

**The Challenges Faced by Young Caregivers of Those with Disabilities Due to Different
Illnesses: A Case Study of PCEA Kikuyu Township Youth Church,
Kiambu County, Kenya**

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Abstract

The purpose of this research was to determine the common challenges faced by the youth as caregivers of those with disabilities and determine ways of overcoming these common challenges that the youth caregivers were facing. This study was conducted at PCEA Kikuyu Youth Church; the target population is youth caregivers, those between 13 and 35 years of age. The main research instruments used were interviews and observation. The research method used was qualitative with a phenomenology approach. Purposive sampling was used, where six respondents who had been caregivers for their family members and students were interviewed and observed. These youth caregivers' common challenges were established by memoing, then color coding, analyzing and finally interpreting the emerging themes, which were the common challenges as spiritual need, financial need, recreation need, knowledge and skills and shattered goals and dreams. The process of coding and theming common ways of overcoming these

challenges were established: pastoral care, prayers, fellowship, financial support, family support, training, outings, breaks, and church and community support.

Keywords: Caregivers, sick, health, financial, recreation, knowledge, skills, challenges, goals, dreams, training, church, community.

Introduction

Different illnesses can result in different disabilities that may require care to be offered to those with disabilities. In most cases, especially in African families, this care is provided by family members, some very young caregivers. This paper focused on young caregivers because of their slightly different challenges from elderly caregivers.

Caring for those with disabilities due to these different illnesses involves many activities. It includes: assisting with the personal care of the patient, essential food preparation, assisting with mobility and transportation for those who are challenged, supervising the patient and ensuring that the patient is safe, supporting the patient emotionally, monitoring the health of the patient like taking the blood pressure, organizing the home for the patient, organizing how the patient can get spiritual nourishment.

The Presbyterian Church of East Africa is known to give holistic support to the members and community surrounding them. The community trusts the church to have spiritual and moral authority and guidance. Hence this research was conducted in a church set-up which was the most appropriate because the researcher was able to interact with the youth caregivers, some of whom were depressed and in need of pastoral counseling.

The PCEA (Presbyterian Church of East Africa) church shows work of mercy as stipulated in the Practice and Procedure Manual of the Presbyterian Church of East Africa. One

of the roles states that the church should show works of mercy, social services and removing the causes of human suffering. This is done by using different church ministries, like the pastoral team and other church groups involved in pastoral care, training, and counseling to encourage, motivate and offer other necessary support to the caregivers. Hence, when the research was carried out in the PCEA church set-up, it was by the church's role in society. The PCEA Kikuyu Township Youth Church was started with a vision of being a role model to other youth churches and the Kikuyu community.

The paper focused on identifying the common challenges that youth caregivers face and ways of overcoming these common challenges. This was done by addressing the two research questions of the study:

RQ 1 What are the common challenges faced by the youth as caregivers of those with disabilities due to different illnesses?

RQ 2 How can these common challenges faced by the youth caregivers of those with a disability be overcome?

The discussion of this paper provided a brief overview of the problem statement, the theoretical framework underpinning the problem, research methods, research findings and discussions, conclusion, and recommendations.

Problem Statement

Taking care of those with disabilities due to different illnesses can sometimes be challenging to young caregivers who do not want interference in their lives, for they usually have so many dreams and ambitions to achieve; caregiving is a distraction in their lives, and hence there is need to give them any necessary support. Hughes (2008) refers to the caregivers mainly from the family who gives care to their family members with disabilities

as “secondary patients” who may be faced with social, physical, spiritual and emotional challenges. The family members' caregivers are normally not financially paid but may be rewarded with food or other basic requirements like clothing for the rest of the family members. Nobody is responsible for giving them financial support. Some youths have been forced to drop out of universities, colleges, secondary and even primary schools for young caregivers cannot multi-task both as caregivers and students.

Schulz and Eden (2016) describe the tasks of the caregivers as dynamic in nature, complex and the responsibilities involved as many and intense. Family caregivers may often feel unprepared to provide care; they often have inadequate knowledge and skills, thus requiring guidance from the health workers. The different disabilities may require different kinds of care, hence the challenge of not being equipped with this knowledge or skills.

The youth caregivers are challenged with balancing the time of giving care and the other activities that concern them, in this case, schoolwork. Providing care considers; the nature of the tasks, the frequency with which the tasks are performed, the hours of care provided each day, the skills and knowledge required, the extent to which the tasks are made routine and the support from the rest the family members.

Theoretical Framework

A critical theory was considered in this research as critical research can be combined with other qualitative research methodologies to bring about a more just society (Merriam, 2009). It was noted that critical theory tries to generate a specific vision of the world as it might be. It springs from a distinct philosophical vision of what it means to live as a developed person, as a mature adult, struggling to realize one's humanity through a creation of a society that is just, fair, and compassionate (Brookfield, 2005, p. 27). This

This study used it as a lens to help focus on the common challenges faced by the youth as caregivers that are dehumanizing and unfair, making them miserable young human beings as they conduct their duties.

Critical theory was applicable in this study because the youths felt their family members were unfair. They also thought that some of their rights, like the right to education, were being violated by the elderly family members of those with patients. The family requiring the youth in the family to be caregivers made the youth caregivers very miserable. Youth caregivers need help and assistance to regain their self-esteem and human rights. According to Carter and Golant (1994), many have suffered from having to take care of others. This caring can tax them financial, emotional and physical disturbances, including lack of privacy, sleep, health, and in this case, education for the youth.

Research Methods

The research design used in this study was a qualitative research method using a phenomenological approach. This approach is recommended, as it can reveal the phenomenon's essence as experienced by the participants (Creswell, 2013). A phenomenological study is a study that attempts to understand people's perceptions, perspectives and understanding of a particular situation. (Leedy & Ormrod 2001,153). This approach was able to provide rich, detailed descriptions of the experiences of the youth as caregivers. The study aimed to collect information from respondents on the challenges the youth caregivers face and ways of overcoming these challenges.

The target population for the study was 30 youth caregivers who were members of the PCEA Kikuyu Township Youth Church and were offering care to those with disabilities in their families. The study used a purposive sampling design, meaning the participants had the same

experiences and characteristics. According to Mugenda and Mugenda (2003), a sample size entails the members of the population that are accessible and who choose to represent the population under study with the required characteristics. Creswell (2013) recommends 3-10 cases for the phenomenological approach, while Morse (1994) suggests 6 participants for the phenomenological approach. In this study, six respondents were interviewed and observed. The main research instrument used in this study was an interview guide with open-ended questions.

The validation of this research involved ethically conducting the study and having adequate engagement in data collection, ensuring that the researcher had enough time to understand the phenomenon. The interview guide was validated by being properly scrutinized by three selected church leaders in the church strategic plan department, who were experts in research in the church and ensured it could answer the study's objectives.

The data collected was analyzed using phenomenological procedures suggested by Creswell (2013). The analysis phases used were memoing, coding, classifying and interpretation. Ethical considerations, rules, and regulations were observed, ensuring that no one was harmed or suffered adverse consequences from the research activities.

Research Findings and Discussions

The respondents were six young caregivers who were all PCEA Kikuyu Township Youth Church students.

Table 1; Demographics

Respondent	Gender	Age	Education level
Respondent 1	Female	18 years	KCSE
Respondent 2	Female	26 years	Masters student

Respondent 3	Male	22 years	Diploma student
Respondent 4	Female	19 years	Diploma student
Respondent 5	Male	21 years	Bachelors student
Respondent 6	Female	20 years	Bachelors student

The researcher went through the data collected by having a repetition reading of the data as it was recorded from the six respondents. It was coded using different colors, wordings, and phrases that were similar to all the respondents were colored in the same color.

The researcher came out with the following themes:

Themes

Spiritual Care

They all expressed how they lacked prayers, fellowship, holy communion and pastoral visits. They missed having time to go to church and felt like the pastors, and members of the church were also tired of visiting them and even offering any spiritual support because they were just the youth. Respondent 1 said, “You know the church elders do not take us seriously on issues of spirituality. They say young people are jokers.” They expressed the need to be taken care of spiritually because they were challenged as young people to play the role of caregiving. Respondent 5 said that their pastors visit a lot of those elderly caregivers, but for the youth caregivers, the church says it is just giving back to their parents; hence it was their obligation to take care of their family members who had a disability due to different illnesses, and there was not much encouragement needed to be offered to these young caregivers. Respondent 5 felt that the reason the church pastoral team was not visiting them at home is that the PCEA church

believes that the youth do not have any monetary value in the church since they do not have enough finances as young people. This is according to Respondent 4, who said,

As the youth, we do not have much finances to give to the church; hence pastors do not recognise us as needing their pastoral care compared to the elderly caregivers who, when they are not well nourished spiritually, may fail to give finances to the church and the church requires every single coin from the members to run. Hence, the pastors focus on those who can provide more, not the youth.

All the respondents felt that it is time the church considers these caregivers' challenges and offers the pastoral care they need.

Financial Support

The respondents expressed a lack of finances as a common challenge for all caregivers because finances are required to run the day-to-day activities of the patient and the caregiver. Young people want to have money to communicate with their peers. This could be through the internet, hence the need for good internet that requires money. The young people want to dress, eat, and have a good lifestyle like their peers but lack resources because all the concentration of the family is on the patient. Respondent 6 expressed how her savings from her university pocket money had been finished. She could no longer enjoy having some of the essentials she needed, like airtime and good internet. "I now borrow internet from my neighbor. I can no longer afford to pay for internet, and I require it to remain in touch with my peers". All six respondents felt there was a need for the entire family to give monetary support to the youth who are caregivers.

Recreation

The youth caregivers expressed how tired and divested they were and had to spend all their time with the patient. They wished someone would come and relieve them, and they could

have a break and spend time with their peers. They expressed how much they felt locked in a cage where they could not get out. “My friends visited me and gave me stories and updates of their latest recreational times; I felt divested hearing how much I was missing” (Respondent 3). Respondents 2 and 3 said they had to spend a lot of time and airtime to get in touch with their peers. They felt that other family members should also be concerned and create time to relieve them so that they could take a break. The youth confessed how they had to lie to the patient to take a short break, and the patient had to suffer as they were left unattended. Hence they felt there was a need to have a family schedule of taking care of the patient and find ways where the youth caregiver can get a break and get time to meet their peers and also have time for recreation.

Knowledge and Skills

As caregivers, the youth feel they are still young and inexperienced. They had not previously seen some of the conditions they handle with their patients. Hence, four thought they did not know how to do their duties and had to keep asking the patient what they wanted and expected. Respondent 1, caring for her mother, who had a spinal injury and mobility problems, asked her mother one day, “Mum, which side should I hold you? Is it the right or the left where you have the disability?” As much as respondent one cared for her mother, who had a spinal injury, she did not have the skills and the knowledge to handle a patient with such kind of disability. Respondent 2 also narrated how she felt while undertaking many duties in her caregiving role. She felt lost and not knowing how to handle her patient in different situations. The other four respondents also expressed how they felt many times in the wilderness as they played their various caregiving roles by not knowing what was expected of them. They

expressed the need to visit other youth who are caregivers to exchange ideas and gain new skills and training as caregivers.

Shattered Dreams and Goals

Young people are usually very ambitious, with many goals and dreams they want to meet at a given time. The six respondents felt they might need more time to meet their goals and objectives in the time frame they had thought. They felt their dreams were shattered, disoriented and left behind by their peers. Respondent 5 narrated how he was called when he had just completed his second year at the university. The family decided that he was the most suitable person to take care of his uncle, who had been bedridden since he was on internship. The family felt that the internship was unimportant but concluded that he could stop that for the sake of his ailing uncle. “The plans and the big dreams of learning more from my internship were shattered when I had to stop my internship in a radio station to go and take care of my uncle.” All six respondents felt that the family members should consider relieving the young youth as caregivers and involving elderly members of the family as caregivers for the older family members have not many dreams like the young people hence the need to relieve the young caregivers and the families to involve older family members.

Conclusion

The research was carried out successfully, and the purpose of the study was achieved by addressing the objectives of the study and being able to answer the two research questions in the study. The research method used, which was qualitative with a phenomenology approach, was adequate for the study. The youth caregivers need to be appreciated, and also they need to appreciate the work they are doing. This could happen if the church identifies with these young

people who deny a lot in their youthful lives and sacrifice to take care of their family members who have disabilities due to different illnesses.

Recommendations

In this research, it was noted that the youth as caregivers face common challenges and that there are ways of overcoming them. The church should find ways of supporting these youth by organizing seminars related to caregiving of the sick and any other training that may be helpful to them. This can be done by creating a special group in the church that addresses the needs of the youth caregivers, which the youth pastor should lead. The church should identify all the youth caregivers and create a schedule of how visits to these homes should be done. The church should also create a special fund to assist caregivers who confess that sometimes they are financially challenged. This could be seen as a way of ministering to these young youth caregivers holistically. The intercessors should be able to identify all the youth caregivers and their patients and create time to pray with them and for them.

The family members who have a patient and have engaged the youth as a caregiver should understand what they have engaged as caregivers are going through and see where they can intervene, especially in financial and relief support. The caregivers, as we have seen, require training to empower them on the skills and knowledge of offering care to their different patients; hence the church, the community, in collaboration with other organizations, should organize to see that training on caregiving takes place regularly and that every necessary support and encouragement is given to these young caregivers not only by the church but also by the community as a whole.

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