



CALMD

UNIT 4. *The role of caregiver*



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Kandinsky (Web)

"In the individual's mental life someone else is invariably involved, as a model, as an object, as a helper, as an opponent, and so from the very first individual psychology is at the same time social psychology as well."

Freud, 1921

Introduction and Objectives

Being a caregiver can be really demanding and requires drawing on one's reserves of energy, strength, patience and compassion on a daily basis.

Objectives of course:

- recognize one's role as a caregiver.
- prevent compassion fatigue.
- identify the burden of illness.
- facilitate the request for help in one's own area.

What is the caregiver?

A caregiver is a person who tends to the needs or concerns of a person with short- or long-term limitations due to illness, injury or disability. The term “family caregiver” describes individuals who care for members of their family of origin, but also refers to those who care for their family of choice. This could be members of their congregation, neighbors or close friends. Family caregivers play a significant role in health care, as they are often the main source of valuable information about the patient.

To understand the importance of a caregiver, think of health care as a three-legged stool. Family caregivers serve as one leg of the stool; professional caregivers (doctors, nurses, etc.) act as another; and the care recipient is the third leg. Without all three legs, health care cannot be as effective as it needs to be.

VIDEO TOOLS

- <https://www.youtube.com/watch?v=oK8eYmJU7Y>

Quiz: Are You a Caregiver?

A family caregiver can be someone caring for a spouse or parent, an extended family member, or even a friend or neighbor. Do you provide someone help with?

- Transportation to medical appointments?
- Purchasing or organizing medications?
- Monitoring their medical condition?
- Communicating with health care professionals?
- Advocating on their behalf with providers or agencies?
- Getting in and out of beds or chairs?
- Getting dressed?
- Bathing or showering?
- Grocery or other shopping?
- Housework?
- Preparing meals?
- Managing finances?

If you answered “yes” to any of the examples listed above, you are a caregiver! ¹

The quiz is a tool for **self-reflection** not a standardized tool.

It allows to reflect on one's own experiences as a caregiver and to be able to find tools and information to better orient oneself during the training.

¹ https://www.hopkinsmedicine.org/about/community_health/johns-hopkins-bayview/services/called_to_care/what_is_a_caregiver.html

The role of caregivers

The involvement of parents/careers is essential in the process of supporting the mental health of the disabled person as it represents a "bridge" between the person and the community, facilitating the transition from the family dimension to the community dimension, thus strengthening the autonomy of the individual and because as primary relationships-of trust allow the individual to comfortably express needs, but also feelings of anger and pain.

It is particularly important that parents/carers have a clear understanding of the problem/need/discomfort that presents the young person with a mental disability and how to intervene at home or outdoors on this problem. The work of psychoeducation for adult caregivers in this perspective aims to enable them to better understand the reactions of young adults with mental suffering facing stressful situations, personal experiences and feelings, and to understand how to intervene to help them cope with daily life and changes in life.

People with mental suffering, like any other human being, perceive the feelings of parents/ caregivers. And this is an extremely important element to consider in the work of care (both towards young adults and towards caregivers).

Helping people overcome their mental health concerns/disability is not an easy task and can be extremely challenging for the person providing help.

Parents/carers may feel so distressed and stressed that the young adult's autonomy process may be compromised.

The signal of distress of caregivers

The carer's experience is often described by the carers themselves, as an ambivalent experience.

On one side there is the desire to help, to make one's own skills available (when the carer is not a family member), hence the sense of fulfilment and support, to make one's own resources available to alleviate the suffering of the family member (when the caregivers is a family member). On the other, especially when the carer is a family member, he/she may experience this role not as a choice but as a necessity obedient to the situation.

Being a family or professional caregiver requires an expenditure of resources on a personal, environmental and economic level. The set of situations they face is often particularly demanding both physically and emotionally.

In both cases, family members and professional caregivers may feel tired, frustrated, anxious, overwhelmed, sad, lonely, resentful or angry. At times, you too may feel guilty or failed in the face of an emotional burden that becomes difficult to manage. The caregiver is a human being like any other and can admit that they have reached their limit and therefore need support to cope with feelings of stress, anger, loneliness.

Parents/caregivers should therefore be encouraged to ask for help, avoiding focusing on the needs and problems of the mentally disabled person/family member, without having more energy and resources.

The carer may have to deal with problems as diverse as stress, anxiety and depression: these are generated by the burden of responsibility on the carer, the emotional involvement that binds the carer to the 'patient', the inability to take a break, and the sense of frustration and helplessness that comes from seeing one's loved one in distress.

In addition to the feelings described above, the following are other warning signs for a caregiver:

- difficulty in relaxing and sleeping;
- increased physical complaints (muscle aches);
- decreased enthusiasm;
- memory and concentration difficulties;
- constant thinking about work/caregiver-related problems;
- constant feeling of uselessness and inefficiency;
- lack of initiative;
- increased anger;
- irritability;
- pessimism;
- agitation;
- anxiety;
- physical and mental fatigue;
- loss of motivation;
- insomnia.

These manifestations of caregiver stress and can be referred to as **Burden of illness**, or more simply Burden: by this concept is meant the state that results from the caregiver's (psychological or physical or social) caregiver burden.

These factors are not to be underestimated and should be measured appropriately: the caregiver's burden should not be too heavy, to avoid it negatively affecting the caregiver's health and quality of life. ²

Public services and social interventions for the mentally disabled also have the task of observing and supporting caregivers.

² <https://www.fedcp.org/cure-palliative/domiciliari/caregiver>

The Burden of Illness

This concept specifically lies between personal experience and community responsibility.

Burden of illness, or more simply Burden is meant the state that results from the caregiver's burden of care (psychological, physical or social). It can be analysed for the caregiver in order to identify the level of heaviness of the burden of care or could be analysed in the community in order to plan the correct political, social and health interventions.

The burden of caregivers of people with affective disorders includes costs and the pain and suffering of affected individuals. Burden can be perceived from social and private perspectives. On subjective side no ideal measure of burden exists, sample evidence documents the extensive cost and other negative impacts of affective disorders, such as:

- disruptive family relations;
- higher health care costs for comorbid conditions;
- elevated rates of suicide;
- lower productivity³.

The term burden of disease on a social point of view describes the total, cumulative consequences of a defined disease or a range of harmful diseases with respect to disabilities in a community. These consequences include health, social aspects, and costs to society. The gap between an ideal situation, where everyone lives free of disease and disability, and the cumulated current health status, is defined as the burden of disease.⁴

This concept is helpful to create social projects in a specific community or for the health system in order to help the caregivers and the community to support people with mental illness/disabilities. The best practice is to involve in the evaluation of the plan for the person with mental disability the burden of illness of his/her caregiver in order to foresee interventions for them and foster a cooperation between families and the broader community.

Useful tips

There are many variables involved in carrying out this activity, such as the different family contexts, the needs of the sick person and the emotionality of the carer, but it is possible to identify some general tips that can help to support this role more serenely:

- learn to express one's needs;
- allow yourself a few moments of respite;
- watch out for the onset of burden symptoms;
- do not be too hard on oneself;
- share your emotions;

³ <https://pubmed.ncbi.nlm.nih.gov/12558002/>

⁴ https://link.springer.com/referenceworkentry/10.1007/978-1-4020-5614-7_297

- talk to other caregivers;
- ask for help from other people who can replace the carer for specific tasks;
- recognise and accept the fact that you need help and support.

In the next chapter you will find video a of possible interventions/tips/ community or social framework that include caregivers in the health path.

**TAKE CARE OF THE CAREGIVERS. Community
based approach**

Below are some pointers for caring for carers:

- Identify caregivers suffering from psychological distress and refer them to the person responsible for providing psychological support.
- Mobilise community resources (extended family, social centres, psycho-educational centres, cultural centres) to support the family in the caregiving task. The community-based approach to mental health is a significant component of mental and social care. And it is therapeutic in itself.
- Community-based approaches to Mental Health and Psychosocial Support is based on the understanding that communities can be drivers for their own care and change and should be meaningfully involved in all stages of responses of care. A community-based approach insists that people receiving care and assistance have the opportunity to participate in decisions that affect their lives. This approach recognises the skills and resources of the individuals concerned and their living environment, this approach allow relevant support can be provided in accordance with the needs of the individual and the characteristics of the community in which he or she lives. Finally, the goals of the community-based approach are to reinforce the dignity and self-esteem of people of concern and to empower all the actors to work together to support the different members of the community in exercising and enjoying their human rights.⁵
- Offer psychosocial groups for caregivers to discuss ongoing difficulties, concerns and experiences, parenting skills, coping strategies and provide a space for mutual support.
- Psychotherapy (and follow-up) for caregivers suffering from moderate to severe psychological distress (depression).

⁵ <https://www.refworld.org/pdfid/47da54722.pdf>

Coping strategies for family caregivers

Suggestions for everyday life family caregivers:

- <https://www.youtube.com/watch?v=yXwQS3ory6E>

Suggestions for family caregivers for a person with a mental illness:

- <https://www.youtube.com/watch?v=d0mFtYPJwhc>

Caregivers coping strategies to take care about yourselves:

- <https://www.youtube.com/watch?v=4jjQn-UbznQ>

What does really mean to be a caregiver? Storytelling of a real personal experience:

- <https://www.youtube.com/watch?v=H3RQ9-hOuIE>

Recommendations and objectives to take care of caregivers and young people with disability

In order to offer a psychosocial and educational intervention that takes into account both the needs of the young adult with disabilities and those of the carer, it is necessary to:

- understand the life context in which people live and work;
- understand the resources and limitations of the area;
- promote mental health and states of well-being;
- explain to parents/caregivers the common symptoms and reactions of stress and distress related to the role of caregiver;
- involve parents in the process of autonomy and feelings experienced by the young adult with mental disabilities;
- describe possible interventions that can be provided by the parent at home;
- describe possible support interventions (how where and when) that the caregiver can receive (group or individual counselling);
- work in the community and not only in the family.

Objectives of caregiver support

- support parents/caregivers by enabling them to feel supported in supporting young people with mental disabilities;
- reinforce the importance of asking for help and sharing feelings at a specific time of pain and suffering;
- improve the relationship between caregivers and young people;
- increase the positive experiences and feelings of caregivers and young people.

Questionnaire

1. WHICH IS THE ROLE OF THE CAREGIVER?

- Is someone who work to support a person with mental disabilities.
- Is someone essential in the process of supporting the mental health of the disabled person as it represents a "bridge" between the person and the community.**
- Is a family member that just live with the person with mental health problems or disabilities.

2. THE BURDEN OF ILLNESS IS:

- The limit of the illness of the caregivers.
- The result from the assessment of the caregiver's burden of care (psychological, physical or social).**
- The weight of the person with mental disability from the caregiver point of view.

3. HOW TO TAKE CARE ABOUT CAREGIVERS?

- Blame them if they take time to rest.
- Feel sorry for them because they sacrifice their life.
- Explain to parents/caregivers the common symptoms and reactions of stress and distress related to the role of caregiver and describe possible support interventions (how where and when) that the caregiver can receive (group or individual counselling).**

4. WHICH ONE OF THOSE SYMPTOMS SHOULD BE CONSIDERED AS DISTRESS INDICATORS?

- Happiness and a sense of interior balance.
- Difficulty in relaxing and sleeping, increased physical complaints (muscle aches), decreased enthusiasm, memory and concentration difficulties, constant thinking about work/caregiver-related problems, constant feeling of uselessness and inefficiency, lack of initiative, increased anger, irritability, pessimism, agitation, anxiety, physical and mental fatigue, loss of motivation, insomnia**
- None of the list above.

5. ARE YOU A CAREGIVER? Self-analysis

A family caregiver can be someone caring for a spouse or parent, an extended family member, or even a friend or neighbour. Do you provide someone help with:

- Transportation to medical appointments?
- Purchasing or organizing medications?
- Monitoring their medical- health condition?
- Communicating with health care professionals?
- Advocating on their behalf with providers or agencies?
- Getting in and out of beds or chairs?
- Getting dressed?
- Bathing or showering?
- Grocery or other shopping?
- Housework?
- Preparing meals?
- Managing finances?



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