CARE FOR CARERS: AN INVESTIGATION ON FAMILY CAREGIVERS' NEEDS, TASKS, AND EXPERIENCES.

Zavagli V^1 , Raccichini M^1 , Ercolani G^1 , Franchini L^1 , Varani S^1 , Pannuti R^1 ¹ANT Foundation, Italy

(email corresponding author: veronica.zavagli@ant.it)

Abstract - Family caregivers have an essential active role in cancer patients assistance at home. They play a key role in the management of patients and provide some caregiving activities once provided only by professional caregivers. Often they are not adequately trained or prepared, however a systematic assessment of their needs is rarely practiced. For these reasons, this preliminary investigation was designed to better identify the needs and changes in the lifestyles of family caregivers of home cancer palliative care. Participants have completed a battery self-report questionnaires, including Caregiving **Tasks** Consequences and Questionnaire (CaTCoN), that measures caregivers' experiences (the extent of cancer caregiving tasks and consequences) and the caregivers' needs, mainly concerning the interaction with the health care professionals. The results confirmed that cancer caregiving is burdensome. Large proportions of caregivers experienced substantial caregiving workload as well as a range of negative consequences, e.g. lack of time for social relations. Furthermore, considerable proportions of caregivers experienced problems or had unmet needs regarding the interaction with health care professionals. Prominent problematic aspects included provision of enough information to the caregivers and attention to the caregivers' well-being and feelings. The assessment of caregivers' needs is a critical step for determining appropriate support services, providing high-quality care, achieving caregiver satisfaction, and decreasing caregiver burden. Findings of this investigation will certainly contribute to develop and publish Guidelines and to provide programmes and on-going education where caregivers feel supported in their role.

Keywords: caregiving, family caregiver, cancer, needs, oncological home-care, palliative home-care

I. INTRODUCTION

Cancer is a family disease and the World Health Organization has recommended approaching patients and their caregivers as a 'unit of care', focusing on the overall well-being of the patient-caregiver dyad rather than just on the patient.

In fact, the current health policy trend is to downsize acute-care hospitals and to transfer a greater portion of care at home, where family members form a substantial part of the care system. It leads an increased pressure mostly for family caregivers, bringing considerable responsibilities, needs and problems [1].

A "family caregiver" is considered anyone (parents, adult children, spouses...) who provides any type of physical and emotional care for an ill loved one at home [2]. Thus family cancer caregivers can be considered an extension of the health-care team, yet often they take on a new role for which they may not feel adequately prepared and are nervous or overwhelmed about what is expected of them. In fact, they find themselves having to perform new and unfamiliar tasks (giving medicines, assisting with meals, and performing medical and nursing procedures) and may experience a number of mixed emotions including anxiety, anger, and sadness [2].

Nowadays family caregivers are essential health team members: they play a key role in the management of patients with cancer and provide some caregiving activities once provided only by professional caregivers. Often they are not adequately trained or prepared and it is well known that caregiving to a family member with cancer might have health implications [3-9]. However limited research has investigated the psycho-physical disorders of home-cared cancer patients family caregivers and a systematic assessment of their needs is rarely practiced. In fact, evaluation is often informal and undocumented, making caregivers' needs less "visible".

Some studies indicate that caregivers' unmet needs are multidimensional and that they affect caregivers' health and well-being as well as the quality of care they provide to the patients [10-22].

Caregivers most frequently identify communication [10,14,16,19,21,22], information [10,18,19,21], assistance with personal care [11,12,16,17,19,20,22], support with technical daily tasks [11,18-20], respite care [11,13,15,19] and financial

assistance [14,20,22] as areas where more support would be needed.

In fact, one of the greatest unmet needs was an open, effective, adequate, and comforting communication healthcare professionals [10,14,16,19,21,22]. Caregivers said that the healthcare staff communicates without understanding and empathy [21], does not pay attention to the necessities of the patient's family [19], and that does not have sufficient time to answer their questions [21]. In a study, the participants said that one of their greatest needs was effective and comforting communication with friends and acquaintances too [22]. According to them, friends should understand the conditions of patients and their caregivers, avoid too many questions about the patient's condition, refrain from discussions of the future and the outcome of the disease. and avoid blame.

The need for more information was identified in several studies as well [10,18,19,21]. Caregivers wanted more information about the illness and how it would progress [19,20], often for the purpose of managing their lives and making decisions [10,22]. In addition, caregivers required more information about what to do at the time of the patient's death. [10,14].

Practical unmet needs were discussed in almost all the studies [11,12,16-20,22]. The greatest necessities were support for care and assistance (e.g. help with the patient's daily activities, symptom management, therapeutic drug monitoring, coordination for examinations and treatment, and equipment provision) and household tasks (e.g. housekeeping, caring for other family members, and other social responsibilities).

Among the psychosocial unmet needs were identified the lack of support with worries, fear of suffering and death, providing emotional support to the patient, and coping with an unpredictable future [10,15,17,22].

Moreover, most caregivers identified many negative reactions to caregiving, such as fatigue or weariness, depression, anger and sadness, financial stresses, and lack of time [14,15,20,22].

Given the interest of the theme and the literature data described above, this investigation was designed to better identify unmet needs and lifestyles' changes of family caregivers of home cancer palliative care and subsequently correlate them with the patients' functional status in order to investigate if caregivers' needs change as the patients' functional abilities change.

II. METHODOLOGY

Data collection has begun.

Participants are enrolled in Italy among the caregivers of the patients assisted by the National Tumor Assistance (ANT) Foundation through its 20 oncological hospitals at home.

ANT is an Italian no-profit Foundation that provides since 1985 free medical, nursing, psychological and social home care and support for cancer patients

through its 20 oncological hospitals at home in 9 Italian regions [23, 24]. ANT is one of the leading organizations in Italy in the field of palliative home care and pain management and since its foundation it has assisted more than 110.000 patients.

Till now data were collected from 87 family caregivers, but data collection is still in progress and the goal is to reach a sample of at least 200 caregivers during the coming months.

A summary of the characteristics of the subjects who took part in the investigation is presented in Table 1. The socio-demographic data of our sample confirm the characteristics already observed in the literature about cancer caregivers. In fact, this role is played mostly by women (70-80%) with an average age of 50-55 years [25].

Caregivers included in this study (I) are all living together with the patient; (II) are regularly providing care to their adult cancer patient at home since the time of diagnosis (by managing the symptoms/pain of the patient at home, giving personal care, supporting the patient in the house and hospital/bureaucratic settings and providing emotional support); (III) are not receiving any financial support for their caregiving work; and (IV) are 18 or older and played a key role in daily contact with physicians.

Participants filled out autonomously a battery of self-report questionnaires focusing on patient's Index of Independence in Activities of Daily Living (i), patient's Index of Independence in Instrumental Activities of Daily Living (ii) and Caregiving Tasks, Consequences and Needs (iii). They underwent tests during the home-care assistance provided by ANT Foundation and completed the first two questionnaires with reference to their patients' condition.

		Caregivers
	N	87
	Age [yrs]	62.2 ± 12.9
	Gender (male/female)	33/54
	Caregiver role:	
-	husband or wife [%]	66.7
-	son or daughter [%]	23
-	other relatives [%]	10.3
	Caregiving duration [mos]	
-	> 6 mos [%] < 6 mos [%]	92 8
	Employment [%]	39
	Years of Education:	
-	0-8 yrs [%]	46
-	13 yrs [%]	36.8
-	≥ 16 yrs [%]	17.2

Table 1 - Study Population

- i. The Activities of Daily Living (ADL) [26] is a scale that contains a series of basic activities performed by individuals on a daily basis. It includes the fundamental skills necessary for independent living at home or in the community and it comprises the following areas: grooming / personal hygiene, dressing, toileting/continence, transferring / ambulating, and eating.
- ii. The Instrumental Activities of Daily Living (IADL) [27] is a scale that contains a series of actions that are important to be able to live independently but are not necessarily required on a daily basis. It can be useful to determine with greater detail the level of assistance required by a sick person.
- iii. The Cancer Caregiving Tasks, Consequences and Needs (CaTCoN) [28] is a 72-item questionnaire that measures cancer caregiving *tasks*, *consequences* and *needs* mainly concerning information from and communication and contact with health care professionals. The validity and reliability of the CaTCoN were evaluated by using psychometric analyses and were found to be satisfactory.

In addition, socio-demographic data were retrieved (sex, age, marital status, education level etc.).

The investigation received a formal approval by the Area Vasta Emilia Centro Research Ethical Committee of Emilia-Romagna Region (CE-AVEC).

Participants gave informed written consent for participation to the investigation, data analysis, and data publication.

III. RESULTS

All analyses were conducted using SPSS 24.0 for Windows. Since the data collection is still in progress, these are preliminary results.

These preliminary results concern only the CaTCoN questionnaire.

For the total sample of caregivers, frequencies, mean and standard deviation scores for each CaTCoN item were calculated. The aspects perceived as most problematic by the total sample are pointed out following, using a cut-off of 30% of caregivers reporting problems or unmet needs [14]. The distribution of the caregivers' answers to the most problematic items is also shown in Table 2.

Caregiving tasks

Large proportions of caregivers experienced substantial caregiving workload: 91.2% of them provided some or a lot of practical help to the patient, 72.4% provided some or a lot of personal care, and 62.8% provided some or a lot of psychological support. Moreover, 51.7% of caregivers have felt to some or to a high degree responsible for keeping track of patient's

referrals and appointments for examinations and treatment, while 52.9% had spent a lot of time transporting the patient.

Caregiving consequences

Regarding the negative social consequences caused by caregiving, 35.6% of caregivers reported that they had not enough time for friends and/or acquaintances.

Caregiving needs

A great number of caregivers referred to problems or had unmet needs regarding the interaction with the health care professionals (HCPs).

Thirty percent (29.9%) of the caregivers reported that had received lacked information about how the health care system works in relation to treating cancer.

Of the caregivers, 60.9% reported that the HCPs in the hospitals rarely/never or only sometimes showed interest in whether they as caregivers have been able to handle the situation. More than half of the participants, 55.1% and 59.7% respectively, referred that the HCPs only rarely/never or sometimes paid attention to them and had shown interest in how they had been feeling.

Regarding provision of information, 32.2% of the caregivers reported that not enough time had been spent informing them and that often they had to ask the HCPs questions in order to get the information they needed (37.9%). Moreover, 32.2% of caregivers had to some degree lacked information about where to get help.

Finally, more than half of the caregivers reported that HCPs had not given them an unrealistically positive idea of the patient's situation (71.3%) or have deprived them of hope (66.7%).

IV. DISCUSSION

The main aim of the present investigation was to provide information about unmet needs and lifestyles' changes of the family caregivers of cancer patients assisted at home.

Family caregivers are an invaluable part of healthcare teams whose needs remain unmet despite their active role in patient care. In fact, it is well known that family caregivers often give priority to their patient's necessities, although they have multiple unmet needs that have a negative impact on their quality of life and consequently on the quality of care they provide to the patient.

The preliminary results confirmed that cancer caregiving is burdensome. Large proportions of caregivers experienced substantial caregiving workload related to practical help, emotional support, and transport. These findings are in agreement with previous findings [11,12,15,16-20,22].

Moreover, participants reported a range of negative consequences of being a caregiver, most commonly lack of time for social relations. Thus, in line with the literature [14,15,20,22], these preliminary results

CaTCoN single items			Frequencies	5%		Mean	S.D.
1. To what extent have you had to provide:	None	A little	Some	A lot	Don't Know/not relevant		
1a. Practical help to the patient?	1.1	5.7	35.6	56.3	1.1	2.51	0.680
1b. Personal care to the patient?	9.2	16.1	29.9	42.5	2.3	2.13	1.021
1c. Psychological support to the patient?	7.0	27.9 To a low	37.2	25.6	2.3	1.88	.951
	No, not at all	degree	To some degree	To a high degree	Don't Know/not relevant		
2. Have you felt that you have been partially responsible for keeping track of whether the patient has been referred and called for examinations and	14.9	19.5	27.6	33.3	4.6	1.93	1.149
treatments quickly and correctly? 3. Have you felt that you have had too much responsibility in relation to home care (personal	21.8	24.1	33.3	18.4	2.3	1.55	1.097
care, medications, etc.)?	No, not at all	Yes, a little	Yes, some	Yes, a lot	Don't Know/not relevant		
4. Have you spent time transporting the patient?	9.2	10.3	26.4	52.9	1.1	2.26	.994
6. Has the patient's cancer disease: 6c. Meant that you have not had enough time for (the	17.2	23.0	26.4	23.0	10.3	1.86	1.250
rest of) your family? 6d. Meant that you have not had enough time for (the rest of) your friends/acquaintances?	9.2	24.1	29.9	35.6	1.1	1.95	1.011
/	Always/almo st always	Mostly	Only sometimes	Rarely/Never	Don't Know/not relevant		
10. Have the health care professionals paid attention to you?	23	17.2	26.4	28.7	4.6	1.48	1.256
11. Have the health care professionals shown interest in how you have been feeling?	16.1	18.4	21.8	37.9	5.7	1.30	1.286
14. We would like to know whether you have lacked (more) information about different areas. Have you as a caregiver:	No, not at all	To a low degree	To some degree	To a high degree	Don't Know/not relevant		
14a. Lacked information about how the health care system works in relation to treating cancer?	14.9	32.2	29.9	21.8	1.1	1.62	1.026
14b. Lacked information about how long one has to wait at different times in the process?	16.1	40.2	25.3	14.9	3.4	1.49	1.044
14e. Lacked information about the illness and its course?	9.2	35.6	37.9	14.9	2.3	1.66	.925
	Always/almo st always	Mostly	Only sometimes	Rarely/Never	Don't Know/not relevant		
15. Have you received adequate assistance when you telephoned health care professionals to ask questions?	10.8	30.8	20	36.9	1.5	1.88	1.083
	No, not at all	To a low degree	To some degree	To a high degree	Don't Know/not relevant		
18. Have you felt that the health care professionals have given you an unrealistically positive idea of the patient's situation?	71.3	16.1	4.6	2.3	5.7	.55	1.086
19. Have you felt that the health care professionals have deprived you of hope?	66.7	10.3	8.0	9.2	5.7	.77	1.264
21. Do you think enough time has been spent informing caregivers?	16.1	32.2	41.4	9.2	1.1	1.47	.913
	Always/almo st always	Mostly	Only sometimes	Rarely/Never	Don't Know/not relevant		
22. Have you had to ask the health care professionals questions in order to get the information you have needed?	11.5	37.9	47.1	3.4	-	1.57	.741
23. Have you lacked being given information from the health care professionals, without having to ask for it yourself?	9.3	22.1	39.5	29.1	-	1.12	.938
29. Have the health care professionals in the hospitals shown interest in whether you as a caregiver have been able to handle the situation?	9.2	27.6	25.3	35.6	2.3	1.17	1.091
30. Have the health care professionals in the hospitals noticed and reacted to signals from you, if you have not been doing well?	5.7	3.4	14.9	56.3	19.5	1.17	1.608
	No, not at all	To a low degree	To some degree	To a high degree	Don't Know/not relevant		
33. Have you lacked information about where to get help as a caregiver?	31.0	32.2	17.2	8.0	11.5	1.37	1.313

Table 2 - Frequencies (%) and mean scores of responses regarding care-giving tasks and consequences (n = 87 caregivers)

demonstrate that being a caregiver is demanding and has its costs.

Finally, this investigation shows that information is an important element of cancer care. In fact, large proportions of caregivers experienced problems or had unmet needs regarding the interaction with health care professionals. Prominent problematic aspects included the provision of enough information to the caregivers and attention to the caregivers' well-being and feelings. These findings are in agreement with previous studies [10,18,19,21], showing that dissatisfaction with information is common to different countries. Therefore, hopefully, these results will lead the way for improving the information and the caregivers' satisfaction with the interaction.

Contrary to some previous research [14,20,22], financial consequences did not appear to be a significant concern for the participants in this investigation. Probably this is due to the fact that in Italy palliative care is available and financed by the government and charity organizations.

Thereby, this study also highlights several directions for future research. The findings of this investigation can be viewed as guidance for healthcare policy planning and the design of interventions for improving quality of life in family caregivers who are high risk. In fact, many European countries are introducing policies to support effective programs to enhance active and healthy ageing [29, 30]. Moreover, some studies have found that integrated care services, closely oriented to the needs of patients/users, multidisciplinary, and anchored in community and home care settings, can benefit informal caregivers [31, 32].

Obviously, this is a preliminary investigation and limitations must be acknowledged. The transferability of the findings to other settings and populations is limited. Our investigation was restricted to family caregivers of palliative cancer patients assisted at home, the results cannot be generalized across all treatment phases.

V. CONCLUSION

We strongly believe that the assessment of caregivers' experiences (caregiving tasks consequences) and needs, mainly concerning the interaction with the health care professionals, is a critical step for determining appropriate support services, providing high-quality care, achieving caregiver satisfaction, and decreasing caregiver burden. In fact, caregivers will feel their roles are validated and their needs become more visible. Moreover, the findings of investigations like these will allow implementing a series of personalized clinical and organizational actions aimed at intervening on the critical issues emerged (in particular, the theme of information).

This can constitute a basis for then develop and publish Guidelines and to provide programs and on-going education where caregivers feel supported in their role.

Furthermore, investigations of this kind can urge legislators to recognize the caregivers' figure. In fact, there is not yet a common European law that protects and improves the role and status of the caregivers and the different countries have a different cultural approach to the issue.

ACKNOWLEDGMENT

We would like to thank all the family caregivers that participated and will participate in the study. This work is possible only because they give their time and share their experiences with us.

REFERENCES

- [1] Hodges LJ, Humphris GM, Macfarlane G. A metaanalytic investigation of the relationship between the psychological distress of cancer patients and their carers. Soc Sci Med 2005;60(1):1-12.
- [2] Donelan KG, Hill CA, Hoffman C, Scoles K, Feldman PH, Levine C, et al. Challenge to care: informal caregivers in a changing health system. Health Aff 2002;21(4):222-231.
- [3] Kitrungroter L, Cohen MZ. Quality of life of family caregivers of patients with cancer: a literature review. Oncol Nurs Forum 2006;33(3):625-632.
- [4] Grov EK, Dahl AA, Fosså SD, Wahl AK, Moum T. Global quality of life in primary caregivers of patients with cancer in palliative phase staying at home. Support Care Cancer 2006;14(9):943-951.
- [5] Swore Fletcher BA, Dodd MJ, Schumacher KL, Miaskowski C. Symptom experience of family caregivers of patients with cancer. Oncol Nurs Forum 2008;35(2):E23-E44.
- [6] Robison J, Fortinsky R, Kleppinger A, Shugrue N, Porter M. A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. J Gerontol B Psychol Sci Soc Sci 2009;64(6):788-798.
- [7] Rohleder N, Marin TJ, Ma R, Miller GE. Biologic cost of caring for a cancer patient: dysregulation of pro- and anti-inflammatory signaling pathways. J Clin Oncol 2009;27(18):2909-2915.
- [8] Zavagli V, Varani S, Samolsky-Dekel AR, Brighetti G, Pannuti F. Worry as a risk factor for mental and somatic diseases. A research on home-cared cancer patients family caregivers. G Ital Med Lav Ergon 2012;34(2):B17-B22.
- [9] Zavagli V, Miglietta E, Varani S, Pannuti R, Brighetti G, Pannuti F. Associations between caregiving worries and psychophysical well-being. An investigation on home-cared cancer patients family caregivers. Support Care Cancer 2016;24(2):857-863.
- [10] Mangan PA, Taylor KL, Yabroff KR, Fleming DA, Ingham JM. Caregiving near the end of life: unmet needs

- and potential solutions. Palliat Support Care 2003;1(3):247-259.
- [11] Hudson P. Positive aspects and challenges associated with caring for a dying relative at home. Int J Palliat Nurs 2004;10(2):58-65.
- [12] Sharpe L, Butow P, Smith C, McConnell D, Clarke S. The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. Psychooncology 2005;14(2):102-114.
- [13] Goldschmidt D, Schmidt L, Krasnik A, Christensen U, Groenvold M. Expectations to and evaluation of a palliative home-care team as seen by patients and carers. Support Care Cancer 2006;14(12):1232-1240.
- [14] Jo S, Brazil K, Lohfeld L, Willison K. Caregiving at the end of life: perspectives from spousal caregivers and care recipients. Palliat Support Care 2007;5(1):11-17.
- [15] Friðriksdóttir N, Saevarsdóttir T, Halfdánardóttir SÍ, Jónsdóttir A, Magnúsdóttir H, Olafsdóttir KL, et al. Family members of cancer patients: needs, quality of life and symptoms of anxiety and depression. Acta Oncol 2011;50(2):252-258.
- [16] Given BA, Given CW, Sherwood PR. Family and caregiver needs over the course of the cancer trajectory. J Support Oncol 2012;10(2):57-64.
- [17] Harding R, Epiphaniou E, Hamilton D, Bridger S, Robinson V, George R, et al. What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. Support Care Cancer 2012;20(9):1975-1982.
- [18] Lambert SD, Harrison JD, Smith E, Bonevski B, Carey M, Lawsin C, et al. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. BMJ Support Palliat Care 2012;2(3):224-230.
- [19] Ventura AD, Burney S, Brooker J, Fletcher J, Ricciardelli L. Home-based palliative care: a systematic literature review of the self-reported unmet needs of patients and carers. Palliat Med 2014;28(5):391-402.
- [20] Lund L, Ross L, Petersen MA, Groenvold M. Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient: a survey. BMC Cancer 2014;14:541.
- [21] Lund L, Ross L, Petersen MA, Groenvold M. The interaction between informal cancer caregivers and health care professionals: a survey of caregivers' experiences of problems and unmet needs. Support Care Cancer 2015;23(6):1719-1733.
- [22] Hashemi M, Irajpour A, Taleghani F. Caregivers needing care: the unmet needs of the family caregivers of end-of-life cancer patients. Support Care Cancer 2018;26(3):759-766.
- [23] Casadio M, Biasco G, Abernethy A, Bonazzi V, Pannuti R, Pannuti F. The National Tumor Association Foundation (ANT): A 30 year old model of home palliative care. BMC Palliat Care 2010;9:12.
- [24] Varani S, Pannuti R, Pannuti F. Progetto Eubiosia: il modello della Fondazione ANT (Eubiosia Project: the

- ANT Foundation model). Fighting pain combattere il dolore 2014;1(3):40-43.
- [25] ISTAT. Caregiver: quanti sono, i dati ISTAT (Caregivers: how many are there, ISTAT data). [Internet] 2011 [cited 2017 March 23]. Available from: https://www.pmi.it/impresa/normativa/approfondimenti/1 49510/caregiver-quanti-i-dati-istat.html (Italian).
- [26] Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. Gerontologist 1970;10(1):20-30.
- [27] Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist 1969;9(3):179-186.
- [28] Lund L, Ross L, Petersen MA, Groenvold M. The validity and reliability of the 'cancer caregiving tasks, consequences and needs questionnaire' (CaTCoN). Acta Oncol 2014;53(7):966-974.
- [29] European Innovation Partnership on Active and Healthy Ageing. [internet] 2018. Available from: https://ec.europa.eu/eip/ageing/home_en.
- [30] European Innovation Partnership on Active and Healthy Ageing. Action Group A3, Renovated Action Plan 2016-2018. [internet] 2018. Available from:
- https://ec.europa.eu/eip/ageing/actiongroup/index/a3/key-documents en.
- [31] Janse B, Huijsman R, de Kuyper RDM, Fabbricotti IN. The effects of an integrated care intervention for the frail elderly on informal caregivers: a quasi-experimental study. BMC Geriatrics 2014;14:58.
- [32] Tziraki-Segal C, De Luca V, Santana S, Tramontano G, Romano R, Scattola P, et al. Creating a Culture of Health in planning and implementing innovative strategies addressing non-communicable chronic diseases. Front Sociol "in press" 2019.