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Fatigue seen in caregivers of the intellectually disabled population

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ABSTRACT

Individuals with disabilities are often dependent on their primary caregivers for assistance and activities of daily living. A caregiver here may either be a family member or a person trained in special health care. Most caregivers are found to be stressed and fatigued due to the nature of their work. In case the caregiver is a member of the family it is important to equally distribute the responsibilities of the disabled person amongst family members to avoid extra burden on any one person.

Keywords: Intellectual Disability, Caregivers, Residential homes, Fatigue

1. INTRODUCTION

Children with intellectual disability face difficulties in intellectual functioning (communicating skills, learning and problem solving) as well as adaptive behaviour (everyday social skills, hygiene, routines) hence it is imperative for them to have an immediate caregiver to assist them. The caregiver is understood as the one responsible for taking care of someone who is sick and/or dependent, assisting in the performance of activities of daily living, such as feeding, hygiene, leisure, medications, and monitoring in health services. The role of a caregiver for an intellectually disabled person is a challenging and exhaustive. As health care programs continue to circumscribe their service to persons with chronic, debilitating health conditions, many family members are compelled to assume caregiving roles (Hoffman, Rice, & Sung, 1996). Those with mild and moderate disabilities can eventually manage some of their independent skills by themselves and may require less support as opposed to those who suffer from severe intellectual disability. For them it is mandatory to be accompanied by an immediate caregiver at all times.

Most of the time it is a family member who assumes the role of the primary caregiver for the intellectually disabled. They are trained and given the required knowledge to perform the tasks however most of the time they function on the basis of instinct as well as experience since they do not have any scientific knowledge. Caregivers are expected to operate competently as extensions of health care systems, often performing complex medical and therapeutic tasks and helping a loved one perform and adhere to therapeutic regimens (Donelan et al., 2002). Caring for people with intellectual disabilities can be a demanding task which involves love, care, respect, dedication and can be a stressful job based on the magnitude of aid needed by the differently abled individual. It is observed that the higher level of caregiver burden is particularly detrimental to family caregiver adjustment, and burden may represent a more subjective process with little association to disability severity or other tasks. (Chwalisz, 1996). When compared to men it is more often women who assume the role of primary caregivers. Women are more likely to assume caregiver roles for individuals who live with severely disabling conditions (Moen, Robison, & Dempster-McClain, 1995) and constitute as much as two-thirds of primary family caregivers, generally. (Donelan et al., 2001).

The immediate caregiver usually has no one to share the care activities with and lands up with the sole responsibility of the intellectually disabled person. They perform multiple functions like meals, home organisation, medicine, hygiene and maintaining the daily routine of the differently disabled person. This leads to over exhaustion, overload and lack of social life for the caregiver. A prolonged role as an immediate caregiver can lead to caregiver burnout and can severely affect the relationship between the intellectually disabled and the primary caregiver. "Caregiver burnout is a state of physical, emotional and mental exhaustion. Stressed caregivers may experience fatigue, anxiety and depression." It could also be followed by an attitude from caring and loving

to one of negativity and indifference. Burnout could be caused when the immediate caregiver is not given the required help and support or if they are overburdened financially.

2. CAUSES OF CAREGIVER BURNOUT

There are numerous causes for caregiver burnout. The most common cause is when the immediate caregiver is so absorbed in tending to the intellectually disabled individual that they often tend to neglect their own social, emotional and mental health. This is ultimately reflected in the form of fatigue, hopelessness and eventually leads to caregiver burnout. Lack of financial aid is another major factor which leads to a state of caregiver burnout, primarily because the caregiver is unable to provide the adequate aid to the intellectually disabled and effectively plan and manage their loved one's care. Caregivers often overburden themselves with the sole responsibility of making a positive impact in the lives of the differently abled, they consider themselves responsible to keep them happy and to see a difference in their health and wellbeing. Lack of any social interaction, being confined to the house and only tending to the intellectually disabled can be another factor which leads to caregiver burnout where the caregiver has little or no social interaction with the outside world.

Caregiver burnout can be recognised in the form of several symptoms in the early stages. It begins with a state of isolation where the caregiver gradually cuts any kind of social interaction with the outside world family, friends and acquaintances. It is followed by indifference towards tasks and activities which were formerly enjoyed by the caregiver. Feeling of restlessness, hopelessness as well as emotional exhaustion are other symptoms of caregiver burnout. The more severe state of caregiver burnout can be accompanied by changes in sleep patterns, appetite as well as weight.

3. CONCLUSION

The role of a caregiver is a demanding and exigent one, mostly when a family member assumes the role as the immediate caregiver, they often end up sacrificing their own needs and desires. Many caregivers also feel guilty if they spend time on themselves rather than on their patient or child. Maintaining a balance between the role as a caregiver and as a person who lives in society is the key to preventing caregiver burnout. One's physical and mental health should not be neglected while fulfilling the role as a primary caregiver.

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