



KABARAK UNIVERSITY

**4TH ANNUAL INTERNATIONAL RESEARCH
CONFERENCE**

GENERAL THEME

**ADDRESSING THE CHALLENGES FACING HUMANITY
THROUGH RESEARCH AND INNOVATION**

SYMPOSIUM

**PALLIATIVE CARE FOR TERMINAL AND CHRONIC
DISEASES (LIFE THREATENING ILLNESSES)**



TOPIC

**REPORT ON PSYCHOSOCIAL EFFECTS OF
PALLIATIVE CARE-GIVING ON PRIMARY CARE-
GIVERS OF ELDERLY PEOPLE WITH ADVANCED
CANCERS IN MANYATTA CONSTITUENCY, EMBU
COUNTY, KENYA**

BY

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GENERAL AIM OF THE STUDY

- To investigate the Psychosocial Effects of Palliative Care-giving on Primary Palliative Caregivers (PPCs) of Elderly people with advanced Cancers in Manyatta Constituency, Embu County, Kenya.
- PPC in this study referred to a relative or a close friend identified by an elderly person with advanced cancer to continuously provide him/her with physical, emotional and psychosocial assistant at home (Armstrong, 2004).

BACKGROUND TO THE STUDY

- Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening illness (WHO, 2006).
- Cancer is the third leading cause of death globally as 21,100 people die of cancer every year (WCO, 2011).
- Cancer is chronic disease with long-term treatment often implemented at home due to economic and policy changes in health care (Given et al., 2001) but places multiple demands on PPCs.
- Advanced Cancer refers to disease trajectory stage estimated to have 3 to 6 months survival prognosis (Stebbing, 2006).

STATEMENT OF THE PROBLEM

- PPCs dealt with many unfamiliar situations and unexpected demands as cancer patients at advanced stage had multifaceted need such as psychological social and physical. This was physically and emotionally challenging to PPCs who had no specialized training for this role (Payne et al., 1999).
- Roles included symptoms management, wound dressings, toileting, bathing, laundry, feeding, emotional support among others (Given et al., 2001).
- The study was therefore done to establish psychosocial effects of palliative care-giving on PPCs of elderly people with advanced cancers,

RESEARCH OBJECTIVES

- To establish the relationship between PPCs and elderly people with advanced cancers.
- To find out the roles played by PPCs of elderly people with advanced cancers.
- To establish psychosocial needs of PPCs of elderly people with advanced cancer.
- To find out psychosocial effects of palliative care-giving on PPCs of elderly people with advanced cancer.

RESEARCH QUESTIONS

- What is the relationship between PPCs and elderly people with advanced cancers?
- Which roles are performed by PPCs to elderly people with advanced cancers?
- Which psychosocial needs do PPCs of elderly people with advanced cancers have?
- What psychosocial effects of palliative care-giving do PPCs of elderly people with advanced cancers experience?

THEORETICAL FRAMEWORK

The study was informed by two theories:

Social Role Theory (William James and others)

- SRT Informed the study on the effects of multiple role demands encountered by PPCs such as role conflict and role strain resulting in role related stress. This led to limited time, energy, and psychological resources.

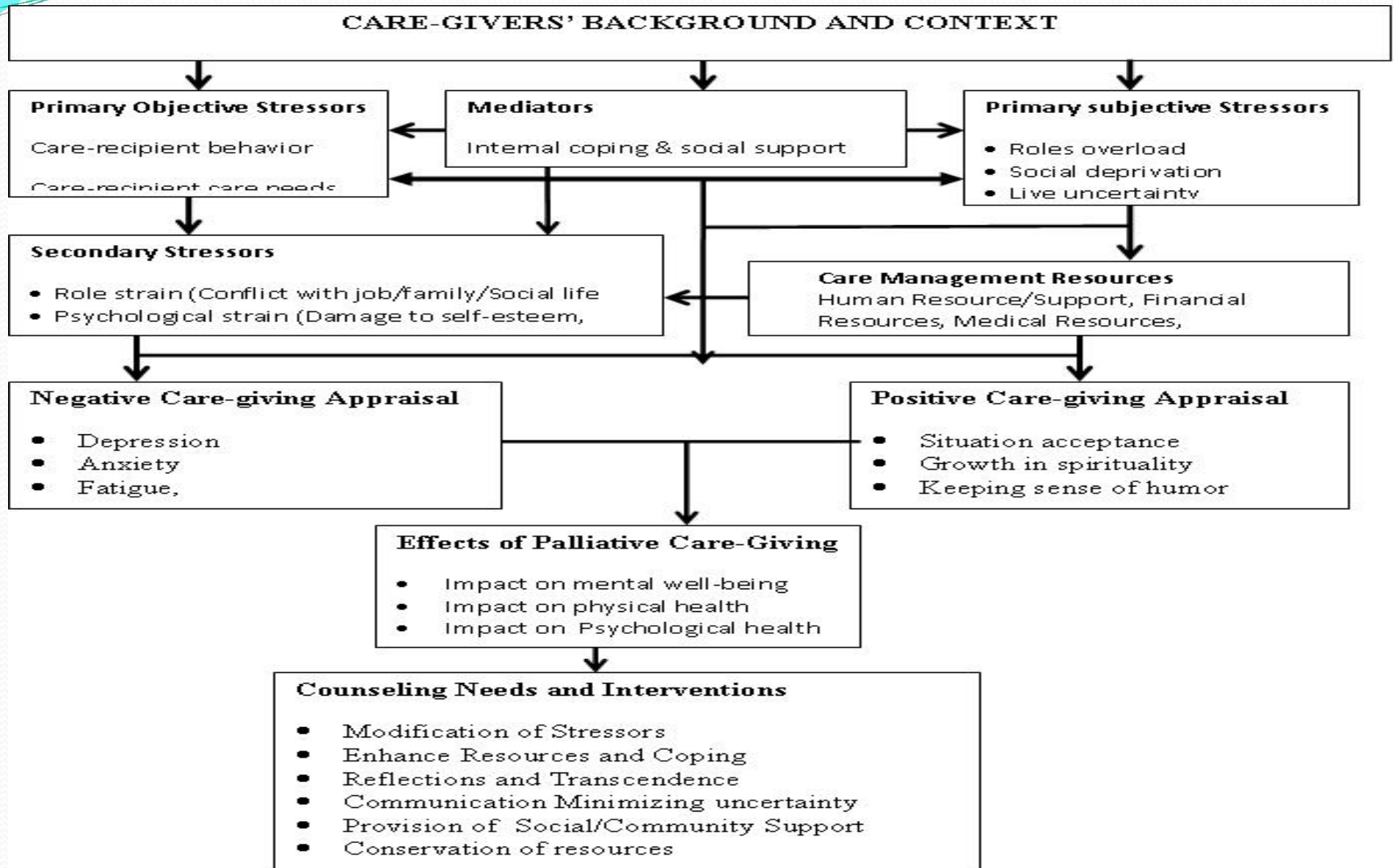
The transactional model of stress and coping (Folkman)

- TMSC informed the study on the palliative care-giving effects on PPCs based on cognitive appraisal of a situation as threatening and their efforts to cope.
- Chronic illness requires continuous reinterpretation of the perceived threat based on primary appraisals (events), secondary appraisals (coping resources) and reappraisals

LITERATURE REVIEWED

- Guberman et al., (1992) family relationship influence decision to provide care.
- Given et al., (2001) palliative roles are complex and include hygiene, symptoms management among others.
- Stajduhar & Davies, (1998), the Psychosocial Needs of Care-givers include emotional support, physical support, information, financial and social support.
- Stajduhar et al., (1998), Psychosocial effects of care-giving include distress, depression and anxiety caused by restrictions in social functioning, fatigue and diminished leisure opportunities

CONCEPTUAL FRAMEWORK



RESEARCH DESIGN, TARGET POPULATION, SAMPLING TECHNIQUES & SAMPLE SIZE

- Descriptive Survey design was used as it enabled the study to get subjective description of psychosocial effects of palliative care-giving as perceived by PPCs.
- Target population was 60 PPCs identified as key care-givers by elderly people with advanced cancers except minors (person below 18 years).
- Purposive Stratified random sampling was used to get a representative sample of 30 participants, 10 from each of the three administrative

RESEARCH INSTRUMENTS, DATA COLLECTION & PRESENTATIONS

- Questionnaires comprised of structured and unstructured questions for ease of completion and in-depth information respectively (Mugenda & Mugenda, 1999).
- A palliative nurse assisted in identification and administration of the instruments
- On-the spot filling and collection of questionnaires ensured 100% return.
- Questionnaires were collected, edited and coded as per score ranks. SPSS computer package was used to analyze data using descriptive statistics.
- Data was presented using modes, ranks, percentages figures and tables.

DATA MANAGEMENT AND ETHICAL ISSUES

- A permit to conduct the study was obtained from National Council of Science and Technology.
- Other stakeholders approached to give permit were District Commissioners in Embu West and Embu North, District Medical Officers of Health in Embu West and Embu North and Embu-Mbeere Hospice in order to comply with legal requirements and access to respondents
- Respondents were briefed before recruitment and those who were willing to participate, signed informed consent.
- Confidentiality and anonymity of respondents was observed.

SUMMARY OF STUDY FINDINGS

Demographic description of PPCs

Data analyzed revealed that majority of the respondents were female aged 42 and above. They had only primary education due to gender inequality in education that existed up to 1970s. Majority of respondents had offered palliative services for 1-2 years because of the nature of disease and its poor prognosis when it reached advanced stage

SUMMARY OF STUDY FINDINGS

PPCs Relationships with Cancer Patients

Majority of the palliative care-givers were spouses (46.7%) and daughters (33.33%) of the patients. Sons were only (6.7%). Majority were female in line with traditional gender role ideologies that women are “natural care-givers” and better placed to offer these services as per family expectations. These meant that PPCs were mainly wives or daughters of the patients.

SUMMARY OF STUDY FINDINGS

The Roles Played by PPCs

PPCs mostly provided domestic (73.33%) and personal care services to the patients (70%). This was because care-giving was linked to domestic chores which were an integral part of women identity hence they learnt them informally. They offered some medical services (40%) due to limitations of skills. Just a few were able to offer counseling and financial services i.e. (16.7%) each due to skills limitations and time limitations

SUMMARY OF STUDY FINDINGS

Psychosocial Needs of PPCs

- (70%) needed finances to help them manage the disease symptoms
- 53.33% needed time to talk to others about their care-giving concerns and socialize.
- 40% needed social support and a reliable helper to regularly relieve them.
- 73.33% required basic counseling and care-giving training in order to help them cope with roles demands.

SUMMARY OF STUDY FINDINGS

Psychosocial Effects of Palliative Care-giving

Psychosocial effects established by the study emanated from role strain and hopelessness of the disease. They were: loneliness 50%, scaredness 60%, hostility 76.66%, not proud to offer care 86.7%, worried 29.9%, not determined to offer care 80% fatigued 69%, hopelessness 43.3% , anxiety 43.3% while 53.3% were happy to offer palliative care services. These meant that effects were not entirely negative to all PPCs especially those who appraised the events positively and

CONCLUSIONS OF STUDY FINDINGS

- PPCSs were mainly females aged 42 years and above. They were female and had acquired basic primary education
- PPCs were mainly wives or daughters of the cancer patients.
- PPCs normally provided domestic and personal care roles to the patients and were mainly not able to offer counseling and financial assistants to the patients
- PPCs' psychosocial needs were financial, time restriction, social support, basic counseling and care-giving skills.
- PPCS' psychosocial effects emanating from role strain and disease hopelessness included anxiety, sacred, worried, fatigue, and hopelessness.

STUDY RECOMMENDATIONS

- More men should be encouraged to get involved in primary palliative care-giving to complement women especially where the daughters are taking care of their fathers.
- It is recommended that the care-giving roles be shared by a number of family members so as to relieve PPCs regularly
- It is recommended that the medical personnel train PPCs on basic counseling and care-giving skills to improve their competencies in palliative care-giving.
- It is recommended that medical personnel and other stakeholders should provide counselling therapies regularly to sustain PPCs psychological resources and their well-being.

FURTHER RESEARCH SUGGESTION

Based on the study carried out, it was clear that there was limited *research* in the field of palliative care giving. Owing to the sensitivity of the issue and ever increasing cases of cancers in Kenya, it is recommended that further research be carried out to establish PPCs financial needs and ways of helping them to meet costs of managing cancers' symptoms at advanced stage, without neglecting their own personal financial needs and those of their families.

END THANK YOU