HEALTH MANAGEMENT OF INFORMAL CAREGIVERS OF CANCER PATIENTS : A REFLECTIVE REVIEW

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ABSTRACT

An informal caregiver is an unpaid individual who can be a family member, a friend or a neighbor involved in assisting the patient with activities of daily living and/or medical tasks. As cancers have been identified as one of the leading causes of mortality and morbidity worldwide, it has tightened its grip in India too. Experts have predicted that the incidence of cancer would raise five- fold by the year 2025. With the rise of cancer cases in India, the need for informal caregiving for cancer patients would also take a leap. With the role of informal caregiving, come a lot of responsibilities and insurmountable tasks that need to be performed. Caring for a beloved member of the family or a friend who is suffering from a deadly disease is in itself a big challenge. Taking on new responsibilities on one hand and worrying about the future can be very exhausting at the very least and might quickly lead to numerous psychological and physical problems for the caregivers of the cancer patients. The main question that haunts us is that when you are busy taking care of your beloved person with cancer, then who is managing your own health. Keeping in mind the same concern, a number of studies, review articles and meta-analysis of studies pinpointing on the health management of informal caregivers were considered for perusal. Thus, the present review paper aims to contribute to the society at large, by focusing on studies that discuss the effects of various types of intervention plans that have been applied on the caregivers of cancer patients. It also throws light on the various caregiving skills, care demands, caregiving tasks and certain other factors that need to be considered before coming up with the intervention strategies for managing the overall health of the informal caregivers of cancer patients.

Keywords : Informal caregivers, health, cancer, management, intervention, skills

INTRODUCTION

The task of providing informal caregiving to a person with a chronic disease like Cancer is a very challenging task. The patients with cancer have intricate treatment protocols that require the involvement of the caregiver. This further complicates the already difficult care as the informal caregivers of cancer patients do not receive any formal training for the task of caregiving that they have to carry on a daily basis. The better treatment facilities have increased the life span of patients suffering from cancer. Thus increased life span and shorter hospital stays have increased the demand of informal caregivers for several years (Given and Kozachik, 2001).

Studies on informal caregivers report that the caregivers feel unprepared and lack confidence to carry on their role of caregiving. The reason behind is that they don't have the needed knowledge and skills to provide sustained

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** Research Scholar, Department of Psychology, Faculty Social Sciences, Banaras Hindu University, Varanasi (Uttar Pradesh)* care to the person suffering from cancer. As a consequence to this, the caregivers report lack of guidance. They say that they are not familiar with the type and amount of care that is needed and they don't know how to access and utilize the available resources (Given and Given, 2002).

Insurmountable studies have been done to see the positive and negative consequences of informal caregiving on the informal caregivers of cancer patients. Various studies have reported that informal caregiving leads to subjective and objective caregiver burden. But the major concern that needs to be paid heed is that very little knowledge is available about the skills and knowledge that the caregivers possess and how these skills and knowledge affect the care that is provided to the care recipient (Farran, Gilley, McCann, Bienias, Lindeman, and Evans, 2007).

Various efforts are being made to help the caregivers to cope up with the odds of caregiving. For this the researches have organized certain intervention plans also. But the drawback of these is that most studies have classified the intervention plans without considering the caregivers tasks or knowledge and skills that they require. However this information is very vital in order to implement the intervention strategies to help the informal caregivers (Archbold et al., 1995; Silver, Wellman, Galindo-Ciocon, and Johnson, 2004).

CAREGIVING SKILLS

Studies have reported that the informal caregivers not only need knowledge to perform the caregiving tasks but they also need to possess or acquire certain caregiving skills so that they can provide care without affecting their own wellbeing (Gallagher and Coon, 2007). Family caregiving skill is the "ability to engage effectively and smoothly" in nine care processes that require psychomotor, cognitive, and psychological skills (Schumacher, Stewart, Arcbold, Dodd, and Dibble, 2000). However skill has been defined as "goal-directed, well-organized behaviour that is acquired through practice and performed with an economy of effort" (Farran et al., 2007).

A caregiver skill is "something that caregivers do" using "goal-directed behaviours based on knowledge, experience, or personality style" (Farran et al., 2007). The requisite caregiver skills described by Schumacher and colleagues include monitoring, interpreting, making decisions, taking action, adjusting to changing needs, comforting with hands-on care (direct care), accessing resources, working with the ill person, and negotiating the health care system. Here the skills such as monitoring and interpreting require complex reasoning (Schumacher, Stewart, Arcbold, Dodd, and Dibble, 2000).

In order to manage the health of the informal caregivers of cancer patients, it is desirable to firstly probe into the basic knowledge that caregivers use to make decisions and solve problems. It would provide foundation for developing and improving skills. Not only this, the caregivers will also receive guidance, counselling, and direction from health clinicians regarding the appropriate action that needs to be taken by them with their family members. As a result, caregivers can develop their skills overtime. Studies have reported that the caregivers who possess these caregiver skills report lower levels of caregiver burden, stress and distress (Archbold, Stewart, Greenlick, and Harvath, 1990; Scherbring, 2002). This enabled them to provide the care to their loved ones with improved outcomes.

CARE DEMANDS

In order to evaluate the caregiver's availability, knowledge, skills, competence and resources, the professionals must firstly assess the care demands. The demands of providing care depends on numerous factors like such as the patient's personality, the type or stage of illness and the caregivers' physical, cognitive, social, organizational, and psychological knowledge and skills. Studies have also indicated that the predictability and routine nature of the care as well as it's duration and quantity are some of the important factors that must be considered when implementing therapeutic plans of care with the family (Bakas, Austin, Jessup, Williams, and Oberst, 2004; Langa, Vijan, Hayward, Chernew, Blaum, and Kabeto, 2002).

CAREGIVING TASKS

Caregivers not only need to perform activities of daily living but they also have to perform complex medical tasks, supervise the care recipients, make decisions, solve various problems and also provide emotional support and comfort. Caregivers also provide custodial care, transportation and advocacy. Some caregiving tasks are merely time-consuming while others are difficult. Caregivers also need to learn to monitor patients for new signs and symptoms, adverse events, and positive responses to treatment. Along with all these, the family caregivers also typically manage the household. At times, the caregivers may need to modify the environment and acquire equipment and assistive devices in order to improve function and safety for the patient (Bakas, Austin, Jessup, Williams, and Oberst, 2004; Langa, Vijan, Hayward, Chernew, Blaum, Kabeto, 2002).

Studies have reported that the demands on caregivers escalate as treatment plans change, the disease progresses, the patient's functional or cognitive capacity deteriorates or the patient nears the end of life. Hence in order to proceed further for the health management of informal caregivers of cancer patients, the capabilities of the caregivers must be reassessed by the nurses, social workers or researchers (Given et al., 2006; Sherwood et al., 2005).

INTERVENTIONS FOR HEALTH MANAGEMENT OF INFORMAL CAREGIVERS

Interventions are the helpful strategies that are recommended and guided by health care clinicians that is expected to make the task of caregiving easier and less stressful. Most interventions provide basic written materials that teach caregivers about the expected course of an illness, treatment plans, short- and long-term adverse events, or strategies for dealing with these effects.

Given at al. (2006) implemented a cognitive behavioural intervention to assist caregivers of cancer patients with symptom management (Sherwood et al., 2005; Sikorskii et al., 2007). The study reported that when the patient's symptoms responded to the intervention and the number and severity of symptoms were reduced, caregivers were not as negative about each symptom and experienced less distress per symptom. The intervention had addressed specific symptoms and severity levels. Caregivers became involved in symptom management and were able to help patients control their symptoms. Caregivers used information, direct care strategies, coaching, and emotional support to work with the patients. In turn, the patients also experienced fewer symptoms that were also less severe, had less interference from symptoms, and showed improved physical function.

An intervention plan was implemented to help the spouse caregivers of cancer patients by helping them to develop problem-solving skills. The results indicated that those who needed social support felt encouraged to continue providing care and to be open to problem solving when they could no longer provide care. Thus it can be stated that interventions that use problem definition and formulation, generate alternatives, involve decision making, and implement strategies should increase a caregiver's sense of effectiveness (Blanchard, Toseland, McCallion, 1996).

Interventions have also been given in the form of psycho educational programs that addressed symptom management, psychosocial support, and resource identification (Pasacreta, Barg, Nuamah, and McCorkle, 2000). The post intervention results of the study showed that the caregivers became informed and confident about giving care and weren't more burdened when patient care demands increased. Other studies document that problem-solving programs help caregivers feel informed about community resources (Bucher, Loscalzo, Zabora, Houts, Hooker, and BrintzenhofeSzoc, 2001).

Studies have indicated that psycho educational interventions provide emotional and educational support to caregivers. One such intervention was carried by Jepson and colleagues that was telephone-based intervention. It focused on monitoring problems, managing symptoms, performing self-care, and coordinating resources. The post intervention results after 3 months showed improvement in the psychosocial well-being of the caregiver. The effectiveness of the intervention depended on several factors, including the physical health of the caregiver (Jepson, McCorkle, Adler, Nuamah, and Lusk, 1999; Chee , Gitlin, Dennis, and Hauck, 2007).

Studies have also shown that often caregivers and families are not given information about available social and emotional support sources or how to utilize community resources (Given et al., 2006; Jansen et al., 2007). However the informal caregivers also may need to know how to deal with difficult situations like anger, depression, rehabilitation, disruptive behaviours and incontinence (Bakas, Lewis, and Parsons, 2001). Thus it must be borne in mind that families want information about symptoms, disease progression, treatment, and possible adverse events. Also the caregivers seek information on skills they need for providing day-to-day care.

The management of symptoms in order to comfort the patient often becomes a major family concern. Hence some psycho educational and cognitive behavioural interventions for caregivers have focused on symptoms also. Family caregivers need to be able to monitor, interpret, and manage symptoms and may need booster sessions to learn additional knowledge and skills. Pinquart and Sörenson used meta analysis to integrate the results of 127 such intervention studies (Pinquart and Sorensen, 2006). They concluded that many interventions had little effect on the emotional health or the abilities and knowledge of the caregiver. However the Psycho educational interventions that required active participation and involvement by caregivers had the broadest effects.

CONCLUSION

On the basis of the above literature review it can be said that the informal caregivers have considered the concepts of mastery, preparedness, and competence as the backbone of the effective decision making and problem solving. But to our misfortune the formal care system has paid little attention to these components. Studies suggest that in order to improve the quality of patient care, it is highly essential to assess the caregivers' capacity to provide care and identify the caregivers who need assistance.

Very few studies look at how caregivers care and what care family caregivers should provide. The care system does not incorporate "family care" into plans of care. Therefore, the contribution of family care to patient outcomes has not been evaluated. On the basis of the perusal of studies it can be said that practitioners should evaluate caregiving skills, care demands, caregiving tasks, caregiver knowledge and capacity, family roles, and available resources in order to manage the health of the informal caregivers through various intervention plans. Assessments should also include the number of hours of care required and the expected duration of care. Competing demands such as work, travel, and child care should alert professionals to the risk of overload, strain, or an inability to continue to provide care. Hence the plans of care should be based on a thorough assessment of both recipient need and caregiver' capacity.

In a nutshell, family caregivers need a working knowledge of the patient's plan of care and they must be able to interact with nurses and social workers. Health professionals and family caregivers should collaborate to ensure that optimal care is given. To bring about changes in practice, nurses and social workers need to develop evidence-based professional standards and guidelines to help families care for those with common chronic diseases. These should cover the types of knowledge and skills family caregivers need, the conditions under which information and skills should be evaluated, and who should be responsible for determining caregivers' abilities. Professional organizations or disease specialty groups, such as those for cancer, heart disease, and stroke, can endorse these standards.

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