

Original Article

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Taking care of who cares: Evaluation of a training program for home palliative care professionals

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Abstract

Objectives. To evaluate an enrichment training program targeted at home palliative care professionals in terms of its effects and participants' satisfaction. The program had 2 main aims: give voice to professionals' emotional fatigue and promote their personal resources.

Methods. One hundred twenty-three home palliative care professionals participated in 12 parallel training courses; each course consisted of four 3-hour meetings led by 2 trainers and involved about 10–15 participants. The program adopted the method and tools typical of the enrichment approach, with the insertion of an art therapy exercise in the central meetings. The topics addressed were the following: emotional awareness in care relationship; the recognition of the needs of the patient, the family, and the professional himself; the inevitability of the death of the patient; and the challenges and resources of the multidisciplinary care team. At the first (T1) and last (T2) meetings, participants filled in a self-report questionnaire assessing work emotional fatigue, empowerment, generativity, and satisfaction with the course.

Results. Participants were highly satisfied with the course. They reported a higher level of work emotional fatigue and a higher perception of personal resources, in terms of empowerment (both individual-oriented and relationship-oriented) and generativity at the end of the program than before.

Significance of results. Results confirm the need to provide home palliative care professionals with trainings in which they can express, share, and deal with personal and professional needs. This course gave voice to professionals' work emotional fatigue and promoted their personal resources, while enhancing collaboration in the multidisciplinary team.

Introduction

Home palliative care professionals are faced with many challenges in their assistance work (e.g., Salifu et al. 2021). At home, professionals not only take care of the patient's health but also try to meet the support needs of family members caring for their relative (Hudson et al. 2004; Valera and Mauri 2008). In addition, they are confronted with the existential suffering of the family, who perceives “death at home” (Boston et al. 2011). Home palliative care professionals often feel gratified in their work, but, at the same time, working in direct contact with death puts them at risk of being overwhelmed by the situation, especially if they are not adequately supported or do not have the opportunity to elaborate on their experiences of assistance (Zambrano et al. 2014). Professionals may experience feelings of helplessness, meaninglessness, moral distress, and fear of death. If unrecognized, this emotional burden can lead them to disengage from their work and can promote the onset of burnout symptoms (Ercolani et al. 2020), which may affect the quality of their assistance and increase the risk of errors and conflict within the team (Brazil et al. 2010).

Given these critical aspects, it is important to support home palliative care professionals in giving voice to the emotional burden deriving from the constant contact with the patient and the family's suffering and in promoting the dimensions that can protect their well-being (Koh et al. 2015). These dimensions cannot be reduced to medical and nursing coping skills but can include individual resources, such as empowerment (Hernández-Marrero and Pereira 2015; McLean 1995; Rappaport 1987) and generativity (Erikson 1963; McAdams and de St Aubin 1992), which can be useful in the professionals' care relationship with the ill person and his/her family.

In this article, we present the results of a pilot evaluation study of the training program “The Groups for Professional Enrichment” (Bertoni et al. 2017) applied to the context of palliative care (Health-care version, The Groups for Professional Enrichment_Healthcare [GPE_H]), developed specifically for an Italian professional association for home palliative care. In particular, the program, entitled “Dedicated to you, patient, dedicated to me, home palliative care professional,” was evaluated in terms of both its effects and participants’ satisfaction. In line with the goals of the program, which aimed to give voice to participants’ work-related emotional fatigue, on the one hand, and to promote personal resources, on the other, we investigated whether a change occurred between before and after program participation in their perception of work emotional fatigue, empowerment (both self-oriented and relational-oriented), and generativity.

Methods

Participants and procedure

One hundred twenty-three home palliative care professionals participated in the program “Dedicated to you, patient; dedicated to me, home palliative care professional.” Most participants were women (63.4%), and the majority were nurses (29.3%). Other professions were represented as follows: health-care assistants (18.7%); psychologists (17.1%); physical therapists (15.4%); physicians (9.8%); and social workers (9.8%). Age range was 23–69 years ($M = 36.64$; $SD = 9.30$).

The training course aimed to give voice to professionals’ emotional fatigue and, at the same time, recognize and promote their personal resources. To meet these objectives, the methods and tools typical of the Enrichment approach were used (Iafrate et al. 2010; Iafrate and Rosnati 2007; L’Abate and Cusinato 2007), together with some exercises of art therapy. Enrichment programs are psychosocial interventions, delivered in small groups and adopting an active-inductive methodology, specifically designed for family relationships (Bertoni et al. 2017; L’Abate and Cusinato 2007), but can also be applied to other relational contexts such as professional settings (e.g., The Groups for Professional Enrichment, Bertoni 2020). In particular, Enrichment programs help individuals reflect on their identity, elaborate on their resources and limits, develop relational competences, and reinforce social bonds, thereby providing an opportunity for personal growth, self-reflection, and reinforcement of relationships. Twelve parallel training courses took place from September to December 2019; each course included 4 meetings of 3 hours led by 2 trainers and involving about 10–15 participants. Each meeting had a specific focus (see Table 1 for a description), but these core topics were addressed throughout the meetings: emotional awareness in the care relationship; the recognition of the needs of the patient, the family and the professional himself; the inevitability of the death of the patient; and the challenges and resources of the multidisciplinary care team. In particular, the first and last modules were led by 2 psychologists, while the central modules by a psychologist and an art therapist.

Participants filled in a self-report, paper and pencil questionnaire at the first (T1) and last (T2) group meeting. They signed an informed consent form before filling in the questionnaire and were not rewarded or paid for their participation in the research. All procedures were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Measures

Satisfaction with the course

We assessed the global degree of satisfaction with the course with the item “How much are you satisfied with the course you have just attended?” on a 10-point Likert scale ranging from 1 = not at all satisfied to 10 = completely satisfied. Moreover, we assessed the degree of satisfaction with the specific aspects of the course (the exchange with the group; the competence of trainers; and the exercises proposed) with 3 ad hoc items rated on a 5-point Likert scale ranging from 1 = not at all satisfied to 5 = completely satisfied.

Work emotional fatigue

To measure professionals’ emotional fatigue deriving from their work, we used the Link Burnout Questionnaire by Santinello et al. (2006). It includes 24 items measuring 4 dimensions (6 items for each dimension, 3 with negative polarity and 3 with positive polarity): psychophysical exhaustion (item example: “I feel physically drained because of my work”; $\alpha = 0.66$ at T1 and 0.64 at T2), relational deterioration (item example: “I have the feeling that most of my patients do not follow my instructions”; $\alpha = 0.60$ at T1 and 0.61 at T2), professional inefficacy (item example: “I feel that my skills are not sufficiently adequate to deal with unexpected circumstances”; $\alpha = 0.76$ at T1 and 0.77 at T2), and disillusion (item example: “I think that if I could do it all over again, I’d choose another job”; $\alpha = 0.69$ at T1 and 0.63 at T2). All items were rated on a 6-point scale ranging from 1 = never to 6 = always. Following the authors’ suggestions, the scores of the items measuring the same dimension were first summed together in order to create a composite index of that dimension. Second, to facilitate the interpretation of these scores, they were converted into standardized standard points using stanine points ranging from 1 to 9 and with an average of 5 and a standard deviation of about 2.

Empowerment

We used the Italian validated version (Straticò et al. 2007) of the Adult Consumer Empowerment Scale (Rogers et al. 1997), an instrument designed to measure subjective feelings of empowerment on a 4-point Likert scale ranging from 1 = “strongly disagree” to 4 = “strongly agree.” In particular, we measured 2 facets of empowerment: self-oriented empowerment using the subscale of self-esteem (item example: “I have a positive attitude toward myself”; $\alpha = 0.72$ at T1 and 0.83 at T2) and relationship-oriented empowerment, using the subscale of community activism (item example: “People have more power, if they join together as a group”; $\alpha = 0.60$ at T1 and 0.61 at T2). For each subscale, a composite index was created by averaging the scores of the items. Higher scores indicated greater levels of the empowerment dimensions.

Generativity

The 20-item Loyola Generativity Scale by McAdams and de St Aubin (1992) was used to assess the degree of generativity. Since this scale has not been yet validated in Italian, the items were translated and back-translated. The items were rated on a 4-point scale ranging from “definitely not true of me” (1) to “definitely true of me” (4). Example items are: “I try to pass along the knowledge I have gained through my experiences” and “Others would say that I have made unique contributions to society.” A global index of generativity was computed by averaging the scores of the items. Higher scores indicated greater levels of empowerment dimensions. Cronbach’s alpha was 0.77 at T1 and 0.86 at T2.

Table 1. The program “dedicated to you, patient, dedicated to me, home palliative care professional”

Meeting title	Goals	Activities and instruments
Meeting 1: “ <i>The care relationship in home palliative care</i> ”	Facilitate group formation; reflect on the challenges and the resources in the care relationship in home palliative care.	Presentation of participants’ personal and professional skills; exercise on the expectations about the course; joint creation of a shared metaphor of the care relationship; group discussion.
Meeting 2: “ <i>Dedicated to you, patient in home palliative care</i> ”	Help professionals identify the resources, needs, and desires of the patient in home palliative care. Reflect on the importance of saying goodbye to the patient.	Administration of the symbolic-graphic instrument “The patient’s coat of arms”: professionals, in subgroups, identified the most important strength, the most important limit, and the greatest desire of the patient in palliative care; art therapy exercise: professionals created a painting for a patient and wrote a dedication to him/her; group discussion.
Meeting 3: “ <i>Dedicated to me as a home palliative care professional</i> ”	Help participants recognize their own resources, needs, and desires as home palliative care professionals. Reflect on the importance of taking care of oneself as a professional.	The same tools (coat of arms and art therapy exercise) as in the second meeting were used but with the focus on the home palliative care professional.
Meeting 4: “ <i>I will take care of you and me</i> ”	Reflect on the role of the family in the care relationship; reflect on the importance of good relationships in the multidisciplinary team; close the group experience.	Creation, in subgroups, of 3-dimensional objects, one representing the patient, another one the family and another one the home palliative care team; group discussion.

Data analyses

Statistical analyses were performed using SPSS 20.0 software (IBM Corp., Armonk, NY). Descriptive statistics (frequencies, means, and standard deviations) were conducted to assess participants’ level of satisfaction with the course (global satisfaction and satisfaction with specific aspects of the course) and to describe participants with regard to our variables of interest (work emotional fatigue – 4 dimensions – individual and relational empowerment and generativity). In addition, to establish whether there were significant differences between T1 and T2 in each variable, a series of repeated-measures analyses of variance (ANOVA) were performed. A 2-tailed alpha value of 0.05 was used to determine statistical significance.

Results

Means and standard deviations of the variables measuring participants’ satisfaction with the course are reported in Table 2. Participants showed high levels of both global satisfaction with the course. Specifically, the analysis of frequencies showed that, on a scale ranging from 1 to 10, 73.4% of participants were extremely satisfied with the course (scoring 9 or 10), 23.4% were satisfied (scoring 7 or 8), and only 3.3% were slightly unsatisfied (assigning a score of 5). Also, participants expressed satisfaction with specific aspects of the course. To this regard, the analysis of frequencies showed that on a scale ranging from 1 to 5, most participants were highly satisfied, assigning the maximum score (exchange within the group: 66.7%; trainers’ competences: 67.5%; and exercises: 50.7%), a consistent part expressed a good level of satisfaction, scoring 4 (exchange within the group: 27.6%; trainers’ competences: 26%; and exercises: 37.4%), while the remainder were moderately satisfied (exchange within the group: 3.3%; trainers’ competences: 3.3%; and exercises: 10%). Table 2 also displays means and standard deviations of our variables of interest (awareness of work emotional challenges and fatigue – 4 dimensions – individual and relational empowerment, and generativity) at both T1 and T2 together with ANOVAs results.

With regard to work emotional fatigue, on average, participants reported medium levels on all the 4 dimensions in both waves. However, T2 scores were significantly higher than T1 scores,

indicating that participants reported higher levels of emotional fatigue at the end of the course. As for empowerment, participants reported medium-high levels of self-esteem and community activism. Significant differences between T1 and T2 scores were found for both empowerment dimensions. In particular, participants reported an increase in the level of self-esteem and community activism. With respect to generativity, participants reported medium levels in both waves, but T2 scores were significantly higher than T1 scores, indicating an increased perception of generativity after the course.

Discussion

Palliative care professionals often experience a feeling of helplessness in the face of a care process in which the patient cannot be healed. Moreover, they are constantly confronted with the challenge of managing both the patient and the family at home. Therefore, it is important that professionals are supported with training opportunities that may help them express, share, and deal with their personal and professional needs.

An important intervention to deal with professionals’ both personal and job-related needs is represented by The Groups for Professional Enrichment (Bertoni 2020). In this study, we presented the evaluation of a version of GPE_H, specifically targeted to palliative care home professionals and entitled “Dedicated to you, patient, dedicated to me, home palliative care professional.” This program had 2 main objectives: to give voice to professionals’ work emotional fatigue and to implement their personal resources. To achieve these aims, the main working tool was groupwork and the topics covered across the meetings were emotional awareness in the care relationship; the recognition of the needs of the patient, the family, and the professionals themselves; the inevitability of the death of the patient; the challenges; and resources of the multidisciplinary care team. The program took place in four 3-hour meetings.

Results highlighted a high level of satisfaction among participants. In particular, they were satisfied with the group dimension, confirming the training method chosen and showing to appreciate the group as a resource at work. Indeed, the group can be a real multiplier of relational energies (Bertoni 2021). Moreover, after the

Table 2. Descriptive statistics and repeated-measures ANOVA results

Variables	T1		T2		Repeated-measures ANOVA results			
	Mean	SD	Mean	SD	F	df	p	η_p^2
Global sat. with the course	/	/	8.968	1.212	/	/	/	/
Sat. with the exchange within the group	/	/	4.650	0.545	/	/	/	/
Sat. with the trainers' competence	/	/	4.655	0.574	/	/	/	/
Sat. with the exercises	/	/	4.400	0.715	/	/	/	/
Psychosocial exhaustion	4.293	1.530	4.577	1.373	5.041	1,122	0.027	0.040
Relational deterioration	4.968	1.604	5.325	1.496	6.999	1,122	0.006	0.054
Professional inefficacy	4.098	1.539	4.390	1.446	5.602	1,122	0.020	0.044
Disillusion	3.810	1.401	4.176	1.434	10.373	1,122	0.002	0.078
Individual empowerment (Self-esteem)	3.069	0.290	3.130	0.347	5.063	1,121	0.026	0.040
Relational empowerment (community activism)	3.362	0.332	3.493	0.315	18.687	1,121	0.000	0.134
Generativity	2.497	0.358	2.606	0.439	17.066	1,122	0.000	0.123

Parameter estimates are standardized coefficients (β).

training, professionals displayed higher levels of emotional fatigue. This result is challenging as it indicates an increase in professionals' malaise after program participation. Probably, the creation of a space where they had the opportunity to express, share, and elaborate on their needs and fatigue led them to be more aware of their emotional burden. Future evaluation studies of this program may confirm this pattern of results and may help analyze them also from a qualitative point of view. However, it is important to recognize that naming and sharing with one's colleagues the difficulties and the emotional challenges related to one's work might be the first step to deal with them and to manage the complexity of the care work. In addition, professionals reported higher levels of self-oriented and relationship-oriented empowerment at the end of the training. Professionals showed higher self-esteem and higher community activism: higher self-esteem indicates a greater confidence in personal skills, which can protect and support the person at work, while higher community activism indicates a greater confidence in relationships, which can be a resource in the multidisciplinary team and more generally in relational and social life. Results indicated also an increase in generativity, an important dimension of adult functioning that drives individuals to care for others and cope with death anxiety (Bertoni et al. 2012; Erikson 1963; McAdams and de St Aubin 1992). Indeed, generativity is associated with death awareness (Major et al. 2016): people defy mortality salience by caring for others and constructing a legacy that lives on. For palliative care professionals, who are constantly in contact with death and human limits, generativity could be a resource that allows to give meaning to the dramatic experiences they face every day. This increase confirms the achievement of the training goals of the program, which aimed at making professionals more aware of their care tasks and also at recognizing both themselves and the patients as 2 subjects belonging to the same care relationship. This is especially valuable in palliative care, as it adds quality to the care relationship when there is no possibility of recovery.

This study had some limitations that should be taken into consideration. First, we collected data from a relatively small number of home palliative care professionals who belonged to the same organization. This limits the generalizability of the present findings,

which may be different in other samples. Moreover, we did not collect data from a control group and it cannot be determined with certainty whether the changes that occurred from before to after the course can be attributed to the participation in the program. Finally, the absence of a follow-up phase prevents us from monitoring long-term effects of the program. Despite these limitations, the strength of this program was to give voice to professionals' needs and fatigue and to enhance their awareness of their personal resources, while enhancing collaboration in the multidisciplinary team.

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Conflicts of interest. None declared.

References

- Bertoni A (2020) I percorsi di enrichment professionale. In Manzi C and Mazzucchelli S (eds), *Famiglia E Lavoro. Intrecci Possibili*. Studi Interdisciplinari sulla Famiglia, 31. Milano: Vita e Pensiero, 175–182.
- Bertoni A (2021) *Passi Di Gruppo*. Milano: San Paolo.
- Bertoni A, Donato S, Morgano A, et al. (2017) A qualitative evaluation of a preventive intervention for parents: The Groups for Family Enrichment_Parent version (GFE_P). *Journal of Prevention & Intervention in the Community* 45(3), 215–229. doi:10.1080/10852352.2016.1198135
- Bertoni A, Parise M and Iafrate R (2012) Beyond satisfaction: Generativity as a new outcome of couple functioning. In Esposito PE and Lombardi CI (eds), *Marriage: Psychological Implications, Social Expectations, and Role of Sexuality*. Hauppauge: Nova Science Publisher, 115–132.
- Boston P, Bruce A and Schreiber R (2011) Existential suffering in the palliative care setting: An integrated literature review. *Journal of Pain and Symptom Management* 41(3), 604–618. doi:10.1016/j.jpainsymman.2010.05.010
- Brazil K, Kassalainen S, Ploeg J, et al. (2010) Moral distress experienced by health care professionals who provide home-based palliative care. *Social Science & Medicine* 71(9), 1687–1691. doi:10.1016/j.socscimed.2010.07.032
- Ercolani G, Varani S, Peghetti B, et al. (2020) Burnout in home palliative care: What is the role of coping strategies? *Journal of Palliative Care* 35(1), 46–52. doi:10.1177/0825859719827591
- Erikson HE (1963) *Childhood and Society*, 2nd edn. New York: Norton.

- Hernández-Marrero P and Pereira SM** (2015) Professional caregivers' emotional well-being, empowerment and burnout prevention: Lessons to be learned from palliative care. In Malecka K and Gibbs R (eds), *And Death Shall Have Dominion: Interdisciplinary Perspectives on Dying, Caregivers, Death, Mourning and the Bereaved*. Leiden: Brill, 73–87.
- Hudson PL, Aranda S and Kristjanson LJ** (2004) Meeting the supportive needs of family caregivers in palliative care: Challenges for health professionals. *Journal of Palliative Medicine* 7(1), 19–25. doi:10.1089/109662104322737214
- Iafrate R, Donato S and Bertoni A** (2010) Knowing and promoting the couple bond: Research findings and suggestions for preventive interventions. *INTAMS Review* 16, 65–82. doi:10.2143/INT.16.1.0000000
- Iafrate R and Rosnati R** (2007) *Riconoscersi Genitori. I Percorsi Di Promozione E Arricchimento Del Legame Genitoriale*. Trento: Erickson.
- Koh MY, Chong PH, Neo PS, et al.** (2015) Burnout, psychological morbidity and use of coping mechanisms among palliative care practitioners: A multi-centre cross-sectional study. *Palliative Medicine* 29(7), 633–642. doi:10.1177/0269216315575850
- L'Abate L and Cusinato M** (2007) Linking theory with practice: Theory-derived interventions in prevention and family therapy. *The Family Journal* 15(4), 318–327. doi:10.1177/1066480707303745
- Major RJ, Whelton WJ, Schimel J, et al.** (2016) Older adults and the fear of death: The protective function of generativity. *Canadian Journal on Aging/La Revue Canadienne du Vieillessement* 35(2), 261–272. doi:10.1017/S0714980816000143
- McAdams DP and de St Aubin ED** (1992) A theory of generativity and its assessment through self-report, behavioral acts, and narrative themes in autobiography. *Journal of Personality and Social Psychology* 62(6), 1003–1015. doi:10.1037/0022-3514.62.6.1003
- McLean A** (1995) Empowerment and psychiatric consumer/ex-patient movement in the United States: Contradictions, crisis and change. *Social Science & Medicine* 40(8), 1053–1071. doi:10.1016/0277-9536(94)00179-W
- Rappaport J** (1987) Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. *American Journal of Community Psychology* 15(2), 121–148. doi:10.1007/BF00919275
- Rogers ES, Chamberlin J, Ellison ML, et al.** (1997) A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatric Services* 48(8), 1042–1047. doi:10.1176/ps.48.8.1042
- Salifu Y, Almack K and Caswell G** (2021) “My wife is my doctor at home”: A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliative Medicine* 35(1), 97–108. doi:10.1177/0269216320951107
- Santinello M, Verzelletti C and Altoe G** (2006) Sviluppo e validazione del Link Burnout Questionnaire [Development and validation of Link Burnout Questionnaire]. *Risorsa Uomo* 4, 1000–1012.
- Straticò E, Mirabella F, Degli Espositi M, et al.** (2007) Psychometric properties of the SESM, Italian version of the “Consumer constructed Scale to measure empowerment among users of mental health services”. *Epidemiology and Psychiatric Sciences* 16(3), 256–264. doi:10.1017/S1121189X00002360
- Valera L, and Mauri C** (2008) Il contesto familiare del malato terminale è una risorsa da conoscere e supportare: Alcune riflessioni. *Giornale Italiano di Medicina del Lavoro ed Ergonomia* 30(3), 37B–39B.
- Zambrano SC, Chur-Hansen A and Crawford GB** (2014) The experiences, coping mechanisms, and impact of death and dying on palliative medicine specialists. *Palliative & Supportive Care* 12(4), 309–316. doi:10.1017/S1478951513000138