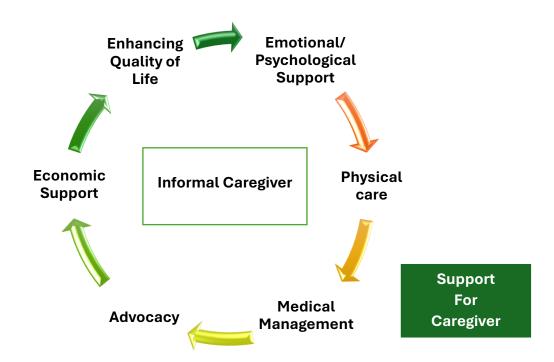
The role of Caregivers in the oncology setting

Francesca Cardone (Italy), EONS WG

The role of caregivers in the oncology setting is multifaceted and crucial for the well-being of cancer patients. With the rising incidence of cancer and longer survival, caregivers are increasingly vital in providing comprehensive support to those undergoing cancer treatment. Caregivers can be paid workers "formal caregivers", or oftentimes, they are friends or family members who provide care without economic compensation, known as "informal caregivers". This combination of increased incidence and longevity has resulted in the need for greater assistance from informal caregivers (Zabora et al., 2003).



Roles of caregivers:

1. Emotional and Psychological Support

- ✓ Providing Emotional Stability: Caregivers offer a stable and comforting presence, helping patients manage the stress that often accompanies a cancer diagnosis. They listen, empathize, and provide encouragement.
- ✓ Supporting Mental Health: Caregivers play a key role in recognizing signs of depression, anxiety, or other mental health issues, and can facilitate and anticipate access to professional mental health services if needed.

2. Physical Care

✓ Assisting with Daily Activities: Many cancer patients need help with daily activities such as bathing, dressing, eating, and mobility. Caregivers provide this essential support, helping patients maintain dignity and independence as much as possible.

✓ Managing Symptoms and Side Effects: Caregivers monitor the patient's symptoms and side effects, helping to manage pain, nausea, fatigue, and other common symptoms. They can provide medication, comfort measures, and liaise with healthcare professionals for further management.

3. Medical Management

- ✓ Medication Management: Ensuring that the patient takes their medications correctly and on time is a critical duty. Caregivers track prescriptions, administer medications, and watch for adverse reactions.
- ✓ Coordinating Medical Appointments: Caregivers schedule and accompany patients to medical appointments, ensuring that they receive necessary care and information. They also help communicate with healthcare providers and keep track of medical instructions.

4. Advocacy

- ✓ Advocating for the Patient's Needs: Caregivers advocate for the patient's needs. They ensure that the patient's voice is heard and that their rights are respected.
- ✓ *Making Informed Decisions*: In partnership with the patient, caregivers help make informed decisions about treatment options and care plans, often discussing the risks and benefits of different approaches.

5. Economic Support

- ✓ Managing Finances and Paperwork: Caregivers often help manage and provide to the patient's finances, reducing the burden on the patient and ensuring that all necessary documents are in order.
- ✓ *Providing Transportation*: Caregivers often provide or arrange transportation to and from medical appointments, treatment sessions, and other necessary outings.

6. Enhancing Quality of Life

- ✓ *Providing Companionship*: Companionship is a crucial aspect of caregiving, helping to alleviate feelings of loneliness and isolation. Caregivers spend quality time with patients, engaging in activities that the patient enjoys.
- ✓ Maintaining a Positive Environment: Caregivers work to create a positive and supportive home environment, which can significantly impact the patient's overall well-being and outlook on life.

Support for Caregivers

✓ Seeking Support and Respite: Caregivers also need to care for themselves as this role often comes with substantial burden and distress (Kent et al., 2016), which can lead to lasting, long-term negative health effects (Kim et al., 2015). They should seek support from friends, family, support groups, or professional counselling, and take regular breaks through respite care services. Health systems and nurses, need to acknowledge caregivers, assess their needs, and offer support as needed.

✓ Education and Training: Health systems should include caregivers in their educational programs, and include teaching regarding, symptom management, and other relevant topics to provide the best possible care. A recent study showed that enhanced training for informal caregivers, organized by nurses, resulted in short-term improvements in self-efficacy for managing patients' cancer symptoms, as well as reduced caregiver stress and increased preparedness for caregiving (Hendrix et al., 2016).

Conclusions

The role of caregivers in the oncology setting is comprehensive and demanding (LeSeure & Chongkham-ang, 2015). Their indispensable interventions range from providing emotional support and physical care to managing medical treatments and advocating for the patient's needs. As integral members of the cancer care team, caregivers contribute significantly to the patient's quality of life and overall well-being, making their role indispensable in the journey through cancer treatment and beyond. Therefore, oncology nurses need to be knowledgeable on how to include informal caregivers in their treatment plans, and how to support their needs.

References

- Hendrix, C. C., Bailey, D. E., Steinhauser, K. E., Olsen, M. K., Stechuchak, K. M., Lowman, S. G., Schwartz, A. J., Riedel, R. F., Keefe, F. J., Porter, L. S., & Tulsky, J. A. (2016). Effects of enhanced caregiver training program on cancer caregiver's self-efficacy, preparedness, and psychological well-being. *Supportive Care in Cancer*, 24(1), 327–336. https://doi.org/10.1007/s00520-015-2797-3
- Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. S., Shelburne, N., Timura, C., O'Mara, A., & Huss, K. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, 122(13), 1987–1995. https://doi.org/10.1002/cncr.29939
- Kim, Y., Carver, C. S., Shaffer, K. M., Gansler, T., & Cannady, R. S. (2015). Cancer caregiving predicts physical impairments: Roles of earlier caregiving stress and being a spousal caregiver. *Cancer*, 121(2), 302–310. https://doi.org/10.1002/cncr.29040
- LeSeure, P., & Chongkham-ang, S. (2015). The Experience of Caregivers Living with Cancer Patients: A Systematic Review and Meta-Synthesis. *Journal of Personalized Medicine*, *5*(4), 406–439. https://doi.org/10.3390/jpm5040406
- Zabora, J. R., Loscalzo, M. J., & Weber, J. (2003). Managing complications in cancer: identifying and responding to the patient's perspective. *Seminars in Oncology Nursing*, 19, 1–9. https://doi.org/10.1053/j.soncn.2003.09.005