Doi: 10.6092/2282-1619/2013.1.942

Mediterranean Journal of Clinical Psychology MJCP
ISSN: 2282-1619
Vol.I, N.3 (2013)

Original article

Palliative care home service. An explorative research on care workers in an integrated home-assisted center for palliative care

Maria C. Quattropani[1], Vittorio Lenzo[1], Rosalba Rossello[2], Ferdinando Grimaldi[2], Daniela Grasso[2]
[1] Department of Human and Social Sciences – Psychology Unit - University of Messina, Italy
[2] Palliative home care service ASP Messina, Consorzio SISIFO

E-mail corresponding author: mquattropani@unime.it

Abstract

The study aims at investigating the operators' impressions about the needs of patients and their families, their idea of palliative care, their moods and what they consider important in everyday clinical activity.

Specifically, the study involved a group of 20 operators in a home palliative care service. Data were obtained through a self-report questionnaire. The results find the operators' strong need to share their work experience. Moreover the whole team is reputed to be important. This work is considered to be a source of human and professional gratification rather than economic. Finally, according to operators home palliative care involve a strong interplay between the operators' technical skills and their human resources.

Keywords: cancer, final stage of life, palliative care in the home, care teams.

Introduction

Numerous scientific findings, better hygiene and health conditions, together with medical progress and technology have reduced the numbers of death rates in the course of the last centuries in developed countries. This has determined a rise in the number of people who live with acute or terminal illness, with few possibilities of healing. With this prospective, the population needs care and special assistance which represent a challenge for those responsible for public health.

A model example of this can be that of terminally ill neoplastic disease (Davies, & Higginson, 2004). Despite numerous and significant scientific progress in cancer disease, which have permitted a substantial improvement in therapeutic methods and also in the growth of patient outliving the disease, cancer today remains one of the most widespread illnesses and the main cause of death worldwide. Only in Sicily each year, figures show and average of 6.353 men and 4.507 women with malignant tumors (ReNcaM, 2004-2005).

Having cancer is not a single or acute stress event, but a chronic one which is considerably modified by other stressful events caused by other severe events (Aaronson, Ahmedzai, & Bergman, 1993).

The impact on psychological functions in the patient begins with communicating the diagnosed illness and rises in the case of progression towards its terminal phase. Changes in personal and interpersonal character are triggered, beginning with the diagnostic phase and extending to the patient's family.

New health policies, which reduce to a minimum the amount of time a patient spends in hospital, set their objectives to better the quality of life and limit the costs related to hospitalization. At the same time, requests to better cope with the illness are rising both physically and psychologically from those family carers who assist, the so-called "informal caregivers"(Carpiniello, 1992; Ferrel, Grant, Rhiner, & Padilla, 1993; Nijoboer, Tempelaar, & Sanderman, 1998). However, when the patients and their family members are faced with the terminal phase of the illness, characterized by the progressive loss of autonomy and the manifestation of physical and psychic problems, it seems of vital importance to provide adequate support of a multidiscipline care team who better respond to the complexities and needs of patients and their families.

Ethical questions related to the care of patients, tough influence in daily clinical practice, recurrent difficulties in controlling symptoms, continuous undertaking of responsibilities on difficult decisions cause repeated and extreme pressure on emotional and cognitive levels for those carers involved in palliative therapy.

The difficulties are frequently higher when the palliatives are dispensed in the patients' home by means of home care services. The multidisciplinary team deal with a personalized assistance plan relating to the patient's case and illness identity. With this in mind, carers acquire a particular importance, considering the lack of attention dedicated in the past to palliative therapies in health operations formation.

Give that a recent law number 38 of 2010 which introduced the extreme differences in palliative home therapies in Italy, studies now seem to be aimed mainly at organizational research (Age.Na.S., 2010) and less towards those aimed at exploring perception, behavior, feelings and specialists' objectives of various nature involving home care palliatives by doctors in General Medicine, palliative practitioners, professional nurses, clinical psychologists, social workers, etc.

At the same time, the research seems crucial as a guideline apt to better the quality of palliative therapies dispensed and the professional formation for the carers (WHO, 1990).

The peculiarity of palliative therapies, together with the numerous difficulties to adopt in full the methodologies in *evidence*-based (Tassinari, & Maltoni, 2004). Medicine, demand researchers to continuously put together data outlining the clinical reality by the carers. Unlike others types of intervention, the carers point of view, which is far from an eventual bias to control, represent an important link in research regarding the clinical effectiveness of intervention, even more when the setting is the patient's home.

From this point of view, this study aims to collect data from various aspects used in everyday clinical practice. Among these, the carers' need in relation to their patient and their family, their knowledge of palliative care, attitude and sensitivity which are important features in home-made palliative therapies.

Materials and methods

Subjects

The study specifically examines a group of twenty carers of the A.D.I.P. (Assistenza Domiciliare Interdisciplinare Palliativa) belonging to the A.S.P. (Azienda Provinciale Sanitaria), provincial health service for interdisciplinary palliative home care in Messina, supervised by the Consorzio SISIFO, a union of Social Cooperation.

Method

The explorative research was aimed at obtaining information from carers who involved on a daily basis in clinical practice in the patient's home. On one hand, the purpose is to locate the need and critical urgency and resources, on the other, to improve training and professional procedures in this field.

The data was collected between March and April 2012 using an ad hoc research criteria, distributed to the carers who examined various aspects (for example, the feelings towards those involved in the patient's needs and those of his family, work-related objectives and different aspects regarding the importance of doing well, in their state of mind, etc).

Instruments

The procedure is made up of data sheets. The first (*Sheet A*) contained information from the carers relating to age, gender, work and level of work experience, etc.

The second (*Sheet B*), consisted in data regarding perception, sensitivity, objectives, needs and knowledge of palliative therapy. The third (*Sheet C*) contained important data from the carers related to team work in palliative therapy in relation to each individual. Because of the diversity in each field and the information obtained in literature (Lenzo, Rossello, Grimaldi, & Quattropani, 2012), both empathy and technical criteria were related. A list of characteristics were extracted from a focus group which were performed on a limited numbers of operators. Regarding the evaluation of data sheets, B and C, a 7 point Likert Scale was used (from "not at all" to "very much") contextualizing the professional experiences of the carer.

Results

Data Sheet A

The research involved 7 Palliative Practitioners (PP), 5 Professional Nurses (PN), 4 Clinical Psychologists (CP), 1 Social Health Worker (SHW) and 2 Physiotherapists (P). There were 10 males and 11 female operators. The mean age was 34.5 years of age with a standard deviation (SD) of 6.5 years, while the average working years in the palliative therapy in the home equaled 4.50 years (SD = 3.6 years). Each carer had 10 patients at the time of the research. Furthermore, 12 operators were also employed in other work fields, 9 of which in Oncology.

Data Sheet B

The majority of the data indicates that the objectives were based on "bettering the quality of patient's life" and to "give relief for the symptoms" (in total 17 answers), followed by "ease of patient's pain" (15 answers).

Data also showed that the carers considered that the patients who were assisted at home for palliative treatment were less aware (3.7) of the meaning of the therapy with respect to their family (5.5). However, the results show that having a positive outcome on the carers work, the knowledge of the therapy by the family (6.3) is considered more important than that of the patient's (5.3). In addition, based on their professional experience, the carers considered the patient's needs in order of Helpfulness (6,4), medical and psychological (both 6.2), social (5.7) and spiritual (5.5).

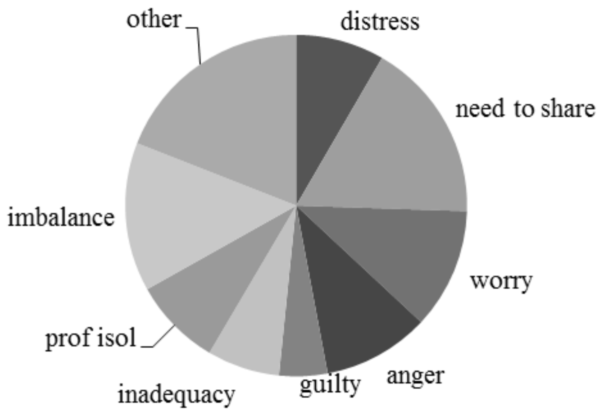
Based on their experience, the results show that the carers, first of all, view their work on a humane level, followed by the professional and economical with mean ratings 6.4, 5.9 and 3.9. Satisfaction on a compassionate level obtained the highest accord among the carers (DS =1), while a higher variance regarding economical satisfaction registered a higher standard deviation (1.7).

As seen in Fig. 1, the emotional state of mind experienced by the carers, especially in patient terminal phase, are divided into two aspects according to the Likert Scale. The "Need to share their work experience with colleagues" (4.5) and an "Imbalance between the resources at their disposal and the patient and patient's family needs" (3.7) are those collocated in a very high position.

In a lower position, "Worry" (3.0), "Anger" (2.7), "Sense of professional isolation" (2.2), "Distress" (2.2), "Inadequacy" (1.8) and finally "Guilt feelings" (1.2).

As shown, at the same time, there is a variation between the carers' answers, especially with "Need to share experiences with colleagues" (SD=1.9) and emotional state of mind "Anger" (SD=1.9) and "Worry" (SD=1.7).

Fig. 1. Emotional state of mind by carers



Another evaluation aimed at how much the palliative therapists reputed the importance of home palliative cares was the role of the professional figure involved. As shown in Table 1, column A, all professionals has been considered important with a score above 5 on the Likert Scale.

From the data, the most appreciated professional figure in home palliative care was the Professional Nurse (IP) (6.8) followed by the Palliative Practitioner (MP) (6.6), the "Social Heath Worker (OSS) (6.3) and Clinical Psychologist (PC) (5.7). Finally there are the General Medicine Doctor (MMG) and the Physiotherapist (FKT) both with 5.0.

There is no significant difference when the same question in used related to the specific professional experience as seen in Column B in Table A.

In fact, the carers give a lower point to MMG (4.4) while the others remain mainly on the same level (IP= 6.8; MP = 6.6; OSS = 6.4; PC = 6.0; AS = 5.4; FKT = 5.2).

Table 1. Importance reputed by professional figures

	GMD		PP		PN		CP		SA		SHW		P	
	A	B	A	B	A	B	A	B	A	B	A	B	A	B
M	5.1	4.4	6.6	6.6	6.8	6.8	5.7	5.9	5.4	5.4	6.3	6.4	5.1	5.2
SD	1.7	2.1	0.7	0.8	0.5	0.6	1.2	1.3	1.4	1.8	1.0	0.9	1.6	1.8

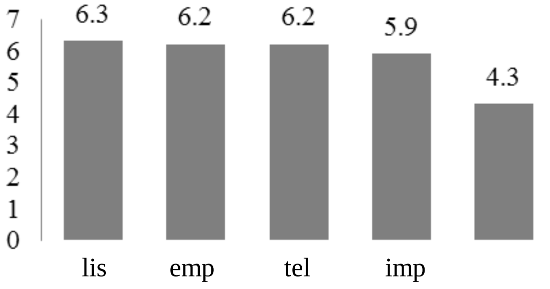
Notes: a = perception importance professional figures; b = perception importance professional figures related to their professional experience; GMD = General Medicine Doctor; MP = Palliative practitioner; IP = Professional Nurse; PC = Clinic Psychologist; SA =Social Assistant; SHW = Social Health Workers; P = Physiotherapist.

Data Sheet C

The results relating to data Sheet C regard the single role of the professional figure. As can be seen in Fig. 2 the carers awarded a very high score to the “Ability to Listen” related to the Palliative Practitioner who works in a team of home Palliative Therapists (6.3) followed by a score of 6.2 there are “Empathy towards the patient and his family” and “telephone availability out of his regular work hours”.

It also shows the importance of “importance of being firm and clear when explaining and agreement on therapy” and “punctuality and regular weekly appointments” which scored 5.9 and 4.3 respectively.

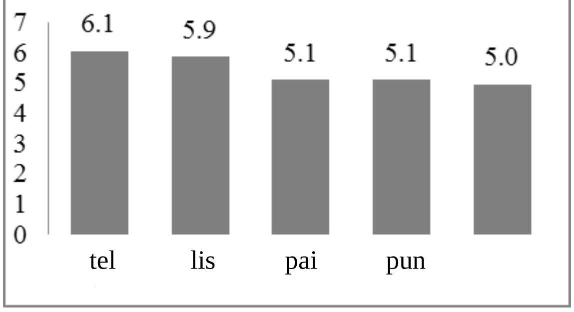
Figure 2. Palliative Practiotioner



Notes: lis = ability to listen; emp = empathy towards the patient and his family; tel = telephone availability; imp = Importance of being firm and clear when explaining; pun = punctuality in appointments.

In the case of the Professional Nurses, as can be seen in Fig. 3, telephone availability (6.1) followed by “Ability to listen” are the most important points. From the results, the importance of “Avoiding pain while maneuvering”, “Punctuality in weekly visits” and “Work-load schedule” obtained a 5.0 score.

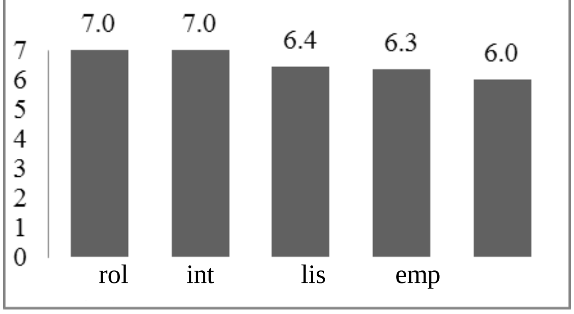
Figure 3. Professional Nurse



Notes: tel = telephone availability; lis = ability to listen; pai = avoiding pain while maneuvering; pun = punctuality in weekly visits; wor = work load schedule.

Regarding the Clinical Psychologist figure, the carers considered very important the "role specification and objectives of attending the patient and his family" along with "intrusiveness and discretion" , giving the maximum score on Likert Scale. Furthermore, from the results "Ability to listen" and "Empathy towards the patient and his family" scored 6.4 and 6.3 respectively

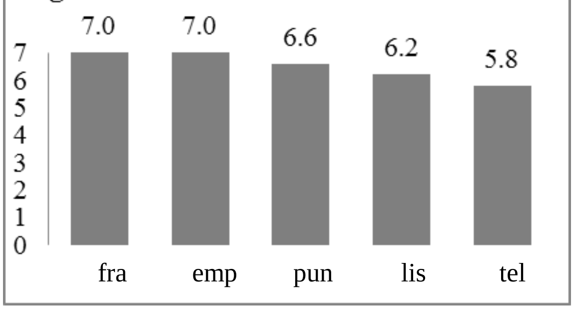
Figure 4. Clinical Psychologist



Notes: rol = role specification and objectives of attending the patient and his family; int = intrusiveness and discretion; ; lis = ability to listen; emp = empathy towards the patient and his family; pun = punctuality in weekly visits.

As can be seen in Fig. 5, in the case of the Social Assistant, the most important aspect is the "Frankness when describing the bureaucratic procedures" (e.g. aid) together with "Empathy towards the patient and his family" scoring 7.0. From the results, an important aspect can be seen in the "Punctuality in weekly visits" which scored 6.6. Finally, as for the other figures, another important aspect is the "Ability to listen" scoring 5.8

Figure 5. Social Assistant



Notes: fra = frankness when describing the bureaucratic procedures; emp = empathy towards the patient and his family; pun = punctuality in weekly visits; lis = ability to listen; rin = telephone availability.

As can be seen in Fig. 6 relating to the figure of the Social Health Worker, the results show the importance of "Ability to listen" and "Professional and technical ability" with a score of 6.6. Immediately followed by "work planning" (6.2) and finally the "Ability to talk" and "Empathy towards the patient and his family" (6.1).

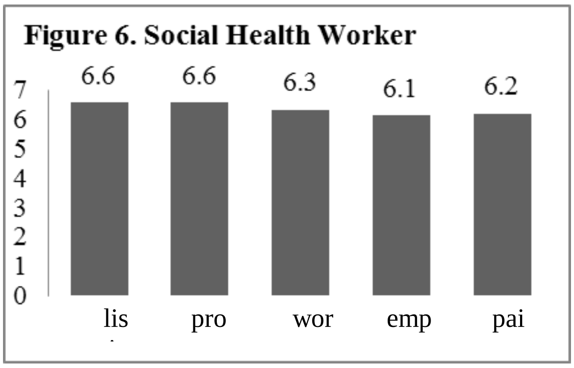


Figure 6. Social Health Worker

Notes: lis = ability to listen; pro = professional and technical ability; wor = work planning; emp = empathy towards the patient and his family; pai = avoiding pain while maneuvering.

Regarding the physiotherapist, as can be seen in Fig 7, the carers considered important three important sectors each scoring 7.0: “Professional and technical ability”, “Ability to listen” and “Empathy towards the patient and his family” followed by “Avoiding pain while maneuvering” (6.7) and finally “Punctuality in weekly visit” (6.1).

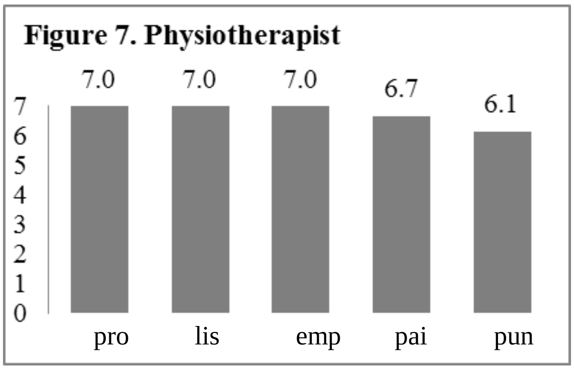


Figure 7. Physiotherapist

Notes: pro = professional and technical ability; lis = ability to listen; emp = empathy towards the patient and his family; pai = avoiding pain while maneuvering; pun = punctuality in weekly visits.

Discussion

Despite the restrictions are tied to the research project which limit the possibilities in generalizing the results obtained, in our opinion it is possible to formulate some important considerations. From results, a substantial group agreement on behalf of the carers regarding the objectives of palliative therapy. Although there is an important association between Palliative Therapy and Cancer Pain Therapy, this latter, for the carers seems to guarantee a better quality of life for the patient.

As can be seen by the results, the strategic role in relationship-wise aspects are often neglected by *evidence-based* medicine and in professional formation programs. The carers entrust great importance to work gratification on a human level rather than an economical or professional one. Another aspect which seems to distinguish the field of home palliative therapy is the value associated to the relationship with the family, an important and vital condition for the positive outcome of team work. From the results, a continuous comparison emerges on behalf of the work team with the patient and his family regarding the therapeutic approach, unlike the concept between the patient and his family which are characterized by a one-way and passive relationship.

The outcome of the carers’ replies show moreover, the close link, in each expert, between technical abilities and those relationship-wise, distancing the risk of considering palliative therapies exclusively as an additional sector of modern medicine.

The importance allocated to relationship-wise aspects such as the “Ability to listen”, “Empathy towards the patient and his family” clearly shown by the answers given from the carers, are a clear sign that these abilities become an essential part of professional formative training and not something confined to the sensitivity of those carers or professional figures.

As mentioned above, the relationship-wise aspects take on a strategic role in those figures who are more frequent in home palliative therapies and who have a amore emotional bond between the patient and his family, such as Professional Nurses and Social Health Workers.

Conclusion

The data obtained from this study still represent the first step of a wider project research which was partnered by the Home Palliative Therapy Unit of the Provincial Health Care in Messina and the University of Messina.

In agreement with the complexity of this specific area of intervention, the research aims to involved patients and their families together with the territorial carers.

Among the main objectives, there are those aimed at examining clinical intervention dispensed by the service, starting from the different stand points. Furthermore, research sets out to explore how the effectiveness is tied to the operation of a multidiscipline team of experts and to the relationship with the patient and his family.

Obtaining results can permit, on the one hand, to implement operation of increasing importance, starting with the patient and his family's needs and, on the other, to build a formative path leading to more focused requirements by carers.

References

Davies, E., & Higginson, I.J. (2004) (eds.). *The solid facts. Palliative care*. World Health Organization.

Atlante sanitario della Sicilia - Registro nominativo delle cause di morte (ReNcaM) dati D.O.E. Regione Sicilia anni 2004-2005.

Aaronson, N., Ahmedzai, S., & Bergman, B. (1993) The European organization for research and treatment of cancer QLQ-C30: a quality-of–life instrument for use in international clinical trials in oncology. *Journal of International Cancer Institute*, 85, 365–376.

Carpiniello, B. 1992. “Family burden e disturbi mentali”. In Carpiniello B. (ed.), La dimensione psicosociale in Psichiatria (pp. 284-305). Cagliari: Saredit.

Ferrel, B.R., Grant, M.M., Rhiner, M., & Padilla, G.V. (1993). Home care: maintaning quality of life for patients and family. *Oncology*, 3, 136-40.

Nijoboer, C., Tempelaar, R., & Sanderman, R. (1998). Cancer and caregiving: the impact on the caregivers health. *Psychooncology*, 7, 3-13.

Age.Na.S. (2010). *Le cure palliative domiciliari in Italia*. I Quaderni di Monitor, 7° Supplemento al numero 26 di Monitor.

Tassinari D., & Maltoni M. (2004). *Outcome research e cure palliative. Concetti generali e aspetti applicativi della ricerca di esito alle cure palliative*. Roma: Il Pensiero Scientifico Editore.

Lenzo V., Rossello R., Grimaldi F., & Quattropani M.C. (2012). *Le cure palliative nella mente degli operatori. Uno studio esplorativo*. Atti del I° Congresso Internazionale "Dinanzi al morire: percorsi interdisciplinari dalla ricerca all'intervento palliativo". Padova, 6-7-8 settembre 2012.

World Health Organization (1990). *Cancer Pain Relief and Palliative Care*. Geneva: WHO, Technical Report Series.

Paper presented: Nov 2013; Published online: Dec 2013.

Mediterranean Journal of Clinical Psychology, Vol. I, No. 3.
Doi: 10.6092/2282-1619/2013.1.942