

EDUCAZIONE MEDICA
MEDICAL EDUCATION

Care pathways and management: a health education program for family caregivers

Il ruolo e il valore dell'educazione alla salute per il caregiver nel percorso di cura e assistenza

CLAUDIA CIANFROCCA¹, ANTONELLA SISTO², FLAVIA VICINANZA², LIVIA QUINTILIANI², ILARIA QUAGLIA³, DANIELA TARTAGLINI⁴

¹ RN Nursing Direction Campus Bio-Medico University Hospital, Rome

² Clinical Psychology, Campus Bio-Medico University Hospital, Rome

³ RN Campus Bio-Medico University Hospital, Rome

⁴ Associate Professor in Nursing; Nursing Direction Campus Bio-Medico University Hospital, Rome

When an illness is diagnosed, it does not only affect the patient, but it involves the whole family, especially the caregiver that takes care of the relative affected by the pathology. Caring for someone implies a constant and long-term commitment, which can become exhausting and cause high levels of stress and psycho-physical discomfort.

It is essential to implement supportive actions addressed to the family caregiver that should be gradually educated to take care of the loved one and at the same time supported and accompanied in the proper management and enhancement of its role.

This paper illustrates the experience of a multidisciplinary free of charge training course for family caregivers on caregiver's burden related to the psycho-social impact of the disease on the family system.

The course, provided by Campus Bio-Medico University Hospital of Rome since 2011, offers theoretical and practical tools to enable the family caregiver to handle primary care, everyday life activities, emotional load conditions and stress in safety and quality in the home.

Key words: Caregiver, burden, care, self-care, training needs

La diagnosi di malattia non colpisce solo il paziente, ma ricade sull'intero nucleo familiare, investendo in modo particolare il caregiver, ovvero colui o colei che si prende maggiormente cura dell'assistenza al proprio congiunto malato. L'attività di caregiving, implica un impegno costante e a lungo termine, che può diventare logorante e provocare elevati livelli di stress e disagio psico-fisico.

Pertanto, riteniamo fondamentale implementare azioni di sostegno al caregiver: egli deve essere gradualmente educato a prendersi cura del proprio caro e, al contempo, sostenuto e accompagnato nella corretta gestione e valorizzazione del proprio ruolo.

Il presente lavoro illustra brevemente l'impatto psico-sociale della malattia sul sistema familiare e descrive l'esperienza maturata presso il Policlinico Universitario Campus Bio-Medico che, dal 2011, promuove gratuitamente corsi di formazione teorico-pratici, rivolti ai caregiver familiari.

Parole chiave: Caregiver, assistenza, auto cura, bisogni formativi.

Address for correspondence
Indirizzo per la corrispondenza

Claudia Cianfrocca
Nursing Direction
Campus Bio-Medico University Hospital
via Alvaro del Portillo 200, 00128 Roma
e-mail: c.cianfrocca@unicampus.it

Introduction

The continuous improvements in living conditions and in medical care have made chronic diseases an increasingly important topic, due to the implications for the patient, the family, and the care services system. Chronic conditions are often associated with the progressive decline of the autonomy in both the simple and instrumental activities of daily life, which causes the increase of stress levels throughout the family.

According to ISTAT data (2015), 38.3% of Italian citizens reported having at least one chronic disease, while 19.8% suffer from two or more chronic conditions; comorbidity is 65% (57% among men and 71% among women).

As healing will not be possible, therapeutic goals regards the improvement of quality of life by the control of symptoms and by preventing disability (Ministero della Salute 2016).

It is evident that the proper management of the patient and the study and planning of long-term care pathways appears to be of crucial importance especially for the involvement of the patient's family context.

Whether it is neurological, oncological or other disease, the common feature of chronic illnesses is to affect the quality of life of both the patient and his family, threatening and interfering with multiple dimensions of the human Being: physical, psychological, relational, spiritual, and existential.

The psychosocial impact of chronic disease on the family and the caregiver

Whenever a member of the family gets ill, the whole family experiences it as something unexpected, negative, and often devastating. Any long-lasting pathology therefore represents an obstacle to the evolutionary tasks and the prerogatives of each phase of the life cycle. The term "experience of disease" clearly describes the condition of dealing with symptoms and suffering secondary to the illness (Kleinman 1988).

In particular, it refers to the ways the patients and their families perceive, manage and coexist with physical, emotional and psychosocial discomfort at all stages of the disease.

The acceptance of the illness of a loved one can be influenced by many variables such as the age of both the caregiver and the patient, the socio-cultural level, the affective ties between the members, the caregiver's health condition and the possibility of access to territorial health services (Silvano 2004).

The emotional dimension is crucial too as every disease, and even more a chronic disease, triggers the activation of multiple emotional experiences that both the patient and the family have to face. This dimension is largely influenced by the subject's entire life, the coping and problem solving

strategies adopted to manage stress, the presence of a social network of support or, the social isolation lived (Waldron et al. 2013).

In this setting the family caregiver plays a key role, he has to take responsibility of the care and has to face with the needs of the patient throughout the phases of the illness. In Europe almost the 80% of the care provided to not self-sufficient patients is given by spouses, children and other family members (Naiditch et al. 2013).

The term caregiver derives from the Anglo-Saxon words give and care and refers to "those who care". The ones that responding to an affiliated or familiar affair, take care, informally and freely, of a relative and loved one in a condition of not self-sufficiency, disability, or in need of long-term care (McCullagh et al. 2005).

In most of the cases the care is yield by a family member, who is in charge of taking care of his relative, assuming many functions. This experience often results in a "biographical breakdown" a drastic change in lifestyle (Bury 1985) that can manifest itself with the waiver of leisure time, social life and relationships.

Family caregivers show that they are engaged in various degrees on two fronts: the first one of care and of emotional support that is the second one. They have to support loads of physical fatigue and psychological stress, although they do not have specialized training to play this role, and are directly involved in the affective point of view.

This involvement may have psychophysical repercussions on the caregivers as shown in literature (Ripamonti et al. 2015).

Many studies have shown that caregivers live a number of stress factors, defined as burden (Nobili et al. 2011). This term indicates the impact and the relapse of the care burden on psychophysical well-being and their quality of life.

Family members directly involved in patient care may develop depression, anxiety and sleep disturbances that may affect their daily life such as the workplace, relational and family sphere, until they cause physical illness (Luchetti et al. 2012).

High levels of caregiving may lead to psycho-physical discomfort symptoms such as sleep disorders, asthenia and, in some cases, gastrointestinal problems, headaches and arterial pressure disorders. Psychological disorders, particularly anxiety and depression, frequently cause a relevant deterioration of quality of life (Ronald et al. 2014).

In their study, Gritti et al. (2011) show that emotional tension (distress), objective load (burden) and worry (strain) for the relative are the main indicators reflecting the psychosocial family disease. At the same time, the ability to cope with the disease and to implement cognitive and coping behavioral strategies are influenced by specific concomitant variables such as social support available for the family, psychological resilience of each person, other stressful events.

The family is the most involved in the care path of the loved ones, setting up a relationship based on love and the need to provide adequate care. There is a need for care choices and professional support to enable families to face the difficult tasks of caregiving, which can be supported in turn to address the disease path to the best possible extent.

Recent studies confirm that the ability to acquire specific skills and perceive high levels of self-efficacy in the care and self-care context is a protective factor for the onset of psychological discomfort and the maintenance of a good quality of life of the caregiver (Van der Lee et al. 2014). It is essential to develop practical training courses for the caregivers in order to allow them to increase the competencies that are necessary to provide a good quality of care in daily life at domicile, to reduce the sense of social isolation, and to increase personal and family resilience.

Informal caregiver's health education: the experience of Policlinico Campus Bio-Medico of Rome

Self-care and family coaching care models are increasingly widespread, due to the high increase in chronic diseases and the need to optimize resources (Righi et al. 2014).

Dorothea Orem, in her theory stated that the patient needs to bring out all his internal resources to restore the state of wellness and that the main task of nursing is to help the person to carry out self-care activities, to preserve life and health, to recover from illness or injury, and to cope with the consequences of such events.

Therefore, both patients and family members, if adequately supported, can play an active role in caring, through the implementation of measures to prevent a worsening of patient's conditions.

Several studies have dealt with the theme of caregiving, they showed how training courses for caregivers enabled them to take an active and conscious role in caring and that such consciousness emerged in positive health benefits, and improved patient's quality of life. This allowed in freeing up resources from the territory with a consequent increase in intensifying assistance at a higher index of complexity.

Moreover, the greatest stress levels are related to the objective burden due to the burden of technical expertise in supporting or replacing the assisted person in daily life activities (Morley e Dummett 2012; Grün et al. 2016; Raccichini et al. 2015).

The main task of the caregiver is about providing a supportive care to the loved ones that are no longer able to carry out the so-called "activities of daily living". These activities can be divided into basics – as feeding, washing, dressing, using the toilet, moving home, be continent – and instrumental: using the phone, shopping, preparing food, governing the house, washing the laundry, moving away from home, handling medicines and money.

Often, the family caregiver is committed in providing actions of care based on specific indications of healthcare providers such as prevention of decubitus, dehydration, and constipation. There is a wide range of care commitments, with strong differences between one case and another, concerning both the complexity and the duration of the engagement.

Starting from 2011, the Nursing Direction of Campus Bio-Medico University Hospital of Rome, has promoted and delivered a theoretical-practical training course for family caregivers with the aim of teaching to caregivers the basic home care techniques.

The willingness to promote a training course is the result of an analysis of family caregiver's needs, drawn up by the Counseling Center "VoiNoi".

The "VoiNoi" Counseling Center of Campus Bio-Medico has been in place since 2011 to support caregivers in the difficult task of providing care, delivering free psychological support services, local hospitality guidance, and health care and self-care education.

The course, at the fifth edition now, aims to go along with the family members during the care path, by teaching the most useful skills necessary to provide the best care as possible for their loved ones in everyday life, concerning the medical, nursing and psychological fields.

In order to convey the basic basics useful for proper family home management, ten theoretical frontal modules were organized, in these classes, subjects such as oncology, radiotherapy, hepatology, cardiology, neurology, geriatrics, Therapeutic food, social care and ethical aspects related to the management of the chronic patient were taught. Each module saw the participation of doctors and nurses who provided the participants the basic knowledge to ensure proper care and self-care.

In addition to the theoretical content, a practical training course has been developed structured in five experiential nursing laboratories, two emotion management labs, and a psychological support group.

During the nursing laboratories, participants learned some of the most useful welfare techniques, including basic care techniques, vital parameter recognition, proper family or dependent employee mobilization, management Simple dressings and first home aid.

The emotion management labs have been designed as an experiential training aimed at acquiring tools to manage the emotional stress related to the care burden.

Finally, psychological support groups have been created with the aim of creating a support network around the patient's family to encourage the encounter, exchange and sharing of thoughts and emotions among people living the same sufferings and difficulties every day. 290 caregivers attended the courses.

The report on training data and experimental labs shows that more than 90% of participants are "totally satisfied" and

feel that they have developed new skills that are useful in the activities and instrumental activities of daily life related to the caring.

According to literature data, the results confirm the importance of psycho-educational interventions for caregivers, as they favor the improve of self-efficacy, the increase of the competence and contribute to the reduction of burden, through a greater use of coping and problem solving strategies, that lead to an improved caregiver's well-being (Lopes, Cachioni 2012).

Currently the Course provides training on multiple issues related to caregiving, with a specific focus on welfare aspects and primary care. In the future it would be desirable to expand the training section dedicated to the social contents of caregiving, deepening the current legal regulations, the rights of the patient and the family member and the social and health services provided at the local level.

The importance of the caregiver's role in patient's care it's evident in the international literature, where the need to train the caregiver through training courses clearly emerges.

Some studies aim to highlight the importance of a very technical and individualized training performed by an expert geriatric nurse at caregiver's domicile. This kind of course helps to better know the pathology, to manage internal and external environmental stimuli and to formulate a home care plan re-evaluating it through periodic follow-up. The study conducted by Kuo et al. (2017) follows this methodology, it points up the positive outcomes of the course on caregivers, by showing the comparison between a group of caregivers that received this kind of training compared to a control group.

In a study conducted by Blom et al. (2015), instead, an online training course was organized for a group of caregivers who received telematic support from a psychologist who supported caregivers and gave them regular feedbacks. This group was compared to a control group that only received e-mails without course and feedback, the study shows that online support and online training also help to reduce anxiety and depression of the caregiver.

Finally, a study conducted by Katsuki et al. (2011), demonstrates the effectiveness of a 6-weeks training course for caregivers in which both theoretical topics related to the pathology of the assisted family member were discussed, as well as issues related to emotional distress, care burden and Expressed Emotions. In this study the method of sharing was used, caregivers were encouraged to give the narrative of their experience of taking care.

The study shows how the improvements of caregivers in their mental health, caregiver burden and expressed emotion after the course are remarkable.

In conclusion, some thoughts, emotions, and experiences written by the caregivers that summarize their perception of the training course that we consider important to give them voice, are reported in Appendix 1.

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Appendix 1: the caregiver's voice

Thank you for the opportunity you have given us; a special thank you to your nurses, Angels on earth and example of integrity, and dedication.

Anonymous

TO YOU AND TO US:

Thanks for the reliability, availability and responsibility expressed during the course.

Thanks for the shared skills.

Thanks from ours relatives.

Anonymous

These meetings made me better understand my limits, and helped me in understanding that taking more space for me could helped to create a less conflictual relationship with my mother.

C.

This training course allowed me to "rehabilitate" and "ennoble" my volunteer/involuntary caregiver function. I have discovered with you the best sides of this important commitment.

I perceived the value of the actions.

I became aware of the importance of this role that has deprived me of many things, from work to serenity, but now I feel I have also received a great gift.

I understand so many things, I have re-evaluated life and relationships and today, thanks to you also, I appreciate myself in this particular state of partial isolation from the productive world.

You let me "know me again".

Thank you.

M. D.

Keep in mind that the feeling you have is loneliness!

You feel abandoned... alone in facing the chronic illness... it's terrible!

Thanks to you and this course I feel better!

Anonymous

It is difficult to enclose in a sentence the significance of the course and what has transmitted... but if we wanted to condense it, I would say so...

During these months with you, you helped us to understand a stage of life, tragic for sure but still life, giving us useful operational tips and not... you made us feel NOT ALONE!

You have given us more strength to deal with the difficulties because you have infused the HOPE!

Thank you so much.

C.P.

Very positive and engaging, it stimulates the sense of community.

A.S

An interesting course, conducted by competent and kind people.

Interestingly all the topics discussed.

Thank you for everything, for the time dedicated to us, for your availability.

It is obvious the love you dedicate to your work. Thank you!

L.

with these few lines I WANT TO THANK YOU for this unforgettable experience. Thank you for your generosity of mind.

Thank you for your attention, professionalism and patience.

Thank you for being always available to answer every request.

Thank you for everything you've taught us.

Thanks from the depths of the heart.

We hope to have the opportunity to meet you again.

S.

Thank you very much for your dedication, for the professionalism with which you have exposed the lessons, for how you answered all the questions and for your patience.

I have noticed the joy you have in carrying out this project, I have noticed the love and the esteem you have among you. It helps me to think of you, do a wonderful job with the sick.

I will remember each of you.

D.

At the Direction of the training course for caregivers, promoters, nursing director, at the VOINOI listening center.

We would like to express our sincere gratitude to the caregiver course, which has provided us with a valuable help to help our families get sick.

Our initial expectations have been broadly overcome for various reasons.

The various professional figures have clearly and highly professionally exposed the topics argued in a joyful and passionate way. We have noticed the desire to convey knowledge and to let us learn what we already have to put into practice in various family situations.

It was helpful to note a unity of intent, which some voice summed up in "service philosophy". We hope it will be reopened over the next few years.

Thank you very much for each one.

D.A.V. e V.

It was a positive experience and I am very pleased to have attended the course.

The welcoming and pleasant environment. The polite, courteous, reliable, professionally prepared and humble staff in the most generous and precious meaning of the term, and ultimately, so important, full of healthy contagious enthusiasm.

Thanks for everything!

P.

The course was very interesting: there were deep topics that I knew in a very "generic" way and so it was very useful to look into it.

I thank the CAMPUS and all the staff for the expertise, kindness and clarity of the show.

Thank you again and congratulations for this initiative.

A.P.

Get Caregiving Support. We support family caregivers and aging in place. Search for Home Care. Need Caregiving Advice? Ask Nurse Clare. As a former home health care nurse, I have spent a considerable amount of time helping family caregivers deal with the challenge of preventing bedsores. I will pass on some practical tips and care techniques regarding effective bedsore prevention that I have learned through my own and other's experiences. Some states provide programs that pay family members to care for loved ones at home however they are usually somewhat limited. These programs vary widely from state to state and even within the same state. Although most states offer some type of respite or temporary relief for family caregivers, they often. Bringing Cancer Care Home. Engaging dental professionals in collaborative care with other health care providers and delegating areas of the care pathway to the interprofessional team can provide better outcomes for preventing early childhood caries. Currently, almost all states reimburse (through Medicaid) primary medical providers for oral health preventive visits. Effect of training pediatricians and family physicians in early childhood caries prevention. *J Pediatr.* 2015;166:1055-1061. The formal continuing education programs of this program provider are accepted by the AGD for Fellowship/Mastership and membership maintenance credit. Approval does not imply acceptance by a state or provincial board of dentistry or AGD endorsement. The current term of approval extends from 7/1/2019-6/30/2022. Resources for health care leadership. Amid the COVID-19 global outbreak, it's likely to be a stressful time for those who work on the front lines of health care. Featured updates: COVID-19. Track the evolving situation with the AMA's library of the most up-to-date resources from JAMA, CDC and WHO. Read the Latest. One system reported a program in which staff members who must stay home to care for their children are still paid their regular rate if they agree to care for children of two other staff members. Personal protective equipment (PPE). Personal protective equipment (PPE). Consider making mental health resources available to families of clinicians (PDF), as traumatic experiences from COVID-19 will affect them as well. Health care for spouses, dependents, and family caregivers. If you're the spouse, surviving spouse, dependent child, or family caregiver of a Veteran or service member, you may qualify for health care benefits. In certain cases, you may also qualify for health care benefits due to a disability related to your Veteran's service. Find out if you qualify and how to apply. TRICARE. This program offers support and services for family caregivers of eligible Veterans who were seriously injured in the line of duty during certain time periods and meet other eligibility requirements. Services for eligible participants may include a financial stipend, access to health insurance, mental health counseling, caregiver training, and respite care. Learn more about eligibility and how to apply.