

Palliative Care in Cancer Patients - The Main Caregivers Point of View

Davidovitch T^{1,2}, Livshits E², Yarom N^{2,3}, Nissanholtz Gannot R¹

¹Public Health Management Program, Ariel University, Israel. ² Oral Medicine Unit, Sheba Medical Center, Israel. ³ School of Dental Medicine, Tel-Aviv University, Israel.

Introduction

Palliative care including pain management, was recognized as a major factor affecting the wellbeing of cancer patient as well as their family members. Over the past years palliative care has established rapidly in many countries. In this study we would like to assess the steps made by the Israeli Ministry of Health since their policy was established in 2009. The scope of palliative services provided in Israel has improved in the last decade, but we find it still quite limited, considering the needs of the population, and it unfortunately does not measure up to the level of services provided by different developed countries over the globe.

Our aim is to review the extent of palliative measures available to the Israeli cancer patient and his caregivers. We wish to question the availability of these services, as well as the quality, variability and extent of these services that the patients are susceptible to. ^{1 2}

Methods

Validated questionnaires such as the FAMCARE scale, and GAD-7 scale that are validated in the Hebrew language, were filled out by the primary family caregiver. Data extracted from each questionnaire was synthesized by statistical analyses. We present the preliminary results of a total of 20 cancer primary caregivers that were recruited from a single tertiary medical center. The scales achieved a high level of internal consistency.

GAD-7 Anxiety

Over the last two weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid, as if something awful might happen	0	1	2	3

Column totals: + + + + +
Total score: _____

Scoring GAD-7 Anxiety Severity

This is calculated by assigning scores of 0, 1, 2, and 3 to the response categories, respectively, of "not at all", "several days", "more than half the days", and "nearly every day".
GAD-7 total score for the seven items ranges from 0 to 21.

0-4: minimal anxiety
5-9: mild anxiety
10-14: moderate anxiety
15-21: severe anxiety

FAMCARE Scale

Instructions: Think about the care that your family member has received. Please answer the questions below indicating how satisfied you are with the care received: very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D), or very dissatisfied (VD). Please circle the letters below that best match your experience.

How satisfied are you with:

1. The patient's pain relief	VS	S	U	D	VD
2. Information provided about the patient's prognosis	VS	S	U	D	VD
3. Answers from health professionals	VS	S	U	D	VD
4. Information given about side effects	VS	S	U	D	VD
5. Referrals to specialists	VS	S	U	D	VD
6. Availability of a hospital bed	VS	S	U	D	VD
7. Family conferences held to discuss the patient's illness	VS	S	U	D	VD
8. Speed with which symptoms are treated	VS	S	U	D	VD
9. Doctor's attention to patient's description of symptoms	VS	S	U	D	VD
10. The way tests and treatments are performed	VS	S	U	D	VD
11. Availability of doctors to the family	VS	S	U	D	VD
12. Availability of nurses to the family	VS	S	U	D	VD
13. Coordination of care	VS	S	U	D	VD
14. Time required to make a diagnosis	VS	S	U	D	VD
15. The way the family is included in treatment and care decisions	VS	S	U	D	VD
16. Information given about how to manage the patient's pain	VS	S	U	D	VD
17. Information given about the patient's tests	VS	S	U	D	VD
18. How thoroughly the doctor assesses the patient's symptoms	VS	S	U	D	VD
19. The way tests and treatments are followed up by the doctor	VS	S	U	D	VD
20. Availability of the doctor to the patient	VS	S	U	D	VD

Figure 1. FAMCARE-2, GAD7 Questionnaires

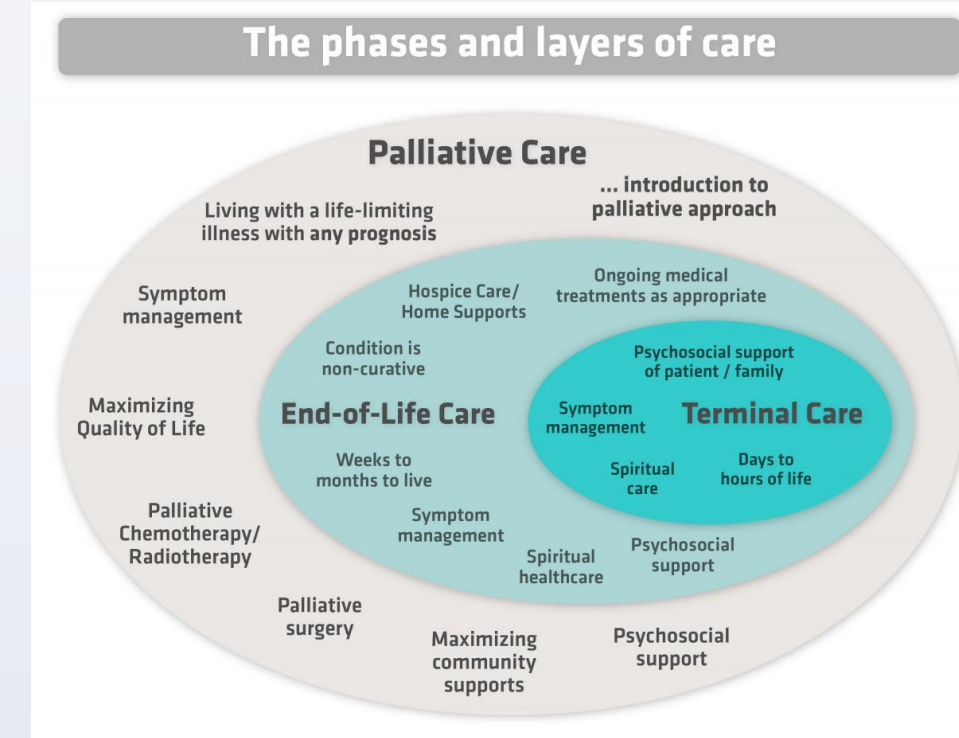


Figure 2. layers of Palliative Care ⁸

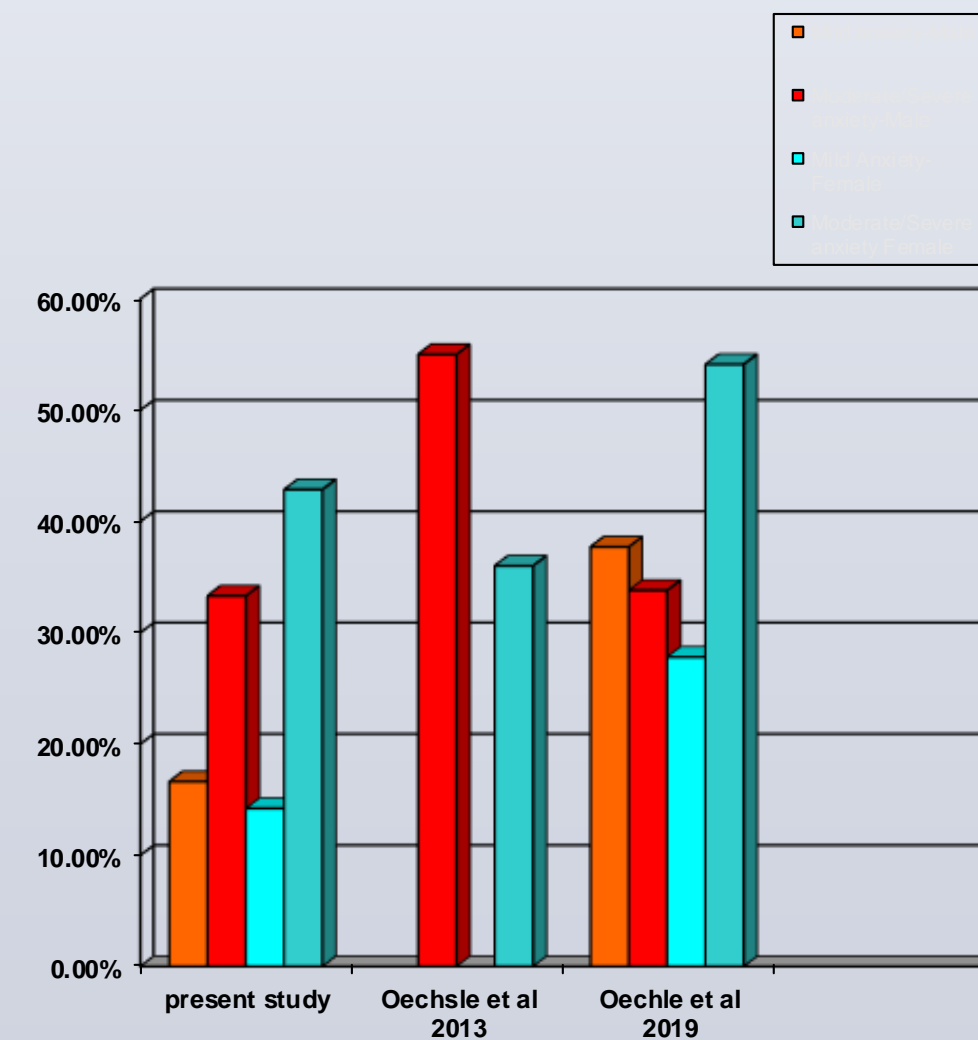


Figure 3. GAD7 anxiety charts ^{6 7}

subscale	Present Study	Aoun 2010 ³	D'angelo 2017 ⁴	Ooraikul 2020 ⁵	
Management of physical symptoms and comfort	The patient's comfort	3.85	4.5	4.43	4.45
	Speed with which symptoms are treated	3.95	4.4	4.42	4.64
	Palliative care team's attention to the patient's description of symptoms	4.15	4.6	4.36	4.52
	The way in which the patient's physical needs for comfort are met	3.95	4.6	4.34	4.48
	The doctors attention to the patient's symptoms	4.1	4.5	4.34	4.74
Provision of information	The way in which the patient's condition and likely to progress have been explained by the palliative team	3.75	4.4	4.39	4.53
	Information given about the side effects	4.25	4.2	4.14	4.48
	Meetings with the palliative team to discuss patient condition	3.85	4.3	4.38	4.50
Family support	Info. Given about how to manage patient symptoms	4.05	4.4	4.30	4.38
	Availability of palliative team to family	4.15	4.5	4.50	4.56
	Emotional support provided to family by palliative team	4	4.3	4.35	4.41
	Practical assistance provided by palliative team	4.25	4.3	4.30	4.48
Patient psychological care	The way family is included in decisions	4.35	4.4	4.33	4.63
	The respect of the palliative team of the patient's dignity	3.85	4.8	4.56	4.56
	The efficacy of managing the patient's symptoms	4.05	4.5	4.36	4.53
	The teams response to changes in patient's care needs	4.15	4.6	4.35	4.45
Emotional support provided to the patient by the palliative team		4.15	4.5	4.35	4.41
		68.85	75.8	74.2	76.75

Figure 4. FAMCARE-2 survey results in different studys. A comparison

Results

The preliminary results of our study revealed unsatisfactory palliative treatment in Israel, regarding education, patient psychological care and family support. Our total FAMCARE-2 scores suggest moderate satisfaction of the palliative care services in Israel when compared to other countries. Interestingly, the highest ranking question "The way the family is included in treatment decisions" (4.35), is similar to other studies, as well as the other questions in that specific subset – Family support. Unfortunately, the other subsets in our study ranked lower than the average and "Management of symptoms" exceedingly lower compared to the other studies. The prevalence of anxiety in caregivers reflecting from the GAD-7 was 42%, which is similar to the 34% to 43% reported in oversea studies. It is evident there are vast differences between the female and male caregivers as well as in comparison to studies performed in different countries over the globe.

Discussion

In Israel, palliative care is mandatory by law. Therefore, there is a need to improve the relationship between the family primary caregiver and the palliative team, and to perform a consistent evaluation of the satisfaction and feelings of the caregivers' family. In ill patients, especially in end of life situations, the family is an inseparable part of the treatment and difficulties, and they must be taken into consideration. It is recommended to expand our study population so as to assess the real situation regarding palliative treatment in Israel, so that it can be approached and improved accordingly.

References

- Bentur N et al. Progress in palliative care in Israel- comparative mapping and next steps. Israel J of Health Pol Res 2012;1:9
- Bingley A et al. A Comparative Review of Palliative Care Development in Six Countries Represented by the Middle East Cancer Consortium. J Pain and Symptom Management. 2009;37:3
- Aoun S et al. Reliability testing of the FAMCARE-2 scale-measuring family carer satisfaction with palliative care. Palliative Medicine. 2010;24:7
- D'Angelo D et al. Translation and Testing of the Italian Version of FAMCARE-2:Measuring Family Caregivers' Satisfaction With Palliative Care. J of Family Nursing. 2017;23:2
- Ooraikul L et al. Reliability and Validity Testing of the FAMCARE-2 Scale-Thai Translation. Asia-Pacific J Oncology Nursing. 2020;7:3
- Oechsle K et al. Anxiety and Depression in Caregivers of Terminally Ill Cancer Patients-Impact on Their Perspective of the Patients' Symptom Burden.J Palliative Medicine. 2013;16:9
- Oechsle K et al.Psychological burden in family caregivers of patients with advanced cancer at initiation of specialist inpatient palliative care.2019;18:102
- <https://hpc.providencehealthcare.org/about/what-palliative-care>