

WHO FORGOT WHO? A TWIST IN ELDORET HOSPICE CAREGIVERS

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Abstract: In Kenya there have been many challenges creating many social, economic, political and psychological problems. Many efforts have been done and even institutions created to address them. However, those involved in the caregiving in those institutions seem to be a forgotten lot. The main question is who forgot caregivers? Caregiving is a rewarding process but demanding on the side of the caregiver. Much have been done on the clients but caregivers have been a forgotten lot in that the public as well as caregivers themselves put little effort, if any, on psycho-social attributes of caregivers. The public think that caregivers are well equipped with head knowledge on care and therefore need no care from outside at all. The study was done in Eldoret Hospice in Eldoret town between November 2014 and April 2015 using a case study research design and qualitative approach. The sample size was 6 caregivers identified with purposive sampling method. Psychological assessment, In-depth interviews, Focused group discussion and Life histories were used as the study methods facilitated by Psychological assessment tools, in-depth interview guide, Focused group discussion guide and interview guide respectively as the instruments. Trustworthiness was ensured through Methodological Triangulation, Peer consultation and Consultation with supervisors. Data collection was done on 24 sessions where Saturation method marked the end of the process. Data was analyzed through recursive abstraction technique where descriptions, narrations, quotes and citations were used. The findings revealed that Lack of adequate information was one of the major concerns of caregivers especially on palliative care, basic counselling skills and handling depression when in the field resulting to frustrations and anxiety. Striking a balance between caregiver's needs and that of client also seemed a challenge.

Keywords: Eldoret Hospice caregiver's, social, economic, psychological problems.

1. INTRODUCTION

From a practical point of view, there have been incidences where the caregivers have gone through more vicarious traumatization, compassion fatigue, caregiver syndrome and burn out experiences that need more attention than even their clients. These have caused health issues and social problems like phobias, hypertension, depression, broken families, addictions, psychopaths, etc.

Theoretically, many studies conducted on caregivers' psychosocial attributes have been carried out outside Kenya, western world, and a few done in Africa. For example, Juan, et.al (2014) study on 'Needs and Psychosocial Outcomes of Caregivers of Individuals with Multiple Sclerosis in Guadalajara, Mexico' was conducted in Mexico. Again many studies are carried out on family and primary caregivers and a few on caregivers across institutions. For example, Laurel Northouse, et.al (2012) conducted a study on 'Psychosocial Care for Family Caregivers of Patients With Cancer' where the focus was on the family caregivers. So, the study thus, was conducted in order to create awareness on the psychosocial attributes of the caregivers.

A twist emerged in the findings as far as who forgot caregivers in their line of duty. Do you think caregivers are a forgotten lot? Caregivers lamented that they were forgotten, but by who? Since caregiving is challenging call though rewarding, how do caregivers cope with psychosocial attributes, needs and challenges, they face? This paper elaborates these questions.

2. METHODS

The study used a case study research design and qualitative approach. A case study helped in description of a situation, gaining insights to a particular practice and thereby carrying out a detailed study. Qualitative approach refers to development of concepts which enables us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences and views of the participants (Pope and Mays 1995).

Conceptual framework was used in expounding concepts for more clarity. Psychosocial attributes was the independent variable whereas caregiver well-being dependent variable. Psychosocial attributes according to the study refers to psychological needs and challenges which cuts across information need, social and psychological well-being. This was further broken to ignorance, confusion, and uncertainty as issues that emerge when information needs is not met on caregivers. Debriefing and meaning of life were seen as issues that contribute to psychological well-being whereas loneliness and social support affected social well-being of caregivers.

The sample size was 6 caregivers identified with purposive sampling method. The researcher used a sample size of six respondents to collect data which was determined by saturation method whereby it is a stage where additional interview or observation is not believed to add new information- enough is enough. This was guided by Morse (1994) and Creswell (1998) who suggested that from all of the phenomenological studies identified had at least six participants and while just over two thirds identified (68%) fell within range of five to 25 respectively. Data collection was done on 24 sessions where Saturation method marked the end of the process. Data was analyzed through recursive abstraction technique where descriptions, narrations, quotes and citations were used.

Psychological assessment, In-depth interviews, Focused group discussion and Life histories were used as the study methods facilitated by Psychological assessment tools, in-depth interview guide, Focused group discussion guide and interview guide respectively as the instruments. Trustworthiness was ensured through Methodological Triangulation, Peer consultation and Consultation with supervisors.

3. PROCEDURES

The study was conducted between November 2014 and April 2015. Qualitative data collection methods entailed methods that were brief enough to capture explanation observations needed by the researcher. The researcher got close enough to study subjects to observe (with/without participation) usually to understand whether people do what they say they do, and to access tacit knowledge of subjects Interview. This involved asking questions, listening to and recording answers from an individual or group on a structured, semi-structured or unstructured format in an in-depth manner Focus Group Focused (guided by a set of questions) and interactive discussion session with a group small enough for everyone to have chance to talk and large enough to provide diversity of opinions.

The researcher held 24 sessions with the caregivers which were done as follows. Three (3) sessions were held on each of four (4) caregivers where administration of assessment tool, in-depth interview and counselling sessions were carried out. Two (2) focused group discussions were done on the four (4) caregivers. Two (2) sessions with the two (2) key informants. The data collection stopped when the saturation or redundancy happened.

4. RESULTS

The findings revealed that Lack of adequate information was one of the major concerns of caregivers especially on palliative care, basic counselling skills and handling depression when in the field resulting to frustrations and anxiety as one caregiver lamented, "...i faced this challenge whereby I had said all that I knew of saying and the client was at the advanced level of severe pain and the morphil, painkiller drug, couldn't help to ease the pain any longer...I felt inadequate since I didn't know what to do when observing the agony of the client...."

On psychological well-being, six (6) caregivers experienced compassion fatigue and caregiver syndrome in their course of work as they help clients cope with cancer as a chronic illness whereas five (5) reported to experience burnout in their course of duty. Some said, "...i get directly affected that I start feeling for the client...." "...sometimes I feel like quitting my job because I really get tired...." "...i get angry with emotional clients who may not want to listen to you and don't take their health seriously as they don't plan...no insurance cover...come for late screening when the condition has deteriorated....this make me mad..."

Striking a balance between caregiver's needs and that of client also seemed a challenge as shown by the table below:

Table 1: caregivers' and clients' needs balance

	Caregiver's needs	scores
Client's needs	Caregiver A	2.7
Client's needs	Caregiver B	5.7
Client's needs	Caregiver C	4.8
Client's needs	Caregiver D	6.4
Client's needs	Caregiver E	5.0
Client's needs	Caregiver F	6.6

From the scores one showed under care for the client(s) and five maintained a balance of moderate care to caregiver's own needs/ moderate care to the client's needs.

This was derived by the use of Caregiver's self-rating scale by Judy Bradley, 1993 whereby, a caregiver rated himself/herself the Scale of Caregiving to determine how he/she value the client as compared to himself/ herself. The low numbers (1, 2, and 3) give little or no value (honor) to the needs of the client. The high numbers (8, 9, and 10) give little or no value to your own needs as an individual and as a caregiver. The numbers in the middle (4, 5, 6, and 7) are where you find a balance between undercare and overcare. Neither of the two extremes is healthy; they represent positions where the caregiver is not helping the client.

Coping strategies:

Caregivers' reports on how they coped with psychosocial attributes were unique with individuals and they cut across differentiation of self, spirituality as well as intrinsic motivation ones they get a motivated client who has the will to continue living despite the situation at hand. This was well explained by some caregivers when responded, ".....i found this client who told me, 'next time call me that I speak to those who are suffering like me and have given up in life and I will tell them....umekufa mara nyingi, anza kuishi, (u have been dying many times, start living now)....."

Bowen, 1990, defines *Differentiation of self* as one's ability to separate one's own intellectual and emotional functioning from that of family. He spoke of people functioning on a single continuum or scale. Individuals with "low differentiation" are more likely to become fused with predominant family emotions. The caregivers who were able to differentiate themselves from the clients scored moderate in Caregiver's self-rating scale and this was marked by some of the statements like: ".....I cope by being myself first then the clients to follow..."

Spirituality was seen to have helped the caregivers in dealing with cancer by helping the caregivers derive meaning of life out of a hopeless situations that they found their clients being exposed to which affected them directly or indirectly. It also helped in providing an existential perspective on hope and suffering as well elaborated in logo therapy. Some even spend time to pray for their clients and their lives as well and this gives them strength to move on. Hope in the midst of suffering was seen to be instilled by posing existential questions about the meaning of life and this was some of questions posed by the researcher and the responses of the caregivers:

Caregiver: "... I told God to allow me serve other people wholeheartedly but never to allow any person of my family go through this horror. So I hope I care for these clients and never to care for any of my family member....."

5. DISCUSSION

Lack of information really caught researcher's attention. Where should caregiver get information from? Who should do it? What information did they really need? The findings showed that palliative care, basic counselling skills and handling depression emerged as a major concern. A twist came from findings that caregivers themselves knew that 'they need care' but fail to substantiate this concept. This care is primarily upon them to take the initiate to 'look for care' and not wait for the 'care to come.'

Ironically this care is just within the caregiver as a person and need to examine himself /herself. The researcher found that caregivers were well equipped with the care they need as the coping strategies shown. Personality affected the coping process. Personality is the uniqueness of a person.

Again, when the caregivers find themselves in challenges like caregiver syndrome, burnout and compassion fatigue, it upon them to 'look for care' in areas like debriefing sessions, education programs, team building activities, regular meeting and group counselling as they recommended in the study and not sit back and wait for 'care to come.' However, the study tends to create awareness to the institutions and the public to establish these programs of caring for psychosocial attributes of caregivers. So the care is both within and without the caregivers.

6. CONCLUSION

In conclusion, it is the caregivers themselves who forgot themselves. It is upon them to gain self- awareness that are able to know what they need and when as well as how to access the care. Self- awareness is the ability to recognize and understand your moods, emotions, strengths, weaknesses, needs and drives, as well as their effects on others (Daniel Goleman, 1998). This brings about self-confidence, realistic self-assessment and a sense of humor that are very critical in coping with life situations.

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