

ADDRESSING CAREGIVER'S NEEDS

Palliative care is about support of patients and their families or significant others, during the disease and for families also in the time of bereavement. In order to offer efficient support the needs of the caregivers have to be assessed. Caregivers are usually family members, but they can include every person that patient is naming as significant.

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1	Enter and present yourself amiably: Good morning. I am Dr. XXX, the YYY (hematologist, oncologist, or any other) of your relative. Please can you tell me who you are and what is your relation to the patient?				0 1 3
2	How are you feeling today? (Provide enough time to answer your questions) <i>(Perceive the caregiver's mood from the first moment it helps to understand if is the right moment to talk about the subject)</i>				0 1 3
3	Ask open questions to build initial rapport with caregiver: Mr. X, would you mind if we talked some time? Are there any specific concerns you would like me to address at this time? In case of a negative response: When would you prefer to talk? <i>(Leave the option to select other moment to discuss the subject if required. Conversation must be free and volunteer and caregiver's involvement is essential)</i>				0 2 5
4	In case you are in a home setting or in a hospital having patient and caregiver together observe the patient's environment, and his/her behavior towards his/her caregiver/s: Do they show close communication? How do they interact?				0 1 3
5	Ask the caregiver how he/she feels, and if there would be any specific concerns regarding the patient's care that he/she might like to address today. <i>(Identify a specific and sustainable role for the caregiver in the care plan, avoiding excesses of charges from a psychological, social and economical point of view. Patient's and caregivers needs are equally important for the efficacy of the care plan)</i>				0 2 5
6	Offer the caregiver the opportunity to discuss their concerns/needs in private <i>(We will offer them the option to analyze in objectively the real circumstances of care, thinking about the resources available for the caregiver to support the patients: physical, psychological, social and financial. In this way decision making about care plan will be considering caregiver as an active partner in the treatment that must be protected and supported)</i>				0 2 5
7	If the caregiver does not want to speak in private, offer your availability to discuss any possible concerns he/she might have.				0 1 3
8	If caregiver is willing to speak in private, ensure a comfortable space for the interview. <i>(To avoid interruptions, respect confidentiality and discuss in comfortable setting the care plan)</i>				0 1 3
9	Use active listening and emphatic communication <i>(promote a shared decision-making respecting patient's values, cultural background and respond to psychological or cultural requirements)</i>				0 3 6

10	How do you feel caring for patient X? (<i>Verify if caregiver requires psychological or spiritual support</i>)				0 1 3
11	Is there anything you might need in which we could be of any help? (<i>Verify if the type of resources available in health care service are enough to support the caregiver in his/her patient's care</i>)				0 1 3
12	Do you think your home is prepared to ensure proper care for patient X? Do you need any change/adaptation could be necessary (doors, bathroom, corridor railings, entrance ramp...)? (<i>Verify if home care is an possible and right solution for patient's and caregiver</i>)				0 1 3
13	Are you currently working? Do you think your present job is compatible with caring for Mr. X? If not so, what would be needed to make it compatible? (<i>Caregivers charges can impact on their life in term of economic losses and conflict whit their professional life. This point is important to evaluate the sustainability of care plan from the caregiver's point of view</i>)				0 1 3
14	Do you think your current economic resources might be appropriate to care for Mr. X? Do you have any concerns regarding how caring for Mr. X might strain your current economic resources? (<i>This aspect must be assessed in order to include any kind of social support for caregivers if available, or make decisions considering the limited resources</i>)				0 1 3
15	Regarding Mr. X's current care, do you think he could/would receive better care in another place? (<i>Admission to hospital, hospice facility, nursing home...)</i> (<i>Health care services available resources must be integrated to enhance caregivers' coping with care demands in term of time for displacement, social support, caregivers capacity to coordinate home care in patient's best interests</i>)				0 1 3
16	In case Mr. X would require emergency care or placement in another appropriate facility, do you know what steps to take? (<i>This aspects it's a way to discuss if caregiver can manage any change of the care plane due to the illness evolution and how to adequate his role to the new situation</i>)				0 1 3
17	Do you feel capable of caring for Mr. X? If not, why? How could we be of any help? (<i>Caregiver should have all the information required to make decision and offer the best care to the patient. Psychological and social support must be available in case of difficult situations, and optional and alternative course of action should be discussed if any doubts affect the caregiver</i>)				0 1 3
18	Could we help you in any specific aspect of Mr. X's care? (<i>It helps to detect aspects not previously considered</i>)				0 1 3
19	Considering the evolution of Mr. X disease, and as you see him now, do you think his needs might be overwhelming for you at some point? If so, what would you fear, and why? (<i>A final assessment of the interview could help to understand caregiver satisfaction for the care plan and overcome barriers and obstacles</i>)				0 1 3
20	In the event that the end of Mr. X might come at home, do you feel prepared? Do you feel you have enough resources to provide care under those circumstances at home? (<i>It is really important consider the caregiver will and motivation to care patient at home, in case of doubt think about a psychological support</i>)				0 1 3

21	Do you feel alone? Do you have any support while caring for Mr. X?	ESSENTIAL		
22	Show disposition for any further enquiry, and inform caregiver how to contact you again. Ask again if the caregiver has any final questions or worries.			0 2 5
23	Take leave amiably.			0 1 3
24	Document the summary of the conversation in patient's file			0 1 3
Total score: 80		<input type="radio"/>		%
		<input type="radio"/>		%
		<input type="radio"/>		%

Legend: – unfulfilled criterion; - partially fulfilled criterion; – completely fulfilled criterion
(score according to column P)

Selective references

1. Bee PE, Barnes P, Luker AL. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of Clinical Nursing* 2008; 18:1379-1393