

EFFECTIVENESS OF CARE GIVING SKILLS IN COMBATING SELF STIGMA AMONG FAMILY CAREGIVERS OF PERSONS WITH PSYCHOLOGICAL DISORDERS IN THARAKA NITHI COUNTY IN KENYA

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Abstract

Institutionalization was ruled out in favour of community based care for persons with psychological disorders. However, communities and families of persons with psychological disorders are not adequately prepared to co-exist with persons experiencing psychological impairment. Hence, family members have to shoulder the care giving role while providing services initially entrusted to mental health professionals. It is important to note that basic care giving responsibility involves more than just providing the necessities of life such as medication, shelter, food and clothing. It encompasses ensuring that the patient complies with treatment, enhancing the safety of the patient and others, informing the psychiatrist about the patient's progress while reporting any deviations from the norm, providing psychosocial support and contending with stigma allied to psychological disorders. Stigma of psychological disorders can be disabling and self stigma among family care givers not only affects the individual but also interferes with the care giving role. While care giving skills aid in supporting the ailing member, it is not clear whether the skills combat self stigma among care givers. Therefore, this study examined the effectiveness of care giving skills in combating self stigma among family caregivers of persons with psychological disorders in Tharaka Nithi County in Kenya. The study employed the Pre-test/Post-test Quasi Experimental research design. The target population was 1,966 respondents who comprised of family caregivers and counsellors in Tharaka Nithi County. Snowball and purposive sampling techniques were used to select a sample 322 participants. A family caregivers' self stigma scale and the counsellors' interview guide were used to collect the desired data. The independent t-test statistic was employed for data analysis. The findings indicated that care giving skills were effective in combating self stigma among the family caregivers. The study recommended that mental health providers can consider enhancing care giving skills among family caregivers.

Key words: Care giving skills, Family caregivers, Psychological disorders, Self stigma.

1. Introduction

Introduction of home based care for psychological disorders has compelled most patients to live with and totally dependent on their families who must take up the intricate role as mental health service providers (Shah, Wadoo & Latoo, 2010). However, majority of the family caregivers are not equipped with the necessary knowledge, skills and resource support to competently perform this vital task (Chan, 2011). Therefore, a lot of time, energy and family resources are wasted while trying to vainly reason with the patient, seek incompetent moral support and meet the patient's delusional demands. The family caregivers become physically, emotionally and economically overwhelmed by the care giving responsibility such that psychosomatic ailments ensue (Srivastava, 2005). This points to the significance of supporting family caregivers in their care giving role by disseminating necessary care giving knowledge and skills.

Home based management for psychological disorders entail both direct and indirect costs. Examples of these costs are financial implications, work disruptions due to a crisis and constant worrying about the patient's well-being especially over the risk of harm or suicide (Chan, 2011). Frequent hospitalization of persons with psychological disorders may elicit resentment among family members because of financial drain resulting from the high costs involved. This may explain why some persons with psychological disorders are either left to roam the streets or are disowned at psychiatric hospitals by their family members (Ndetei *et al.*, 2009). However, ignoring the plight of an ailing family member may have both emotional and psychological toll on family caregivers who are likely to struggle with emanating feelings of guilt, fear, sadness, loss, anxiety and depression. Therefore, insight into the care giving responsibility is critical for family caregivers as they take up more of the roles initially played by the mental health service providers.

The experience of psychosis as described by Gur and Johnson (2006) is like living in an uncontrollable nightmare or persistently being under the influence of hallucinogenic drugs. Mostly persons with psychological disorders perceive everyone else as crazy except themselves. This is because they may see objects and people as having exaggerated features, hear voices that critically comment on their behaviour and issue commands or even think that family, friends and neighbours are out to harm them (Feldman, 2008). This may explain why during psychotic episodes persons with psychological disorders run away from home, talk to themselves or seem fearful and withdraw socially. This knowledge can inform family caregivers in the care giving role so as to understand the plight of the ailing member instead of being critical, judgmental and superstitious about the emanating abnormal behaviour.

Majority of adult family members especially siblings tend to avoid sharing in the care giving responsibility (Torrey, 2006). This avoidance is commonly attributed to factors such as insufficient funds; wanting to move on with one's own life; strained relationship with the ailing member; and a feeling that the patient should learn to be independent. In addition, long standing resentment arising from the patient's demands having taken up most of the family resources at the expense of unmet needs of other family members may also justify the avoidance (StSberg, Ekerwald & Hultman, 2004). Hence, a clear understanding of possible reasons behind avoidance by some family members may help ease the emotional distress occasioned by single handedly accepting the care giving responsibility among family caregivers. This insight may also assist the sole family care giver to focus more on the care giving responsibility instead of feeling left out and dejected.

In contrast to avoidance, those family members who accept the care giving responsibility may do so because it is a parental role; there is no one else interested in caring for the ailing member; a compassionate bond with the ailing member; fear of God; or just out of sympathy or empathy towards the suffering family member (Dean, 2009). These family caregivers experience feelings of anger, frustration, helplessness, loneliness and depressive thoughts mainly induced by the unpredictability of the ailing member's psychotic behavior (Torrey, 2006). Seeking the support of psychiatrists, therapists and community facilities may help to alleviate the care giving burden among the family caregivers (Ndetei *et al.*, 2009) Therefore, family members who naturally take up the care giving role may find psycho-education interventions necessary in coping with challenges allied to this intricate but noble task.

The care giving role may be faced with diverse challenges such as financial difficulties; having to frequently ask for time off work to attend to multiple crisis; long distances to mental health facilities; many hours and sleepless nights spent on monitoring the ailing member's movements;

and having to remain calm even when constantly provoked by the ailing member's irrational behaviour and accusations (StSberg *et al.*, 2004). To cope with these challenges and meet the ailing member's demands, family caregivers may be compelled to seek extra income, reduce social contacts or compromise personal needs, dreams, goals and life satisfaction (Dean, 2009). Therefore, more informed and creative family caregivers may efficiently balance work, family and the care giving responsibility.

Living with and caring for a person with a psychological disorder may not only generate emotional and psychological distress but also make it almost impossible for family members to sustain an ideal quality of life (Awadalla, Ohaeri, Saliah & Tawfiq, 2005). Disruptions in families' daily routines, social interactions, work commitments, life goals and financial aspirations are inevitable. This may be attributed to the care giving responsibility, patient's health demands, misconceptions, grief associated with losing a loved one to a psychological disorder and social stigma linked to the disorder (Gur & Johnson, 2006). Most often family members accuse the ill relative of being lazy, lacking in will power or pretence (Nirmala, Vranda, & Reddy, 2011). Others blame the disorder on witchcraft, curses or punishment for sin. This assignment of blame may lead to seeking religious or cultural remedies which may temporarily relieve the family members' stress levels but not improve the situation (Ombati, 2013). It is therefore crucial for family caregivers to adopt positive and effective care giving skills in order to facilitate family functioning, enhance personal growth and improve the quality of life for all family members.

Most burdened are spouses who must take over the unexpected additional family roles initially played by the ailing spouse in addition to distress occasioned by the lost marital bliss and closeness (Stanley & Shwetha, 2006). Male spouses are reported to adapt negative distractive coping such as alcoholism while female spouses resort to emotional or religious coping and sometimes a divorce may be inevitable (Jungbauer, Wittmund, Dietrich & Angermeyer, 2004). Children and siblings of persons with psychological disorders are not spared the confusion which is mainly confirmed by declining grades at school, loss of friends due to stigma and a feeling of having grown up too fast (StSberg *et al.*, 2004). Parents of persons with psychological disorders generally feel obliged to care for their ill child with aging parents often worrying about what their death or incapacitation may mean to the ill child (Dean, 2009). A study by (St-halaise, Hill & Docherty, 2007) suggests psycho-education on future planning and strategies for reducing stress as beneficial for such parents, siblings and spouses.

2. Objectives of the Study

The main objective of this work was to examine whether there is significant difference in the effectiveness of care giving skills in combating self-stigma between family caregivers of persons with psychological disorders exposed to the skills and those who were not in Tharaka Nithi County in Kenya.

3. Hypotheses of the Study

This study sought to test the following hypothesis:

H₀₁: There is no statistically significant difference in the effectiveness of care giving skills in combating self-stigma between family caregivers of persons with psychological disorders exposed to the skills and those who were not in Tharaka Nithi County in Kenya.

4. Methodology

The study employed the Pretest/Posttest Quasi Experimental design. The population of the study

was 1,966 respondents. Purposive and snowball sampling techniques were used in selecting 322 study participants comprising of 157 family caregivers for the experimental group, 157 family caregivers for the control group and eight counsellors. The criteria for inclusion of family caregivers was attainment of the age of majority, an encounter with a psychiatric doctor, living with and caring for a family member ailing from a diagnosed psychological disorder as well as a written consent to participate in the study. A self stigma scale was used to determine the levels of self stigma against psychological disorders among family caregivers before and after the caregiving skills training. The counsellors were interviewed to triangulate data obtained from the family caregivers. Data collected was cleaned then coded and entered into the computer for analysis using SPSS version 21.0. The independent t-test statistic was employed for analysis of quantitative data. The qualitative data from interviews were analyzed thematically. To fulfill the legal and ethical requirements for undertaking the research, a research permit was obtained from the National Commission of Science Technology and Innovation after ethical clearance from Chuka University Research and Ethics Committee. The participants completed a written voluntary and informed consent to participate in the study. Freedom to exit from the study at any point without any penalty was accorded to participants. Confidentiality was promised and maintained throughout the study. The participants were also informed about the beneficence and true purpose of the study.

5. Results and Discussion

The following were the findings of the study and the discussion of the findings.

5.1 Care Giving Skills and Self-stigma against Psychological Disorders

The last objective was to examine whether there was significant difference in the effectiveness of care giving skills in combating self-stigma between family caregivers of persons with psychological disorders exposed to the skills and those who were not in Tharaka Nithi County in Kenya. The self-stigma of family caregivers was measured before and after provision of care giving skills sessions. An independent samples t-test was employed to analyze the mean differences between the pre-test and post-test assessment results obtained from the experimental as well as control groups involved in the study. The mean scores obtained from the self-stigma scale were graded as 1-1.5 Low self-stigma, 1.6-3.5 Moderate self-stigma and 3.6-5 High self-stigma.

5.2 Experimental/Control Groups Pre-test Independent Samples t-test

The independent samples t-test data analysis results between the experimental and the control groups for the care giving skills pre-test scores are represented in Table 1. The data analysis was meant for determining the equivalence in self-stigma between the experimental and control groups before provision of care giving skills.

Table 11

Experimental/Control Group Pre-test Independent Samples t-test Statistics

	Groups	N	Means	Std. Deviation	t	df	Sig
Care Giving Skills	Experimental Group	157	4.4570	0.23713	-0.816	313	0.401
	Control Group	157	4.4793	0.27874			

Information in Table 1 highlights a variation between the pre-test means with 4.4570 as the mean for the experimental group and 4.4793 for the control group. The data analysis results generated a t statistic value of -0.816 and a P-value of 0.401. Since the P-value is greater than the set Alpha value

of 0.05, then it suffices that the pre-test mean difference between the experimental and the control groups was statistically insignificant. In view of these findings, there was no statistically significant difference between the self-stigma of the experimental and control groups at the onset of the study.

It can be inferred from the data analysis results that family caregivers experienced high levels of self-stigma indicated by high means scores on the care giving skills test items on the self-stigma scale. This finding relate to the outcome of a research by Worku and Shiferaw (2014) who documented that the general public do stereotype, prejudice and discriminate persons with psychological disorders. When family caregivers of persons with psychological disorders internalize the stereotyping, prejudices and discrimination, experiences of negative emotions and social alienation ensue leading to self-stigma. The effectiveness of care giving skills in combating self-stigma among family caregivers of persons with psychological disorders was done by examining whether there was a significant mean difference between the pre-test and post-test scores. An independent samples t-test was conducted to test the mean differences between the two tests.

5.3 Experimental Group Pre-test/Post-test Independent Samples t-test

An independent samples t-test was run to determine the mean difference between pre-test and post-test scores for the experimental groups' care giving skills. Information in Table 2 represents the independent samples t-test statistics data analysis results.

Table 2

Experimental Group Pre-test/Post-test Independent Samples t-test Statistics

		N	Means	Std. Deviation	t	df	Sig
Experimental Group	Pre-test	157	4.4570	0.23713	-3.565	313	<0.001
	Post-test	157	1.6465	0.27885			

The data analysis results in Table 2 indicate a difference in the pre-test and post-test scores that the pre-test means (4.4570) were greater than the post-test means (1.6465) for the experimental group. Since greater mean scores were associated with high self-stigma, the reduction in the post-test means scores signifies that family caregivers experienced less self-stigma after acquisition of care giving skills. As indicated in Table 2, the t-test statistic value is -3.565 and the P-value is less than the set Alpha value of 0.05. This means that the mean difference between the pre-test and post-test scores for the experimental group was statistically significant. The implication is that care giving skills were effective in combating self-stigma among family caregivers of persons with psychological disorders.

5.3 Control Group Pre-test/Post-test Independent Samples t-test

To determine whether there were differences in the means of control group's pre-test and post-test scores, independent samples t-test statistics were computed. Information in Table 3 displays data analysis results.

Table 3

Control Group Pre-test/Post-test Independent Samples t-test Statistics

	Tests	N	Means	Std.		t	df	Sig
				Deviation				
Control Group	Pre-test	157	4.4793	0.27874		-0.429	313	0.632
	Post-test	157	4.5191	0.22917				

As indicated in Table 3, there is a difference between the pre-test mean (4.4793) and post-test mean (4.5191) for the control group. The data analysis results generated a t statistic value of -0.429 and a P-value of 0.632. Given that the P-value is greater than the set Alpha value of 0.05, it implies that the mean difference between the pre-test and post-test scores for the control group was statistically insignificant. This means that the control group experienced similar levels of self-stigma during the administration of both the pre-test and the post-test. Therefore the time lapse between the two tests did not have a significant effect on the self-stigma of the family caregivers.

5.4 Experimental/Control Groups Post-test Independent Samples t-test

Information in Table 4 represents care giving skills post-test independent samples t-test statistic results between the experimental and the control groups. The independent samples t-test was run in order to determine whether the mean difference in the post-test scores between the experimental and the control groups was significant.

Table 4

Experimental/Control Group Post-test Independent Samples t-test Statistics

	Groups	N	Means	Std.		t	df	Sig
				Deviation				
Care Giving Skills	Experimental Group	157	1.6465	0.27885		-3.346	313	<0.001
	Control Group	157	4.5191	0.22917				

Based on the information in Table 4, the care giving skills post-test mean score for the experimental group was 1.6465 and that of the control group was 4.5191. This is evidence that the experimental group experienced less self-stigma than the control group after provision of care giving skills. The t statistic value is -3.346 and the P-value is <0.001. Since the P-value was less than the set Alpha value of 0.05, then the mean difference was statistically significant. This means that care giving skills were effective in combating self-stigma against psychological disorders among the family caregivers of persons with psychological disorders. It can be inferred that the care giving role has challenges that the family caregivers were not well equipped to handle due to deficits in care giving skills. This observation aligns with the findings of Shah, Wadoo and Latoo (2010) who documented that family caregivers faced distress in the care giving role owing to incompetence, limited resource endowment and insufficient support.

Challenges in the care giving role are diverse including financial difficulties, time off work to attend to multiple crisis, long distances to mental health facilities, many hours and sleepless nights spent on monitoring the ailing member's movements and provocative accusations and irrational behaviour of the ailing relative (StSberg *et al.*, 2004). These challenges may make it difficult for the family caregivers to balance work, family, personal goals and the care giving responsibility. According to Dean (2009) family caregivers of persons with psychological disorders try to cope by seeking

opportunities for extra income, reduce social contacts or compromise personal needs, dreams, goals and life satisfaction. For example, spouses may have to take over the unexpected additional family roles initially played by the ailing partner in addition to distress occasioned by the lost marital bliss and closeness (Stanley & Shwetha, 2006).

Care giving skills are essential in moderating the distress experienced by family caregivers of persons with psychological disorders. Male spouses are reported to adapt negative distractive coping such as alcoholism while female spouses resort to emotional or religious coping and sometimes a divorce may be inevitable (Jungbauer, Wittmund, Dietrich & Angermeyer, 2004). Dysfunction among children and siblings of persons with psychological disorders is mainly indicated by declining grades at school, loss of friends due to stigma and a feeling of having grown up too fast (StSberg *et al.*, 2004). A study by St-halaire, Hill and Docherty (2007) suggested psycho-education on future planning and strategies for reducing stress as beneficial for such spouses, children and siblings.

Family caregivers' ability to share the care giving roles was effective in combating negative emotions and social alienation. This is in support of the view that seeking the support of psychiatrists, therapists and community facilities helped to alleviate the care giving burden among the family caregivers (Ndetei *et al.*, 2009). This means that family members who naturally took up the care giving role find care giving skills necessary in coping with challenges allied to this intricate but noble task of supporting the ailing family member. Torrey (2006) purports that many adult family members especially siblings tend to avoid sharing in the care giving role. Some of the reasons put forward for avoiding the care giving responsibility were insufficient funds, wanting to move on with one's own life, strained relationship with the ailing member and a feeling that the patient should learn to be independent. This may be the reason why most family caregivers were reluctant in seeking support in the care giving role.

Insufficient support in the care giving role may enhance feeling of social isolation and dejection among family caregivers of persons with psychological disorders. This is especially so where there are inconveniences in one's normal daily work routine due to multiple crises and when the care giving costs escalate. This situation can be exacerbated by limited skills in managing hospital bills and other care giving expenses. These results are in line with what (Dean 2009) explains about the coping behaviour of family caregivers trying to meet the ailing member's demands, being compelled to seek extra income, reduce social contacts or compromise personal needs, dreams, goals and life satisfaction.

5.5 Counsellors' Views on Care Giving Skills and Self-stigma

Counsellors were interviewed in order to obtain more information regarding the effectiveness of care giving skills in combating self-stigma against psychological disorders among family caregivers. Responses from the counselors are presented in the following Excerpt.

Excerpt

Researcher: How effective are care giving skills in combating negative emotions and social alienation among family caregivers of persons with psychological disorders?

Probes:

- i. Crisis management skills
- ii. Skills of sharing the care giving role with other family members
- iii. Ability to empower the ailing family member to contribute positively to the society
- iv. Skills for managing hospital bills and other care giving expenses

Counsellor B: Caring for a person with psychological disorder is a role that is spontaneous and hardly ever anticipated. Therefore most family caregivers are not trained on how to handle a loved one with a psychological disorder. Family caregivers blame themselves for having not sought psychiatric intervention on realizing the early signs of psychosis. Others feel they are to blame for having caused the condition of the ailing relative through ignorance. This is especially the case when the condition is believed to be genetic in nature or having being caused by stressful life events. The family caregivers wonder what they did wrong. Such negative emotions and feelings of loneliness can be avoided by providing care giving skills to the family caregivers. This is because being able to effectively support the ailing relative can be reassuring for the family caregivers.

Counsellor E: Having to spend much money on medication and hospitalization for an ailment that is chronic can be frustrating for family caregivers. Some family caregivers feel guilty because they do not have enough money to provide the best psychiatric attention for their ill relative. This means the patients may stop taking medication for a while leading to relapse and therefore more feelings of guilt and shame on the part of the family caregiver. Some family caregivers avoid social places like the market place where their loved one roams when ill because of embarrassment. In such a case skills for managing hospital bills and other care giving expenses can contain the negative emotions and social alienation among the family caregivers.

Counsellor F: Crisis management skills can effectively combat negative emotions among family caregivers. This is because mental health crisis bring much embarrassment and emotional pain to family caregivers who have to ensure forced emergency psychiatric care or hospital admission for the ailing relative. This can be a big challenge based on the resistant and offending behaviour of the patients, having to take time off from work as well as long distances to the hospitals. Sometimes neighbours and other well-wishers may be called upon to assist during crisis. Therefore the ability to avert mental health crisis are essential among family caregivers.

Counsellor H: Patients who present with depression, schizophrenia and substance dependence rarely take initiative to work for a living. Majority depend entirely on the family caregivers and well-wishers for their upkeep. The ability of resourcefully engaging persons with psychological disorders in income generating activities or house chores can relieve the family caregivers from worrying about the patient's whereabouts or provision of personal effects.

The counsellors suggested that lack of care giving skills among family caregivers generated negative emotions and social alienation. This argument supports the findings of Chan (2011) who stated that most home based caregivers of persons with psychological disorders were ill equipped with knowledge, skills and resource support to effectively perform the care giving roles. The inadequate care giving skills may result in family caregivers distorted perceptions of the circumstances they find themselves in. Srivastava (2005) reports that family caregivers become physically, emotionally and economically overwhelmed by the care giving responsibility. This may

explain the reason behind some family caregivers leaving persons with psychological disorders to roam the streets or disown them at psychiatric hospitals (Ndetei *et al.*, 2009).

The complexities of caring for persons with psychological disorders by family caregivers tended to deplete family resources in terms of time spend monitoring the ailing relative, financial responsibilities and social disconnect. Torrey (2006) explains that family caregivers experienced feelings of anger, frustration, helplessness, loneliness and depressive thoughts mainly due to the unpredictability of the ailing member's psychotic behavior. Therefore managing a crisis becomes a daunting task for the family caregivers who have limited care giving skills. Much time, energy and family resources are wasted while trying to vainly reason with the patient, seek incompetent moral support and meet the patient's delusional demands.

6. Recommendations

- i. The MoH may need to advocate for special crisis emergency leave days for employed family caregivers of persons with psychological disorders. This will minimize the distress and negative emotions occasioned by having to ask for time off work during crisis related to the care giving role.
- ii. Mental health professionals may need to provide customized care giving skills to family caregivers of persons with psychological disorders based on the unique nature of the psychological condition suffered by the ailing relative. This will enable the family caregivers to become proactive in their care giving role instead of indulging in self-pity and feeling helpless in the case of an impending crisis.
- iii. The MoH may consider including mandatory psycho-education interventions for family caregivers as part of patient's mental health treatment plan in the Kenya Mental Health policies.

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