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Adjustment of Persons with Acquired Disability and Its Impact on Caregivers

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Abstract:
Back ground: Acquired disability has been a big challenge to many people. The onset of the disability is usually a confusing period for the family members and the significant others. Many caregivers end up expressing learned helplessness therefore not able to adequately support the Person with acquired disability.
Objective: This study sought to find out if the caregivers are affected by the caregiving activities as they helped the person with acquired disability regain the their residual abilities.
Method: Qualitative and quantitative data was used to draw conclusions regarding the topic. Questionnaires and scheduled interviews were distributed and carried out respectively to the caregivers and analyzed using thematic approach and SPSS.
Findings: The caregivers in the study were n = 112.Results showed that two thirds of the caregivers 64% got positive change of attitude at x = 9.84, df = 3 significance level 0.020 and more experience and training led to better service to persons with acquired disability the education level of the caregivers influenced the quality of service to the persons with acquired disabilityx= 6.46, df = 2 significance level 0.039 .
Conclusions: From these findings it is evident that caregivers need support so as to enhance the service they provide persons with physical disability. It is also needful for policies and programs that would support caregivers of persons with physical disability be put in place to help them gain knowledge and the psychosocial support that would enable them to provide better care.

Keywords: *Caregivers, persons with acquired disability, adjustment, attitude, service*

1. Introduction

A person with disability is one who is regarded as such because of appearance, behavior and functional limitation or activity restriction that does not fit within the norm of physical abilities. The World Health Organization (WHO, 1999) estimates that one out of ten of any given population in the world has disability and that four out of five of these live in developing countries. High levels of poverty and illiteracy in the developing countries, which inhibit access to medical facilities, contribute to these statistics. Individuals with disabilities act (IDEA) a legislation of the United States regarding special education defines disability as orthopedic impairment and a severe condition that affects a child's education. The Kenyan Special Education Policy (2009) defines disability as lack or restriction of ability to perform an activity in the manner and the range considered normal within the cultural context of a human being.

In her report, Einar Helander, as cited by Wangai (2000) indicates global estimates of 140 million children have disability and four fifths of these live in developing countries. Global causes of disability are presented in the table below:

Cause of Disability	Percentage
Trauma	18.0
Mental illness	16.0
Communicable diseases	23.0
Non communicable diseases	26.0
Unexplained causes	17.0

Table 1: Distribution of Causes of Disability
Adapted From: Prejudice and Dignity 1990 Report by Einer Helander

From Table 1, it is evident that disease takes up the highest proportion of disability. Trauma takes up a lower percentage and is likely a result of accidents. Most people acquire disability through trauma and disease. The acquisition of disability may cause deterioration of the quality of life of the person with disability this would affect their quality of life both psychologically, environmentally and physically (Seena, 2013) since this influences the ability to interact socially and with the environment. It calls for adjustment for the person with acquired disability (PWAD) so as to be able to move on with the new life.They have to learn to carry out their activities of daily living in a new way or depend on someone else or an assistive device. All this require adjustment. Caregivers are the significant others who are involved in providing physical, emotional spiritual and moral support to the person with disability. This may include the parents, siblings or other people who care for the persons with acquired disability.

Most people who experience disability later in their lives experience a great challenge adapting to their new status. This provides a need for caregivers to walk with them in the journey of adjusting to the new status. In this case adjusting would refer to responding to sudden disability and this entails the psychological adaptation, social changes at the onset of the disability (Alvani, Hosseini, Mehrshad, Alvani 2012).This adjustment process is experienced by both the caregiver and the PWAD.Support is provided by the caregivers enable the PWAD to cope better with the disability and this may be financial, spiritual or physical support. The way they perceive the disability may influence how the caregiver and PWAD respond to the change.The physical changesthat may influence them such that they are dissatisfied with maintaining personal relationships (Abraham, 2013) causing them not to maintain friendship. There are various theoretical perspectives of adjustment.

2. Theories Related to Issues of Adjustment

There are various psychological theories that are useful in understanding the adjustments made by PWADs. Hammel as cited by Chubon (1994:137) described adjustment as performance of activities of daily living (ADL), employment and other functional indicators. Rehabilitation is the ability of the individual to live quality life in view of the extent of his disability. This includes therefore the ability to be involved in community activities, to look for employment, to psychologically accept the new condition and positively live with it, while allowing significant others to participate in their lives without resentment.

Darwin's Theory of Evolution

Darwin's theory of evolution stipulates that species adapt to their environment in order to survive. Theoretically adjusting to various issues could be referred to in psychology as dealing with life stressors and coping with them as a way of adaptation. The therapist or caregiver focuses more on the enhancement of the PWAD's residual body functioning rather than on his painful internal needs. The components in adaptation are coping, crisis and defense mechanisms (Chubon 1994:147). The individual therefore begins to find a new way of surviving with the new body changes, making efforts to function as much as possible with the new conditions.

Behaviorism theories

Behaviorists explain that appropriate behaviors are reinforced while the inappropriate ones are discouraged (Calabro 1990). This would help the people with acquired disability to adjust well and cope with life. Exhibition of undesired behavior is an indicator of an individual's maladjustment. An indicator of proper adjustment includes being able to cope with the acquired disability in a manner that leads to quality life through the use of the residual parts of the body. Coping may include religious coping and spiritual wellbeing (Alvani et.al 2012)

Sociological theories

The social theories focus on people's behavior based on the social systems. The systems would either encourage adjustment of the PWD or totally discourage it through the societal reactions and response to the persons with physical disability. Social learning approach theory is interactional, interdisciplinary and multimodal (Corey 2000). It affects one's thinking processes, attitudes and values. The individual's behavior is highly affected by the environment and what is happening to them.

Brown (1998) as cited by Wallen (1993) reviewed findings on research of families with physically challenged members. He found out that these families "develop defensive maneuvers aimed at maintaining family stability in the face of disruption caused by the presence of the disabled family member." The family systems seek to adjust to the disability by changing the way they carry out their activities, so as to fit in the needs of the disabled members or at times to make their lives comfortable regardless of the presence of the family members who have disabilities. This is evident in the Samburu community, for example. The people with disability among the Samburu are either eliminated from the community or abandoned by their families. Such people are perceived as hampering the activities of the community (*The Daily Nation,* 16th January 2006). Seneiya, in an interview, reported that the Samburu refer to persons with physical disability as 'Ngoki', which means "...valueless, useless or incomplete...." They are considered as setbacks to movement or labor and are killed or left to die in vacated 'manyatta'." (*The Daily Nation,* January 2006 Monday 16th Pg 6.)

2.1. Integrated Theories

The integrated theories focus on the fact that a person's reaction is based on the psychosocial models. Triechmann (1988) as cited by Chubon presented a version of the Lewinian Model that explains that "adjustment is a process of restoring balance among the psychosocial, biological and environmental factors in one's life (Chubon, 1994:143). The model is presented as: B = f (P x 0 x E), where B representing behavior is considered to be a function of the psychosocial (P), biological organs (0) and environmental factors (E). This is a combination of the social theory, behavioral theory and biological theories, which are all put together to explain the necessary adjustments that occur in an individual.

Psychology of adjustment has fronted a theory that focuses on behavioral psychology perspectives as well as adjustment to life in a context of continuous change, challenge, opportunity and existential approach to life (Moritsugu, Vera, Jacobs, 2017).This is a combination of several theories discussing the adjustment concept and how it affects human beings.

All the above aspects interact to determine one's response to a traumatic experience such as acquired disability. The integrated approach is applicable in explaining the process of adjustment to disability of an individual following a traumatic experience. The interaction of the psychosocial and biological factors, coupled with the environment lead to a holistic adjustment and coping mechanism. This could include the ability to go through shock, denial, retribution and acceptance, and opting for alternative ways of functioning.

This study adopts the integrated theory as the main theoretical framework because adjustment has to do with the holistic aspect that involves the person's interaction with other people, ability to do what he can do while using his residual abilities, emotional well-being and the biological status of the individual. The variables that relate to the integrated theories include: adjustment to the disability, relationships with the caretakers, attitudes and the PWAD's perceptions of disability.

2.3. Rehabilitation of People with Acquired Disability

Vacc et.al (1995:258) view rehabilitation as 'normalization' and emphasize the need to help persons with disability cope with problems in their natural environment so that the handicapping aspects of their disabilities are minimized and their level of functioning is maximized. Rehabilitation approaches vary with the kind of disability. It is important that one understands some of the aspects that relate to rehabilitation. One of these is psychosocial adjustment.

2.3.1. Psychosocial Adjustment

The efforts to help people adapt to their disabilities vary in terms of approach depending on the extent of disability. Emotional problems and psychosocial distress are common for people experiencing incapacitating situations. Interventions are usually put in place to decrease emotional suffering. Most PWAD experience depression, therefore an assessment and treatment of the psychosocial distress is necessary to facilitate adjustment of the individual. Vachon (1999) emphasizes the need to identify and distinguish change in social roles and isolation as major signs of depression.

The process of adaptation is likely to be determined by variables such as age, stage of family development and nature of disease or injury, trajectory pattern of disease, previous experience and family response on the same (support network), socioeconomic status and cultural variables. Neither Vacc (1995) nor Vachon (1999) address issues concerning the caregivers and their experiences with the members who are adjusting to disability.

The interventions offered should be designed with the family's needs in mind. Vachon (1999) cites the epidemiology of psychosocial distress with the study sample focusing on cancer patients. In the study, nearly a third (30%) of the total population (n = 443) registered high levels of distress. Distress was caused by pain, impaired role performance while carrying out normal activities at home and at work, and other disability related side effects. Fifteen percent of cancer patients experienced major depression. Clinical depression in the United Kingdom was 22.6%, in Canada, 25% of the total population was suffering from cancer.

It is important to note that inability to function as one was used to before disability normally leads to psychological disturbance, especially if one was independent. Having experienced acquired disability, Clifford explains, "It is difficult for many paraplegics to accept attitudes of some people toward them" (Vacc 1995:255).

Social relationships, economic and occupational activities, at times cognitive ability and physical integrity are affected by the presence of the disability. The individual is therefore helped to cope with the changes in his life, while maintaining his mental health. Vacc *et.al* (1995) suggest that counseling of people with disability should include discussion on issues such as mobility, time management, physical or bodily requirements, and personal and social disposition.

2.3.2. Speech Adjustment

Speech may be affected following brain injury of some form or after surgery. There are various ways in which the speech of an individual can be affected and these include: Dysarthia and Hyphonia (inteligibility of speech is affected), expressive and receptive Dysphasia (difficulty in finding words), Dyspraxia (inability to programme, sequence and position muscle movement for articulation). The patient could have difficulty in remembering words. To help the patient adjust, speech therapy may be necessary. The intervention includes: helping the patient use communication modalities, introducing communication aids, educating caregivers to change communication strategies and providing counseling to enable family to discuss the impact of the disorder on the family dynamics. Speech therapists therefore should become instrumental in all the suggested areas (Clark 1999).

2.3.3. Visual Impairment

Adjustment to visual impairment may be done through helping the individual develop tactile sensations. Mobility orientation and the use of a white cane enables quicker adjustment to the environment. Social and emotional skills should to be introduced to the PWADs so as to enable them fit in well in the society in terms of being able to carry out some activities on their own. Daily living skills are introduced to the individual so that he is able to carry out some of the essential chores on their own. Learning Braille or print and training one in the ability to hear, understand, interpret and critically evaluate what one hears can enhance communication (Kirk *et al* 2003).

2.3.4. Physical Disability

Physiotherapy is offered to optimize the PWAD's level of physical, psychological, social and vocational domains of functioning. This is achieved through various exercises, which are designed to discourage dysfunction and develop strength, endurance, cardiovascular fitness, mobility, flexibility, coordination, skill and relaxation. This intervention promotes independence by mobility exercises and reduction of posture and balance reactions.

Stoma management is introduced to patients who are not able to remove waste from their bodies in a natural manner. A stoma is an artificial opening that is introduced surgically to allow the patient to pass urine and faeces to leave the body into the colostrum. The PWAD is helped to choose and check the colostomy and its appliances and the skin care regime, as well as to assess the stomal effluence. The patient is advised about the use of the stoma bag, gas kit and the skin protection lotions (Beckman 1999).

Hicks et.al(2003) carried out a research on long term exercise training in persons with spinal cord injury, focusing on effects of strength, arm egometry performance and psychological wellbeing. He concluded that the exercises made the patients feel good and more confident, hence by developing their self esteem. The purpose of physiotherapy is to ensure that a PWAD is able to use the residual abilities quite well and is empowered both psychologically and physically.

Hearing Impairment

Lack of hearing or the presence of residual hearing abilities may highly affect an individual's mode of communication. The need to learn sign language and alternative methods of communication becomes essential. The individual with the help of significant others can practice lip reading. In this case, learning to read and write is important for effective communication.

2.4. Creation of Competence and Achievement through Occupational Therapy

According to Tigges (1999) occupational therapy helps the PWADs improve their perception of competence and achievement, generating wellbeing and quality of life. It is the first step towards adjustment second to the health management. Occupational therapy helps the patient regain his ability to come out of helplessness, loss of choices and options and is able to gain residual control of their lives.

The activities in occupational therapy include teaching wheelchair mobility, white cane mobility, developing daily occupational routines to facilitate a sense of purpose and accomplishment, recommending adapted environments such as bath or shower seats, wall mounted grab bars, use of splint techniques, ways of avoiding muscle contractures, assessing neuromuscular pain and recommending proper beds, mattresses or use of floatation devices (Kirk *et al* 2003:524) depending on the type of disability.

For the PWADs who become blind, orientation with the use of the white cane is introduced and also reading and writing Braille as the tactile mode of adjustment. Teaching listening skills is essential and this helps the PWAD to be in touch with his environment (Kirk *et al* 2003:441).

2.5. Caregivers and Their Role in the Adjustment of PWAD to Disability

Adjustment as defined earlier is the person's ability to cope with a new condition with an aim to improving the quality of life as much as possible. The PWAD's adjustment is likely to have a significant effect on the caregiver, as the latter's response to PWAD will also affect the former's adjustment.

Care giver PWAD ⇄ PWAD

Tasker (2006) specializes in counseling patients who have experienced brain injury, their caregivers and family members. She emphasizes that family members need to feel understood and emotionally supported, and therefore helped to cope with the changes as they assist the affected person in his functioning. She notes that the patient's ability to cope better in brain injury depends on the nature of traumatic brain injury, the patient's personality and dependence needs. All these factors can lead to depression and conflicts in the family.

When a mother or child is depressed, exhausted or feels overwhelmed, not only does this affect the family unit and the parent as a whole but affects the mother or father, in their efforts to engage and participate in warm and responsive interactions with their little one (Tasker, 2006) . Some parents might not reciprocate the feelings in their relationship with supportive feelings and this could cause a great strain in the family relationships, which could eventually reflect on how they treat the child who has a disability.

Martelli (2006) has listed several survival skills for caregivers. He emphasizes the need for them to watch out for burnout. He proposes that they should take one day off per week to rest and recreate so as to ensure that care giving does not take more than 40 days consecutively. The patient and caretaker are encouraged to ask for help when they need it.

The caregiver - patient relationship should include non care taking activity to allow interaction in the patient's residual areas of strength. This mainly applies more to married couples. The caregiver should be a mirror and not a sponge. He should not absorb all the experiences of the patient but take time to allow the patient to see a reflection of his strength in the caregiver. Both should be able to accept mistakes and not expect perfect situations (Martelli 2006). This implies then that it is important for the caregiver to take care of his own emotional needs as he takes care of those of the PWAD's

3. Methodology

3.1. Research Design

This research is a case study that has been carried out at the Salvation Army sponsored special schools. It has a detailed examination of a specific group (Wellington 2004) and was carried out to ensure perceptiveness and capacity to interpret the studied situations rapidly and at depth.

The research study adopted a cross sectional study design, which is used for assessing the determinants of behavior (Blossfield and Rowler, 1995). The research design was chosen because it enabled the researcher to investigate the factors that influence the rate of adjustment of the PWAD. The researcher has combined descriptive and explanatory approach therefore detailed qualitative and quantitative data.

3.2. Location of the Study

Respondents were drawn from four special schools in Thika municipality, Thika District, Central Province; 50km North of Nairobi city. The specific locations were the schools for the visually impaired and physically challenged, established by The Salvation Army. The schools admit learners with special needs from all over the country with a purpose to rehabilitate them.

3.3. Sampling Procedures

The sample comprised female and male students, parents, siblings and workers in special schools in Thika district. The study controlled for mixed primary and secondary special schools.

Purposive sampling was adopted for the study because the researcher was interested in the learners who had acquired disability and their caregivers. The interviewer sampled teachers, workers, students and selected parents or relatives. The sample design was a non-probability sampling procedure because the respondents were selected deliberately (Kothari 1990). Purposive selection of the students who had acquired disability either visual or physical and their caregivers' (parents, siblings or workers in the schools) was carried out. Non-probability sampling was preferred because the respondents who had acquired disability were very few therefore all of them were involved in the study. The sampling frame used was from students' records in the four Salvation Army sponsored special schools in Thika district, workers in the special schools and relatives of the learners in the special schools.

For the caregivers the sample was based on all the caregivers who visited the students, assist the PWADS. The schools draw their students from all over the country therefore the data collected was thought to be representative. The sample provides collection of information from people with disability from Central, Nairobi, Western, Nyanza, Eastern, Rift valley, North Eastern and Coast provinces in Kenya.

3.4. Data Collection Instruments

The data collection instruments included questionnaires and in-depth interview guides. Orodho (2004) emphasizes the use of in-depth interviews as techniques to describe and analyze the behavior of humans and groups in a particular setting. The researcher used three sets of questionnaires for the learners, workers and significant others for the caregivers to measure the same variables.

3.5. Findings of the Study

3.5.1. Characteristics of Participants

3.5.1.1. Persons with Acquired Disability (PWAD)

The age of the 71 PWADs that were interviewed, ranged from 14 to 26 years. They were drawn from the primary and secondary schools for the visually impaired and physically challenged. An overwhelming majority of the respondents in the study had acquired disability as a result of accident (21%), disease (71%) and unexplained causes (7%). An example of the unexplained causes is where one of the respondents became blind after lightning struck. Ninety five percent of the respondents have lived with the acquired disability for more than five years.

Out of the total number of PWADs who responded, 52% were male and 48% were female.

3.5.1.2. Caregivers

The total number of caregivers was 112, 33% of the respondents were male and 67% were female. The female caregivers were twice as many as the male. The caregivers comprised of parents [22%], guardians [1%], siblings [10%], teachers and workers in the schools [50%] and the students who assist the PWAD [10%]. More of the respondents were workers, fellow students and teachers because the PWADS spend much more time in school than at home.

The caregivers ranged in age from 15 years to 54 years. The caregivers offered help to the physically challenged and visually impaired pupils in the study schools. Some of the student caregivers held various positions of responsibility in the schools, for example some were scouts (33%), the prefects (29%) and peer educators (19%). Ninety seven percent of the student caregivers were drawn from the Schools for learners with physical disability. This is because the two schools had a greater number of dependent PWADs. Most of the PWADs in the special schools require more assistance to carry out their daily activities depending on the level of their disability.

It is clearly shown by the percentages that the larger number of students who also participate in caregiving carry out more responsibilities in the schools. The student caregivers were drawn from all the classes. They included all the students who were able to consistently assist the PWAD students who were dependent on the others for their basic daily activities. There were no student caregivers in the primary school, because the housemothers helped with the ADL activities for the students. The following graph shows the number of student caregivers per class in the secondary schools. The highest percentage of caregivers was found in form one classes in both schools. Most of the students involved in care giving had various responsibilities in the school and they all reported in the interview that they assisted the PWADs voluntarily. The number of caregivers in the classes varied depending on the needs of the PWADs in the classes and in their dormitories.

The following table shows the years of experience for the caregivers.

Years of Experience with PWADS	Percentage (%)
1-2 years	14.2
3-5 years	17.0
6-10 years	25.9
More than 11 years	42.9
Total	100.0

Table 2: Care Giving experience (n=112)

The table 2 indicates a bigger percentage of the caregivers had experience of more than 11 years. These were included caregivers who were working in the institutions and few parents. The caregivers had varying levels of education ranging from primary to post secondary levels. The caregivers with post secondary education level were mainly teachers and workers. The category with secondary and primary educational level comprised of the student caregivers and few of the nonteaching staff. The student caregivers were equally represented by gender. The gender balance was mainly because the students reported that they assisted friends of the same sex.

A higher percentage of the parent caregivers (80%) were female. This could be explained by the fact that generally mothers spend more time with their children compared to the fathers. In all the categories of caregivers, female caregivers were more than the male caregivers. This could be as a result of the females being able to handle the emotional aspect of caregiving more effectively than men (Mosher & Offburg, 2004). Most of the female respondents reported that some of the fathers alienated themselves from the family when a member acquired disability.

A fifth of the parents involved in caregiving were male. This indicates that fathers are not very involved in the caregiving activities. This could be the cause of the low population of men in care giving – they lack male role models in the area of caregiving.

The sibling caregivers were relatively few compared to the other categories. This could be attributed to the fact that the siblings leave the mothers to carry out more of the caregiving. It is notable that among the siblings, the female siblings were almost three quarters leaving the remaining quarter to be male. It could be assumed that the percentage of male caregivers' population is low right from the family level to the community level. The items in the questionnaire aimed at establishing the quality of care given by the caregivers, type of support given to the PWAD by the caregiver and the interaction between the caregiver and the PWAD. The following section will present the findings from the caregivers.

3.5.1.3. Emotional Experience of the Caregivers

Nearly all the caregivers who participated in the study (n=112,93%) assisted PWAD in various ways in accomplishing the activities of their daily living (ADL). The teachers were involved in educating them, housemothers, siblings and parents were assisting them to carry out their activities of daily living: helping them use the mobility appliances, brailers, physiotherapy, funding their education and providing for their material needs.

One fifth (21%) of the caregivers were involved in counseling and providing spiritual guidance to the PWAD as well as helped them with ADL. Some of the caregivers assisted the PWADs to look for jobs after completing their course in school.

Out of the 112 respondents, 21% were excited about helping the PWAD, 69% were happily doing it and few felt drained and low while helping. Thirty percent felt tired while assisting and 69% were willingly carrying out the service. The following table indicates the caregivers' feelings about assisting PWADs in reference to gender.

The caregivers who were happy to assist were 69%. From the caregivers who were happy to assist, 46% cared because it was a calling, 18% cared as relatives and 20% because it was a job opportunity. 7% of the male caregivers felt drained by the activity,most female73% caregivers carried out the role happily while59% male were happy. 60% of the caregiversfelt low as they thought about the care.More of the female caregivers had positive attitudes while giving care as compared to the male caregivers. This could be attributed to the greater ability of women to respond to issues with an emotional angle as compared to men. From the interviews, it was evident that most of the men mainly provided financially and materially for the upkeep of the PWADs but were not directly involved in the caregiving activities.The negative feeling of the caregiving led to health problems and health behaviors (Lawng, Horey, Blackford 2015)similarly another study found out that the negative feeling towards solving problems may lead to caregiver distress (Blucker, Elliot, Warren and Warren, 2011).

A third of the drivers, 78% of the teachers, and 80% of the housemothers were happy with their work. A small population (08%) of the respondents was low and felt drained while carrying out their work. A fifth of the house mothers were not excited with their work neither did they like it. For the house mothers who were emotionally low, emotional support and emotion focused social problem solving would help them deal with the adjustment and develop adjustment (Grant et.al 2006).

The high percentage of caregivers who felt happy yet were tired while assisting is evidence to the fact that caregiving is a task that involves an individual both physically and emotionally.

While dealing with their fatigue, most of the caregivers reported that they kept encouraging themselves, as they had to help their child or friend or sibling. The caregivers devised easier ways to continue assisting without giving up. Most respondents explained that it was a challenge to assist the PWAD because the caregivers had to teach them ADL and be patient while showing them how to carry out various activities. The caregivers had to be more patient, help the PWADs accept themselves and acquire a positive attitude toward life. This kind of emotional stress was reported especially by caregivers who had to attend to long term conditions (Public Policy Institute, 2015)

The PWAD's needs for more specialized attention and high financial expenditure for their special needs, was reported as a challenge to most of the caregivers. Most of the parents and guardians explained that they spent a lot of money for medication and providing specialized attention to the PWADs similar to other studies,(Public Policy institute,2015; Enkhzaya et, al, 2016, Grant et al, 2006).

Response to reception of the services offeredto the PWADs was generally good. More than three quarters of the respondents (n=112, 78.5%) reported that the PWADs appreciated their help; the other smaller percentage reported that some of the help was taken for granted.

The motivation to provide assistance of any kind to the PWAD varied with the individuals who responded. Forty four percent of the caregivers felt that caregiving was a calling (they felt that this was their mission in life), this made more than a third of the respondents while 19% felt it was a job requirement. Those who assisted because the PWAD was their relative formed 17%. Some of the respondents assisted the PWADs because they had no choice (10%). Another 10% explained that they liked helping because that was how they got their blessings. This category of caregivers related their caregiving to a form of spiritual service. Others helped PWADs because they were their friends. The role of the caregiver changes from how it was before the new status (Malachi, 2005), this is because of the new dimension which is care giving.

3.5.1.4. Coping with a PWAD

One third (34%) of the respondents feared the PWDs prior to working with them. Most of the caregivers did not understand the PWD's needs and treated them with apprehension. Some of the caregivers thought that the PWADs were too delicate both physically and emotionally and often questioned why they had to suffer as they did. Fourteen percent of the caregivers sympathized and 20% pitied the PWADs.

One of the caregivers who was also physically challenged reported having previously thought that he was the only disabled person in his community until he met other people who had more disabilities than him.

The caregivers that appreciated the PWADs as they were 29% (n=112); they thought that anything could happen that would lead to any one acquiring disability. Some caregivers liked the PWADs and were ready to assist them. Having had to interact more closely with the PWAD,65% of the caregivers reported of change in their attitude toward PWADs and 39% of the caregivers did not have a problem with their attitude toward PWADs. Some of the caregivers had to change their attitudes toward PWADs so as to be able to assist them.

Out of the participants, 62% of the males and 66% of the females changed their attitude during their care giving. More than a half of the caregivers had to change their attitudes towards the PWADs so as to assist them well. This is shown by the response to the question about whether the respondents had to change their attitudes towards the PWADs as they interacted with them. It is apparent from the interviews that most of the caregivers had unhealthy attitudes towards the people with disability therefore they had to change so as to serve them better.

Status	Response (%)	
	Yes	No
Student	65.3	34.7
Parent	60.0	40.0
Worker	76.0	24.0
Sibling	27.2	72.8

Table 3: Response to the Change of Attitude in Relation to the Status of Caregivers

A higher percentage of the worker, student and parent caregivers reported in the interview that they had never interacted with people who had disabilities. They therefore had formed attitudes toward them that were incorrect.

Continued interaction with PWADs enabled the caregivers to change their attitudes, from what they initially thought of PWDs to their current experiences with the PWADs as shown in the preceding table. Generally all the caregivers had to adjust to the current situation of the PWAD so as to assist them. Most participants across the education levels changed their attitudes Primary (66),Secondary (65%),tertiary (65%) is evident that the level of education did not necessitate the change of attitude. Almost seven tenths of the respondents had to change their attitude across the different educational levels.

A quarter of the drivers, seven tenths of teachers, half of the grounds men, four fifths of the housemothers and three fifths of the siblings, parents and guardians reported positive change of attitude. This change could be attributed to the amount of time spent with the PWADs. Chi square test indicated Pearsons Chi value at 9.840, df = 3, significance = .020 with p <0. 005.this shows that the caregiver's attitude highly influenced the quality of care given to the PWAD hence their adjustment.

The respondents reported that their own attitudes changed after interacting with the PWADs, understanding their problems and needs. The more they interacted with them, the more they were able to accept and appreciate PWADs. The caregivers were able to cope well with the PWAD by focusing on the PWAD's strengths and giving them unconditional love. One of the caregivers reported,

"I later on realized that people with challenges do not need sympathy. They say they are the same as those with no disabilities. The only difference is the use of mobility devices, lack of sight or limited sight."

The respondents realized that they could treat the PWAD well and as normally as they did to other people. In reference to PWAD, another caregiver observed,

"...experience with them and the inservice course that I attended have helped me to understand theirpsychology, thereby equipping me better to serve them."

A chi square test indicated Pearson's chi at the value of 6.469, df = 2 and significance of .039, p<0.005 meaning that the training of the caregivers influenced the quality of service impacted on the PWAD. Training played a great role for this respondent to ensure that he was able to help PWAD. This shows that specific training in the area concerning disability can make it easier for the caregiver to assist the PWAD better. This finding is similar to a study that reported that problem solving training led to remarkable decrease in depression, health complaints dysfunctional problem solving styles and reduces stress (Rivera, Elliot, Berry and Grant, 2008; Blucker et al 2011). Once AWPD are trained they are able to manage the needs of PWAD with knowledge and understanding this helps them work without feeling like attending PWAD is a burden.

When asked about assisting the PWADs, three quarters of the drivers, 82% of the teachers, two thirds of the grounds men, and 80% of the parents, siblings and guardians felt that working with the PWADs was a great challenge. With this perception, the quality of service rendered to the PWADs is compromised. There is need for the molding caregiver's outlook towards helping the PWAD so as to enable the caregiver to perceive their work positively. Results from a chi square test reported that Pearson's chi square value at 26.209, df = 3,significance of .000 at p < 0.005,thisshows that there is a significant influence of the caregivers feeling that the caregiving is a challenge to them. This may affect the quality of service they give to the PWAD

Being able to see the changes and improvements registered by the PWAD was a great motivation for the respondents. Most caregivers reported that giving the PWAD opportunity to participate in their daily activities (including decision making where they could) made it easier to assist the PWAD. This involved recognizing their abilities and potentials.

Some respondents remarked that the community had a great role to play in helping to shape the caregiver's attitudes. Other caregivers had external emotional support from church and medical practitioners; while others had been discouraged by comments from close acquaintances so their attitudes have had to be geared toward assisting the PWAD.

Sixty nine percent of the respondents reported that other people's attitudes toward the PWADs affected their service to the latter and 30% reported that they were not affected in any way.Seventeen percent of the caregivers found it difficult to go to social gatherings with the PWAD because of financial constraints, ill health of the caregiver or inconvenience in traveling with the PWAD. When respondents were asked whether they went to social places with the PWADs, 93% of those who attended gatherings such as going to church, drama festivals, games, family outings or support groups for the children with the PWAD found it very important to ask for help. They reported that going out with the PWAD enabled the PWADs to feel better about themselves.

Eighty two percent (n=39) of the caregivers who had experience of 5-10 years asked for help. This figure is high when compared to 67% (n=48) of the caregivers who have experience of more than eleven years. The difference could be as a result of frequent interaction with the PWAD therefore they know their expected needs and so can ask for help where need be. With more experience, the caregiver may not ask for much help probably because they know alternative ways of solving the problem. It is noted that the caregivers with very little experience (of less than 5years) do not ask for help much. This may be due to lack of assurance as to whether the PWAD needs the assistance or their personal attitudes toward asking for help.

Most of the caregivers reported that they asked for help when they needed it, while assisting the PWAD. The 93% who asked for help had various responses on whether they got the help or not. Most of them got people who volunteered to assist. Some people were not ready to help and others acted with too much sympathy, which made the PWAD uncomfortable. Some of the people they asked to assist them were not very ready to assist; others did not take the physically challenged seriously, while most people offered to help voluntarily. More than 80% of the respondents asked for help when they required it. A minority of less than a quarter of the respondents did not ask for any help. On average 88% percent of those who asked for help were housemothers, grounds men and teachers. Social support and assistance for the care givers played a great role in helping the caregivers to adjust (Grant, Elliot, Weave, Glandon, Raper, Giger 2006)

Apart from helping PWADs, some of the caregivers were involved in recreational activities such as sewing, cooking, drawing, keeping gardens, traveling and socializing. This enabled them to relax away from caregiving activities.

Fifteen percent of the 112 respondents were not able to take a break from the helping activities because they felt that the people they took care of needed them. Five percent took time off frequently. Almost half of the caregivers stayed away over the weekends and took breaks; this comprised of the teachers and some of the workers in the offices. This is the category of caregivers who were workers in the schools. A total of 85% of the caregivers took time off for rest, away from care giving.

Above four fifths of the caregivers who had experience of 5-10 years and above 11% took days away from caregiving experience. This shows that with continuous encounter with the PWADs the caregiver learns the importance of rest and varying activities as a way of taking care of themselves even as they offer assistance to the PWAD. One hundred percent of the respondents with 1-2 years' experience took time off. This large percentage is accounted for by the fact that most of them are students therefore they would spend some time in class or participating in co-curricular activities. The need for a break is very important, a study in the US reports that the longer a caregiver has been giving care increases their likelihood to report poor or fair health and the longer they provide care the health becomes worse (Public Policy Institute, 2015).

3.5.1.5. The Attitude of Caregivers toward the PWAD and the Services Offered

About two thirds (65%) of the respondents strongly agreed that they enjoyed their work, 31% agreed and 4% were undecided. Out of the total population of the caregivers, 61% felt that they gave the best service, 35% agreed with the statement and 5% were undecided. Seven tenths of the caregivers strongly agreed that the PWAD appreciated their services. The caregivers who strongly agreed that they liked interacting with the PWAD were 93%.Eleven percent of the respondents agreed with the statement that they wished they worked elsewhere, 14 % were undecided, 76% disagreed and strongly disagreed with the statement. The respondents who expressed that their experience with PWADs helped them grow were 88%.

The caregivers' attitudes were measured using the Likert scale. It was evident that a large percentage of the caregivers had moderate attitudes (57%) and 17% negative attitude. This made up 74% of the caregivers who needed to be assisted to develop positive attitudes so that they effectively assist PWADs. A quarter of the caregivers had positive attitudes towards their work of assisting PWADs. This finding is strengthened by a finding in a study that reported that the caregiver's negative outlook towards solving the problems was significantly predictive of higher depression (Krylo, DeVivo, Elliot, Dreer, 2004).The caregivers need to be helped to have a positive orientation towards the PWAD this provides for better care and the caregiver does not feel the burden of the service.

3.5.1.6. Recommendations from the respondents about what needs to be done to assist the PWAD

The respondents listed several issues that needed to be addressed to help them assist the PWADs better. These included helping the society to appreciate the PWAD better by creating awareness through seminars and the media, and educating the public about the needs of the special population so that they could be well absorbed in the community and allowed to participate in the activities they are be able to carry out.

The caregivers recommended that educational policies should be put in place to ensure that PWAD are able to live productive lives. Quality education should be offered to the people with special needs to enable them cope and get good jobs so that they become self-reliant. The government needed to provide material and all facilities that would make it possible for PWADs to be well prepared academically. This included financial assistance and provision of literature (Braille and printed matter for the visually impaired). The teacher - learner ratio in the special schools needed to be revised to facilitate individual attention for the learners. The recommendation for financial assistance was also in other studies (Enkhazaya et.al.2016;Grant 2006). This shows that PWAD influence the budget of the family. The participants proposed services as shown in the graph

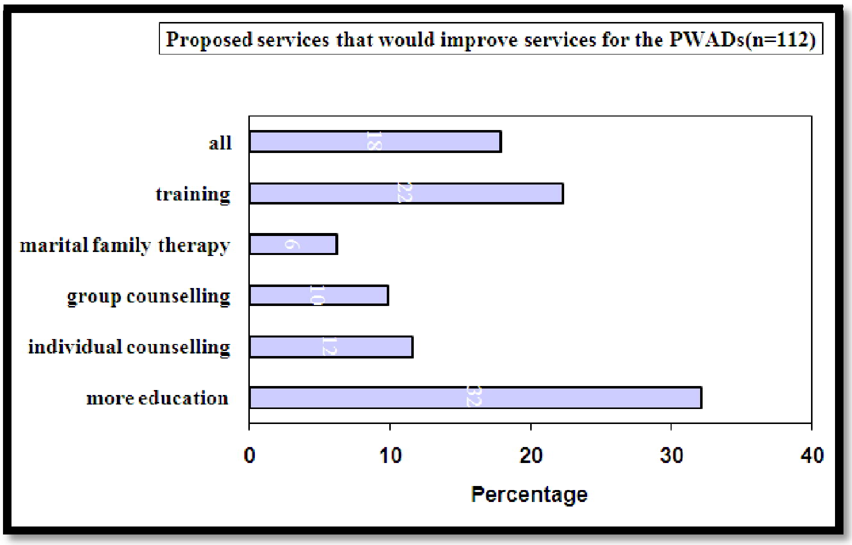

Figure 1: Proposed Services for PWADs

One third of the caregivers proposed more education on particular disabilities, this would enable them to give proper care and understand the needs of the PWADs. A tenth of the respondents indicated the need for individual counseling, group counseling and marital therapy that would enable them to cope with the issues that arise in their lives so as to deal with the conflicts they have as they help. Twenty two percent of the caregivers preferred more training on how to help a disabled person. A fifth wanted all the suggested services to be provided for them. Rehabilitation therapy and disability training were part of the recommendation in another study (Enkhzay,et.al 2016;Blucker,2011).

4. Conclusion

From the findings of this study, the care giver is very important in the life of PWAD. The perceptions the caregiver holds regarding the PWAD highly influence the adjustment of the PWAD. The support that the PWAD receives makes it easier for them to have a better quality of life. In this regard, the caregivers need to receive adequate support which will enable them to work with the PWAD towards successful growth. The caregiver needs to take care of themselves to avoid burn out and poor health that results from poor self care.

5. Recommended Study

There was limited literature for this study, more work needs to be done to explore management of burn out for the persons with disability. It is also imperative to find out how the government can be involved in supporting the care giver to ensure quality care for the PWAD. Government policies on medical care, counseling and rehabilitation of persons with disability are necessary to help ensure manageable adjustment of the PWAD to their new status.

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