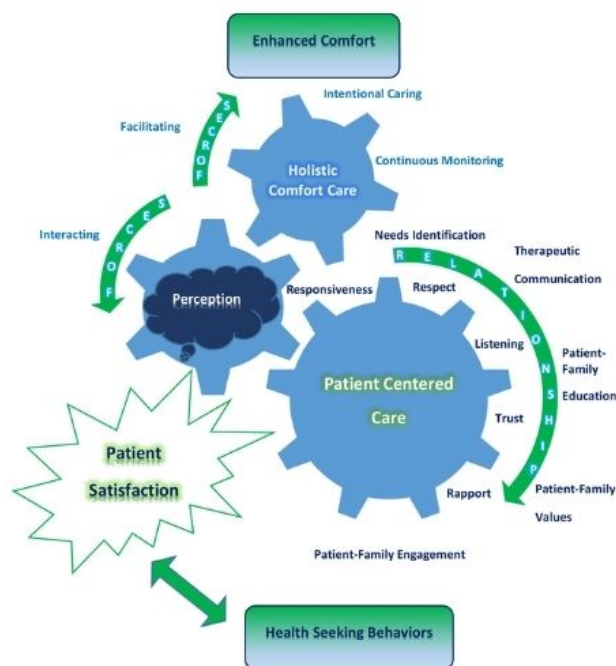


Cancerworld

The case of the caregivers

Adriana Albini / 14 July 2021



The seventh [SPCC Webinar “Spotlights on Improving Efficiency in Cancer Care”](#) entitled [“The case of the caregivers”](#) was held on June 23, 2021. During the webinar after the introduction and speech by Andreas Charalambous, Professor of Oncology and Palliative Care at the Cyprus University of Technology, Adjunct Professor at the University of Turku in Finland, President Elect of the European Cancer Organization, three experts from different professional backgrounds and contexts presented stimulating and diverse perspectives on the subject.

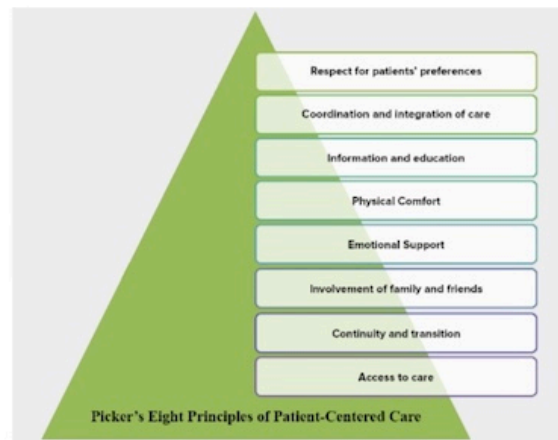
Andreas Charalambous, also member of the Scientific Advisory Board of the SPCC presented on:

Is there a role for (informal) caregivers in cancer care efficiency?

Informal caregiving is a concept subject to different interpretations, but it can be broadly defined as assisting personally and providing medical care, performing household tasks, arranging for outside services, visiting regularly, or helping with coping, by someone who is not paid for doing so. The role of the informal caregiver is usually assumed by a relative, a friend, or a significant other, who may or may not live in the same household as the care recipient.

Patient-centered care

Can be defined as
“providing care that is respectful of, and responsive to, individual patient preferences, needs and values.”



The role of the informal (and formal) caregiver supports the principle “outpatient before inpatient”, when patients can be nursed in their home environment. Although it is not easy to get a precise estimate, around 4.6 million people in the United States alone care for someone with cancer at home. Even in countries with a well-developed supply of formal long-term care, the number of informal (family) carers is estimated to be at least twice as large as the formal care workforce. Estimates also suggest that the economic value of unpaid informal care, as a percentage of the overall cost of informal long-term care provision, in the EU is a massive 50% to 90%.

According to studies by EUROFARMCARE and SHARE, around 19 million individuals are providing care to an older individual, not specifically a cancer patient, in Europe. The number of informal caregivers is on the increase, a trend that is likely to continue because many treatments are now provided in ambulatory or home settings, patients tend to live longer (but often with long-term consequences of the illness and treatment), and healthcare resources are limited. The number of people in need of care is projected to rise by 115% in the European Union between 2007 and 2060, while in the US it is expected to double, from 13 million in 2000 to 27 million in 2050. The shift towards community-based care for cancer patients increases the likelihood of a family member assuming the role of carer. This is further strengthened by the patients’ own preference to receive care, primarily supportive care, in their home, or home-like environment.

Health systems are shifting gears. Around the world, we are witnessing ground-breaking health reforms and new ways to deliver care, some prompted by the SARS-COV-2 pandemic, which has created new needs, as well as challenges, also for informal caregivers. We are transitioning from a provider and procedure focussed system to one that puts the patient at the centre of care. Patient-centred care can be defined as “providing care that is respectful of, and responsive to, individual patient preferences, needs and values.” In this context, the critical role that family caregivers play in the patient’s satisfaction and health outcomes is acknowledged and embraced. Placing patients at the centre of care should not only be considered a desired model of care, but also viewed as a means for achieving better efficiency in cancer care. The family caregiver can become the mediator between the provider and the patient, helping and facilitating the care to be more patient centred.

Patient-centered care

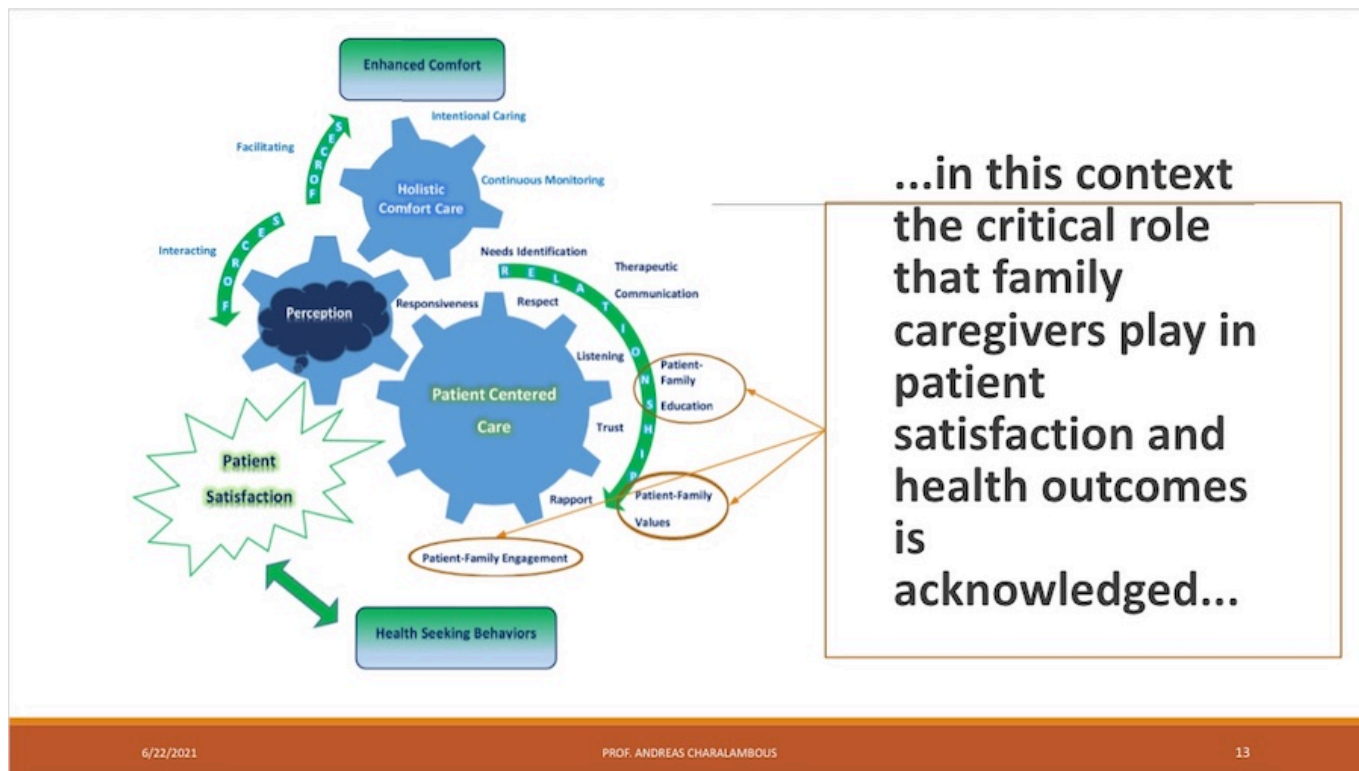
Patient-centered care is the practice of caring for patients (and their families) in ways that are **meaningful** and **valuable** to the individual patient



Caregiving is a rewarding but also demanding and challenging role for the person who assumes it. It encompasses nursing, emotional, and practical domains, and entails many duties, such as managing symptoms, administering medication, assessing the response to therapeutic interventions, and administering medical treatments. Informal carers contribute greatly towards an efficient cancer care by ensuring that the best possible health outcomes are delivered to the patient, e.g., through maintaining the continuation of care after the person is discharged from hospital, or assuring adherence to treatments. Informal caregivers also play an important part in breaking down silos, as they are often the go-betweens for the service providers and the individuals in need of care. Unfortunately, they can themselves experience negative outcomes, such as caregiver- and psychosocial burden, psychiatric morbidity, sleep disturbances, fatigue, and vulnerability to infections. Negative outcomes on the caregiver can also reflect upon the patient, and ultimately have a wider impact on society as a whole.

To become and remain drivers of cancer care efficiency, informal caregivers need appropriate and consistent support. It is important to “care for the carers” because studies systematically indicate that while looking after someone with a chronic disease, such as cancer, they may be less likely to meet their own health needs, by eating a poor-quality diet, neglecting medical appointments, cancer screenings, and so on. Carers may face higher allostatic load levels and have higher levels of mortality and morbidity as they age. Measures are needed throughout the care continuum, to help caregivers maintain their everyday living and their sense of normality and control over life. There are several ways to achieve this. For example, the Prolepsis Project (prevention in Greek), is being developed by Prof. Charalambous and his team, to provide a mobile phone-based health intervention for female caregivers that promotes and supports individually tailored preventive behaviours. Caregiving has many positive personal outcomes for the informal (family) carers, most of whom would describe it as inspiring, rewarding, and life enriching. Instead of regarding the positive aspects of caregiving and its burden as bipolar ends of a continuum, the two dimensions can be seen as a case of coexistence and as such, supportive measures to strengthen the positive experience of caregiving can be introduced throughout the continuum.

In conclusion, it is crucial to support the role of the caregiver across the care continuum as a mediator that can influence and support the provision of care efficiency.



The second presentation was by **Elizabeth Hanson**, Professor of Health Care Sciences, Linnaeus University, Sweden, Swedish Family Care Competence Centre, and Eurocarers Board member.

Supporting caregivers to optimize their role

Informal carers comprise approximately 10-20% of the total EU population. They are often a family member, predominantly a wife or a daughter, but they can also be a friend or neighbour. Women provide 2/3 of all care. The estimated value of informal care in Europe is between €320 & 368 billion – a substantial figure. Without the input of informal carers, our health and social care systems would almost certainly collapse overnight. Within the European policy context there is a strong focus on cancer right now, particularly with the ambitious Europe’s Beating Cancer Plan. Eurocarers – the European network representing informal carers and their organizations – has welcomed the plan’s clear recognition of the crucial role of informal carers. In collaboration with the European Cancer Patient Coalition, Eurocarers has produced a joint white paper outlining the role of cancer carers and their needs for support. An online Cancer Carers Toolkit was also co-produced, a useful information resource with tips and tools for carers of cancer patients.

The impact of caring varies, some caregivers find it intrinsically satisfying, meaningful, and rewarding, whereas others perceive it as stressful and burdensome. Women to a greater extent than men experience caring as physically and mentally demanding. Higher intensity caring, entailing more demanding tasks and longer hours, often carries a ‘triple penalty’: it can impact one’s own health and wellbeing, upset the balance between work, life, and care, and affect one’s social situation. Many carers can become socially isolated and excluded. They might also experience financial restrictions, because of the need to reduce their paid working hours, or even leave the workforce altogether to provide care for a sick relative. The COVID-19 pandemic has brought the spotlight on informal carers, as their situation has been exacerbated, with patients relying more on home care, and less support services being available both for caregivers and recipients.

Although most family members wish to care, not everyone does. Some relatives and friends may prefer to remain just that and not take on a caring role. Some may be ambivalent; some may be anxious about it. In the scenario of a conflict-filled relationship, for instance, assuming a caring role

may lead to further strain. Choice here is key. Caring is not a static experience; it changes over time in response to the illness trajectory of the patient. For example, there can be more intensive periods of caring during the course of chemotherapy, followed by a relatively stable time, and so on. It is important that health care professionals work in partnership with families. For those **carers who wish to care**, the main goal should be to enable them to go from novice to “co-expert” as smoothly and quickly as possible, by providing information, education, training, and support tailored to the needs of the individual and the phase of caring they are facing. Healthcare professionals should carry out a carer assessment to explore to what extent a family member wishes to care for the patient, if at all, and to agree with both caregiver and recipient which tasks they prefer to carry out, which they would like to be helped with, and which they do not want to do at all. Top of the list of needs expressed by carers, time and again, is information. It would therefore be useful to assess the individual carer’s information needs and level of health literacy, including digital, in order for health carer professionals to present the appropriate information accordingly. It is also important to establish the carer’s preferred role in decision making together with their relative with cancer regarding the course of treatment of their relative. Many carers often request education and skills training because they want to do caring well and safely, without hurting their loved one or themselves. Education and training today can come in many formats: courses, individual or group sessions, and so on. Commonly the topics include the cancer illness, treatment, prognosis, coping strategies, planning ahead, and available supports. Multi-component psychoeducation seems to be more effective than single-component education. The core elements within multi-component psychoeducation are condition management, problem solving, communication skills, and assertiveness skills training to boost one’s confidence and coping strategies.

Key take home messages

Involve carers as partners in health care alongside the person living with cancer:

- Recognise and reach out to potential carers as early as possible
- Assess each family situation – not all family members may want to take on a caring role!
- Provide tailored information on a regular basis
- Signpost carers to:
 - i) education and training opportunities
 - ii) local sources of support available
- Enable carers to put on their own life vest first!
- Respect and take into account the carer's lived expertise at every possible opportunity



All carers need support, especially high intensity carers, who may well have been overworked for a long period of time. It can be practical help, such as night sitting services, assistive devices, and home adaptations. Working carers should be granted access to paid leave or, if not possible, unpaid leave. Equally important is information on, and help with, the financial supports that are available, such as benefits and pension credits. Carers need emotional and psychological support as well, in the form of talking to someone they can trust, and individual or group counselling. For high-intensity carers, access to quality respite care is essential, and to receive regular physical and mental check-ups, as they tend to put their own health needs last. Healthcare professionals should reach out early

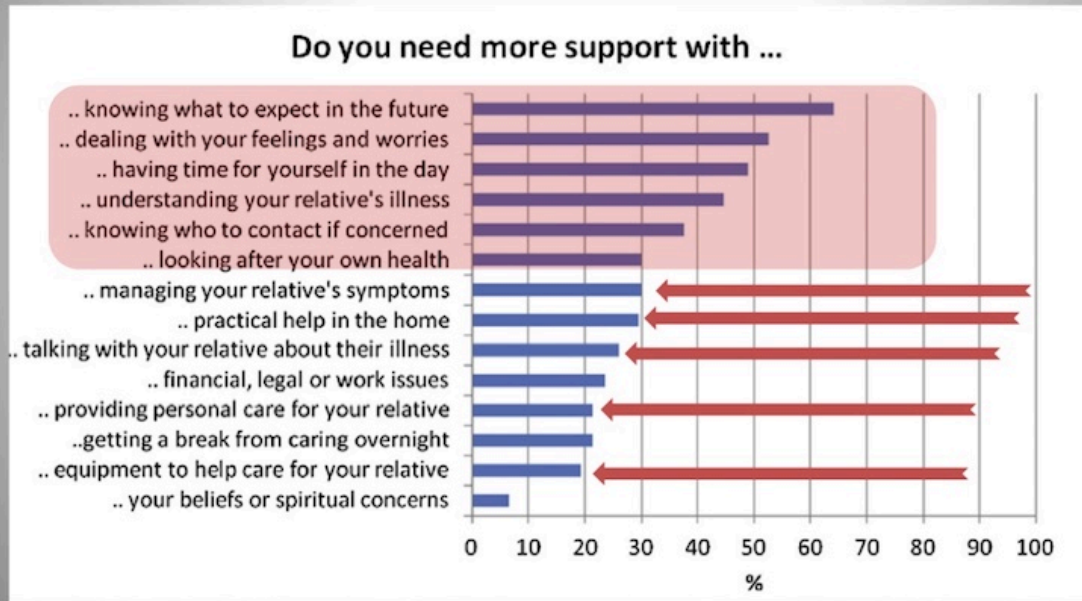
to family members and especially look out for those groups of carers who may be hidden from view, such as children and young adults, distance carers based in another part of the country or abroad, rural carers, and male carers, to name a few. A key strategy is to help maximize the positives and minimize the negatives of caring, that is, to encourage the carer to do those tasks they do well and enjoy doing, and arrange for help with the ones they do not want to do. Carers can benefit from sharing tasks with others, such as family members or friends, but also from receiving local professional support from the voluntary sector. Support to the carer should continue throughout the illness trajectory, and for a time after the end of treatment or following the death of the patient.

If adequately supported and based on choice, the caring experience can be an enriching one: a period of personal growth, leading to new roles and life opportunities.

The final presentation was delivered by **Sam Ahmedzai**, Emeritus Professor of Supportive Care, University of Sheffield, UK, NCRI Chair of Living With & Beyond Cancer Group

Challenges and opportunities: successful examples including breathlessness

There are many common symptoms in patients with cancer, especially, but not exclusively, in advanced stages, such as fatigue, constipation, breathlessness, anxiety, depression. Focussing on breathlessness, the symptom can arise from the disease itself, the treatment adverse effects and comorbidity. Among the diseases causing it are lung cancer, mesothelioma, lung metastases, lymphangitis, pleural effusion, VTE; adverse effects of treatment can include anaemia, acute/chronic pneumonitis (from chemotherapy or immunotherapy,) late radiation pneumonitis/fibrosis, cardiac toxicity, pneumonia. Respiration is also affected by the co-morbidity of conditions such as asthma, COPD, heart failure, ILD. Lastly, ageing can also contribute, as it brings many changes alongside the ones brought by cancer. Breathlessness is not necessarily the most common symptom in cancer patients, fatigue usually is, but it is certainly **the most frightening one**. When people with cancer, COPD, or other conditions, are breathless, they may fear they are about to die. Fear of immediate death is not as common as other symptoms, such as fatigue or even pain. For the family caregiver, watching a loved one struggling for air can also be very distressful. Some cancer patients may have had previous COPD or other lung diseases, and thus be already acquainted with dyspnoea, but now they may be faced with a different type of breathlessness, for which the strategies they used in the past offer little or no relief. For many, though, breathlessness is a new symptom, unlike pain, which most of us have experienced at some point. As such, patients and family caregivers may have no experience of how to manage it.



What is the current best practice for tackling breathlessness? The first line of action is to **manage any reversible cause**, such as airflow obstruction, anaemia, VTE, pleural or pericardial effusion. **Anti-cancer interventions** such as radiation, chemotherapy, immunotherapy should be employed to reduce or eliminate the underlying cause. **Oxygen**, non-invasive ventilation, is beneficial, but only for patients who are hypoxemic and/or hypercapnic. **Pharmacological** drugs can be administered: short and long-acting opioids, short and long-acting benzodiazepines or corticosteroids, but evidence of their effectiveness is limited and poor, while adverse effects are numerous. **Non-pharmacological** treatments include breathing training, pacing, lifestyle modifications, airflow over the face, relaxation, massage, acupuncture, and acupressure. There is a limited but growing evidence of their effectiveness, and there are few or no adverse effects. With all of these, informal caregivers can help. They can make use of a hand-held fan directed on the patient's face, help them to mobilize with walking aids, educate and inform them on strategies, such as activity pacing and positions to be in, and also use distraction techniques. When patients are given oxygen, they often feel better. In many cases this is a placebo reaction. The cool airflow across the face and nose reduces the sensation of dyspnea by activating the trigeminal nerve receptors, in exactly the same place in which oxygen is delivered. In other words, delivering oxygen is often just a way of delivering a facial airflow. A handheld fan, or a larger fan, or an open window, increases facial airflow, making people feel less breathless, and more relaxed.

Family caregivers are in the best position to know what the patient is experiencing, what the impact of a symptom, e.g. breathlessness, has on the patient's independence, their activity and quality of life. Carers can monitor whether a treatment is working or not and give feedback to the clinicians. They can also judge when to call for extra help. In the case of chronic breathlessness, carers can help the patient with mobility aids, and encourage them to take regular exercise. In acute periods of episodes of breathlessness, the physician can advise them to apply some of the non-pharmacological measures such as facial airflow, fan, opening window, they can think of ways to distract them, music, massage, relaxation, the view from a window. Even for severe end-of-life dyspnoea, caregivers can be instructed to give PRN or anticipatory medications, such as oral opioids, sublingual fentanyl, oral midazolam, even subcutaneous injections.

Education before hospital discharge is helpful to support and empower caregivers. To take the

caregiver to the bedside and helping go through everything that the patient needs to know and to have: what medications, at what time, and how they should be administered. An enhanced training program for cancer caregivers can also teach techniques like pursed lips breathing - used a lot in COPD - and positioning. Projects such as the Australian Caring@Home provide resources to train and support carers in their duties, including handbooks and factsheets. The role of a family caregiver covers a wide range of practical, physical, and emotional tasks. It is a commitment that can have a toll on their own health. To take good care of the patient but also of themselves, carers need tailored support. One of the tools available to them is the Carer Support Needs Assessment Tool. Based on research informed by carers and practitioners, CSNAT facilitates tailored support for family members and friends of adults with long term life-limiting conditions.

Supported and empowered informal caregivers play a fundamental role in improving efficiency in cancer care.

Our webinar had the purpose of underlining problems and needs related to informal and formal caregiving and to suggest pathways, education, strategies to make caregiving a more rewarding, less stressful activity, to the benefit of the cancer patient, the society and, equally important to the relief of the caregiver her or himself.