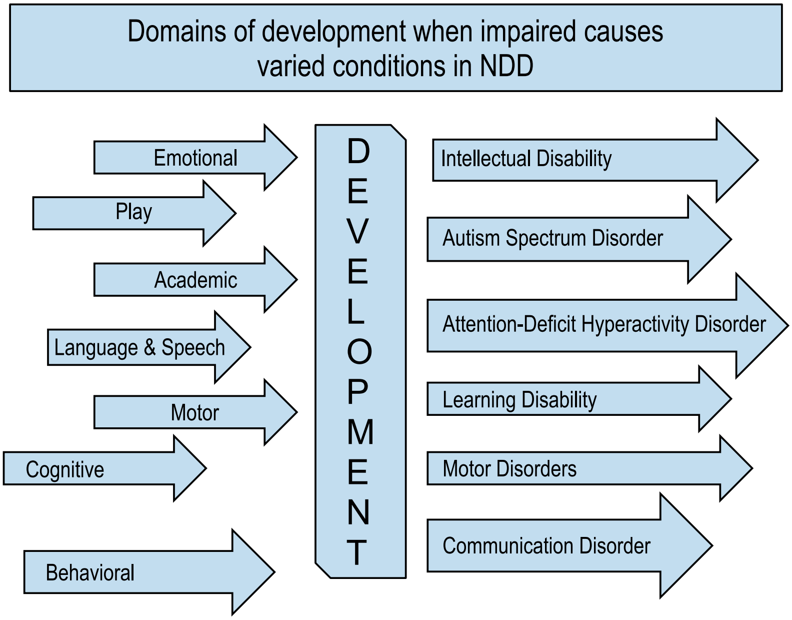
The genetics of cognition and brain-behaviour relationships in healthy and pathological states are a major aspect of research and treatment in this century (Kremen et al, 2016). In psychiatry and psychology, one method of understanding the gene action on behaviour is to have a clearly defined disease entity such as a diagnosis, for example with DSM 5 (Glahn et al, 2014). Another method is to use endophenotypes, which are heritable "markers" associated with disease genes and measurable in both affected and unaffected individuals (Glahn et al, 2014).

The term "neurodevelopment" is defined as the dynamic inter-relationship between genetic, brain, cognitive, emotional and behavioural processes across one's developmental life span (Boivin et al, 2015). Any significant and persistent disruption to this dynamic relationship through such factors as environment or/ and genetic, can lead to NDD and disability (Boivin et al, 2015). Though NDD are of importance, it has not been considered as a significant public health problem of children in a developing country like India (Rathi & Francis, 2009).

India has the world's largest birth cohort of about 26 million (Arora et al, 2018; Gavi, 2018). With better infant survival rates (Gavi, 2018) of the neonates born pre-term and with lower gestational age, the risk of NDD in countries such as India has increased (Zaka et al, 2018). The prevalence rates of NDD in Indian children in the age-group of 2-6 years were found to be between 2.9% and 18.7%, depending on the sites examined, according to the Inclen trust study (Arora et al, 2018). Children in the age-group of 6-9 years had prevalence rates of about 6.5% to 18.5% for any one of the aforementioned NDD, with 1/5th of these children having a co-morbidity of one or more NDD (Arora et al, 2018).

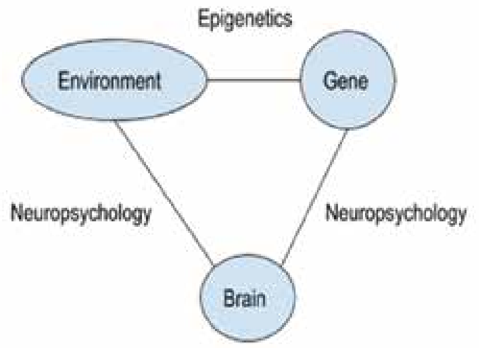
NDD are conditions that are difficult to conceptualise (Thapar et al, 2017). NDD arise due to impairments in the developing brain and/or central nervous system (Bakare et al, 2016). They originate during the developmental stages of the antenatal, post-natal, infancy and early childhood periods and are characterised by a delay or disturbance in the acquisition of skills under various domains such as motor, sensory, speech and language, social and cognition, presented in heterogeneous conditions such as Attention-Deficit-Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Vision Impairment (VI), Epilepsy (Epi), Neuromotor Impairments such as Cerebral Palsy (NMI-CP), Hearing Impairment (HI), Speech and Language Disorders and Intellectual Disability (ID) (Jeste, 2015). Figure 1 presents a diagrammatic representation of the domains of development and the conditions of NDD. Many studies have established the genetic basis for a few of the NDD such as ADHD, ASD, and LD (e.g., Doyle et al, 2005a; Rommelse et al, 2008; Jester et al, 2009; Moll et al, 2014; Losh et al, 2017).

Figure 1: Diagrammatic Representation of Domains of Development and Conditions of NDD



Boivin et al (2015) suggest that genetic studies on NDD have been due to three mutually interactive domains, as given in Figure 2.

Figure 2: Interactive Domain of 3 Mutual Areas of Research (Boivin et al, 2015)



Taken from Boivin et al (2015)

Figure 2 suggests that epigenetics is the area of research between the environment and gene socio-evolutionary processes while neuropsychology is the strategic area of research between environment and brain as well as brain and gene processes (Boivin et al, 2015). One domain by which neuropsychology can contribute towards deciphering genes and brain and vice versa, is through the concept of endophenotypes (Glahn et al, 2014).

Endophenotypes are popular in psychiatry and psychology ever since their introduction by Gottesman and Shields in 1972 (Gottesman & Shields, 1976) and then later by Gottesman and Goulds (2003), due to their apparent proximity to genotypes (Insel & Cuthbert, 2009). If any symptoms of the disorder or traits of the disorder run in families by expressing themselves as subclinical, genetically meaningful traits, then they are believed to constitute endophenotypes (Losh et al, 2017). According to these researchers, heritability and stability (state independence) represent pivotal components of any useful endophenotype from the six criteria provided (Gould & Gottesman, 2006). These endophenotypes can be cognitive, neuroanatomical, biochemical, endocrinological or neurophysiological in nature (Cruz et al, 2013). The criteria for a neurocognitive function are provided by Rommelse et al (2008) as follows:

1. Heritability of neurocognitive dysfunction in which at least the same genes influence both the endophenotype and phenotype.
2. As the first-degree relatives are more likely to carry some of the susceptible genes of the disorder, neurocognitive dysfunction is to be seen in non-affected first-degree relatives of the proband.
3. Such neurocognitive dysfunction is observed in the disorder.

Hence, this states that for any neuropsychological deficits to be useful as endophenotypes, it is imperative to include both the affected and non-affected individuals in the study (Rommelse et al, 2008).

One of the functional domains for which there is considerable evidence of meeting the endophenotypic criteria in first-degree relatives having deficits, is that of EF (Rommelse et al, 2011). Also, as one of the factors affecting EF in parents, genetic studies have reported as much as 40-80% influence in EF skills in young children (Leve et al, 2013).

Just like any other neuropsychological constructs, EF is also wide- ranging and multidimensional. Many functions such as prioritising and sequencing of behaviour, inhibiting familiar or stereotyped behaviours, maintaining a mental set or an idea of what task or information is needed at any moment, ignoring tasks that are irrelevant or distracting, switching between various relevant information, categorising, multi-tasking different situations or information are included in the term of EF (Banich, 2009).

Many views are prevalent on the cognitive components of EF and in the manner in which the frontal lobe is linked to various executive functions. Nevertheless, there is general agreement on three core components of EF which were given by Miyake et al (2000) and later agreed upon by many other researchers (e.g., Lehto et al, 2003). They are:

a. Inhibitory control or inhibitions of dominant or prepotent responses,

b. Shifting between mental sets or tasks also called cognitive flexibility,

c. Updating and monitoring of working memory representations.

From these basic components, other higher order cognitive functions of creativity, reasoning and decision-making adaptive behaviours emerge (Collins & Koechlin, 2012).

Executive Function, therefore, is an overall term referring to varied neuropsychological processes such as inhibition, working memory, cognitive flexibility/set shifting, fluency, planning and inhibitory control. EF processes involve a distributed cerebral network (Colette et al, 2006).

Objective

The main objective of this review is to explore such cognitive endophenotypes in first-degree relatives of children with NDD.

METHOD

Study Design

A survey research design was adopted for the purpose of this study. It was conducted from May 2018 – January 2019, using Google and MSN search engines in the following databases: NCBI, Semantic Scholar, Google Scholar, Researchgate and PubMed - where national and international publications in the field of psychology and neuroscience were available. Studies published from

1993 to 2018 were considered for review. The key words used were: Executive functions deficit in parents as endophenotype, Parental executive functions, Executive functions in parents, Autism endophenotype, ADHD endophenotype, Dyslexia endophenotype, Learning

Disability endophenotype, Cerebral palsy endophenotype, Families of Neurodevelopmental disabilities, Cognitive deficits in parents of children with NDD.

Procedure

Data collection procedure was according to the inclusion and exclusion criteria provided in Table 1.

Table 1: Inclusion and Exclusion Criteria

No.	Inclusion Criteria	Exclusion Criteria
1.	Any research article / book published in reputed Indian and/or International Journals	Opinion and Call-for-research papers in the area of Endophenotypes
2.	Original studies published in English Journals only	Studies that investigated only siblings and teachers in EF as Endophenotypes of children with NDD
3.	Study objectives with cognitive or EF in parents of children with NDD	Studies that investigated EF in parents of children with mental disorders
4.	Full-text articles with DOI only	Studies that investigated other cognitive functions such as face-recognition, phonetic processing, reading ability, visual processing, reaction time, memory, eye-movement tracking ability, Broader Autism Phenotypes, Cognitive models in ASD without EF, in parents as endophenotypes or biochemical or neuroanatomical endophenotypes in NDD

5.	Studies from 1993 to 2018 on EF as neuropsychological measure	Studies on EF in parents of adolescents and adults with ASD, ID, LD only

On the basis on inclusion and exclusion criteria, the studies reviewed in this article are depicted in the PRISMA Flow Diagram (Moher et al, 2009) given in Figure 3.

Figure 3: PRISMA Flow Diagram (Moher et al, 2009)

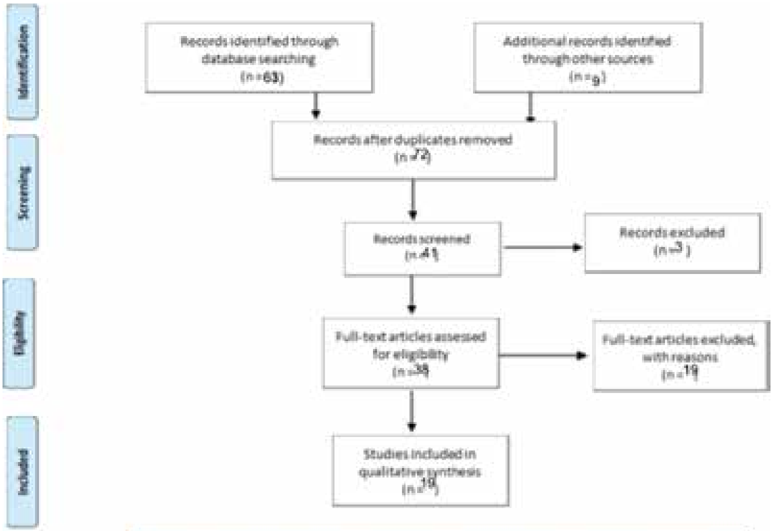


Figure 3: Prisma Flow Diagram depicting the procedure for review

RESULTS and DISCUSSION

In keeping with the aim of the paper, 19 studies were identified in the area of EF in parents of children with NDD, and their usefulness as neurocognitive endophenotype construct (Table 2).

Table 2: Studies on EF as endophenotypes in Parents of Children with NDD

Sl. No.	Sample Size of Parents	Type of NDD in children	EF Components Assessed	Results	References
1.	46 parents 33 parents 16 parents	ASD Down Syndrome TD	Verbal and Spatial WM & Language Comprehension	No significant difference between groups	Szatmari et al (1993)
2.	25 parents of children with severe symptoms 25 parents of children with mild symptoms 25 parents	ADHD ADHD TD	Attention, Set-shifting, Verbal WM	No significant difference between groups	Murphy & Barkley (1996)
3	48 parents 60 parents	ASD Down Syndrome	Planning	Significant difference between groups	Piven & Palmer (1997)
4	40 parents 40 parents 40 parents	ASD LD TD	Attention, Cognitive Flexibility, Planning, Spatial WM, Spatial STM	Few differences between parents of ASD and LD groups. Impaired EF in ASD group compared to control group	Hughes, et al (1997)

5	160 parents 36 parents 42 parents	ASD ID - Down Syndrome TD	Intellectual functioning having WM tasks, Reading and Spelling ability	No significant differences	Fombonne, et al (1997)
6	190 parents 79 parents 115 parents	ADHD COS TD	Attention, Set-shifting	No differences between groups	Asarnow et al (2002)
7	11 parents of children & adolescents 17 parents of children & adolescents	ASD TD	Spatial WM using oculomotor delayed response task	Significant difference found	Koczat, et al (2002)
8	165 parents 80 parents 141 parents	ADHD Combined type ADHD Inattentive type TD	Response Inhibition, Set-shifting, Planning and Processing Speed	Impairment in parents of combined ADHD type in set-shifting and processing speed	Nigg et al (2004)
9	106 parents 189 parents 243 parents	ADHD unaffected parents members ADHD parents affected TD	Set- shifting, WM, Attention and Response Inhibition	Impairments in both the parents of ADHD as compared to controls	Doyle et al (2005b)

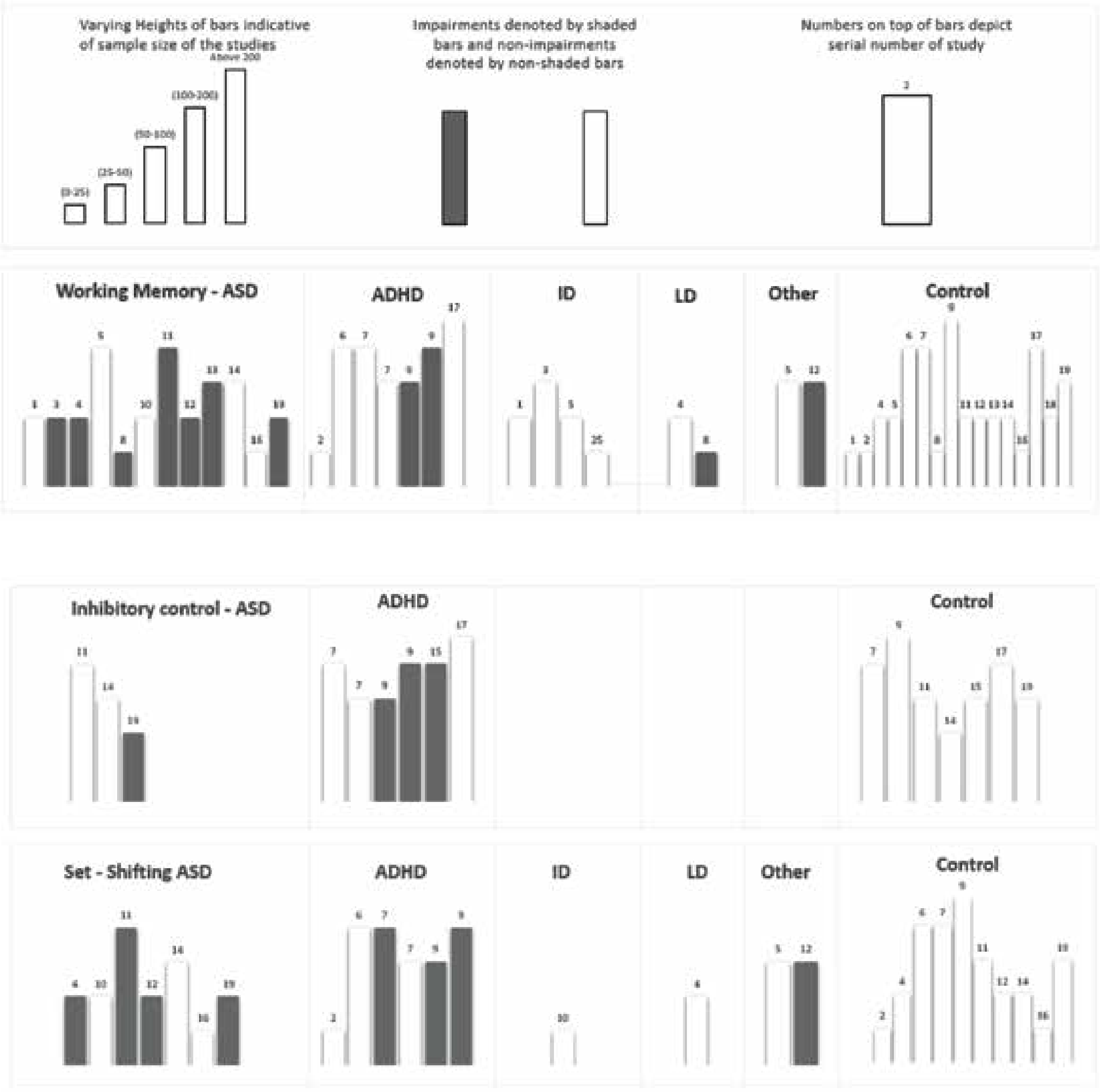
10	62 parents 30 parents	ASD ID	Set-shifting ability, Planning, Visuo-motor function and attention	No significant effects seen	Bolte & Poustke (2006)
11	145 parents 96 parents	ASD TD	Planning, Set-shifting, Response Inhibition, Verbal and Nonverbal WM	ASD and control parents differed in WM and Set-shifting. No significant difference between planning or inhibition seen.	Wong et al (2006)
12	39 parents of children and adults with ASD 53 parents of children and adults 47 parents	ASD OCD TD	Planning, WM--Verbal Spatial, Attention, Mental Set--shifting	Compared to control parents, both ASD and OCD parents performed worse.	Delorme et al (2007)
13	76 parents 41 parents	ASD TD	Verbal WM	Significant differences between the groups	Gokcen et al (2007)
14	83 parents 32 parents	ASD TD	Planning, Set-shifting, Cognitive control	No significant difference found	Losh et al (2009)

15	104 parents 88 parents	ADHD TD	Inhibitory control	Significant difference between the 2 groups	Goos et al (2009)
16	36 parents 28 parents	ASD TD	Planning and Set-shifting	All performed poor in EF tasks	Nydén et al (2011)
17	238 parents 147 parents	ADHD TD	Inhibition, Verbal WM, Spatial WM	No significant differences found	Thissen et al (2012)
18	40 parents 40 parents	LD TD	Verbal WM	Significant difference found	Bonifacci, et al (2013)
19	37 parents 58 parents	ASD TD	Inhibition, Cognitive Flexibility, WM, Planning	Significant difference in WM, Cognitive flexibility & Response inhibition	Van Eylen et al (2017)

[WM = working memory, ASD = Autism Spectrum Disorder, LD = Learning Disability ADHD = Attention Deficit Hyperactivity Disorder, ID = Intellectual Disability, OCD = Obsessive-Compulsive Disorder, COS = Childhood onset Schizophrenia, TD = typically developing]

These studies have been plotted in a Harvest Plot (Figure 4), which is a mainstay of this study. Harvest Plot, which was introduced by Ogilvie et al (2008), is a unique method of plotting a matrix of evidence gathered on a given topic (Crowther et al, 2011). This method presents information in a unique schematic manner, which can encompass any number of similar studies put in a definitive manner and is mostly used in interventional studies (Ogilvie et al, 2008); however, in the present instance, the same has been attempted on a survey design. The rows depict the three aspects of EF. The columns depict the varied conditions of NDD and the control population of normal adults, while rows depict the components of EF. The bars are depicted in varying heights, denoting the sample size of the study. The bars have numbers on them, again indicative of the serial number of the studies as in Table 2. The shaded and unshaded bars are indicative of results showing significance and non-significance in the differences obtained between the NDD and control groups of the studies, respectively.

Figure 4: Harvest plot depicting evidence for components of EF as Endophenotypes in parents with children with NDD and their respective control groups.



Though this list is neither exhaustive nor all-inclusive in the domain of NDD and endophenotypes, these studies on first-degree relatives of NDD seem to have emerged from the genetic emphasis of ASD and Down syndrome in the late 1980s and 1990s. In ASD, the general cognitive impairments, communication, language and social skills were explored, mostly as a part of Broader Autism Phenotype (e.g., Bolte & Poustke, 2006).

Many neuropsychological aspects have been explored in the first-degree relatives of children with NDD such as intellectual functioning, EF, reading and spelling ability, eye-movement abnormality, local visual processing, Central Coherence Theory, Theory of Mind, reading speed, phonological awareness (Piven & Palmer, 1997; Koczat et al, 2002; Bolte & Poustke, 2006; Nyden, 2011; Bonifacci et al, 2013). After a clear enumeration of criteria on identifying the "endophenotype" in psychiatry and psychology (Gottesman & Gould, 2003), many family studies on ADHD, ASD and Schizophrenia, in particular, were published (Rommelse et al, 2008; Allen et al, 2009; Rommelse et al, 2011). Other areas where this construct was explored are bipolar disorders (Raust et al, 2014), major depression (Merikangas et al, 2017) and anxiety disorders (Müller et al, 2015).

One of the salient features of the reviewed studies has been the type of design used. All of them have a case-control group as the research design (Table 3). The age group of the parents in most of the studies has been in the range of 23 - 50 years, with both mothers and fathers considered, though there seems to be an underestimation of fathers in most of the studies (e.g. Szatmari et al, 1993; Murphy & Barkley, 1996; Asarnow et al, 2002; Nigg et al, 2004; Bolte & Poustke, 2006; Wong et al, 2006). The age group of the proband children varies from 2 -18 years (e.g., Asarnow et al, 2002; Doyle et al, 2005b; Goeken et al, 2009), with some studies considering adults with NDD and their parents (e.g., Piven & Palmer, 1997; Delorme et al, 2007; Thissen et al, 2012). Many studies have considered the siblings as well, along with parents (Wong et al, 2006; Delorme et al, 2007; Goos et al, 2009; Van Eylen et al, 2017).

Table 3: EF Studies and Nature of Study

Sl. No.	Study	Design of the Study	Aim of the Study
1.	Szatmari et al, 1993	Case-Control	To compare the siblings & parents of ASD probands with those of Down's Syndrome

2.	Murphy & Barkley, 1996	Case-Control	To examine if biological parents of ADHD children show impairment in EF tests as compared to biological parents of TD children
3.	Piven & Palmer, 1997	Case-Control	To examine rates of more broadly defined ASD phenotype in a sample of multiplex ASD families and comparison subjects
4.	Hughes, et al., 1997	Case-Control	To examine if impairments in EF are apparent in parents of children with ASD and, if so, whether they are associated with abnormalities in everyday interactional skills
5.	Fombonne, et al., 1997	Case-Control	To examine if the first unaffected relatives of ASD exhibit higher ID & impairments and show cognitive profile of BAP
6.	Asarnow et al, 2002	Case-Control	To examine the performance of first-degree relatives of COS and ADHD in neurocognitive assessments
7.	Koczat, et al.,	Case-Control	To evaluate whether the delayed oculomotor response task abnormalities demonstrated by ASD probands also exist in parents of ASD children
8.	Nigg et al, 2004	Case-Control	To evaluate the endophenotype neuropsychological hypothesis in ADHD-affected and unaffected relatives of children with ADHD
9.	Doyle et al, 2005b	Case-Control	To examine the neuropsychological deficits in relatives of girls with ADHD with unaffected and control group relatives

10.	Bolte & Poustke, 2006	Case-Control	To investigate the tendency for local processing style and executive dysfunction in parents of subjects with ASD as compared with EOS and ID
11.	Wong et al, 2006	Case-Control	To examine the potential endophenotypes for ASD by specifying the EF profile characterising BAP
12.	Delorme et al, 2007	Case-Control	To see if different components of EF in first-degree unaffected relatives of ASD & OCD are endophenotypes
13.	Gokcen et al, 2007	Case-Control	To examine if Verbal WM and different aspects of Social Cognition are endophenotypes of ASD
14.	Losh et al, 2009	Case-Control	To gain insight into neuropsychological features that index genetic liability to ASD
15.	Goos et al, 2009	Case-Control	To compare the inhibitory control in children with ADHD, their siblings and their parents
16.	Nyden, et al., 2011	Case-Control	To examine the endophenotype of ASD in multiple incidence families
17.	Thissen et al, 2012	Case-Control	To investigate the association between ADHD and EF during adolescence
18.	Bonifacci, et al., 2013	Case-Control	To examine if parents of children with LD show endophenotypes for reading disorders and other cognitive, behavioural, environmental characteristics as compared to children who are TD
19.	Van Eylen et al, 2017	Case-Control	To evaluate the endophenotypic criteria for EF and local global visual processing in ASD and TD relatives

[ASD = Autism Spectrum Disorder, TD = Typical Development, ID = Intellectual Disability, EOS = Early Onset Schizophrenia, ADHD = Attention Deficit Hyperactivity Disorder, EF =Executive Functions, BAP = Broader Autism Phenotype, COS = Childhood Onset Schizophrenia]

Most of the studies have stratified the sample on the basis of age, sex, IQ, socioeconomic status (SES) of the first-degree relatives (e.g., Murphy & Barkley, 1996; Fombonne et al, 1997; Hughes et al, 1997). All the assessments for EF have been chosen on the basis of the specific cognitive functioning they tap (e.g., Murphy & Barkley, 1997; Piven & Palmer, 1997; Wong et al, 2006) though limitations on account of not using a wide range of cognitive measures to tap EF have been reported (e.g., Szatmari et al, 1993; Doyle et al, 2005b; Losh et al, 2009). The use of more ecologically valid tasks for the assessment of EF is observed (Wong et al, 2006; Thissen et al, 2012).

Perhaps to yield more precision, measures from experimental neuroscience could be used, as suggested by Doyle et al (2005b). Studies have been particularly salient on account of the varied research questions probed in the first-degree relatives (parents) of children with NDD and the endophenotypic construct. For example, Doyle et al (2005b) attempted to study the relatives of female probands alone in the area of ADHD. This can be seen as important, as females might require more familial risk factors to express the disorder (Nigg et al, 2004; Doyle et al, 2005b).

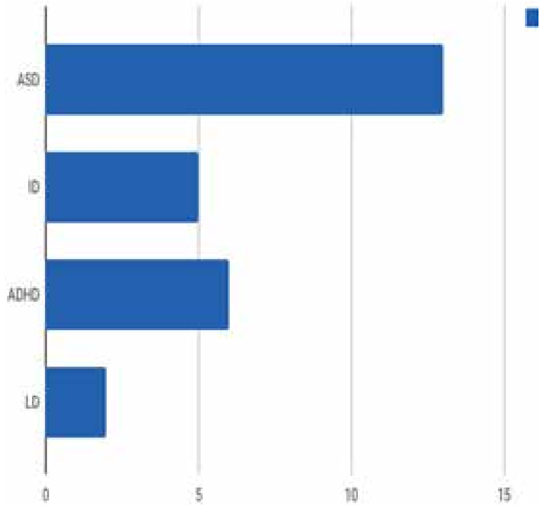
Similarly, one of the first studies to report the cognitive, behavioural and emotional profile of the parents of children with LD is by Bonifacci et al (2013). A few studies have investigated probands with childhood-onset schizophrenia and probands with NDD in the context of executive function (e.g., Asarnow et al, 2002; Bolte & Poustke, 2006). Multiple incidence families in ASD and EF have been examined (Piven & Palmer, 1997; Nyden et al, 2011), though sparse in other conditions of NDD.

The need for a larger sample size has been stated in most of the studies reviewed. The researchers of many of these aforementioned reviewed studies have not been blind to the diagnosis of the probands during assessment of their relatives. This is another difficulty in such family studies, as it could introduce bias or other confounding factors (Piven & Palmer, 1997). Again, when participants have been recruited through a tertiary source of referral, as in some studies, the representativeness of the sample is a matter of concern (Fombonne et al, 1997).

In the analysis of the results obtained, there is a clear and significant difference in the parental groups of NDD as compared to their control groups, in 14 out of the 19 studies highlighted.

Moreover, the number of conditions in each of the NDD is also demarcated in this set of studies, as given in the bar chart in Figure 5. This shows that the first-degree relatives in most of the studies are considered to be endophenotypes in comparison to their control group.

Figure 5: Number of Studies on Conditions of NDD



[ASD - Autism Spectrum Disorder; ADHD - Attention Deficit Hyperactivity Disorder; LD - Learning Disability; ID - Intellectual Disability]

Studies in neurocognitive endophenotypes are extensive in the area of ASD and ADHD and highly limited on other disorders of neurodevelopment. Furthermore, such studies are highly restricted in the Indian population. As per this review, there are also no reports on NDD within a single study, although there are various studies targeting ADHD, ASD, and LD separately.

CONCLUSION

Studies on endophenotypes from the field of neuropsychology have contributed to the field of epigenetics. It is important to identify such "markers" as cognitive endophenotypes of NDD, not only for theoretical reasons but also to provide further impetus to genetic investigations from fields such as neuropsychology. The current trend of neuropsychological traits seeking correlation with biochemical / neuroanatomical / physiological measures in NDD can also be observed (Baroni & Castellanos, 2015), which further highlights the immense scope of genetic studies in the present era.

Moreover, such studies might also guide the development of interventional and educational programmes (Moll et al, 2014).

ACKNOWLEDGEMENT

Sincere thanks to the Director, All India Institute of Speech and Hearing (AIISH) and the Chairperson, Department of Studies (DOS) in Psychology, Mysore, for their valuable contributions to this paper.

REFERENCES

Allen AJ, Griss ME, Folley BS, Hawkins KA, Pearlson GD (2009). Endophenotypes in Schizophrenia: A selective review. Schizophrenia Research; 109(1-3): 24-37. https://doi.org/10.1016/j.schres.2009.09.002 https://doi.org/10.1016/j.schres.2009.01.016 PMid:19223268 PMCid:PMC2665704

Arora NK, Nair MKC, Gulati S, Deshmukh V, Mohapatra A, Mishra D, Patel V, Pandey RM, Das BC, Divan G, Murthy GVS (2018). Neurodevelopmental disorders in children aged 2-9 years: Population-based burden estimates across five regions in India. PLoS Medicine; 15(7): p.e1002615. https://doi.org/10.1371/journal.pmed.1002615 PMid:30040859 PMCid:PMC6057634

Asarnow RF, Nuechterlein KH, Subotnik KL, Fogelson DL, Torquato RD, Payne DL, Asamen J, Mintz J, Guthrie D (2002). Neurocognitive impairments in nonpsychotic parents of children with schizophrenia and attention-deficit/hyperactivity disorder: The University of California, Los Angeles Family Study. Archives of General Psychiatry; 59(11): 1053-1060. https://doi.org/10.1001/archpsyc.59.11.1053 PMid:12418939

Bakare MO, Bello-Mojeed MA, Munir KM, Ogun OC, Eaton J (2016). Neurodevelopmental delay among children under the age of three years at immunization clinics in Lagos State, Nigeria-Preliminary report. Scientific Reports; 6: p.25175. https://doi.org/10.1038/srep25175 PMid:27125631 PMCid:PMC4850395

Banich MT (2009). Executive function: The search for an integrated account. Current Directions in Psychological Science; 18(2): 89-94. https://doi.org/10.1111/j.1467-8721.2009.01615.x

Baroni A, Castellanos FX (2015). Neuroanatomic and cognitive abnormalities in attention-deficit/hyperactivity disorder in the era of 'high definition' neuroimaging. Current Opinion in Neurobiology; 30: 1-8. https://doi.org/10.1016/j.conb.2014.08.005 PMid:25212469 PMCid:PMC4293331

Boivin MJ, Kakooza AM, Warf BC, Davidson LL, Grigorenko EL (2015). Reducing neurodevelopmental disorders and disability through research and interventions. Nature; 527 (7578): S155-S160. https://doi.org/10.1038/nature16029 PMid:26580321

Bölte S, Poustke F (2006). The broader cognitive phenotype of autism in parents: How specific is the tendency for local processing and executive dysfunction? Journal of Child Psychology and Psychiatry; 47(6): 639-645. https://doi.org/10.1111/j.1469-7610.2006.01603.x PMid:16712641

Bonifacci P, Montuschi M, Lami L, Snowling MJ (2014). Parents of children with dyslexia: Cognitive, Emotional and Behavioural Profile. Dyslexia; 20(2): 175-190. https://doi.org/10.1002/dys.1469 PMid:24265066

Collette F, Hogge M, Salmon E, Van der Linden M (2006). Exploration of the neural substrates of executive functioning by functional neuroimaging. Neuroscience; 139(1): 209-221. https://doi.org/10.1016/j.neuroscience.2005.05.035 PMid:16324796

Collins A, Koechlin E (2012). Reasoning, learning, and creativity: Frontal lobe function and human decision-making. PLoS Biology; 10(3): p.e1001293 https://doi.org/10.1371/journal.pbio.1001293 PMid:22479152 PMCid:PMC3313946

Crowther M, Avenell A, MacLennan G, Mowatt G (2011). A further use for the harvest plot: A novel method for the presentation of data synthesis. Research Synthesis Methods; 2(2): 79-83. https://doi.org/10.1002/jrsm.37 PMid:26061676

Cruz LP, Camargos-Junior W, Rocha FL (2013). The broad autism phenotype in parents of individuals with autism: A systematic review of the literature. Trends in Psychiatry and Psychotherapy; 35(4): 252-263. https://doi.org/10.1590/2237-6089-2013-0019 PMid:27000471

Delorme R, Goussé V, Roy I, Trandafir A, Mathieu F, Mouren-Siméoni MC, Betancur C, Leboyer M (2007). Shared executive dysfunctions in unaffected relatives of patients with autism and obsessive-compulsive disorder. European Psychiatry; 22(1): 32-38. https://doi.org/10.1016/j.eurpsy.2006.05.002 PMid:17127035 PMCid:PMC1894853

Doyle AE, Willcutt EG, Seidman LJ, Biederman J, Chouinard VA, Silva J, Faraone SV (2005a). Attention-deficit/hyperactivity disorder endophenotypes. Biological Psychiatry; 57(11): 1324-1335. https://doi.org/10.1016/j.biopsych.2005.03.015 PMid:15950005

Doyle AE, Biederman J, Seidman LJ, Reske-Nielsen JJ, Faraone SV (2005b). Neuropsychological functioning in relatives of girls with and without ADHD. Psychological Medicine; 35(8): 1121-1132. https://doi.org/10.1017/S0033291705004496 PMid:16116938

Fombonne E, Bolton P, Prior J, Jordan H, Rutter M (1997). A family study of autism: Cognitive patterns and levels in parents and siblings. Journal of Child Psychology and Psychiatry; 38(6): 667-683. https://doi.org/10.1111/j.1469-7610.1997.tb01694.x PMid:9315977

Gavi (2018). Gavi Factsheet: India [online]. Available at: https://www.gavi.org/programmes-impact/country-hub/south-east-asia/india [Accessed on 5 Dec 2018]

Glahn DC, Knowles EE, McKay DR, Sprooten E, Raventós H, Blangero J, Gottesman II, Almasy L (2014). Arguments for the sake of endophenotypes: Examining common misconceptions about the use of endophenotypes in psychiatric genetics. American Journal of Medical Genetics Part B: Neuropsychiatric Genetics; 165(2): 122-130. https://doi.org/10.1002/ajmg.b.32221 PMid:24464604 PMCid:PMC4078653

Gokcen S, Bora E, Eramis S, Kesikci H, Aydin C (2009). Theory of mind and verbal working memory deficits in parents of autistic children. Psychiatry Research; 166(1): 46-53. https://doi.org/10.1016/j.psychres.2007.11.016 PMid:19200606

Goos LM, Crosbie J, Payne S, Schachar R (2009). Validation and extension of the endophenotype model in ADHD patterns of inheritance in a family study of inhibitory control. American Journal of Psychiatry; 166(6): 711-717. https://doi.org/10.1176/appi.ajp.2009.08040621 PMid:19448185

Gottesman II, Shields J (1976). A critical review of recent adoption, twin, and family studies of schizophrenia: Behavioral genetics perspectives. Schizophrenia Bulletin; 2(3): 360-401. https://doi.org/10.1093/schbul/2.3.360 PMid:1034336

Gottesman II, Gould TD (2003). The endophenotype concept in psychiatry: Etymology and strategic intentions. American Journal of Psychiatry; 160(4): 636-645. https://doi.org/10.1176/appi.ajp.160.4.636 PMid:12668349

Gould TD, Gottesman II (2006). Psychiatric endophenotypes and the development of valid animal models. Genes, Brain and Behavior; 5(2): 113-119. https://doi.org/10.1111/j.1601-183X.2005.00186.x PMid:16507002

Hughes C, Leboyer M, Bouvard M (1997). Executive function in parents of children with autism. Psychological Medicine; 27(1): 209-220. https://doi.org/10.1017/S0033291796004308 PMid:9122301

Insel TR, Cuthbert BN (2009). Endophenotypes: Bridging genomic complexity and disorder heterogeneity. Biological Psychiatry; 66(11): 988-989. https://doi.org/10.1016/j.biopsych.2009.10.008 PMid:19900610

Jeste SS (2015). Neurodevelopmental behavioural and cognitive disorders. CONTINUUM: Lifelong Learning in Neurology; 21(3): 690-714. https://doi.org/10.1212/01.CON.0000466661.89908.3c PMid:26039849

Jester JM, Nigg JT, Puttler LI, Long JC, Fitzgerald HE, Zucker RA (2009). Intergenerational transmission of neuropsychological executive functioning. Brain and Cognition; 70(1): 145-153. https://doi.org/10.1016/j.bandc.2009.01.005 PMid:19243871 PMCid:PMC2680419

Koczat DL, Rogers SJ, Pennington BF, Ross RG (2002). Eye movement abnormality suggestive of a spatial working memory deficit is present in parents of autistic probands. Journal of Autism and Developmental Disorders; 32(6): 513-518. https://doi.org/10.1023/A:1021246712459 PMid:12553588

Kremen WS, Panizzon MS, Cannon TD (2016). Genetics and neuropsychology: A merger whose time has come. Neuropsychology; 30(1): 1-5. https://doi.org/10.1037/neu0000254 PMid:26710091 PMCid:PMC4758834

Lehto JE, Juujärvi P, Kooistra L, Pulkkinen L (2003). Dimensions of executive functioning: Evidence from children. British Journal of Developmental Psychology; 21(1): 59-80. https://doi.org/10.1348/026151003321164627

Leve LD, DeGarmo DS, Bridgett DJ, Neiderhiser JM, Shaw DS, Harold GT, Natsuaki MN, Reiss D (2013). Using an adoption design to separate genetic, prenatal, and temperament influences on toddler executive function. Developmental Psychology; 49(6): 1045-1057. https://doi.org/10.1037/a0029390 PMid:22799580 PMCid:PMC3509265

Losh M, Adolphs R, Poe MD, Couture S, Penn D, Baranek GT, Piven J (2009). Neuropsychological profile of autism and the broad autism phenotype. Archives of General Psychiatry; 66(5): 518-526. https://doi.org/10.1001/archgenpsychiatry.2009.34 PMid:19414711 PMCid:PMC2699548

Merikangas AK, Cui L, Calkins ME, Moore TM, Gur RC, Gur RE, Merikangas KR (2017). Neurocognitive performance as an endophenotype for mood disorder subgroups. Journal of Affective Disorders; 215: 163-171. https://doi.org/10.1016/j.jad.2017.03.021 PMid:28340442 PMCid:PMC5441552

Miyake A, Friedman NP, Emerson MJ, Witzki AH, Howerter A, Wager TD (2000). The unity and diversity of executive functions and their contributions to complex “frontal lobe” tasks: A latent variable analysis. Cognitive Psychology; 41(1): 49-100. https://doi.org/10.1006/cogp.1999.0734 PMid:10945922

Moher D, Liberati A, Tetzlaff J, Altman DG, Prisma Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. PLoS Medicine; 6(7. https://doi.org/10.1371/journal.pmed.1000097 PMid:19621072 PMCid:PMC2707599

Moll K, Loff A, Snowling MJ (2013). Cognitive endophenotypes of dyslexia. Scientific Studies of Reading; 17(6): 385-397. https://doi.org/10.1080/10888438.2012.736439

Muller JDL, Torquato KI, Manfro GG, Trentini CM (2015). Executive functions as a potential neurocognitive endophenotype in anxiety disorders: A systematic review considering DSM-IV and DSM-5 diagnostic criteria classification. Dementia & Neuropsychologia; 9(3): 285-294. https://doi.org/10.1590/1980-57642015dn93000012 PMid:29213974 PMCid:PMC5619371

Murphy KR, Barkley RA (1996). Parents of children with attention-deficit/ hyperactivity disorder: Psychological and attentional impairment. American Journal of Orthopsychiatry; 66(1): 93-102. https://doi.org/10.1037/h0080159 PMid:8720646

Nigg JT, Blaskey LG, Stawicki JA, Sachek J (2004). Evaluating the endophenotype model of ADHD neuropsychological deficit: Results for parents and siblings of children with ADHD combined and inattentive subtypes. Journal of Abnormal Psychology; 113(4): 614-625. https://doi.org/10.1037/0021-843X.113.4.614 PMid:15535793

Nydén A, Hagberg B, Goussé V, Rastam M (2011). A cognitive endophenotype of autism in families with multiple incidence. Research in Autism Spectrum Disorders; 5(1)L: 191-200. https://doi.org/10.1016/j.rasd.2010.03.010

Ogilvie D, Fayter D, Petticrew M, Sowden A, Thomas S, Whitehead M, Worthy G (2008). The harvest plot: A method for synthesising evidence about the differential effects of interventions. BMC Medical Research Methodology; 8(1): 8. https://doi.org/10.1186/1471-2288-8-8 PMid:18298827 PMCid:PMC2270283

Piven J, Palmer P (1997). Cognitive deficits in parents from multiple-incidence autism families. Journal of Child Psychology and Psychiatry; 38(8): 1011-1021. https://doi.org/10.1111/j.1469-7610.1997.tb01618.x PMid:9413799

Rathi SK, Francis MR (2009). Neurodevelopmental disorders among Indian children: Needs attention. Electronic Physician; 4(2): 493-496. Retrieved from www.ephysician.ir/2012/493-496.pdf

Raust A, Daban C, Cochet B, Henry C, Bellivier F, Scott J (2014). Neurocognitive performance as an endophenotype for bipolar disorder. Frontiers in Bioscience (Elite Ed); 6: 89-103. https://doi.org/10.2741/E694 PMid:24389145

Rommelse NNJ, Altink ME, Martin NC, Buschgens CJM, Buitelaar JK, Sergeant JA, Oosterlaan J (2008). Neuropsychological measures probably facilitate heritability research of ADHD. Archives of Clinical Neuropsychology; 23 (5): 579–59. https://doi.org/10.1016/j.acn.2008.06.00

Rommelse NN, Geurts HM, Franke B, Buitelaar JK, Hartman CA (2011). A review on cognitive and brain endophenotypes that may be common in autism spectrum disorder and attention-deficit/hyperactivity disorder and facilitate the search for pleiotropic genes. Neuroscience & Biobehavioral Reviews; 35(6): 1363-1396. https://doi.org/10.1016/j.neubiorev.2011.02.015 PMid:21382410

Szatmari P, Jones MB, Tuff L, Bartolucci G, Fisman S, Mahoney W (1993). Lack of cognitive impairment in first-degree relatives of children with pervasive developmental disorders. Journal of the American Academy of Child & Adolescent Psychiatry; 32(6): 1264-1273. https://doi.org/10.1097/00004583-199311000-00022 PMid:8282674

Thapar A, Cooper M, Rutter M (2017). Neurodevelopmental disorders. The Lancet Psychiatry; 4(4): 339-346. https://doi.org/10.1016/S2215-0366(16)30376-5

Thissen AJAM, Rommelse NNJ, Hoekstra PJ, Hartman C, Heslenfeld D, Luman M, Van Lieshout M, Franke B, Oosterlaan J, Buitelaar JK (2014). Attention deficit hyperactivity disorder (ADHD) and executive functioning in affected and unaffected adolescents and their parents challenging the endophenotype construct. Psychological Medicine; 44(4): 881-892. https://doi.org/10.1017/S0033291713001153 PMid:23721667

Van Eylen L, Boets B, Cosemans N, Peeters H, Steyaert J, Wagemans J, Noens I (2017). Executive functioning and local-global visual processing: Candidate endophenotypes for autism spectrum disorder? Journal of Child Psychology and Psychiatry; 58(3): 258-269. https://doi.org/10.1111/jcpp.12637 PMid:27804132

Wong D, Maybery M, Bishop DVM, Maley A, Hallmayer J (2006). Profiles of executive function in parents and siblings of individuals with autism spectrum disorders. Genes, Brain and Behavior; 5(8): 561-576. https://doi.org/10.1111/j.1601-183X.2005.00199.x PMid:17081261

Zaka N, Alexander EC, Manikam L, Norman IC, Akhbari M, Moxon S, Ram PK, Murphy G, English M, Niermeyer S, Pearson L (2018). Quality improvement initiatives for hospitalised small and sick newborns in low-and middle-income countries: A systematic review. Implementation Science; 13(1): 20. https://doi.org/10.1186/s13012-018-0712-2 PMid:29370845 PMCid:PMC5784730

BRIEF REPORTS

Participation of Persons with Disabilities in Political Activities in Kumasi Metropolis, Ghana

Ernest Appiah Kyei[1*], Joslin Dogbe[1]

1. Centre for Disability Studies, Department of Community Health, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana

ABSTRACT

Purpose: *The opportunity to participate in political activities is at the heart of life in a just and democratic community. This paper attempts to assess the participation of persons with disabilities in political activities in Kumasi Metropolis, Ghana.*

Method: *A cross-sectional study design with a quantitative approach was followed. A multi-stage sampling technique was adopted to select three disability groups (physically impaired, visually impaired and hearing impaired) from the study area. Using a random sampling method, 415 participants were included in the study. Data was collected with the help of a structured questionnaire, and analysed using SPSS version 20.*

Results: *Most of the respondents did not participate in any political activities other than voting in elections. Other types of non-involvement included: Not contributing money to a political party or a candidate (75%); not having written or spoken to an elected representative/official (52%); not attending political meetings (51%); not writing letters to newspapers on a political issue (53%); not contributing money to an organisation trying to influence government policy/legislation (55%); and, not working with groups or on their own to change government laws or policies (51%).*

Conclusion: *Participation of persons with disabilities in various types of political activities was generally low, apart from voting. The government should actively promote an accessible environment in which persons with disabilities can effectively and fully participate in public affairs, without discrimination*

---

[*] **Corresponding Author:** Ernest Appiah Kyei, Centre for Disability Studies, Department of Community Health, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana. Email:rastugajr@yahoo.com

and on an equal basis with others. This could encourage greater interest in political participation.

Key words: *persons with disabilities, political participation, Kumasi metropolis*

INTRODUCTION

Political participation plays an essential role in the eradication of political marginalisation, promotion of democratic governance, social inclusion, and advancement of all human rights with reference to persons with disabilities (Hall & Alvarez, 2012). Article 29 of the UN's Convention on the Rights of Persons with Disabilities (CRPD) guarantees political rights and the opportunity to enjoy those rights on an equal basis with others. The participation of persons with disabilities in politics could have a positive impact in shaping other areas where their interests are affected, such as their access to education, employment, livelihood, health and other social areas (Human Rights Commission, 2014).

In general, the level of participation of persons with disabilities in political activities has been low, with a range as low as 10-21% (Schriner et al, 1998); with participation of women with disabilities lower as compared to men with disabilities; with participation of the aged lower as compared to the youth; and also, lower participation of persons with severe disability (Guldvik et al, 2013).

In countries like the United States of America, the participation of this populace is very low as compared to persons without disabilities, despite the fact that they enjoyed independence earlier as compared to other countries (Schur et al, 2002). In Canada, their participation has also been low, especially in contesting as candidates in municipal, provincial and federal elections (Prince, 2007). Schur et al (2002) and Prince (2007) have attributed the under- representation of persons with disabilities in politics to negative public attitudes like stigmatisation and discrimination linked with disability. Studies done in African countries like Cameroon have also revealed that the involvement of persons with disabilities in politics is low (Opokua et al, 2016).

In a developing country like Ghana, the 1992 Constitution granted every citizen (including those with disabilities) the fundamental human right and freedom to participate in social activities (Aidoo, 2008). In addition, the Persons with Disability Act, 2006 (Act 715) was meant to protect and promote equal rights of participation among them. However, it appears that one area in which persons with disabilities in Ghana have not performed so well is their participation in politics (Sackey, 2014). Another study done by Mensah et al (2008) found that the level of participation of persons with disabilities in politics is generally low, including low representation in terms of appointments to Parliamentary or Ministerial positions, and positions in Metropolitan, Municipal and District Assemblies (MMDAs). Currently there is no representative of persons with disabilities on the Council of State to advice the President on the serious issues facing the country (Mensah et al, 2008). According to Mensah et al (2008), some of the reasons for low participation by persons with disabilities are the negative societal attitudes which come with discrimination and stigma, economic factors, the low level of education affecting their knowledge of politics, and inaccessibility.

Voting is one way in which individuals may voice their choice, but participation in electoral processes goes beyond voting, as it includes the ability to take part in the conduct of public affairs, the opportunity to register as a candidate, to campaign, to be voted and to hold office at all levels of government (Inclusion International, 2015a).A study done in Ghana by Jonah (2001) in Ahanta West and Shama constituencies found that voting in general elections had been high as compared to low levels of participation in other political activities like attending political gatherings, contributing money to political parties, party affiliation and standing for political office from political parties.

Objective

Previous studies done in Ghana on participation of persons with disabilities in politics focused largely on their participation in voting. Very few studies looked at their participation in other political activities. In order to unearth or add new knowledge to the few studies on the subject, this study attempts to assess the participation of persons with disabilities, in Kumasi Metropolis, in political activities other than voting; activities such as contributing money to a political party or candidate, writing or speaking to elected representatives/officials, attending political meetings, writing letters to newspapers on political issues, contributing money to an organisation trying to influence government policy/ legislation, and working with groups or on their own to change government laws or policies.

METHOD

Study Design

A descriptive cross-sectional study design was adopted, with a quantitative approach.

Study Site

Kumasi Metropolis is the capital city of the Ashanti Region of Ghana, and is the country's second largest city after Accra. According to the 2010 Population and Housing census, it is estimated that 42,060 persons (2.4%) in the city of Kumasi have some form of disability, 2.5 % of whom are females with disabilities and 2.3% are males (Ghana Statistical Service, 2014). The distribution by type of disability in the Metropolis is shown in Table 1.

Table 1: Population by Type of Disability and Gender

Disability Type	Both Sexes		Male		Female	
	Number	Percentage	Number	Percentage	Number	Percentage
Total	1,730,249	100.0	826,479	100.0	903,770	100.0
No disability	1,688,189	97.6	807,422	97.7	880,767	97.5
With disability	42,060	2.4	19,057	2.3	23,003	2.5
Sight	17,984	42.8	7,704	40.4	10,280	44.7
Hearing	5,014	11.9	2,170	11.4	2,844	12.4
Speech	5,423	12.9	2,971	15.6	2,452	10.7
Physical	9,465	22.5	4,303	22.6	5,162	22.4
Intellectual	6,054	14.4	2,962	0.4	3,092	0.3
Emotional	7,613	18.1	3,486	18.3	4,127	17.9
Other	4,860	11.6	2,106	11.1	2,754	12.0

Source: Ghana Statistical Service, 2010 Population and Housing Census

Study Sample

The sample size for this study was calculated by using the total number of the population in Kumasi Metropolis who had various forms of disabilities. Hence, the 2010 population census District Analytical Report estimation gives the figure of 42,060 (see Table 1) as the total for Kumasi metropolis population with disabilities (Ghana Statistical Service, 2014).

A simple random sampling technique, using Yamane (1967) simplified formula, was adopted to select 415 respondents.

$$n = \frac{N}{1 + N(e)^2}$$

Where *n* = sample size, *N* = population size, and *e* = level of precision.

The formula was applied to the aforementioned sample:

$N = 42{,}060$

$e = .05$

$1 + N\,(e)^2 = 1 + 42060(.05)^2$

$$n = \frac{42060}{1 + 42060\,(.05)^2}$$

$n = 396$

A 5% non-respondent rate was assumed. The number 19 was randomly obtained from a tally sheet after calculating 5% of 396 which is 19.8, and 19 was added to 396 to give a sample size of 415. To achieve a representative number of respondents from three categories of persons with disabilities (physically impaired, visually impaired and hearing impaired), the sample size was proportionally distributed by probability proportional to size method as shown in Table 2.

Table 2: Sample Size Distribution for Three Disability Groups

Disability Type	Population per Disability Type	Sample Size per Disability Type	Total
Physically Impaired	9,465	(9,465/32,463)*415	121
Visually Impaired	17,984	(17,984/32,463)*415	230
Hearing Impaired	5,014	(5,014/32,463)*415	64
Total	**32,463**		**n=415**

Sampling Technique

A multi-stage sampling technique was adopted where 3 disability groups (physically impaired, visually impaired and hearing impaired) were conveniently selected because they were within the study area and could be reached easily through their respective Associations at their monthly meetings. After that, a simple random sampling technique was used to select respondents from each of the 3 disability groups.

Respondents were selected by balloting. The words, either 'Yes' or 'No', were written on pieces of papers and those who picked 'Yes' were selected for the study. The sample size of 415 respondents consisted of 121 persons from the physically impaired group, 230 from the visually impaired group, and 64 from the hearing impaired group. This distribution was done as per the calculations made in Table 2.

Inclusion Criteria

Respondents were selected on the basis of the following criteria:

- Males and females from three categories of persons with disabilities, namely the physically impaired, visually impaired and hearing impaired;
- Those who were 18 years of age and older;
- Those who were registered members of the Ghana Disabled People's Organisations (DPO's); and,
- Those who consented to be part of the study.

Data Collection

Data collection took up to 3 months, to allow time to reach all respondents.

The researchers developed an instrument (see Appendix) for measuring the level of participation of persons with disabilities in other types of political activities apart from voting. It was measured with an index of 6 questions each on a 4-point Scale, with responses ranging from 'Frequently', to 'A few times', 'Only once/ twice', and 'Not at all'. Those who responded with 'Frequently' were classified as 'High Participation', 'A few times' and 'Only once/twice' were 'Average', and 'Not at all' was 'Low Participation'.

The questionnaire was explained to the respondents and those who could not read were taken through it by the researchers. Provision was also made for the hearing impaired group, by assigning them a sign language interpreter.

Data Analysis

Statistical Package for Social Sciences (SPSS), software version 20, was used to analyse the data. The results were presented using simple descriptive statistics of percentages and frequencies in graphs such as pie charts.

Ethics Approval

Before the data was collected, ethical clearance was obtained from Kwame Nkrumah University of Science and Technology, School of Medical Sciences, the Committee for Human Research and Publication and Ethics, KNUST, Department of Social Welfare, and from Disabled Peoples' Organisations (DPOs) in Kumasi Metropolis. A written informed consent form was translated and explained to prospective study respondents in a language they could understand well, before their enrolment in the study. The respondents were assured of anonymity and confidentiality. Codes were assigned in place of their formal names in the data and their information was not passed on to anyone.

RESULTS

Demographic Characteristics of Respondents

Table 3 shows that among the participants, 55.4% were visually impaired, 29.2% were physically impaired, and 15.4% were hearing impaired. There were more male participants (62%) than female (38%). The mean age of respondents was 31.2 years. About 42% of the respondents were married, while 30% were single, 24% widowed and 4% divorced. As for level of education, 21% had no formal education, while 79% had completed at least primary education. In relation to employment, 10% of those surveyed were employed in the formal sector, 30% were artisans, 13% were traders, and the remaining 47% were unemployed.

Table 3: Demographic Characteristics of Respondents

Variables	Frequency	Percentages (%)
Disability Type		
Physically Impaired	121	29.2
Visually Impaired	230	55.4
Hearing Impaired	64	15.4
Gender		
Male	257	62
Female	158	38
Age		
18 - 25 years	54	13
26-35 years	109	26
36-45 years	129	31
46-55 years	113	27
56 years and above	10	3
Mean	31.2	
Marital Status		
Married	176	42
Single	124	30
Widowed	98	24
Divorced	17	4
Ethnicity		
Ashanti	220	53
Fanti	110	27
Ga	43	10
Ewe	27	7
Gonja	10	2
Others	5	1
Education		
No formal education	87	21
Primary	86	21
JHS/ Middle	111	27
SHS/A level	99	24
Tertiary	32	7
Occupation		

Unemployed	194	47
Formal	40	10
Artisan	126	30
Trader	55	13

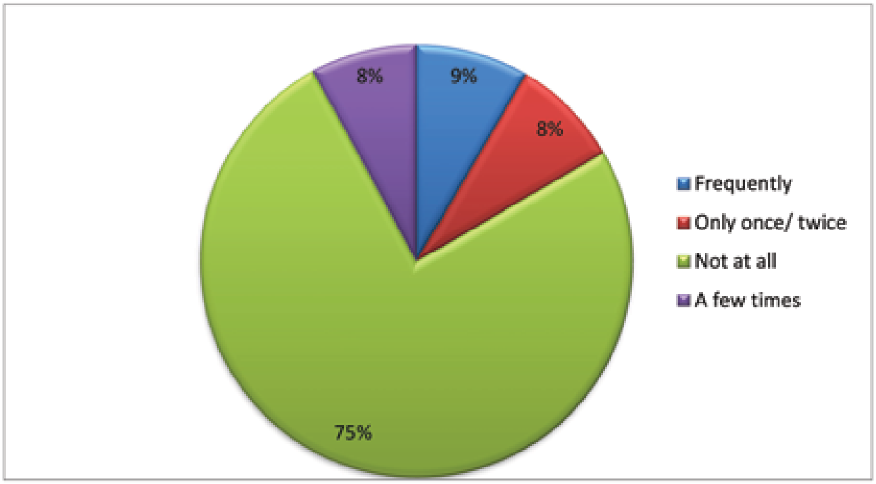
(Source: Field work, 2018)

Level of Participation of Persons with Disabilities in Political Activities other than Voting

a) Contributing money to a political party or a candidate

Figure 1 shows that majority (75%) of the respondents indicated that they had never, in any way, contributed money to a political party or a candidate before, while 8% said they had contributed money to a political party a few times and only once/twice to a candidate. However, only 9% of the respondents indicated that they frequently contribute money to a political party or a candidate.

Figure 1: Contributing Money to a Political Party or Candidate



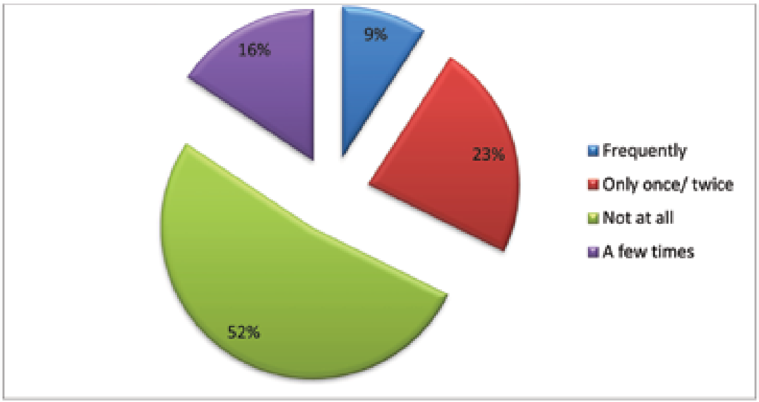
(Source: Field work, 2018)

b) Writing or speaking to an elected representative/official

Figure 2 shows that 52% of the respondents surveyed said they had not written or spoken to any elected representatives or officials. While 23% said they had written or spoken to elected representatives or officials only once/twice, about

16% of the respondents said they had written or spoken to elected representatives or officials a few times. However, only 9% claimed that they frequently write or speak to elected representatives or officials.

Figure 2: Writing or Speaking to an Elected Representative/Official

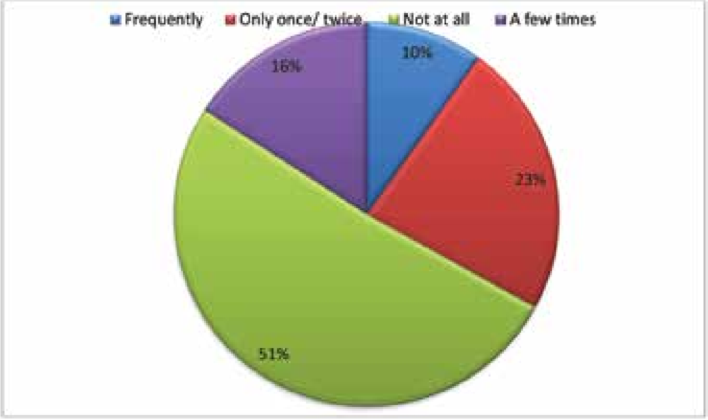


(Source: Field work, 2018)

c) Attending political meetings

Figure 3 reveals that 51% of the respondents had never attended a political meeting. While 23% said they had attended political meetings only once/twice, 16% said that they had attended political meetings a few times. However, only 10% of the respondents confirmed that they frequently attend political meetings.

Figure 3: Attending Political Meetings

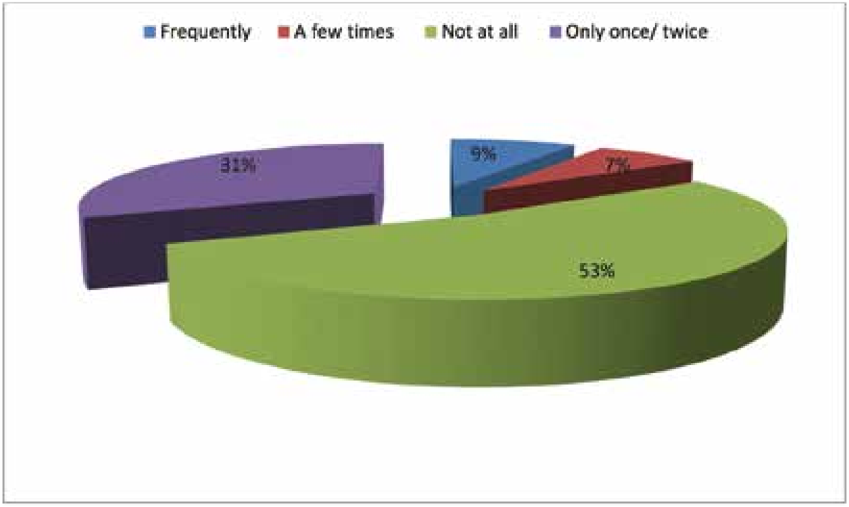


(Source: Field work, 2018)

d) Writing letters to newspapers on a political issue

Figure 4 shows that more than half or 53% of the respondents stated that they had never written letters to newspapers on any political issue. While 31% said they had written letters to newspapers only once/twice, 7% claimed that they had written letters to newspapers a few times. However, only 9% of the respondents indicated that they were frequently engaged in writing letters to newspapers on political issues.

Figure 4: Writing Letters to Newspapers on a Political Issue

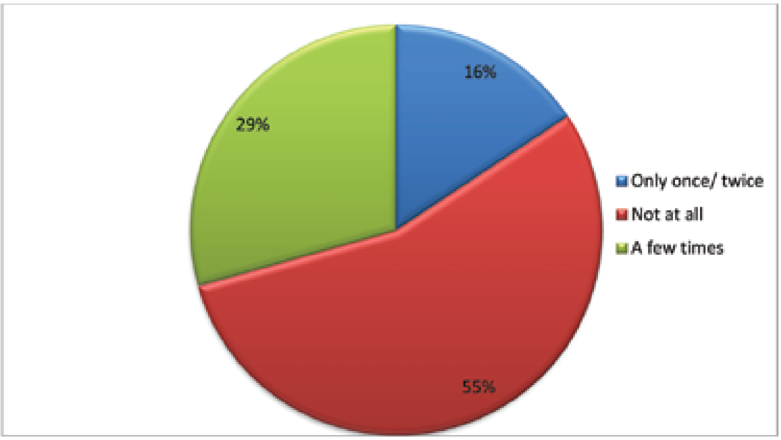


(Source: Field work, 2018)

d) Contributing money to an organisation trying to influence government policy/legislation

Figure 5 reveals that more than half or 55% of the respondents had never contributed money to an organisation trying to influence government policy or legislation. While 29% confirmed that they had contributed a few times, 16% said they had contributed money only once/twice to an organisation trying to influence government policy or legislation. However, none of the respondents claimed that they did so frequently.

Figure 5: Contributing Money to an Organisation trying to Influence Government Policy/Legislation

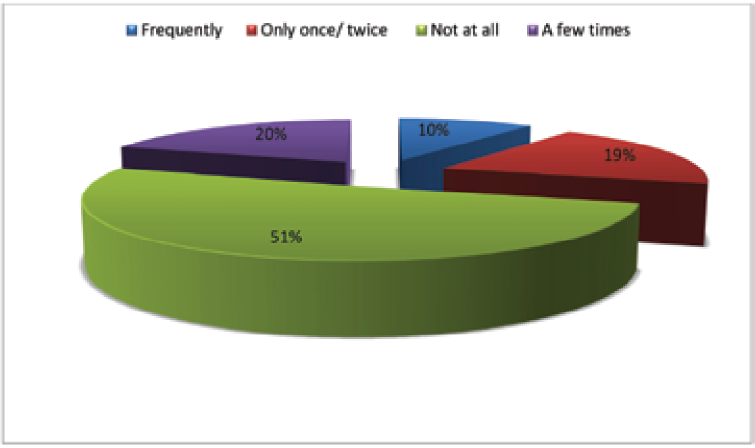


(Source: Field work, 2018)

e) Working with groups or on one's own to change government laws or policies

Figure 6 shows that while 51% of the respondents had not worked with groups or on their own to change government laws or policies, only 10% confirmed that they frequently did such work. About 20% responded that they had worked with groups or on their own a few times to change government laws or policies, and 19% said they had done such work only once/twice.

Figure 6: Working with Groups or on One's Own to change Government Laws or Policies



(Source: Field work, 2018)

DISCUSSION

The study revealed that, apart from voting in elections, persons with physical, visual and hearing impairment have not been participating in other types of political activities. Most of the respondents had never, in any way, contributed money to a political party or candidate, written or spoken to any elected representatives or officials, attended a political meeting, written letters to newspapers on any political issue, contributed money to an organisation trying to influence government policy or legislation, nor worked with groups or on their own to change government laws or policies. The study finding of low participation in political activities is similar to the findings of Jonah (2001) that voting in general elections had been high as compared to low levels of participation in other political activities. It is also supported by the study of Sackey (2014) that persons with disabilities have not performed so well when it comes to participation in politics.

In this study, the low political participation of respondents could be attributed to economic problems, due to which they probably do not have the financial means to engage in political activities. They may also be faced with problems of accessibility caused by inaccessible roads, the difficult nature of transportation, and unsuitable infrastructure in buildings, that hinder their free movement and equal participation with others. Lack of reasonable accommodation for people with visual and hearing impairment could also be a challenge, as they may not be getting information in accessible formats from political parties and politicians or may not be able to communicate with others. Also, low participation could be attributed to their lack of interest in various types of political activities, apart from voting.

CONCLUSION

The study concluded that apart from voting in elections, the level of participation of persons with disabilities was very low in other types of political activities, such as attending political meetings, contributing money to political parties or candidates, and contacting elected representatives or officials, among others. The proposed recommendations could make a difference to them and consequently benefit the country.

Limitations

The major limitation of the study was the non-inclusion of other disability groups. As mentioned under Sampling Technique, the study focused only on physically impaired, visually impaired and hearing impaired persons for data collection. It was further limited to only persons with disabilities in the Kumasi Metropolis. These limitations might reduce the validity, reliability and generalisation of the study findings. Also, the study did not look into the reasons for non-involvement in political activities as it was not part of the study objectives.

ACKNOWLEDGEMENT

The authors extend their sincere gratitude to all the lecturers in the Community of Health Department of the School of Medical Sciences, KNUST, and to the executives of the Kumasi Branch of the Disabled People's Organisation, who made a positive impact on this study.

They are also grateful to all those who participated in the study and made it a success.

REFERENCES

Aidoo MT (2008). Political participation, governance and neopatrimonial rule in Africa. Germany: VDM Verlag Dr. Muller Aktiengesellschaft & Co. KG.

Guldvik I, Askheim OP, Johansen V (2013). Political citizenship and local political participation for disabled people. Citizenship Studies; 17(1): 76-91. https://doi.org/10.1080/13621025.2013.764219

Hall T, Alvarez RM (2012). Defining the barriers to political participation for individuals with disabilities. The Information Technology and Innovation Foundation Accessible Voting Technology Initiative.

Human Rights Commission (2014). Factors that impede equal political participation and steps to overcome those challenges. Report of the Office of the United Nations High Commissioner for Human Rights, 30 June 2014, A/HRC/27/29. Retrieved from: http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session27/Doc uments/A_HRC_27_29_ENG.doc

Jonah K (2001). Election 2000 in Ahanta West and Shama constituencies and democratic consolidation in Ghana. Deepening Democracy in Ghana. Accra: Freedom Publications.

Mensah O, Williams J, Atta-Ankomah R, Mjomba M (2008). Strengthening the disability movement in Ghana through organizational capacity and advocacy: Contextual analysis of the disability situation in Ghana.

Opokua MP, Mprah WK, Saka BN (2016). Participation of persons with disabilities in political activities in Cameroon. Disability and the Global South; 3(2): 980–999.

Prince JM (2007). The electoral participation of persons with special needs. Working Paper on Electoral Participation and Outreach Practices, Electoral Commission of Canada, Ontario.

Sackey E (2014). Disability and political participation in Ghana: An alternative perspective. Scandinavian Journal of Disability Research; 17(4): 366-381. https://doi.org/10.1080/15017419.2014.941925

Schriner KF, Shields TG, Schriner K(1998). The effect of gender and race on the political participation of people with disabilities in the 1994 mid-term election. Journal of Disability Policy Studies; 9(2): 53-76. https://doi.org/10.1177/104420739800900204

Schur L, Shields T, Kruse D, Schriner K (2002). Enabling democracy: Disability and voter turnout. Political Research Quarterly; 55(1): 167-190. https://doi.org/10.1177/106591290205500107

APPENDIX

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY

SCHOOL OF MEDICAL SCIENCES

DEPARTMENT OF COMMUNITY HEALTH

CENTRE FOR DISABILITY AND REHABILITATION STUDIES

QUESTIONNAIRE

This questionnaire is aimed at collecting data for a study on:

“PARTICIPATION OF PERSONS WITH DISABILITIES IN POLITICAL ACTIVITIES IN KUMASI METROPOLIS” .

This data is purely for academic purpose and your responses will remain confidential and will not be shared with anyone. Thank you for participating.

Section A: Socio-Demographic Characteristics

1. Type of disability?

   (Tick the nature of your disability)

   a. Physically impaired ☐

   b. Visually impaired ☐

   c. Hearing impaired ☐

   d. Other, (Specify)……………………

2. Sex: Male ☐ Female ☐

3. Age ………………

   a. 18 – 25 ☐

   b. 26-35 ☐

   c. 36 - 45 ☐

   d. 46 - 55 ☐

   e. 56 and Above ☐

4. Marital Status:

a. Married ☐ b. Single ☐ c. Divorced ☐ d. Widowed ☐

5. Ethnicity:

  a. Ashanti ☐
  b. Fanti ☐
  c. Ga ☐
  d. Ewe ☐
  e. Gonja ☐
  f. Other, (Specify)………………………

6. Level of education:

  a. No Formal ☐
  b. Primary ☐
  c. JHS/Middle ☐
  d. SHS/ O Level/ A Level/ Tech/Voc. ☐
  e. Tertiary (Univ. / Poly. / Post-Sec.) ☐
  f. Other, (Specify)………………………

7. Occupational Status:

  a. Unemployed ☐
  b. Formal ☐
  c. Artisan ☐
  d. Trader ☐

Section B: The level of participation in other types of political activities besides voting

(Tick as appropriate)

8. Here is a list of political activities people sometimes participate in besides voting. For each of these, please tell me whether you, personally, have done any of these before?

a. Contributed money to a political party or candidate?

Frequently ☐ A few times ☐ Only once ☐ Not at all ☐

b. Written or spoken to elected representative/official?

Frequently ☐ A few times ☐ Only once ☐ Not at all ☐

c. Attended a political meeting?

Frequently ☐ A few times ☐ Only once ☐ Not at all ☐

d. Written letters to newspaper on a political issue?

Frequently ☐ A few times ☐ Only once ☐ Not at all ☐

e. Contributed money to an organisation trying to influence government policy/ legislation?

Frequently ☐ A few times ☐ Only once ☐ Not at all ☐

f. Worked with groups or on your own to change government laws/policies?

Frequently ☐ A few times ☐ Only once ☐ Not at all ☐

Outcomes of Self-Care in Clients with Heart Failure before and after Treatment, using a Case Management Approach

Kanokporn Khankaew[1], Nalintip Ongsombat[1], Atchariya Wonginchan[2]*, Vichai Senthong [3], Chollada Thronsao[4]

[1]Nursing department, Queen Sirikit Heart Centre, Faculty of Medicine, Khon Kaen University, Thailand
[2]Nursing department, Faculty of Nursing, Khon Kaen University, Thailand
[3]Division of Cardiology, Department of Medicine, Faculty of Medicine, Khon Kaen University, Thailand
[4]Faculty of Medicine, Mahasarakham University, Thailand

ABSTRACT

Purpose: *Heart failure (HF) is a clinical syndrome that is the final stage of most types of heart diseases. Thailand - in the Asia-Pacific region - has an unusually high incidence as the risk factors for heart disease increase due to population structure changes. This article aims to compare the self-care of heart failure clients before and after treatment using case management.*

Methods: *A quasi-experimental research design was employed with 30 clients who were treated at the Khon Kaen University Heart Failure Clinic (KKU-HF) between April 2017 and March 2018. The research tool was a 2-part questionnaire that included demographic data and the comparison of scores of self-care before and after treatment using case management. Inferential statistics and paired t-test were used to analyze the data.*

Results: *Most of the clients were males (80%), and most of them (56.67 %) were around 60 years of age and older. A comparison of scores for knowledge and understanding of self-care, before and after the treatment, showed a statistically significant improvement at the level of 0.05. Self-care behavior had also improved. The general quality of life had improved by up to 66.67%.*

Conclusion and Implications*: The goal of this research study was to reduce the rate of re-hospitalization, the cost of medical treatment, and the death rate of heart failure clients. The findings can be used not only to develop self-care systems of the Khon Kaen University Heart Failure Clinic (KKU-HF) but also for other clinics to adopt.*

---

* **Corresponding Author:** Atchariya Wonginchan, Ph.D. (Nursing), Faculty of Nursing, Khon Kaen University, Thailand. Email: atchawong@hotmail.com

Key words: *case management, heart failure, self-care, treatment comparison*

INTRODUCTION

Heart failure (HF) is a clinical syndrome that is the final stage of most types of heart diseases. There are 170 million heart failure clients worldwide and the figure is expected to increase to 200 million in the next 10 years. In 2012, for example, the United States had an average of more than 650,000 HF clients, 65 years of age and older (Masresha, 2014), while in 2014, there was an average of 360,000 clients in Germany (Hendricks et al, 2014). Thailand – based in the Asia-Pacific region, has an unusually high incidence as the risk factors for heart disease increase as the population structure changes (Kanjanawanich and Pornhaminthikul, 2017). It is reported that clients with HF have a high mortality rate of 10 % per year, on average. They have a reduced quality of life and Thailand is spending 150,000 baht per person per annum on care for those having heart failure, and being admitted in hospital with an average period of 10-20 nights per visit (Maharaj Nakorn Chiang Mai Hospital, 2016). The data also shows that more than half of the heart failure clients return to hospital within 3 - 6 months, and that the number of cases increased by 25 % - 54 % compared to the previous year (Therdsuthironnaphum, 2015). The number of people with cardiovascular diseases including heart failure in Thailand, increased from 887.20 in 2013 to 1,011.70 in 2015 (Apiromrat, 2017). In addition, the 2016 data found that in the mortality rate per 100,000 people, there were 32.3 deaths from heart disease and 48.7 deaths from vascular disease (Ariyachaipanich et al, 2019).

Chronic heart failure in Thailand is classified as a cardiovascular disease. There are as many as 3 conditions in this group of diseases (Medical Information Unit, 2017). In 2009, there were 142,843 persons with chronic heart failure, accounting for 46.55% of those diagnosed with cardiovascular diseases. The central region has the highest number of such clients, followed by the northeastern region, north region, and southern region, respectively (Chuekich and Srida, 2013). The Heart Failure Clinic of the Sirikit Heart Centre, connected to the Faculty of Medicine Khon Kaen University (KKU-HF), is one of the hospitals in the northeast region that has the largest number of clients with chronic heart failure. The statistics for clients diagnosed with chronic heart failure over the period of 2013 to 2015, were 1,146 cases (in 2013), 1,497 cases (ln 2014), and 1,297 cases (in 2015), respectively (Medical Information Unit, 2017). These individuals were at high risk of developing chronic heart failure due to their constant use of salt in foods such as fish sauce and fermented fish. Symptoms exhibited by clients included signs of racing sensation in the chest, inability to lie down, getting tired while sleeping, fatigue, palpitations, swelling, and rapid weight gain (Chuekich and Srida, 2013). Besides, the clients were also affected psychologically and emotionally. Having to deal with stress or fear had caused breathing difficulty, and diuretics resulted in frequent bathroom visits. Feeling confined or excluded and isolated could have resulted in anxiety and depression, leading to their taking medication incorrectly or intermittently. The inability to take responsibility for themselves and be in control makes them feel uncertain, powerless, and unsafe (Tupairoa et al, 2009).

Clients should take care of themselves in order to reduce depression and to improve their quality of life after treatment. Previous studies have shown that the ratio of clients who receive care as per the hospital's requirements will have a reduced return or return to hospital (Hendricks et al, 2014). Clients who gain knowledge and understanding about self-care have better health care behavior than those who do not receive care according to the hospital's requirements (Moshki et al, 2016). For better understanding of health conditions, it is essential to convey information individually. Behaviors motivated by the patient's daily routine tools were: doing physical activities, exercising regularly, measuring one's own pulse, self-observation of abnormal symptoms, appointment with the doctor, compliance with doctor's recommendations while being treated, taking precautions while travelling, treatment of pacemaker infection, and managing self-stress properly (Pensri, 2017). Also, proper treatment of the disease by eliminating the most likely causes of heart failure or risk factors for heart failure, results in improved performance of the heart and/or prevents severe heart failure (Buttaro et al, 2013). Prevention and care of this disease is necessary; therefore, health personnel should learn how to manage clients appropriately and instruct their relatives accordingly, so that they have a better understanding of the kind of care required.

The concept of case management is one way to provide integrated and continuous health services. It focuses on patient-centered care, based on the coordination among various health services, to achieve treatment goals with efficient use of resources (Ross et al, 2011). The KKU-HF is a hospital that applies the aforementioned concept, for instance, nurses do a screening for heart failure before patients receive treatment at the Outpatient Nursing Registration Office.

1) Nurses evaluate health status by recording the client's history, making a physical examination, checking vital signs, conducting chest X-ray

examination, electrocardiogram, and blood collection; assess physical fitness with a 6 MWT walk (six-minute walk test); assess swelling and weight gain, and ask about symptoms of overweight conditions, such as tiredness, sleep, head elevation, inability to lie down, and activities that clients are able to do at home; perform three blood pressure measurements, including posture, sitting and standing, determine orthostatic hypotension, pulse, and oxygen saturation; assess knowledge and understanding of client care issues in matters such as medication, observing abnormal symptoms, and preliminary remedies dealing with swelling and tiredness; assess self-care behavior appropriately and evaluate drug collaboration with pharmacists, emphasizing that clients should bring the drugs they use, each time they visit.

2) Nurses make a nursing diagnosis and increase the accuracy of information on health problems of the clients.

3) Nurses teach their clients to take care of themselves. Teaching is based on the real experiences of the client; reflection of lessons learned takes place in order to ensure that clients better remember the necessary information. Moreover, nurses provide - on a case-by-case basis - knowledge and understanding on topics which the client does not understand and give them a self-care guide. After that, the client is referred to a doctor in order to get a medical diagnosis. Finally, the client will receive a prescription for drugs and can go home.

4) The final step is the continuous monitoring of the well-being of the client. Nurses do so by telephonic inquiry about the client's self-care behavior. In addition, it also provides an opportunity for the client to consult the nurse about other health problems.

With regard to this group of clients, the KKU-HF has a policy of quality development, to provide medical treatment on par with international standards and to be a top center for heart services. Therefore, it has supported the development of client care systems in all departments, both nursing and outpatient services. Accordingly, the nursing department has collaborated with a multidisciplinary team to develop a method for the management of clients with chronic heart failure. They then apply the case management model to establish client care systems in the KKU-HF. However, the guidelines used are still not as clear as they should be, in order to develop the quality of care that would help clients to remain as active as possible.

Objective

This research aimed to make a comparison of the outcomes of self-care before and after the treatment of heart failure clients using a case management approach.

METHOD

Study Design

This is a descriptive study of quantitative data for the period between April 2017 and March 2018. The case management model has been used for clients with heart failure who received treatment and follow-up at the KKU-HF. The study examined the outcomes of care on the knowledge and self-care behavior of clients.

Study Population

The study sample consisted of 30 people, 15 years of age and above, who had a doctor's diagnosis of cardiac and vascular heart failure. They were undergoing treatment and follow-up in the hospital's heart failure clinic. Outpatients are seen every Wednesday of the week, and approximately 2-3 clients are admitted at the hospital every week. There are also some clients who return to the hospital within 2-3 months.

The selection criteria were as follows:

1) Clients who were 15 years of age and older, who were able to communicate and had volunteered to participate;
2) Clients diagnosed with heart failure by cardiovascular specialists;
3) Clients having echocardiogram results with ejection fraction (EF) less than or equal to 40% (Pelico, 2013); and,
4) Clients recommended by doctors or nurses for a case management approach because of the risk of repeated hospitalization.

The researcher and research assistants explained the purpose of the study to the clients and their relatives and obtained their written consent before data collection.

Procedure

This was quasi-experimental research to study a single group over time. Data were collected the first time from the enrolled client prior to admission. Data were collected the second time from the same client after the first treatment, approximately three months later. Between the first and second time, the researcher made a follow-up call with the client at least once, to check on their knowledge and understanding of self-care and self-care behavior and to stress the importance of the next appointment with the doctor.

Tools

The tool used in this research was a questionnaire consisting of 2 parts. The first has details about the general characteristics of the client. The second part is the assessment of the client's self-care approach. The questionnaire was examined for the validity of the content and reliability by 5 qualified persons with experience in heart failure. As a result, it has a content validity index of 0.88 and confidence with the Cronbach's alpha coefficient of 0.70 (Maharaj Nakorn Chiang Mai Hospital, 2016).

Data Analysis

After every set of queries in the data collection process had been verified to ensure accuracy and completeness, inferential statistics were used, such as frequency, percentage, mean, and standard deviation. Statistical software packages were used for data processing.

Ethical Considerations

This research article has been approved by the Khon Kaen University Ethics Committee in Human Research, ethical number HE611353.

RESULTS

Demographic Data

The majority of the 30 heart failure clients in the study sample were male (80%) and 20% were female. As many as 56.67% of them were 60 years of age and older, and 73.33% were using gold patents (special welfare benefit from the government) to receive treatment. Most of the clients were married (73.33%) and around

56.67% had their husbands or wives as caregivers while undergoing treatment. The majority (66.67%) had received primary school education and most of them were farmers (53.34%). Coronary heart disease was the cause of heart failure for 63.33% of the clients in the sample, while cardiovascular diseases accounted for 36.67% of them. The data is shown in Table 1.

Table 1: Personal data of clients (N = 30)

General information	Pop	Percent
Sex		
Male	24	80.00
Female	6	20.00
Age		
Not over 60 years	13	43.33
More than 60 years	17	56.67
Treatment rights		
Individual welfare (gold cards)	22	73.33
Government welfare	8	26.67
Caregiver		
Husband or wife	17	56.67
Children/grandchildren or relatives	12	40.00
None	1	3.33
Marital status		
Married	22	73.33
Single	5	16.67
Widowed/ divorced	3	10.00
Education level		
Primary school	20	66.67
Secondary up	7	23.33
Bachelor's Degree or higher	3	10.00
Occupation		
Farmer	16	53.34
Business / Government employees	7	23.33
Housewife / Not a career	7	23.33
Causes of heart failure		
Coronary artery disease	19	63.33
Other cardiovascular diseases	11	36.67

Clients' Knowledge and Understanding of Self-care

Comparison of the clients' knowledge and understanding before and after treatment showed that, in almost all aspects, clients had better knowledge after treatment, with statistical significance at the level of 0.05. Knowledge had improved with regard to reasons for heart failure, limiting of salt in food and controlling the amount of water intake, taking medication according to the doctor's treatment plan, and monitoring and managing symptoms of excess sodium and water. On the other hand, at the 0.05 level, there was no significant difference in their perception of regular exercise before and after treatment. The data is shown in Table 2.

Table 2: Comparison of self-care knowledge and understanding before and after treatment (N = 30)

Knowledge and understanding	Mean	SD	Paired t-test	Sig.
Heart failure before being treated	1.83	0.38	2.112	0.043*
Heart failure after being treated	1.97	0.18		
Limiting sodium salts and controlling drinking water before treatment	6.83	1.21	3.034	0.005*
Limiting sodium salts and controlling drinking water after treatment	7.53	0.63		
Planning for medication adherence before admission	4.47	0.94	2.719	0.011*
Taking the medication according to the doctor's treatment plan after treatment	5.00	0.98		
Exercise regularly before being admitted.	1.77	0.43	1.140	0.264
Exercise periodically after being admitted.	1.87	0.35		
Surveillance and management of symptoms of sodium and excess water before treatment	7.83	1.29	5.761	0.000*
Monitoring and control of signs of sodium and excess water after treatment	9.13	1.01		

** Statistical significance at the level of 0.05*

Clients' Self-care Behavior

After receiving treatment, the changes among clients were as follows:

In terms of regularity and attention to medication, herbal medicine, bolus dose or dietary supplements, 73.33% had the highest level of self-care behavior of 3.70 points.

In following the doctor's treatment plan, 70% had a level of self-care behavior of 3.67 points.

On the other hand, the most neglected aspects of self-care was the limited sodium and water intake. Only 13.33 percent of the sample had a self-care behavior score of 2.85 points. The data is shown in Table 3.

Table 3: Score comparison of self-care behavior before and after treatment (N = 30)

Self-care behavior	Mean	SD	Paired t-test	Sig.
Sodium restriction in food and control of drinking water before treatment	2.85	0.58	2.940	0.006*
Sodium restriction in food and monitoring of drinking water after treatment	3.08	0.43		
Taking medication according to the doctor's treatment plan before treatment	3.67	0.42	1.153	0.258
Taking medicines according to the doctor's treatment plan after treatment	3.75	0.33		
In the use of other medicines, herbs, bolus dose or dietary supplements before treatment	3.70	0.45	1.564	0.129
In the use of other medicines, herbs, bolus dose or dietary supplements after treatment	3.78	0.40		
Monitoring and management of symptoms caused by sodium and excess water before treatment	3.08	0.75	2.151	0.040*
Monitoring and management of symptoms caused by sodium and excess water after treatment	3.34	0.49		
Overall score before treatment	3.12	0.37	3.182	0.003*
Overall score after treatment	3.31	0.30		

* Statistically significant 0.05

Quality of Life of Clients

Before treatment, most of the clients were not walking (60%). While 73.33% had no problems in bathing or wearing their clothes, 86.67% had issues with pain or physical discomfort. Some of them faced problems in performing regular activities and experienced anxiety or depression (66.67%).

After the treatment, the number of clients with such issues had decreased. Improvement in their general health had improved their quality of life. They are classified into 3 groups on the basis of their problems:

1) Initially 66.67% had problems in performing routine activities and experienced anxiety or depression, but after therapy the figure went down to 43.33%. The percentage of clients who complained of pain or discomfort reduced slightly from 86.67% to 83.33%.
2) Among those with walking problems (12 individuals or 40%), no difference was found after treatment.
3) The number of clients who had problems in bathing or putting on their clothes increased after treatment from 26.69% to 33.33%. It is possible that the clients' ability to help themselves deteriorates as the duration of illness increases. The data is shown in Table 4.

Table 4: General quality of life of clients

Health dimension	Quality of life	Before		After (6 months)	
		Amount	%	Amount	%
Mobility	1. No problem walking	18	60.00	18	60.00
	2. Have a problem	12	40.00	12	40.00
Help yourself for bathing and wearing	1. No problem	22	73.33	20	66.67
	2. Have a problem	8	26.67	10	33.33
Doing regular activities	1. No problem	10	33.33	17	56.67
	2. Have a problem	20	66.67	13	43.33
Pain or discomfort	1. No problem	4	13.33	5	16.67
	2. Have a problem	26	86.67	25	83.33
Anxiety or depression	1. No problem	10	33.33	17	56.67
	2. Have a problem	20	66.67	13	43.33

Client Satisfaction from Admission to Treatment

Over fifty-nine percent (59.26%) of clients rated the heart failure clinic as being excellent. Furthermore, the mean satisfaction rating of 3.59 out of a 4 is high. Satisfaction levels for individual aspects of the service give a different view. Clients are most satisfied with the information, advice, problem-solving, and clarification of queries given by the health staff: a mean score of 3.68 points. This was followed by satisfaction of clients with the behavior of health staff with a mean of 3.64: e.g. good manners in welcoming and caring for customers. Satisfaction with time spent at the health centre was slightly less valued with a mean of 3.26. Finally, satisfaction with the facility itself was rated lowest with a mean of 3.18. In conclusion, the scores indicate that clients were quite satisfied with the services (See Table 5).

Table 5: Number, percentage, mean and standard deviation of client satisfaction

Satisfaction issue	Excellent	Good	Medium	Less	Mean	SD
1. Personnel are courteous to welcome and pay attention to clients	64.29	35.71	-	-	3.64	0.49
2. Knowledge of service providing, advice, problem-solving, and clarification of queries by personnel	67.86	32.14	-	-	3.68	0.48
3. Appropriateness of service duration	37.04	51.85	11.11	-	3.26	0.66
4. The service place is clean and convenient, adequate numbers of clean and tidy bathrooms	35.71	50.00	10.71	3.57	3.18	0.77
Overall satisfaction	**59.26**	**40.74**	**-**	**-**	**3.59**	**0.50**

DISCUSSION

In this study, the number of male clients with congestive heart failure was four times more than the female clients. Most of them were around 60 years of age. It shows that heart failure is most likely to occur in the elderly. Part of the problem comes from the elderly being left alone and often lacking in primary caregivers (Piwinram, 2013). However, there are other factors that indicate that the elderly are likely to be affected, such as low levels of education, farming careers, or no occupation, no income, making it difficult for them to reach a good healthcare system (Thepthong, 2012; Amporn, 2018). Since more than 70% of the clients in the sample were using the free public health benefits (gold card), it is likely that their heart failure had other causes, including coronary heart disease and high blood pressure (Smeltzer, 2015).

By understanding the self-care of clients before and after treatment, many issues can be dealt with and clients can be guided in the right direction. It is important to limit sodium and control excessive drinking of water, and to take medication according to the doctors' prescribed treatment and supervision. Management of symptoms of excessive sodium intake can be done by watching relevant videos, reading manuals, or through telephone consultations. All these methods are to encourage clients to have correct knowledge and understanding in taking care of themselves efficiently (Pelico, 2013). On the other hand, there are some issues such as knowledge and understanding of exercise, in which there has been almost no change after treatment. It is possible that the client has knowledge and understanding, but cannot put it into practice. Therefore, the case management approach should be appropriate for each client, such as introducing light exercises for those who require it. Even walking is useful to help strengthen the body. In some cases, clients cannot exercise because of their physical condition. They tire easily because of reduced blood volume. The solution to this problem is to reduce activities by about 70% (Blinderman et al, 2008). However, case management is still very important in order to reduce the rate of recurrence as much as possible.

With regard to self-care behavior, after treatment there was an improvement in some areas, such as decreasing rates of taking herbal medicine, bolus dose or dietary supplements. Clients also began to pay attention to medication according to the doctor's treatment plan. They read the drug labels and followed the doctor's prescription. The reason could be anxiety that their illness would become worse. Moreover, they had faith in the advice of people who were knowledgeable and convincing, such as medical personnel, nurses, etc. In contrast to these changes, however, the clients continued to eat salty food. This deeply ingrained personal preference has become permanent behavior which is difficult to change and is a barrier to protecting themselves from heart failure. Instead of controlling sodium intake in food, they continued to prefer to cook with fish sauce, salt, soy sauce, soup cubes, and monosodium glutamate. They were also in the habit of buying ready-to-eat food from stores or markets. There is a risk of high levels of sodium in these foods (Sutthichareon, 2015). However, individual case management can be used to solve these problem behaviors. It can make the client aware of the importance of reducing or stopping the behavior that is detrimental to his/her treatment.

Case management also places great importance on the satisfaction of clients with services received. This leads to better cooperation with the course of treatment. Client satisfaction has many aspects. The first is satisfaction with the expertise of the personnel who provide information and advice to solve clients' problems. Next is satisfaction with the courtesy shown in the hospital, the enthusiasm and service of the medical personnel. Finally is their satisfaction with the cleanliness, comfort, and orderliness of the premises, such as having clean and adequate number of bathrooms. Since case management is effective for self-care of clients, the aspect of satisfaction should also be looked into in order to gain clients' cooperation.

Limitations

The study has several limitations. As a quasi-experimental research work, there are limitations to the internal fidelity of implementation. That is to say, there was a wide time span in the data collection period after the first treatment of the sample. Some clients returned to treatment within 1 month, while others took more than 3 months to revert. These factors, as well as different behavior patterns among clients, affect knowledge and understanding. Moreover, the clients in the sample group may have different characteristics and live in different environments, and this study has not focused on the individual factors that go into their care. In fact, the knowledge and capabilities of caregivers may vary greatly, and it is difficult to control such variables as the quality of caregivers, their knowledge, and their understanding. It is possible for other variables to influence the results of the study. Ultimately, the results of the single data collection cannot be relied on totally. For greater reliability, it is recommended that future studies should control other relevant factors. Additionally, the study of these factors should be further expanded to include issues such as the quality of caregivers.

CONCLUSION

The approach to care for clients with heart failure admitted to the heart failure clinic uses the case management model in its multidisciplinary team approach. In such a model there should be one person as a liaison between the client and the healthcare professional over time (Amaritakomol, 2018). For example, when a client is in need of medical assistance, the nurse will coordinate the patient's visit to a doctor during that time. Also, in case the client is confused about taking medicine, the nurse will help to contact and coordinate with the pharmacist to gain the necessary knowledge and understanding and inform the patient accordingly. Moreover, case management increases the likelihood that each client receives accurate information on how to best care for themselves.

In addition, each client had different levels of illness, a different economic status, different levels of knowledge of self-care, and there are also caregivers with different abilities. This study confirmed that a case management approach helps in solving a wide range of issues, giving each client the most comprehensive and timely care as possible. Furthermore, this approach helps nurses to manage a wider variety of cases. The continued improvement and development of a case management approach will help to achieve better quality of client care.

Prior to 2017, clients at KKU-HF Clinic had an average rate of recurring hospitalization within one year at 2.41 times per person. But after the group of clients who participated in a case management program, within one year the rate of re-hospitalization was reduced to 0.1 times per person. Case management of clients with heart failure is therefore likely to be one of the best and appropriate ways to manage clients and it is recommended to study opportunities to scale-up this approach to the care of such clients in other hospitals as well.

ACKNOWLEDGEMENT

The authors would like to thank all the participants, research assistants and colleagues of the The Heart Failure Clinic of the Sirikit Heart Centre, the Faculty of Medicine Khon Kaen University (KKU-HF), for facilitating this study.

The project questionnaire was supported by grants from Maharaj Nakorn Chiang Mai Hospital.

REFERENCES

Amaritakomol A, Kanjanavanit R, Suwankruhasn N, Topaiboon P, Leemasawat K, Chanchai R (2018). Enhancing knowledge and self-care behaviour of heart failure patients by interactive educational board game. Games for Health Journal; 8(3): 177-186. https://doi.org/10.1089/g4h.2018.0043 PMid:30383438

Amporn P (2018). Management model for acute ischemic stroke patients in emergency room Sakon Nakhon Hospital. Journal of Nursing and Health Care; 36(3): 207-220.

Apiromrat R (2017). Promotion of quality of life among patients with congestive heart failure. Thai Journal of Cardio-Thoracic Nursing; 28(2): 1-4.

Ariyachaipanich A, Krittayaphong R, Kunjara Na Ayudhya R, Yingchoncharoen T, Buakhamsri

A, Suvachittanont N (2019). Heart Failure Council of Thailand (HFCT) 2019 Heart failure guideline: Introduction and diagnosis. J Med Assoc Thai; 102(5): 623-7.

Blinderman CD, Homel P, Billings A, Portenoy RK, Tennstedt SL (2008). Symptom distress and quality of life in patients with advanced congestive heart failure. Journal of Pain and Symptom Management; 35(6): 594-603. https://doi.org/10.1016/j.jpainsymman.2007.06.007 PMid:18215495 PMCid:PMC2662445

Buttaro TM, Trybulski J, Bailey PP, Sandberg-Cook J (2013). Primary care: A collaborative practice. Missouri: Elsevier.

Chuekich N, Srida P (2013). Heart attack: Nursing and advice. Journal of Nursing; 27(1): 131-132.

Hendricks V, Schmidt S, Vogt A, Gysan D, Latz V, Schwang I, Griebenow R, Riedel R (2014). Care management program for patients with chronic heart failure. Deutsches Arzteblatt International; 111(15): 264-270. https://doi.org/10.3238/arztebl.2014.0264 PMid:24776611 PMCid:PMC4004935

Huntley AL, Johnson R, King A, Morris RW, Purdy S (2016). Does care management for patients with heart failure based in the community reduce unplanned hospital admission? A systematic review and meta-analysis. BMJ Open; 6(5): e010933. https://doi.org/10.1136/bmjopen-2015-010933 PMid:27165648 PMCid:PMC4874181

Kanjanawanich R, Pornhaminthikul O (2017). Chronic heart failure patient handbook (copies). Maharaj Nakorn Chiang Mai Hospital, Faculty of Medicine, Chiang Mai University: 42.

Maharaj Nakorn Chiang Mai Hospital (2016). Comprehensive heart failure management program. Keeping heart failure patients away from the hospital. Faculty of Medicine; Chiang Mai University: 11

Masresha A (2014). Adherence to evidence-based pharmacological guidelines and outcomes for heart failure in primary care providers. The Faculty of the College of Nursing, The University of Arizona: 13-15. Retrieved from https://repository.arizona.edu/handle/10150/347052.

Medical Information Unit (2017). Statistics of heart failure patients from 2013 to 2015. Heart Failure Clinic Queen Sirikit Heart Hospital, Faculty of Medicine Khonkaen University: 25.

Moshki M, Dehnoalian A, Alani A (2016). Effect of Precede-Proceed model on preventive behaviours for Type2 Diabetes Mellitus in high-risk individuals. Clinical Nursing Research; 26(2): 241-53. https://doi.org/10.1177/1054773815621026 PMid:26749209

Pelico LH (2013). Focus on adult health: Medical-surgical nursing. China: Aptara: 61.

Pensri L (2017). The effect of education and social support program on health behaviours in patients with a permanent cardiac pacemaker (Thesis). Bangkok: Chulalongkorn University.

Piwinram K (2013). Cases management of pulmonary tuberculosis patients and their families. Khon Kaen: Independent study Department of Family Nursing, Faculty of Nursing, Khon Kaen University.

Ross S, Natasha C, Nick G (2011). Case management. What is it, and how it can best be implemented. The Kings Fund: London. Available at: https://www.kingsfund.org.uk/sites/default/files/Case-Management-paper-The-Kings-Fund-Paper-November-2011_0.pdf

Smeltzer SC, Bare BG, Hinkle JL, Cheever KH (2015). Brunner & Suddarth's textbook of medical-surgical nursing.

Sutthichareon U (2015). Relationship between perceived severity of symptoms, risk of heart failure, and health behaviour of patients with valvular heart disease at Mahasarakham (Thesis). Department of Adult Nursing College Mahasarakrm University.

Therdsuthironnaphum P (2015). Effects of self-care promotion programs on self-care behaviours and quality of life of patients with heart failure, Prachuap Khiri Khan Hospital. Journal of Cardiothoracic Nursing; 26(1): 2-4.

Thepthong T (2012). Effectiveness of using best practices for care of patients with transitional heart failure from hospital to community at Udondit Hospital (Thesis). Department of Adult Nursing Graduate Schools; Chiang Mai University.

Tupairoa P, Tosuksri W, Sriprasong S (2009). Nursing care for heart failure patients, Medicine 1, NP-Press Bangkok.

Implementation of a Remote Control Application for Elderly People in Brazil: Analysis of the Factors Involved in the use of a Technological Innovation related to Telecare

Cristina Nieves Perdomo Delgado[1*], Luis Carlos Paschoarelli[1]

1. Paulista State University (UNESP), Brazil

ABSTRACT

Purpose: *The rapid ageing of the Brazilian population highlights the importance of new assistive technologies. The objective of this study was to analyse the positive and negative factors involved in the implementation of a Remote Care App for the elderly in Brazil.*

Method: *A qualitative method as been used, based on discussion groups involving 30 older Brazilian people who participated via a Telecare App.*

Results: *The results obtained highlight positive factors such as security, independence and personal tranquillity, and negative factors such as the privacy of the elderly, the social differences of Brazil, and the design and utility of the App.*

Conclusion: *Discourses on ageing at home using assistive technologies are cultural resources from which older people can make sense of their experience as users of Remote Care. It is also relevant information for the improvement of public policies aimed at caring for the elderly, by considering assistive technologies as factors for independent ageing.*

Key words: *assistive technology, Telecare, independence, elderly people*

INTRODUCTION

In societies of today there are two topics that call attention to ageing: one is the significant growth of the population of advanced years, and the other is the importance of assistive technologies for improving the independence of the elderly. These two issues have related concepts.

Accelerated demographic transformations in recent decades have caused Latin America to be in a period when the population is increasingly ageing (Giatti et

---

[*] **Corresponding Author:** Cristina Nieves Perdomo Delgado, Doctorate in the Post-Graduate Programme in Design, Paulista State University (UNESP), Brazil. Email:cristinepd@hotmail.com

al, 2003). In Brazil, the number of people over 60 years of age went from three million in 1960 to seven million in 1975, 14 million in 2002 and 20 million in 2010, with an estimated 32 million people reached in 2020 (Bezerra et al, 2012).

One of the challenges for the 21st century is to take care of the ageing population and provide new technologies that can help them maintain their independence and improve their quality of life.

Attention and care for the elderly today have positively been accepted as the model of "ageing in place" (Rowles, 1993). This model consists of the permanence of the elderly in their usual living environment, as much as possible (Pastalan, 2013). This new form of care for the elderly makes it necessary to design technologies related to Telecare, which help both the elderly and their families by providing greater security, independence and quality of life at home.

Different studies in Europe show that elderly people have a positive attitude about ageing at home and the use of different types of Telecare (Agrell et al, 2000). However, in countries like Brazil, there are very few studies on the meaning and knowledge among older people of ageing at home with Telecare.

Telecare is a social and / or healthcare service at home. The term Home Telecare was originally defined in the 1990s, as a home care system based on communication technologies, aimed at elderly people in need of help in an emergency situation (Valero et al, 2018).

Another more recent reference to Telecare service states: "Telecare is defined as an aid system inside and outside the home that covers the needs of those who may require constant timely attention and rapid assistance in emergencies 24 hours a day" (Akhlaghi & Asadi, 2002).

This definition focuses on the ability of the service to provide assistance, essentially social or medical, in any place and in any situation, regardless of the technologies used. The aforementioned definition of telecare highlights a distance social, medical and family care assistance using new technologies.

Today smartphones are used by people of different ages, highlighting that people over 60 have increased their ability to make use of both the device as well as the internet (Merrouche et al, 2016).

There are more and more applications for the elderly, with the aim of helping them in their day-to-day life, improving their independence, allowing them to control their medication, their medical appointments, their efforts to orient themselves in places during periods of disorientation without having to depend on one another (Merrouche et al, 2016).

Currently the smartphone is a powerful tool offering Telecare applications that can be of importance for the wellbeing of the elderly population. These days many research studies are being carried out on Telecare applications which have the objective of alerting families in emergency situations in which elderly persons living alone could find themselves (Merrouche et al, 2016). The authors wished to find out how elderly people experience smartphone Telecare applications.

Objective

The objective of this study was to determine positive and negative factors experienced by elderly people in the use of a Remote Care Application: Me Cuido App (the application is still in its testing phase and is likely to be launced by January 2021 and will be available in the Android App store).

The experiences of elderly people with the use of the Me Cuido App can further contribute to the implementation of new assistance technologies related to Telecare in the Brazilian population.

METHOD

Study Design

A qualitative study design was used to present the understanding which elderly Brazilians have about ageing at home and using a Remote Care Application (App), while highlighting the positive and negative factors.

Discourse analysis and the identification of interpretative repertoires were used. The interpretive repertoire is a set of linguistic constructions which account for a specific point of view and is based on shared expressions in a social group. Its function is to make a discursive construction of models of reality, while making positions against different social phenomena (Wetherell & Potter, 1996).

Study Sample

In the discussion groups, 30 elderly people participated via a Remote Care Telecare App. The sample included people between 59 and 90 years of age, who live alone in their homes in different cities of the Sao Paulo municipality. Although the intention was that the discussion groups were gender balanced, most of the participants were women.

Data Collection

The discussion groups were held at the home of one of the participants who collaborated in the study and the sessions lasted approximately one hour. For its realisation, there was a script and an explanatory video about Telecare and the Remote Care App; *a posteriori* there was a sequence of questions about the positive and negative factors of a Remote Care App for the Brazilian population.

The meetings were recorded and transcribed in their entirety.

Data Analysis

To identify the interpretative repertoires, the procedure recommended by Wetherell and Potter (1996) was performed. The researchers read the material that led to the first thematic coding. Thus, it was possible to focus the subsequent analysis on relevant fragments organised by positive and negative topics on the App. All segments of the corresponding subject were considered, even at the risk of including some issues which the analysts were not sure about.

From a series of re-readings, patterns of discursive variability and their internal consistency were identified. The identification of these patterns eventually led to the delimitation of a set of interpretative repertoires on the object of interest of the study.

Ethics Approval

The investigation was carried out with the authorisation and signature of the informed consent form by all the participants. This form was approved by the Ethics and Research Committee of Brazil.

RESULTS and DISCUSSION

The results showed that elderly people in Brazil have different ways of understanding ageing at home with Telecare technologies. In this sense, different repertoires have been identified on the positive and negative factors for the implementation of a Remote Care App for elderly people living alone in Brazil.

Positive Factors

Security

A Telecare App is a preventive home assistance service, immediate and permanent, for the care of the elderly who live alone. Several researchers say that this type of assistive technology improves the safety of the elderly by facilitating direct contact with their families and / or caregivers (Lyles et al, 2011). The following fragment reveals this factor. Two users spoke to one of their relatives about a situation they had experienced:

"The other day I went to the doctor and when I left the office I did not remember how to return to my house, I was scared! It had never happened to me. The secretary told me to call my family, but it was so blocked that I couldn't even dial the cell phone ... Now I think that with that application, they could have helped me quickly and without attracting attention in the office"(User 1).

"My daughter lives in another city ... every day she has to call me to remind me that I have to take my medication ... I think that if I used that application, I could have more security in taking the medication and so my daughter would not have to be aware from me ... that she is always at work ... that application would give more peace of mind to me and my daughter"(User 2).

Independence

Independence is something that most people value when they are old. Often related to active or positive ageing, it is considered by some authors as: "independent is who does what one wants, who is able to endow with their own law" (Correa et al, 2013). This factor was highlighted by the majority of users. Two users talked about how important their independence at home was for them, and what could be improved with the use of the App:

"Having a caretaker all day at home, the point that bothers her presence arrives (laughs) *... However, if we have a virtual company, I think it would improve daily independence without having to bother and pay other people ..."*(User 3).

"The use of this application would give more independence and privacy in my daily activities ... and I would not think that I am a girl again ... all I have to do is take my cell phone with me ..."(User 4).

Peace of Mind for the Family

When thinking about the care of the elderly, one of the points taken into account is the tranquillity of family members. While studying Telecare, words like tranquillity, fear, sadness, loneliness, and affection continually appear. A conceptual universe is established that revolves around emotions and affectivity (Tirado et al, 2011). A user revealed that her family, living in another city, need to be calm while she lives alone at home:

"My children who live in other cities are afraid that I live alone in my house ... they don't understand that I want to live alone ... It's my house ... I think that with the use of that application, they could be calmer ... in case something happens with me" (User 5).

Negative Factors

Privacy of the Elderly Person

According to the Inter-American Convention on the protection of the human rights of the elderly, elderly people have the right to privacy and intimacy and not to be subject to arbitrary or illegal interference in their private life, family, home or household, or any other field in which they operate, as well as in their correspondence or any other type of communication. The elderly person has the right not to be subject to aggressions against his dignity, honour and reputation, and to privacy in acts of hygiene or in the activities he develops, regardless of the area in which he operates (OEA, 2017). One user expressed the opinion that the use of the App would impinge on his privacy:

"What I do not like is that I will feel controlled all day, even if I do not have someone by my side ... I will feel that I have no privacy ... Why does my family have to know that I leave home and my location at all times" (User 6).

Social Differences in Brazil

Social differences due to the concentration of income, low wages and unemployment are factors that increase social inequality in Brazil. The social division of health, education and safety is a characteristic of this developing country. This situation means that the Brazilian population does not have the same opportunities in terms of new technologies (Brito, 2008). Several users highlighted the great social disparity that exists in Brazil and how that can have an impact on the use of a Remote Care App for the elderly. Two users pointed out the problem related to this factor:

"Not all people in Brazil have cell phones ... much less internet ... in our country there is a very large social difference ... not all people can benefit from this new technology ..."(User 6).

"It will be a technology destined for a certain Brazilian social class…" (User 7).

App Design and Usability

The technological inclusion of the older population presents a challenge in today's society. Technologies become an opportunity for the elderly to remain integrated in society independently. One of the essential factors in the use of technologies by older people is the design they present. The effects induced by the processing of the device interface type, intervene in the use of technology. The literature shows the so-called superiority effect of the drawings, which highlights the importance of images in long-term mental storage, observing the great capacity to remember drawings presented in short periods of time (Mort et al, 2015).Two users highlighted the problem of using the App related to this factor:

"If it is easy to use, it will be more used…." (User 8).

"Many applications have very small images ... I want to press one button and end up pressing the other ... and the colours are often difficult to identify ..."(User 9).

CONCLUSION

Discourses on ageing at home using assistive technologies are cultural resources from which elderly people can make sense of their experience as users of Remote Care. It is also relevant information for the improvement of public policies aimed at caring for the elderly, by considering assistive technologies as factors for independent ageing.

In order to deepen the meaning that Remote Care for the elderly can have, as well as to better understand its impact on Brazilian society, further studies are required. Future studies have to address the effective practices through which a Remote Care device is introduced into the daily life of the elderly in Brazil, and examine its effects on the quality of life of those who age at home.

ACKNOWLEDGEMENT

This study was developed with the support of the Ibero-American University Graduate Association (AUIP); CAPES (Process 88887.095645 / 2015-01) and CNPq (Process 304619 / 2018-3).

REFERENCES

Agrell H, Dahlberg S, Jerant A (2019). Patients' perceptions regarding home telecare [online]. Available at: https://ucdavis.pure.elsevier.com/en/publications/patients-perceptions-regarding-home-telecare [Accessed on 18 Sep. 2019].

Ahumada M (2019). El ALCA en debate: una perspectiva desde las mujeres [online]. Available at: https://www.worldcat.org/title/alca-en-debate-una-perspectiva-desde-las-mujeres/oclc/50645893 [Accessed on 18 Sep 2019].

Akhlaghi H, Asadi H (2002). Essentials of telemedicine and telecare. Chichester: Wiley.

Allen M, Ruiz M, de la Cruz M, Duboy M (2010). Establecimiento de políticas de seguridad para incorporar las exigencias de la normativa de protección de datos al sistema de telecuidado inteligente SEMPER [online] In Derecho y nuevas tecnologías. Available at: https://www.researchgate.net/profile/Maria_Martin-Ruiz/publication/257663294_ESTABLECIMIENTO_DE_POLITICAS_DE_SEGURIDAD_PARA_INCORPORAR_LAS_EXIGENCIAS_DE_LA_NORMATIVA_DE_PROTECCION_DE_DATOS_AL_SISTEMA_DE_TELECUIDADO_INTELIGENTE_SEMPER/links/00b7d52a70d5a88e60000000/ESTABLECIMIENTO-DE-POLITICAS-DE-SEGURIDAD-PARA-INCORPORAR-LAS-EXIGENCIAS-DE-LA-NORMATIVA-DE-PROTECCION-DE-DATOS-AL-SISTEMA-DE-TELECUIDADO-INTELIGENTE-SEMPER.pdf [Accessed on 18 Sep 2019].

Antaki C (1998). Publicaciones [online] Available at: http://psicologiasocial.uab.cat/lupicinio/index.php/2012-02-17-16-30-01/publicaciones [Accessed on 19 Sep 2019].

Bezerra F, Almeida M, Nóbrega-Therrien S (2012). Estudos sobre Envelhecimento no Brasil: Revisão Bibliográfica [online]. Available at: http://www.scielo.br/pdf/rbgg/v15n1/17.pdf [Accessed 19 Sep. 2019]. https://doi.org/10.1590/S1809-98232012000100017

Brito F (2008). Transição demográfica e desigualdades sociais no Brasil [online]. Available at: http://www.scielo.br/pdf/rbepop/v25n1/v25n1a02 [Accessed on 19 Sep 2019]. https://doi.org/10.1590/S0102-30982008000100002

Correa G, Domènech M (2013). Care networking: A study of technical mediations in a home telecare service [online]. Available at: https://www.ncbi.nlm.nih.gov/pubmed/23880730 [Accessed on 19 Sep 2019].

Gee J (2004). An introduction to discourse analysis: Theory and method. 4th Edition, Routledge. Available at: https://www.routledge.com/An-Introduction-to-Discourse-Analysis-Theory-and-Method-4th-Edition/Gee/p/book/9780415725569 [Accessed on 19 Sep 2019].

Giatti L, Barreto S (2003). Saúde, trabalho e envelhecimento no Brasil [online]. Available at: http://www.scielo.br/scielo.php?pid=S0102-311X2003000300008&script=sci_abstract&tlng=pt [Accessed on 19 Sep 2019].

Lyles C, Harris L, Flowers J, Le T, Tufano J, Britt D, Hoath J, Hirsch I, Goldberg H, Ralston J (2011). Qualitative evaluation of a mobile phone and web-based collaborative care intervention for patients with type 2 diabetes. Diabetes Technology & Therapeutics: Mary Ann Liebert Inc. Publishers. Available at: https://www.liebertpub.com/doi/10.1089/dia.2010.0200 [Accessed on 19 Sep 2019]. https://doi.org/10.1089/dia.2010.0200 PMid:21406018

Merrouche I, Mkhlouf A, Saadia N, Ramdane-Cherif A (2016). Overview and systems of assistance to older people [online]. Cuarta Conferencia Internacional sobre Ingeniería de Control y Tecnología de la Información (CEIT). Available at: http://10.1109 / CEIT.2016.7929050 [Accessed on 19 Sep 2019]. https://doi.org/10.1109/CEIT.2016.7929050

Mort M, Roberts C, Pols J, Domenech M, Moser I (2015). Ethical implications of home telecare for older people: A framework derived from a multisited participative study [online]. Available at: http://10.1111 / hex.12109 [Accessed on 19 Sep 2019].

OEA AG (2017). Convención Interamericana sobre la protección de los derechos humanos de las personas mayores. Cuaderno Jurídico y Político; 2(7): 65-89.

Pastalan L (2013). Ageing in place: The role of housing and social supports. 1st Edition Routledge. Available at: https://www.routledge.com/Aging-in-Place-The-Role-of-Housing-and-Social-Supports-1st-Edition/Pastalan/p/book/9781138881839 [Accessed on 19 Sep 2019]. https://doi.org/10.4324/9781315825960

Rowles G (1993). Evolving images of place in aging and 'aging in place'. Available at: https://www.aarp.org/content/dam/aarp/livable-communities/old-learn/housing/aging-in-place-evolution-of-a-research-topic-whose-time-has-come-aarp.pdf [Accessed on 19 Sep 2019].

Tirado F, Domenech M (2011). Tienen Los Artefactos Técnicos Afectividad? Regímenes de Compromiso y Teleasistencia en España [online]. Available at: https://ufsj.edu.br/portal2-repositorio/File/revistalapip/volume6_n2/Tirado_e_Domenech.pdf [Accessed on 19 Sep 2019].

Valero MA, Sánchez JA, Bermejo AB (2018). Servicios y tecnologías de teleasistencia: tendencias y retos en el hogar digital [online]. Available at: https://www.madrimasd.org/informacionidi/biblioteca/publicacion/doc/VT/VT8_Servicios_Tecnologias_Teleasistencia.pdf [Accessed on 19 Sep2019]

Wetherell M, Potter J (1996). El análisis del discurso y la identificación de los repertorios interpretativos. Psicologías, discursos y poder [online]. Available at: https://dialnet.unirioja.es/servlet/articulo?codigo=5180991 [Accessed on 19 Sep 2019]

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.

* * * * * *

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.

www.dcidj.org

Published by
Stichting Liliane Fonds
5211 TX's-Hertogenbosch
The Netherlands