EFFECTIVENESS OF FAMILY INTEGRATION ON TERMINALLY ILL PATIENTS AT UNIVERSITY COLLEGE HOSPITAL, IBADAN.

By

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Abstract

The place of family among the terminally ill cannot be overemphasised. A state of terminal illness calls for collaborative care in ensuring effective management of the terminally ill. He/She is cared for not only as an individual, but also as a family member whose reaction interlocks within the support system. This study adopted the survey research design. Random sampling technique was used to select 107 respondents namely 51 terminally ill patients and 51 family care givers. The instrument used was family integration scale (r=0.65). Data was analysed using descriptive statistics and multiple regression. Two in-depth interviews were conducted with one terminally ill and one family caregiver. The result shows that family integration correlated significantly with effective care of the terminally ill and jointly accounted for 62.0% of the effective care of these. Observed relationship among family integration factors were financial assistance (r=65), life style modification (r=32,) and reallocation of roles (r=32). Patients expressed anxiety over the outcome of illness, difficulty in adaptation to lifestyle modification while the family care givers expressed satisfaction in involvement of care and financial constraint in some aspects of management of their terminally ill relatives. Therefore there is need for adequate provision of funds and that cost of treatment must be subsidised by the care givers.

Keywords: Family Integration, terminally ill, family care givers.

Introduction

Terminal illness is a term used to describe a disease that cannot be cured or adequately treated. However, early detection, periodic medical examination and good family network has major role in recovery. Examples of these diseases include cancer, heart disease, end stage kidney disease, neurological problems and HIV/AIDS.

Recognising the importance of family necessitates clearly the definition of what is meant by "family." Most often family consists of parents and their children. But in today's world of divorce and re-marriage, step-relatives must also enter into the family portrait. In other instances, people unrelated by blood or marriage may function as family (Panke 2004). Therefore, the definition of family must be expanded. The family is a group of individuals inextricably linked in ways that are constantly interactive and mutually reinforcing. Family can mean direct blood relatives, relationships through an emotional commitment, or the group of persons with which an individual feels most connected (Field & Cassel, 1997). Moreover, family in its fullest sense embraces all generations - past, present, future; those living, those dead, and those yet to be born. Shadows of the past and dreams of the future also contribute to the understanding of families. There is a close connection between the family, the patient and the disease.

Parkes (2002) highlighted three major issues that can emerge even in well-functioning families which are: acquiring information, concealing feelings and coping with helplessness. Tanchell (2003) reaffirms that neutrality is important and at all times, practitioners should be sensitive and aware of their role within the family. Monroe (1999) warns "if the family finds balance only with his family rather than helping them find solution", It will create more problem. The diagnosis of terminal illness is traumatic for everyone, hence the knowledge and understanding of the crisis is important as everyone's realities change within seconds. All that was once certain becomes uncertain and the emotional and physical resources of the entire family are threatened. Even referral to palliative care service is experienced as a major crisis. Family often means more than blood ties with the patient. It stands for those relationships that are significant for the patient. A network of attachment exists within a social and cultural context. Thus, friends, neighbours and work colleagues may be equally important and equally affected by the diagnosis of terminal illness.

Findings make it clear that family members look to health professionals to provide quality care to the patient. Family members also expect health professionals to meet their own needs for information, emotional support, and assistance with care (Rhodes & Mitchel 2008).

Much of the research that purports to address the impact of terminal illness on the family is based on the perceptions of individuals either the patient or adult family members (usually the spouse). Many of the studies were conducted retrospectively, that is, after the patient's death. But even studies conducted during the palliative period frequently exclude the patient who is the one at the center of the palliative care situation.

Relationship between family and the terminally ill

Davies (1995) identified the basis for offering optimal support of the terminally ill, and the research findings that prospectively examined the experiences of such families. The common view is that transitions are initiated by changes, by the start of something new. However, as Bridges (1998) suggests, most transitions actually begin with endings. This is true for families living with serious illness in a loved one. A transition that families themselves labelled as "fading away." The transition of fading away for families facing terminal illness began with the ending of life as they knew it. They came to realise that the family member was no longer living with terminal illness, but was now dying from the illness. Despite the fact that family members had been told about the seriousness of the prognosis, and had experienced the usual ups and downs associated with the illness trajectory, for many, the realisation that the patient's death was inevitable, thus becomes evident.

Opportunities should be provided for patients to talk about the losses incurred due to the illness, the enforced changes, the adaptations they have made, and their feelings associated with these changes, reinforce their normal patterns of living as long as possible and as appropriate. When they can no longer function as they once did, they can be encouraged to focus on what they can do, reinforcing those aspects of self that remain intact (Vachon, 1998). Acknowledging that roles and responsibilities may be expressed in new and different ways, and suggest new activities appropriate to the patient's interest and current capabilities. The focus with spouses and children centers on explaining how the disease or treatment contributes to changes in the patient physically, psychologically, and socially. Temo, Cassey (2009) submitted that spouses should be allowed to talk about how changes in the patient affect their marital relationship, help children appreciate their parent from another perspective, such as in recalling favourite memories or identifying the legacies left, discuss how they can face their own vulnerability by channelling concerns into positive steps for self-care, reinforce the spouse's and children's usual patterns of living for as long as possible and as appropriate when former patterns are no longer feasible, help them to consider adjustments or alternatives (Kissane & Kenzie, 2003), providing opportunities for spouses to discuss how they may reorganise priorities in order to be with and care for the patient to the degree they desire. Considering resources that enable the spouse to do this, the assistance of volunteers, home support services, or additional nursing services is most appropriate as postulated by Bridges (1999).

Caregiving techniques can be taught if the spouse shows interest. With the children, the degree to which they want to be open or private about their parent's illness with those outside the family must be respected. It should also be acknowledged that family members will vary in their ability to assimilate changes in the patient and in their family life. Rituals can be helpful during periods of terminal illness. A family ritual is a behaviour or action that reflects some symbolic meaning for all members of the family and is part of their collective experience. A ritual does not have to be religious in nature. Rituals may already exist, or they can be newly created to assist the family in contending with change. For example, the writing of an "ethical will," whereby one passes on wisdom to others or elaborates on his or her hopes for their loved ones' future, can help ill family members communicate what they might not be able to verbalise to their loved ones (Andershed, 2004).

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> *My body has shrunk so much the other day, I tried on my favourite old blue dress and I could see then how much weight I have lost. I feel like a skeleton with skin! I am getting weaker. I just can't eat much now, I don't want to. I can see that I am fading. I am definitely fading away. (Palliative Care Patient 2008:1015)*

The transition of fading away, according to Davies and Steele (2010), is characterised by seven dimensions: redefining, burdening, struggling with paradox, contending with change, searching for meaning, living day by day, and preparing for death. The dimensions do not occur in linear fashion; rather, they are interrelated and inextricably linked to one another. Redefining, however, plays a central role. All family members experience these dimensions, although patients, spouses, and children experience each dimension somewhat differently. Varying disease trajectories for other conditions, such as dementia, also influence the nature of support that health carers provide for patients and families.

Baker and Teno (2000) explained that supporting patients and other family members with redefining requires that health care providers appreciate how difficult it is for family members to relinquish familiar perceptions of themselves and adopt unfamiliar, unwelcome, and unasked - changes to their self-perceptions. Disengagement from former perceptions and the adoption of new orientations occur over time. Nurses and other care providers are challenged to help family members anticipate and prepare for what lies ahead, while not pushing them at a pace that threatens their sense of integrity. Each family member redefines at his or her own pace; interventions must be tailored according to the individual needs. At the same time, health care providers must support the family as a unit by reassuring family members that their varying coping responses and strategies are to be expected.

In the light of this family integration is the involvement and participation of the patient's family in the care of the terminally ill. This in itself provides a layer of support for the patient and relieves the burden of illness for the terminally ill. At times situation becomes difficult especially when decision has to be made concerning care of the terminally ill that is already overwhelmed. He/She might not be able to make a concise decision or consent thus the involvement of his/her family helps the other health care team to progress in management.

Objectives of the study: The objectives of the study are to:

- determine the extent to which the terminally ill is influenced by family integration.
- assess the relationship between the components of family integration and management of terminally ill.

Research Questions

- To what extent does terminal illness influence family integration.
- What is the relationship between family integration and management of terminally ill.

Hypothesis 1: Terminal illness has no significant influence on family integration.

Hypothesis 2: There is no significant relationship between family integration and management of the terminally ill.

Methodology

The research design adopted for this study was the descriptive survey design of the ex-post facto type, this was chosen because the variables were already in existence and therefore enabled the researcher to collect data without any manipulation .

Sample and Sampling Technique

Proportionate and purposive random sampling procedure was used to select 102 respondents comprising 51 terminally ill patients and 51 family caregivers from three out patients clinics and four wards that have terminally ill patients on admission. Two in-depth interviews were conducted with one terminally ill and one caregiver.

Instrumentation

The instrument used for this study was an 18 item structured questionnaire called the Family integration scale adopted from family strain questionnaire by Robinson and Thummer (2000) and 20 item self structured questionnaire for the terminally-ill. The items were drawn on a 4 point Likert scale of Strongly Agree, Agree, Disagree, and Strongly disagree each carrying the weight of 4, 3, 2, 1 respectively.

Section A focused on socio-demographic background of the patients and their care givers (this includes age, marital status, sex, occupation, religion and duration of illness).

Ethical consideration

Due to the nature of this presentation, ethical approval was sought from relevant institutional authority (UI/UCH Ethical Committee) and same was approved. Informed consent was also obtained.

Table 1: Showing the names of the wards, patients, number of patients and family care givers.

Ward/Clinic	Patients	Family care givers
Radiotherapy clinic	8	8
Surgical Out Patient	7	7
Medical Out Patient	9	9
SW4	7	7
West 3	9	9
WW2	6	6
East 2	5	5
Total	51	51

Analysis of Findings and Discussion

This section presents the results from the test of two hypotheses. The results are presented in tables and references are made as appropriate.

Hypothesis 1: Terminal illness has no significant influence on family integration.

Table 2: Joint Production on Family Integration on care of terminally ill.

Model	Sum squares	DF	Mean Square	F.	Sig.
Regression	58.712	(1.0)	19.570	14.285	000
Residual	67.812	49.5	.342		
Total	126.524	50.7			

R=.681, R^2=.464, Adj R^2= .456

Interpretation and Discussion

Table 2 shows the ratio analysis on the components of family integration (i.e. financial assistance, life style modification and reallocation of roles) on the care of the terminally ill. It showed that family integration on care of the terminally ill was significant at R=681, R^2=464, AdjR^2=456.

Out of 20 item questions for the terminally ill on family integration, item no 9 which states that "I have support for what I do" carried the highest percentage of 62.9% i.e. (31 respondents) in which item no 5 "I get the emotional help and support I need from my family carried 59.4% (i.e. 30 respondents), item 13 however states that "I have information that helps me overcome difficulties carried 54% (i.e. 27 respondents), however, item 16 and 18 carried the highest standard deviation of .87 and .82 respectively. In an in-depth interview with one of the terminally-ill, he had this to say about his condition:

> *My life's work is done, but I am not able to die. How can the day to day time I have left be given a sense of meaning?" The hardest thing is living without a goal a new way of being-just being that is the hardest thing: I know that I'm going to die at some point, but I don't want it to be a painful and undignified death. This is the most important time in my life and yet I feel disconnected from it. It's hard to talk to my family about how I feel-they don't understand.*

In furtherance to the above submission, Tanched (2003) thus commented that:

> *The family integrated components to terminal patient care allows the patient not to be treated as individual with problems and symptoms, but also as a family member whose reactions interlock with the support.*

Davies and Steele (1995) buttressed that family members must be given opportunities to talk as individuals as well as in group regarding the care of their loved ones. In terminal conditions a lot of issues run through the patient's mind especially on outcome of illness, unfinished projects and also the stability of the family he/she belongs. However the family caregiver that occupies a significant position in the terminally ill would assist in relieving burden of illness to a considerable extent.

Hypothesis 2: There is no significant relationship between family integration and management of terminally ill.

Table 3: Relationship between the predictions of family integration (financial assistance, life style modification and reallocation of roles) on care of terminally ill.

Model	Unstandardized coefficient		Standardized coefficient	T	Sig
	B	Std Error	B		
Constraint	1.681	.114		3.663	.000
Financial	.288	.028	.718	2.680	.000
Life style modification	.197	.061	.172	.805	.000
Reallocation of roles	.223	.176	.176	.667	.010

It was shown also in the above table that the joint effect of financial assistance, life style modification and reallocation of roles were significant F(1, 490) = 19.570; R= .68l, R^2 = .464; Adj R^2=.456; $P<.05$). About 46% of the variation in the care of terminally ill by their family care givers. The results on table 3 shows the relative contribution of the independent variable on dependent financial assistance β=.718, ($P<.05$); life style modification (β=.172, $P<.05$) and reallocation of roles (β=.176, $P<.05$). The result shows that family integration components correlated significantly with the care of terminally ill. This agrees with Olivere (2010) that no effective care can be carried out if the terminally ill and the family are worrying about loss of income, he therefore warned that identifying financial need is essential particularly with family caregivers.

Out of the 18 items questionnaire for the family caregivers, item 4 and 5 carried the highest percentage of 58.9% and 54.4%, respectively, in response to the statements, the care positively influences her well-being and" "I am really prepared to take care of him" followed by item 1 that states "Her ailment has caused some emotional disturbance" 56.4%. These are in keeping with the positive influence of the family. In-depth interview conducted with one of the family caregivers on her perception on the mother's illness revealed thus:

> *Ever since my mother's illness started, I had to leave Lagos to come and assist in her care. I never knew what she describe to me as a "lime sized boil" could result into her having a major operation done, she was counselled and I saw that she had a strong will and was quite positive that all would be well with her. I am really prepared to support and take care of her. When we got to the stage of her having to commence chemotherapy, we could afford four courses out of the eight courses that were prescribed for her. We then had to ask other significant family members for financial assistance which they responded within the limits of what they could afford. We are just trusting God for my mum's gratuity to be ready before we exhaust the funds she have presently.*

It can, therefore, be deduced that whichever way one looks at it, the management of terminal conditions has financial commitment deep-rooted and since fingers are not equal, it usually gets to a point when financial assistance needs to be sorted, altered, family process also calls for reallocation of roles to be able to keep body and soul together.

Conclusion

The family as a single unit of the society occupies an important position in the life of the terminally ill person. When the diagnosis of terminal illness is made, it looks as if the whole world is crumbling for that individual, but with the support of a significant person(s) within his/her family; the burden is lifted and thus provides psychological balance for the terminally ill. Usually the family integration provides a layer of support in the management apart from the health care team, through which informed decisions are made on management of the terminally ill. The family's efforts should be acknowledged when they put their own needs and work on hold to care for their ill relative; it is sacrifice and thus gives reassurance to the terminally ill. There is therefore a very strong relationship between family involvements in the care of terminally ill.

Recommendations

Premised on the findings, this study recommends that:

i. All health institutions should give priority to family involvement in the care of their terminally ill individuals.
ii. The wish of the terminally ill (that is still conscious and alert) should strictly adhered and clear understanding should exist between the patient, health care team and family members.
iii. The financial assistance, life style modification and reallocation of roles as evidenced by the variables within which family integration emerges should be the concerns of the extended family members and relevant philanthropic organisation that can assist in the management.

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