

Psychological Distress Among Caregivers

Abstract

Caregiver is the person who takes primary responsibility for someone who cannot care for themselves. It may be a family member, a trained professional or another individual. A person may need care because of loss of health, loss of memory, onset of illness, as a response falling or the risk of falling, to address anxiety or depression, to relieve grief, or due to a disabling condition. A fundamental part of giving care is being a good communicator with the person getting care. Care is given with respect for the dignity of the person receiving care

Researches into experience of caregivers are gradually increasing and their central role in community care is being acknowledged. Caregivers experience a multi dimensional range of problems, often associated with their care giving role. The study sought to determine the prevalence of psychological distress among caregivers. Psychological distress is largely defined as a state of emotional suffering characterized by symptoms of depression (e.g., lost interest; sadness; hopelessness) and anxiety (e.g., restlessness; feeling tense) (Mirowsky and Ross 2012). The burden of caring tends to lead caregivers to psychological distress (Breslau & Davis, 2009).

Keyword: Caregiver, Psychological distress.

Introduction

Caregiver refer to an unpaid family member who provides care to an individual who is ill or have mental health problem and needs assistance to manage a variety of tasks from bathing, dressing, feeding care. Most caregivers are women who handle time-consuming and difficult tasks like personal care. . The caregiver remains in contact with the primary health care provider, often a doctor or nurse, and helps the person receiving care make decisions about their health and matters affecting their daily life. In the course of giving care, the caregiver is responsible for managing hygiene of themselves, the person receiving care, and the living environment. They tend to give themselves little time to adjust. Research studies documented (AARP 2004) that the work of care giving is full of psychological distress and that distress can adversely harm caregivers. Caregiver experience high level of emotional, financial and physical stress.

A number of studies have demonstrated that caregivers experience higher level of psychological distress (e.g. - Hodapp et.al 2013). Research studies revealed that caregivers can face psychological and emotional, social and economic challenges. Psychological and emotional challenges included being stressed by caring tasks and having worries about the present and future of patient. They had feelings of sadness and inner pain or bitter due to disturbing behavior of the patient. They also experience some communication problems with patients due to their inability to talk. Social challenges were inadequate social services for the patient, stigma, burden of caring tasks, lack of social support, and problems with social life. The economic challenges were poverty and extra expenses associated with patient's illness (Ray 2008).

The terms caregiver and caring have been defined as an act of providing concrete assistance, care and mutual support to family members or relatives who are undergoing physical, psychological or developmental problems and are not able to perform certain tasks on their own. Caring in these situations is the increment of extraordinary care that goes beyond the bounds of normal or usual care. It involves a broad range of support including taking care of personal hygiene of patients; emotional support like listening, counseling and companionship and informational caring such as learning how to change the living environment of patient.

Care giving is the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological, or

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developmental needs. Caring for others generally takes on three forms: instrumental, emotional, and informational caring. Instrumental help activities such as shopping for someone who is disabled or cleaning for an elderly parent. Psychologists generally limit their discussion of care giving to unpaid workers. Caregivers are typically family members, friends, and neighbors. Sometimes care giving is done by those affiliated with religious institutions. While care giving of all types is also done by paid workers such as nurses, social workers, and counselors, this is paid work, and thus is not in the same category. Care giving rarely refers to the daily care that parents provide for their children, because this is classified as parenting; however, caring for an adult disabled daughter would be considered care giving because it is outside of the norm of expectations for older adults (Drentea, 2007).

To have a caregiver a person may have to decide on changes on where they live and with whom they live. When someone needs a caregiver, the two must meet, and this typically happens either in the person's own home or the caregiver's home. Consequently, this could mean that a person moves to live with the caregiver, or the caregiver moves to live with the person. It is also possible that the caregiver only visits occasionally or is able to provide support remotely, or that the person who needs care is able to travel to the caregiver to get it.

Concept of Psychological distress

Psychological distress is widely used as an indicator of the mental health of the population in public health, in population surveys and in epidemiological studies and, as an outcome, in clinical trials and intervention studies. Distress is defined as an unpleasant emotional state of psychological or social nature that affects the individual's ability to cope with a particular set of circumstances. Distress has been characterized by the following attributes: a perceived inability to cope effectively, change in emotion, discomfort, communication of discomfort and temporary or permanent harm to the individual as a result. Distress often accompanies depression, either concurrently (Pandey et al., 2007) or as preceding depressive symptoms (Wang, 2005).

Distress symptomatology has also been found to correlate reasonably well with clinically assessed mental disorders (Hoeymans, Garssen, Westert, & Verhaak, 2004) and with the use of mental health services. Thus, measures of distress have been widely used to monitor mental well-being and psychopathology at the general population level. Yet the concept of psychological distress is still vague for some. Indeed, a closer look at the scientific literature shows that the expression "psychological distress" is often applied to the undifferentiated combinations of symptoms ranging from depression and general anxiety symptoms to personality traits, functional disabilities and behavioral problems.

In a review of mental health indicators for mental health monitoring in Europe, psychological distress is defined as 'a non-specific syndrome that covers constructs such as anxiety, depression, cognitive problems, irritability, anger and obsession-

compulsion'. Psychological distress is often experienced as a part of normal life, a consequence of persistent or temporary adversities, such as distress due to normal life transitions, challenges and losses, in education and work, family life, relationships, ageing and so on, and is associated with social deprivation, exclusion or persecution.

One definition combining the causes and psychological and social consequences of psychological distress states following: 'psychological distress is the end result of factors, e.g. psychogenic pain, internal conflicts, and external stress that prevent a person from self-actualization and connecting with "significant others". Psychological distress is largely defined as a state of emotional suffering characterized by symptoms of depression (e.g., lost interest; sadness; hopelessness) and anxiety (e.g., restlessness; feeling tense) (Mirowsky and Ross). These symptoms may be tied in with somatic symptoms (e.g., insomnia; headaches; lack of energy) that are likely to vary across cultures.

Additional criteria have been used in the definition of psychological distress but these criteria do not make consensus. In particular, tenants of the stress-distress model posit that the defining features of psychological distress are the exposure to a stressful event that threatens the physical or mental health, the inability to cope effectively with this stressor and the emotional turmoil that results from this ineffective coping (Horwitz 2007, Ridner 2004). They argue that psychological distress vanishes when the stressor disappears or when an individual comes to cope effectively with this stressor (Ridner 2004). There is plenty of evidence confirming the effect of stress on distress; however, including stress in the definition of distress fails to recognize the presence of distress in the absence of stress.

The status of psychological distress in the psychiatric is ambiguous and has been debated at length in the scientific literature. On the one hand, psychological distress is viewed as an emotional disturbance that may impact on the social functioning and day-to-day living of individuals.

As such, it has been the object of numerous studies seeking to identify the risk and protective factors associated with it. On the other hand, distress is a diagnostic criterion for some psychiatric disorders (e.g., obsessive-compulsive disorders; posttraumatic stress disorder) and, together with impairment in daily living, a marker of the severity of symptoms in other disorders (e.g., major depression; generalized anxiety disorder). Thus, psychological distress would be a medical concern mostly when it is accompanied by other symptoms that, when added up, satisfy the diagnostic criteria for a psychiatric disorder. Otherwise, in line with the stress-distress model, it is viewed as a transient phenomenon consistent with a "normal" emotional reaction to a stressor.

Psychological distress among caregivers Worldwide

Worldwide, 35.6 million caregivers have psychological distress and there are 7.7 million new cases that psychological distress has physical,

psychological, social and economic impact on caregivers. The WHO (2012) reports psychological distress, a public health priority, and aims to provide information and awareness about psychological distress. The burden of caring for a mentally ill individual often falls on the patient's immediate family or relatives. Caregivers of individuals with illness or disability are often unable to work at full capacity due to the demands of caring for the patient, leading to decreased economic output and a reduction in household income. Loss of income and the financial costs of caring for a mentally disabled or ill person put these households at an increased risk of poverty. Caregivers may also experience significant and high levels of psychological distress due to the emotional and physical challenges of caring for a mentally disabled and ill family member.

Although the experience of caring for mentally disabled or ill relatives varies among families and cultures, a 2000 review article reported that family caregivers' largest challenges were providing assistance with daily activities (e.g. providing transportation, offering financial assistance, helping with housework, cleaning, and money management) and stress associated with care (e.g. concerns about possible violence, embarrassing behaviors, and intra-family conflict).

For instance, a 2010 study in Botswana investigated the experiences of families caring for a mentally disabled or ill family member. The study was conducted using in-depth interviews, focus group discussions, and field observations in Gaborone, the capital city, and Molepolole, a rural village. Although the extended family structure common in Botswana allowed for distribution of caregiver responsibilities, most families reported that lack of financial and medical resources at the family and community levels made it difficult and stressful to provide adequate care.

Research studies suggest that caregivers may experience direct or indirect physical health consequences (Glaser et al 2010), higher levels of stress hormones (Gallagher Thompson et al.2006; Vitaliano et al, 2013), and poor sleep quality (Brummet et al.2006). Research studies suggest that caregivers are at risk for negative physical health effects, which may emerge over time as care demands increase (Schulz and Beach 2004). According to Ray (2008) psychological distress occurs when there is an imbalance in the environmental demands.

Psychological distress can affect both physical and mental health of caregivers. Vitaliano 2013 identifies two pathways by which psychological distress can affect caregivers' health. One pathway suggests that psychological distress leads to psycho-social distress and increase in stress hormones. The other pathway links psychological distress to risky health behaviors (e.g. substance abuse, poor nutrition) that are often associated with physical and mental health problems. Caregivers also experience symptoms of depression, anxiety, inadequate time for sleep (Beach & Schlutz 2009). According to estimates from the National Alliance for Caregiving, during the past years, 65.7 million

Americans served as caregivers for an ill or disabled relative.

Psychological Distress among caregivers: India

Caregiver's psychological distress is a condition of exhaustion, anger, rage or guilt that results from unrelieved caring for a dependent patient. The term is often used by health care professionals but it is not listed in the statistical manual of disorders. Almost 66% of the population in India is providing care to those that are ill or disabled. Psychological distress among caregivers is caused by overwhelming caring for a disabled or ill person. Caring for ill or disabled can also have an impact on family functioning. Family function refers to patterns of relationships connecting members of a family system to each other. Life of a caregiver is full of stress. One of the primary stresses of life that caregivers experience is day-to-day care, feeding, dressing and toileting.

Often the emotional and physical demands of that care leave caregivers with no strength for other relationships or activities. Psychological distress is viewed as an emotional disturbance that may impact on the social functioning and day-to-day living of caregivers (Majumdar S.K,2007). Psychological distress is higher in female caregivers than in male caregivers in India. (Srivastava 2011, Juneja, et al. 2005). Females seem more responsive to stress emanating from their social network (Dixit and Madurima 2004) and they tend to be more exposed to marital stress (Gupta, A., & Singhal, N. (2004). Psychological distress is one of the most dominating factors influencing the caregiver's behavior.

In the field of health care, there is a shift towards encouraging community care of patients. Caregivers- like family members or other relatives are of prime importance most especially in India where the extended family system provides most of the social and economic support needed for the ill patients. Illness has a major impact on both patients and relatives.

Care giving on its own comes with several challenges and occasional distress, as the role of caring affects every aspect of the caregiver's life. Caregivers of ill patients experience burden also and this burden can be subjective and objective as well. Subjective burdens refer to psychological consequences on the family such as the relative personal appraisal of the situation and its perceived severity. Objective burdens refer to outwardly measurable demands placed on the family members. These include financial difficulties, strain on interpersonal relationships, a reduction in social support, physical violence.

Caregivers should also take care of themselves. Some different ways for caregivers to care for themselves and let them relieve stress were collected from Caregivers and care managers of the Medicare Alzheimer's Project in Broward and Dade Counties in Florida. They are as follows:

1. Find something to laugh about everyday
2. Take care of yourself physically
3. Eat a well-balanced diet
4. Talk with someone everyday
5. Exercise

6. Get adequate rest
7. Have a bowl of cheerios and milk before going to sleep to promote better sleep
8. Avoid noisy and tension filled movies at night
9. Reduce caffeine intake
10. Seek professional help
11. Take a break everyday
12. Explore community resources.
13. Listen to music
14. Learn relaxation techniques
15. Attend one or more support groups and educational workshops

Conclusion

In closing it is evident that there can be psychological distress among caregivers because caring for ill or disabled patient is not an easy task and it is not in short term, it is long term that made caregivers anxious as to who will look after the ill person after their death. The demands of caring for mentally disabled or ill person tend to lead caregivers to psychological distress. With in complex system of long term care, caregiver's care giving is essential in providing a backbone of support. Care giving has a substantial impact on economic conditions because providing care and care related activities can has serious financial consequences to caregivers. The tolls that care giving tasks are not just financial, higher levels of psychological distress, anxiety and other mental health challenges are common among caregivers. Caring for a loved one may often include assistance with activities of daily living such as bathing, dressing, eating and transferring. These care giving tasks can put a great deal of strain on a caregiver's physical health. Care giving also can have significant consequences on the mental health of caregivers. Caregivers also experience lower levels of subjective well-being and self-efficacy, higher negative affect and poor levels social support.

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