Ambiguous loss and disenfranchised grief in formal caregivers of people with dementia: Effectiveness of a training intervention with psychodrama

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ABSTRACT

Formal caregivers of people with dementia may experience ambiguous loss due to the psychological loss of care recipients before their physical death. They may also experience disenfranchised grief when other people fail to acknowledge their losses. Since the number of studies addressing these topics is fairly restricted, this research investigates the phenomena of ambiguous loss and disenfranchised grief as observed within the staff of a care facility for people with dementia. Moreover, this research evaluates the impact of a psychodrama training course on the processing of such griefs. A mixed-method research design was used. For the quantitative section, the following variables were examined: caregiver grief, well-being, and burnout levels. Fifty-nine health professionals took part in the study. Before and after the psychodrama intervention, participants were interviewed and filled out questionnaires for longitudinal research. The training intervention has resulted in a reduction in formal caregiver ambiguous loss and an improvement of the well-being of participants, as well as in the acquisition of awareness and skills regarding grief, greater validation of one's grief and better communication skills. The training intervention with psychodrama seems to help manage loss experiences in staff working with people with dementia.

Introduction

Caregivers of people with dementia

Caregivers of people with dementia experience a unique kind of grief born out of the multiple and unexpected losses, prior to death, regarding the personality, cognitive and physical abilities of their care recipients, who are the people they assist (Blandin & Pepin, 2017; Large & Slinger, 2015; Lindauer & Harvath, 2014; Noyes et al., 2010). Caregivers can be informal, i.e., family members and/or friends who are not paid for their care activity; or formal, i.e., trained staff, such as nurses and physicians (Alzheimer's Association, 2018). Dementia is often described as "dual dying" (Jones & Martinson, 1992) in that it comprises an initial "death" of people as they were known, only then followed by physical death (Gilsenan et al., 2022; Lindauer & Harvath, 2014). Pauline Boss (1999) uses the term "ambiguous loss" to describe cases of losses without actual death. According to Boss (Boss, 1999; Boss & Yeats, 2014), ambiguous loss can concern both physical losses (physically missing) such as

disappearances, abductions, military departures, and psychological losses (psychologically missing), as in the case of chronic degenerative diseases (e.g., Alzheimer's, ALS, dementia) (Boss, 1999; Boss & Yeats, 2014; Martino et al., 2022; Testoni et al., 2020a; Testoni et al., 2021b).

Healthcare professionals, also referred as formal caregivers (Ku et al., 2013), are affected by the physical deaths of their care recipients and experience a wide range of grief reactions (Carton & Hupcey, 2014). However, the pain derived from the loss of a care recipient is often neither acknowledged nor addressed and thus can be inscribed in the phenomenology of the "disenfranchised grief," a kind of grief that is not socially acknowledged and supported (Brown & Wood, 2009; Doka, 1989; Papadatou, 2000). Social recognition of grief is an important factor for its processing (Testoni et al., 2021a). As a result, this kind of disenfranchised grief can lead to increased levels of stress, loss of compassion, burnout, decreased job satisfaction, psychosomatic distress. In the work context, it can lead to staff turnover, increased absenteeism, decreased quality of care, medical errors and decreased productivity (Carton & Hupcey, 2014; Ounalli et al., 2020; Papadatou,

2009).

Psychodrama and its role in grief processing

Psychodrama is an experiential therapeutic model conceived by Jacob Moreno (1946). During psychodrama sessions, the participants stage their own inner world and explore feelings, thoughts and behaviours. The psychodrama model is based on theories of action, spontaneity and creativity. It is an effective means to promote change (Dayton, 2005, pp. 58) through the application of creative solutions to former issues (Kipper, 1998). Psychodrama offers the participants the opportunity to relive life experiences, meet themselves and analyse self-perceptions and relational experiences. It also allows to change maladaptive behaviours (Dayton, 2005, pp. 58). Psychodrama has proven effective in processing grief and familiarising with the concepts of death and end-of-life (Testoni et al., 2018a; Testoni et al., 2019c; Testoni et al., 2018b). When applied to the field of grief, psychodramatic techniques such as the empty chair, the double, or the role reversal allow one to get in touch with past work situations, analyse them, and foreshadow future problems. Moreover, they are an effective tool to step into the shoes of care recipients and their families, thus promoting effective communication (Biancalani & Testoni, 2021; Testoni et al., 2019a; Testoni et al., 2019b; Testoni et al., 2020b). Indeed, through psychodrama, it is possible to enact a direct dialogue with the deceased person, which in turn allows for closure in terms of unresolved issues within the dramatisation (Giacomucci, 2020). Moreover, psychodrama is useful not only in dealing with grief over the death of a person, but also in dealing with suffering resulting from other types of loss (Testoni et al., 2019b). Given the positive effects of psychodrama for the grieving process (Testoni et al., 2019b) and the ability of psychodrama to provide a context in which people can express their loss-related thoughts and emotions with the support of the other group members (Dayton, 2005; pp. 58; Giacomucci, 2020; Testoni et al., 2019b), a psychodramatic intervention was chosen for the present study.

The present study

The present study aims to investigate two aspects: (1) how ambiguous loss and disenfranchised grief affect formal caregivers of people with dementia and (2) which is the impact of a training intervention with psychodrama on formal caregivers of people with dementia in processing ambiguous loss and disenfranchised grief, reducing their burnout, and promoting their well-being, coping strategies and personal resources. To do so, a mixed method research design was used, integrating quantitative and qualitative data, in order to investigate these aspects in more depth.

Method

Mixed method research design is crucial for studies in the social and health fields, since it allows for a broader analysis of complex issues (Creswell, 2009; Lopez-Fernandez & Molina-Azorin, 2011). The mixed method research design of this study has included only an experimental group that was subjected to both a quantitative survey with questionnaire and a qualitative survey with interviews before and after the psychodrama training intervention. The study did not include a control group.

Participants

The participants in the present research work in a facility in northern Italy that provides both day and residential care for people with neurodegenerative diseases. 64 participants took part in the psychodrama training intervention. They were divided into 9 groups of 6–9 people. Of the 64 participants, 59 completed the surveys pre- and post-intervention. Table 1 shows the socio-demographic and work

Table 1
Description of the participants.

Variable		N (%)[a]
Gender		
	Male	15 (25%)
	Female	44 (75%)
Age		20–63; 47 (10.9)
Marital status		
	Married/Cohabiting	36 (61%)
	Single	15 (25%)
	Divorced	7 (12%)
	Widowed	1 (2%)
Sons and daughters		
	Yes	41 (70%)
	No	18 (30%)
Education		
	Middle school diploma	10 (17%)
	High school diploma	24 (41%)
	Degree	21 (36%)
	Postgraduate	4 (7%)
Religion		
	Religious	49 (83%)
	Not religious	10 (17%)
Occupation		
	Healthcare Worker	32 (54%)
	Physiotherapist	7 (12%)
	Educator	4 (7%)
	Physician	3 (5%)
	Speech Therapist	3 (5%)
	Switchboard operator	3 (5%)
	Social Worker	2 (3%)
	Psychologist/Trainee Psychologist	2 (3%)
	Coordinator	2 (3%)
	Nurse	1 (2%)
Length of time at current facility (years)		
	Up to 5 years	20 (34%)
	More than 5 years	39 (66%)

[a] For the variable Age, the range of values; the mean and the (standard deviation) are reported.

characteristics of the 59 people who carried out both pre-intervention and post-intervention surveys.

Data collection

Quantitative section

The quantitative protocol consisted of the following questionnaires:

- Clinical Outcomes in Routine Evaluation-Outcome Measures, CORE-OM (Evans et al., 2000). This instrument assesses people's levels of well-being/psychological distress in the last 7 days. It consists of 34 items on a 5-point Likert scale (from 0 = not at all to 4 = most or all the time). The items are split into four subscales: Subjective well-being (4 items), Problems/Symptoms (12 items), Life Functioning (12 items), and Risk (6 items). In the present study, Italian validation of the instrument was administered (Palmieri et al., 2009, pp. 646), with good reliability both in the pre-test (Cronbach's alpha =0.89) and in the post-test (Cronbach's alpha =0.88). Example of items: "I have felt overwhelmed by my problems", "I have felt optimistic about my future";
- Single-item measure of burnout (Dolan et al., 2015). A single item instrument was used to assess the level of burnout perceived by healthcare professionals. It comprises 5 response levels. The participants are required to express their perception of their own burnout. The levels can range from not perceiving any symptoms of burnout to feeling completely burnt out. It has been translated into Italian via back translation: "Overall, based on your definition of burnout, how would you rate your level of burnout?";
- The Caregiver Grief Scale (Meichsner et al., 2015). This instrument reflects different aspects concerning the grief of the caregiver of a person with dementia, namely emotional pain, relational loss,

absolute loss, and acceptance of loss. It consists of 11 items on a 5-point Likert scale (from 1 = Strongly disagree to 5 = Strongly agree) and it is divided into 4 subscales: Emotional Pain (3 items), Relational Loss (3 items), Absolute Loss (3 items), Acceptance of Loss (2 items). The items were translated into Italian through back translation and adapted to the study sample, as there is no specific version for the healthcare professionals. The reliability of the scale is acceptable in the pre-test (Cronbach's alpha =0.79) and good in the post-test (Cronbach's alpha =0.83). Example of an item: "It is hard for me to allow myself to grieve and show my sadness".

Qualitative Section

With regard to the qualitative survey, two semi-structured interviews were administered before and after the psychodrama training intervention to all of the 59 professionals. Specifically, the interview prior to the training intervention consisted of 4 questions aimed at examining the experience of ambiguous loss and disenfranchised grief of the professionals in the facility, as well as the expectations and feelings in relation to the intervention. The questions are "Could you tell me about episodes in which you perceived that your experience of grief caused by the death of a care recipient was not acknowledged or was minimised by others?"; "How do you feel about working with people who gradually experience psychological loss before their physical death?"; "What are your expectations, feelings and emotions regarding the training intervention?".

The interview that followed the training intervention included 4 questions aimed at examining the instances of ambiguous loss and disenfranchised grief that emerged during the experience, any subsequent benefits/gains and the operators' thoughts regarding future benefits of their experience. The questions are "Please describe the most significant moments of the course"; "In which ways do you feel that the course contributed to process disenfranchised grief?"; "In which ways do you think the training contributed to process ambiguous loss?"; "Do you think you have gained anything useful for your work from this experience?".

Procedure

The administration took place with prior written informed consent and was carried out by two researchers. The researchers who carried out the data collection were two psychology researchers in training. They were specially trained in administering the questionnaires and conducting the interviews. They had not participated in the training intervention. For privacy purposes, alphanumeric codes have been assigned to the participants, in order to associate the data collected before and after the intervention.

The administration of the questionnaires was carried out both before and a week after the training intervention. It took place in dual mode, i. e., paper/pen or online. Questionnaires took an average of about 15–25 min to complete.

The administration of the interviews was carried out both before and a week after the training intervention. It took place in dual mode, i.e. in person at the facility or remotely via the Zoom platform. The duration was variable, with an average of about 30 min. The interviews, with prior informed consent, were audio-recorded.

Psychodrama training intervention

The training intervention took place over a period of 4 months (October 2021-February 2022). The person who conducted the intervention is a psychologist and psychodramatist in training with 3 years' experience in psychodrama.

The training intervention included three psychodrama group sessions involving different types of professionals. The sessions took place within the facility, within designated training classrooms, and lasted two hours each. All the sessions ended with a sharing moment, in which the participants expressed their feelings. They were organized as follows:

1st meeting: it focused on the acquisition of the concepts of ambiguous loss and disenfranchised grief and it encouraged participants to share their grief experiences in the work setting. In particular, after an initial presentation, participants were asked to think about their grief experiences in the work context and to think about situations in which they didn't feel understood by their significant others. Participants shared their experiences in pairs three times with three different people. Placing three chairs in the middle of the room, the participants who had listened to one person's story sat down and reported the experiences they had heard.

2nd meeting: it focused on the role of the person who works in close contact with illness and death. Through the use of drawing, the participants represented themselves in the centre of a circle in which they had to show their needs, duties, and will with meaningful and symbolic elements. Each participant was then asked to think about someone with whom they can confide openly and to sit in a chair in the middle commenting the draw as if he/she was the other person, with the role reversal.

3rd meeting: it focused on the processing of grief in the workplace. It helped participants express any unresolved issues in relation to care recipients who had passed away by providing a protected and non-judgmental environment. In particular, participants were asked to think of a deceased patient after choosing from some pictures representing the work environment. Two chairs were placed in the centre of the room and each participant (the protagonist) was asked in turn to choose another participant who could play the patient (the auxiliary ego). The protagonist and the auxiliary ego sat down and the protagonist was able to enter into dialogue with the patient and express his or her own's and the patient's emotions and thoughts about their relationship, through role reversal and soliloquy.

During the activities of the training intervention, psychodrama techniques were employed, such as role reversal, soliloquy, double and encounter.

Quantitative analysis

The quantitative analysis was carried out through the statistical software SPSS (Statistical Package for Social Science) (IBM Corp, 2021). Firstly, the results of each subject on each instrument were evaluated. For the CORE-OM, the results were compared with the cut-off values of the literature by calculating first the mean scores (range 0–4), then the clinical scores (0−40) and finally by assigning a severity range: 0–5 healthy, 6–9 low level, 10–14 mild alteration, 15–19 moderate alteration, 20–24 moderate to severe alteration, $> =25$ severe alteration.

For the Caregiver Grief Scale there are no cut-off values, therefore in order to assess the presence of any critical issues, the mean scores were compared with the central point of the Likert scale (3) using the t-test, while the effect size was examined using the Cohen's D coefficient (effect size: small d=0.2; medium d=0.5; large d=0.8). It then followed the calculation of the correlations between the instruments using the Pearson correlation coefficient (correlation: very low r < 0.2; low r between 0.2 and 0.4; moderate r between 0.4 and 0.6; high r between 0.6 and 0.8; very high r > 0.8). Secondly, pre-post differences of the mean scores of the three instruments were assessed with the paired sample t-test in order to determine the changes before and after the intervention. Finally, the change scores were calculated based on the difference between the pre-test and post-test scores, and a multiple regression model was evaluated in order to explain the changes that occurred over time. Only socio-demographic and work variables as well as pre-test scores with a correlation greater than 20 were included in the regression model.

For all statistical tests, the result was considered significant if the p-value was less than 0.05.

Qualitative analysis

Qualitative data were analysed through a reflective thematic qualitative analysis, i.e. an inductive method aimed at identifying the main

meanings and concepts without any preconception on the part of the researcher (Braun & Clarke, 2006). The thematic analysis was conducted on the basis of the six phases outlined by Braun and Clarke (2006): familiarising with data, coding, generating initial themes, reviewing themes, defining and naming themes, and producing the report. The analysis was conducted using the ATLAS.ti qualitative data analysis software (Gibbs, 2007). They were conducted by the two researchers responsible for data collection.

Results

Quantitative results

Evaluation of the results of the pre-test

With reference to the CORE-OM, the number of people who exceed the clinical cut-off at the pre-test are 10 (17%), of whom 6 are mild and 4 moderate (Table 2). As far as the subscales are concerned, greater critical issues are evident in all areas except the "Risk", with 17 people (29%) exceeding the clinical cut-off for "Subjective well-being", 22 (38%) for "Problems/Symptoms" and 20 (34%) for "Life Functioning". More specifically, there is a person with a severe level and five people with a moderate/severe level in "Subjective well-being", four people with a moderate/severe level in "Problems/Symptoms", and, finally, one person with a moderate/severe level in "Functioning".

With reference to the single-item measure of burnout, in the pre-test phase there are only two subjects who have symptoms of burnout, one of which is very severe (Table 3).

With reference to the Caregiver Grief Scale, the pre-test scores are generally low and significantly below the central point of the 1–5 Likert scale (Table 4). In particular, the total score shows a large size deviation of (d = −0.93) from the central point and, in terms of the subscales, "Absolute Loss" is the one that deviates the most from the central point (d = −2.28), followed by the subscale "Acceptance of Loss" (d = −0.96) and by "Emotional Pain" (d = −0.38). Only the mean value of the "Relational Loss" subscale exceeds the central point but not in a statistically significant way (d = 0.15).

The results of the different instruments are correlated. More specifically, there is a positive correlation of moderate size between the single-item measure of burnout score and the CORE-OM total score (r = 0.35 p = .007) and a weak size positive correlation between the Caregiver Grief Scale total score and the CORE-OM total score (r = 0.25 p = .056). The Caregiver Grief Scale, on the other hand, does not correlate with the score of the single-item measure of burnout (r = −0.01 p = .940).

Pre-post test differences

There is a significant improvement in CORE-OM scores. The total score decreases significantly at post-test, in particular in the domain of Problems (Table 5). This is a small to medium size effect (d=0.28 for the total and d=0.37 for the domain of Problems/Symptoms). Also in the Risk domain there is a significant small size reduction (d=0.27). There is

Table 2
Evaluation of the results of the CORE-OM at the pre-test.

CORE-OM	Severity assessment				
	Healthy	Low level	Mild	Moderate	Moderate/ Severe
Total	30 (51%)	19 (32%)	6 (10%)	4 (7%)	0 (0%)
Subjective well-being	23 (39%)	19 (32%)	4 (7%)	7 (12%)	5 (8%)
Problems/ Symptoms	22 (37%)	15 (25%)	14 (24%)	4 (7%)	4 (7%)
Life Functioning	15 (25%)	24 (41%)	15 (25%)	4 (7%)	1 (2%)
Risk	59 (100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

Table 3
Evaluation of the burnout results at the pre-test (N = 59).

	N (%)
I enjoy my work. I have no symptoms of burnout.	21 (36%)
Occasionally I am under stress, and I don't always have as much energy as I once did, but I don't feel burned out.	36 (61%)
I am definitely burning out and have one or more symptoms of burnout, such as physical and emotional exhaustion.	1 (2%)
The symptoms of burnout that I'm experiencing won't go away. I think about frustration at work a lot.	0 (0%)
I feel completely burned out and often wonder if I can go on. I am at the point where I may need some changes or may need to seek some sort of help.	1 (2%)

Table 4
Evaluation of the results of the Caregiver Grief Scale at the pre-test, comparison with the central point of the Likert scale 1–5.

Caregiver Grief Scale	M (SD)	t	p-value	Effect size (d)
Total	2.48 (0.56)	-7.15*	< 0.001	-0.93
Emotional Pain	2.71 (0.77)	-2.89*	0.005	-0.38
Relational Loss	3.12 (0.82)	1.17	0.248	0.15
Absolute Loss	1.44 (0.68)	-17.54*	< 0.001	-2.28
Acceptance of Loss	2.21 (0.82)	-7.37*	< 0.001	-0.96

d=Cohen's d.
* $p < .05$.

no significant change in burnout levels. The change in Caregiver Grief Scale scores is significant: the total score decreases significantly at post-test, particularly for the Emotional Pain subscale. The effect in this case is of medium size for the total (d=0.50) and between medium and large for Emotional Pain. The Absolute Loss subscale also shows a significant reduction but the effect is smaller (d=0.31).

Analysis of change scores

In order to examine the significant changes that occurred at the end of the intervention on CORE-OM and CGS, the change scores relating to the total scores were calculated, i.e. the difference between the pre-test and post-test scores. Preliminarily, the correlations between the change scores and all socio-demographic and work variables as well as the pre-test scores (see Table 6) were examined in order to reduce the number of variables to be included in the regression model.

Only variables with a correlation greater than.20 for at least one of the two change scores were included in the multiple regression model (Table 7). The model explains 45% of the change scores' variance for CORE-OM and 32% for CGS. The analysis of the parameters shows that the most important predictor is always the score of the corresponding pre-test (Beta=0.58 for CORE-OM and Beta=0.40 for CGS) indicating that the higher and thus more critical the initial scores of the participants are, the greater are the changes that occur in the participants. In both models, the effect of age that has a negative impact is also significant (Beta = −0.35 for CORE-OM and Beta= −0.28 for CGS) indicating that the greatest benefits (high change scores) are achieved by younger participants.

Qualitative results

Before the training intervention

The themes that emerged from the analysis of the data regarding the interviews carried out before the training intervention are five: (a) the relationship with the profession; (b) the relationship with care recipients and their families; (c) the relationship with illness and loss; (d) the management of the communication of work experiences; (e) The relationship with the training intervention with psychodrama.

Table 5

Assessment of differences between pre-test and post-test scores (N = 59).

Instrument	Score	Pre-test		Post-test		Test t	
		M	SD	M	SD	t (58)	p-value
CORE-OM							
	Subjective well-being	10.05	7.06	10.22	6.72	-0.18	0.860
	Problems/Symptoms	9.05	5.81	7.17	5.21	2.81*	0.003
	Life Functioning	9.24	4.30	8.81	4.06	0.88	0.382
	Risk	0.31	0.79	0.07	0.37	2.03*	0.047
	Total	7.64	3.98	6.71	3.52	2.18*	0.033
Burnout							
	Single-item	1.71	0.67	1.81	0.73	-1.29	0.203
Caregiver Grief Scale							
	Emotional Pain	2.71	0.77	2.21	0.081	4.83*	< 0.001
	Relational Loss	3.12	0.82	2.96	0.93	1.26	0.213
	Absolute Loss	1.44	0.68	1.25	0.44	2.40*	0.019
	Acceptance of Loss	2.21	0.82	1.97	0.82	1.91	0.061
	Total	2.48	0.56	2.21	0.60	3.87*	< 0.001

* $p < .05$.

Table 6

Correlations between the change scores and all socio-demographic, work variables and the pre-test scores.

Variables	Change scores CORE-OM	Change scores CGS
Gender (female)	0.00	0.12
Age	-0.21	-0.33 *
Education	-0.20	-0.10
Marital status (married/cohabiting)	-0.11	-0.22
Children (Yes)	-0.26 *	-0.06
Occupation (healthcare worker)	-0.09	0.16
Length of time at current facility (up to 5 years)	-0.04	-0.17
Religion (religious)	0.03	-0.06
CGS Total PRE	0.26 *	0.40 * *
CORE-OM Total PRE	0.55 * **	-0.17
Burnout PRE	-0.12	-0.16

Table 7

Multiple regression for change scores (PRE-POST) in CORE-OM and CGS.

Predictors	Change scores CORE-OM		Change scores CGS	
	Beta	p-value	Beta	p-value
Age	-0.35*	0.008	-0.28*	0.051
Education	-0.20	0.066	-0.09	0.441
Marital status (married/cohabiting)	0.21	0.112	-0.06	0.678
Children (Yes)	-0.05	0.757	0.03	0.858
CGS Total PRE	0.12	0.304	0.40*	0.004
CORE-OM Total PRE	0.58*	< 0.001	-0.26	0.063
R-square	45%		32%	

Notes. Only variables with a bivariate correlation greater than.20 are included in the model.

* $p < .05$.

First theme: Relationship with the profession

The first theme takes into account the relationship that the facility workers have with their profession.

First of all, the interviews highlight the issues of continuity and detachment between work and personal life. Some participants report not being able to distance themselves from their work, as reported by a 25-year-old participant: "*It happened to me, especially in the beginning, to return home and take with me so much of the feelings, the emotions that I felt here.*". Others report trying to mentally remove themselves from work, as reported by a 42-year-old professional: "*I always try [.] not to take home the problems I see at work [.] it's a matter of knowing how to separate, divide the two things, private life and work*".

Many professionals report situations of stress at work, or of feelings of fatigue, or somatisation, as reported for example by a 55-year-old participant: "*There was a time when I somatised a lot and this affected my health because it caused me problems*".

Working with care recipients suffering from neurodegenerative diseases leads many professionals to experience frustration due to their helplessness. A 24-year-old participant reports: "*Sometimes work makes you feel helpless, sometimes it makes you feel like you've invested a lot of resources in something and then in the end…*".

Second theme: The relationship with care recipients and their families

The second theme focuses on the relationship between professionals and care recipients and their family members.

Some participants say that they see the humanity of the care recipients and in some cases empathise with their stories, as in the case of a 47-year-old participant, who reports: "*In seeing an elderly person you understand that there is a whole story behind them. it is an investment, it is a legacy, a heritage. I can think of a lady with whom it was possible to relate who talked about the war, about how it was. you feel that there is a whole baggage*".

Another aspect that emerged concerns the sense of familiarity, closeness, and the emotional bond with care recipients. Many participants say they have a more or less strong affinity and bond with some people. A 20-year-old participant reports in relation to a care recipient: "*He really touched me, I had become very fond of him. […] Compared to the others, he talked in a way that I really liked. We had a bit of the same passions and shared almost everything*". Some participants say that their bond with care recipients is similar to the one they have with their own families. A 31-year-old participant reports talking about working with the care recipients: "*I see them as if they were my grandparents, [.] we get attached, I spend 7 h a day with them, longer than with my family or my husband, it feels like I am their grandchild or even their daughter*".

With the families of the care recipients, a sense of sharing of suffering seems to develop in several participants, as reported by a 50-year-old participant: "*The condition of the care recipients makes you suffer, it also makes you suffer the fact that families turn to you, they talk about it, relate to it and vent with you*". Some professionals report difficulties in dealing with the choices and expectations of family members. Regarding the disagreement of choices in some phases of care, a 49-year-old participant for example reports: "*In the end it is the family member who decides, but still, what is really the point of a terminal PEG? It is not a waste because the person was not worthy, but it means insisting and for what reason?*". As for the difficulty in confronting the expectations of family members, a 24-year-old participant reports: "*With some care recipients there is that thought of 'Maybe I could have done something more', there is that element, so you also feel almost indebted to the family basically*".

Third theme: The relationship with disease and loss

The third theme concerns the relationship of professionals with disease and loss.

Participants report different experiences related to the worsening of the disease in the care recipients. In particular, some participants report sorrow due to the consequences of the progression of the disease. A 44-year-old participant reports: "*It is clear that when you then see [the care recipients] get worse, change, or even with me that they no longer recognize me, they no longer recognize our moment, this is sad, very sad*".

Another experience, defined by some participants as grief, is linked to the relocation of care recipients to other facilities due to the worsening of the disease. A 44-year-old participant reports: "*In recent years I feel more a kind of grief that is not really grief, in the sense that there are people who pass here, arrive at the day centre, go through the day rehabilitation centre, then the care centre, then the residential, [.] then with the clinical worsening becoming much more complex, they are transferred to the terminal care facility. And there is a black hole where you ask yourself 'But is he alive? But is he still alive?' That is, there is a lot of confusion inside the head and especially there are these deaths that are not really deaths, that is awful*".

Regarding the death of a care recipient, some participants report that the experiences of grief are linked to the type of relationship with people, as reported by a 44-year-old participant: "*[We professionals] have similarities with people that we don't have with others, so certainly not all losses are as painful, or as intense*". Many participants, in relation to death, say that they feel a sense of liberation for the end of suffering, as reported by a 25-year-old participant: "*When there are many years of suffering and when we say the margin of opening has been reduced for a long time, I live it [the death of a care recipient] a bit like a liberation*".

Another aspect that emerged is the importance of giving the last goodbye to care recipients by attending the funeral. A 44-year-old participant reports: "*We were able to go to [care recipients'] funerals only a few times, but it was beautiful because there was a closure, a formalised closure that serves precisely to say 'Ok, I say goodbye to this person'*".

A further element reported by some participants is that of the emotional detachment that serves as a defence, as emerges from the words of a 59-year-old participant: "*Little by little I began to distance myself, because this was not positive, it was not positive and it was of no help to them and it was of no help to me. [...] Even in the tragedy of the disease, I learned to [.] be supportive but in a more detached way*".

The relationship with the disease and the death of the care recipients leads to an appreciation of life in some participants. A 39-year-old professional reports with reference to working in contact with the disease: "*It makes you think and want to live life to the fullest because you see what life is like unfortunately, you have to live it fully day by day*".

Fourth theme: The management of the communication of working experiences

The fourth thematic area concerns the management of the communication of the professionals' work experiences.

Many participants have difficulties in communicating their experiences. In fact, many report that they seldom or never share the grief experienced in the facility outside of it, as stated by a 24-year-old participant: "*It is a bit difficult for me to talk about it to someone who is not accustomed [.] and anyway it is not a topic that it is nice to talk about at the table*".

Many report a disenfranchisement of their own experiences. In this regard, some report episodes in which their experiences have been minimised by external people, such as family and friends, as reported by a 51-year-old participant: "*Maybe I said [to other people] that I was sad for the loss of this care recipient who had suffered so much and they said 'Come on, I mean he wasn't young anyway' 'But look at this disease as it is, I mean, do you realise what kind of life he was living?'*".

Most participants report the importance of sharing. Some refer to the importance of sharing their experiences with people who have a similar job or have had similar experiences in order to feel understood and to

manage pain, as a 44-year-old participant reports: "*To manage the pain of a care recipients' loss, I talk about it with someone who I know has experienced the same thing and who can understand me*". Some participants express the desire to be able to communicate their experiences or to be understood, as reported by a 51-year-old participant: "*I wish they did not run away from me, that they were closer to me, and not with the usual commonplaces. I would have liked more support, more understanding*".

Fifth theme: The relationship with the training intervention with psychodrama

The fifth thematic area concerns the formal caregivers' relationship with the training intervention with psychodrama, i.e. their feelings, concerns and expectations.

Even if some formal caregivers showed concerns regarding the interactive way in which the training course was conducted, the majority of them stated that they had positive feelings such as curiosity and/or enthusiasm towards the training intervention with psychodrama, as reported by a 44-year-old participant: "*I am curious to participate in the training course because death is a topic that I personally have never dealt with because I feel it is delicate for me, and I am curious*".

Many professionals express expectations concerning the acquisition of competences such as relational competences in the working environment or skills in the processing of grief, one 37-year-old participant referring to the training course reports: "*The expectation [towards the intervention] is maybe to get a little bit closer to the world of processing, which for me is a big thing that I say "What does it mean in concrete terms, so how does it work, how do you deal with a loss?*".

After the training intervention

Analysis of the data from the interviews conducted after the training intervention revealed three thematic areas: (a) impact of the training intervention on the professional and personal sphere; (b) contributions of the training intervention in relation to the work team; and (c) acquisition of awareness and skills regarding grief.

First theme: Impact of the training intervention on professional and personal spheres

The first theme focuses on the positive aspects that participants gained or improved during the training course with psychodrama.

The majority of professionals say that the training intervention had an impact on their professional and personal life. A first positive aspect consists in feeling more prepared and self-confident when approaching the job, as stated by a 48-year-old participant: "*I feel that I have gained something from the work point of view [from this course] because I have acquired more skills, and I am more serene and I feel that I can give more*".

Some participants reported that the training course helped them discover the pleasant side of their work. A 20-year-old professional stated: "*[The course made me realise that] I like this job, in fact it gave me so much desire to continue doing this job here*".

Many participants said that they experienced a rediscovery and appreciation of the relationship with the care recipients under their care, as reported by a 47-year-old participant: "*I discovered in the last meeting [of the course] the special drawers in which I keep my relationships with these residents, the meaningful moments and also the fact of developing feelings even of attachment and the emotional contexts, by reliving these experiences I actually found them again, [.] and I rediscovered myself in the relationship with these residents, and rediscovering it was exciting*".

A renewed willingness to commit oneself to one's work was also reported, both with regard to a greater attention and commitment to caring for the care recipients, as a 20-year-old participant reported: "*[Thanks to the course] the desire to be there for them, to talk to them, to follow them has also increased a bit*"; as well as a greater awareness of one's own role in helping the relatives. A 34-year-old participant stated: "*[From the course I feel I have gained] certainly in terms of relating to the family members, understanding a bit more what they can experience, a bit more empathy [.] also understanding more in what state of mind they arrive*

and maybe how to welcome them".

Regarding gains in the personal sphere, some spoke of having gained better acceptance and management of their emotions. One 63-year-old participant reported: ''*The most important thing for me [gained during this course] is that I think I don't feel ashamed anymore if I have feelings, that is, I will still feel ashamed, but not like before when I had to hold myself back because otherwise my colleagues would see me*''. The training intervention was useful to gain greater awareness of the importance of stopping to reflect on the experiences experienced at work, which for some allowed them to gain greater knowledge of aspects of themselves and their current condition, as a 24-year-old participant reports: "*[The course] was a moment when I actually stopped, I realised: I need this, I want this, and what weight I give it*".

Second theme: Contributions of the training intervention in relation to the work team

The second theme focuses on the positive contributions of the training course in relation to the dynamics within the work team.

Many felt they had a deeper and/or more human understanding of their colleagues as a result of the sessions. A 44-year-old participant states in this respect: "*[Thanks to the course there was] a discovery [.] of the human side [of colleagues] and also how there is a whole world behind a person that we only know a few hours and from a professional point of view, but behind there is a whole world of experiences, past stories, emotions that one has lived*".

In general, the training course seems to have favoured greater closeness and complicity between colleagues and for some it has enabled them to strengthen support within the team, as reported by a 54-year old participant: "*In reference to the difficulties at work, [the course made it possible that] if you have a colleague close to you, a colleague who, on the other hand, lives these things in a certain way, you are closer to them, [.] there are also different energies that you don't think you have, instead you can make them available not only for relatives, care recipients, but also for colleagues*".

Among the support modalities, there emerged a greater awareness of the importance of sharing and talking with colleagues and how the possibility to talk and share in fact makes it possible to lighten the burden of difficulties and tension that comes with caring for care recipients, as one 39-year-old participant reported: "*[The course made me realise that] maybe we need to focus more on a dialogue between us colleagues, that we don't talk so much, so this will maybe encourage us more to stop for 5 min and talk more often about certain aspects of our work*".

One aspect that emerged was a similarity of experiences among colleagues and a normalisation of their own experiences. As one 44-year-old participant put it: "*[The course allowed me to] remind myself that [loss] is something that others also experience, it's not just a feeling I have so I'm not weird*". Some participants also report that the training course helped them to gain a greater awareness of recognising and understanding the experiences of others, especially regarding people with professions other than their own, as a 46-year-old participant states: "*[Thanks to the course] I really realised that even those who do a different job think about these things a lot more than I imagined*".

Third theme: Acquiring awareness and skills regarding grief

The third thematic area that emerged concerns the awareness and skills regarding grief that the training intervention enabled.

Many participants report that the training course enabled them to become aware of the existence of ambiguous loss and disenfranchised grief, as a 46-year-old participant reported: "*The course enabled me to give a name to these griefs and [this] makes me feel a bit more normalised, sometimes I used to say 'but maybe it's just me who has certain thoughts', instead you see that it's normal so it comforts me*".

Regarding the awareness of one's own grief experiences, some reported that the training course enabled them to realise that they had unprocessed grief, as reported by a 57-year-old participant: "*All the work done [during the course] made me discover that there was this very difficult grief inside me that was denied [.] but it was good that it came out because. it was really unresolved*".

For many, the training course allowed them to experience the feeling of solving and bringing closure to unresolved issues relating to care recipients and their loss, as reported by a 44-year-old participant: "*[The intervention allowed one to] really close a circle [.] and this definitely allows one to move forward and not to leave the obfuscation, the sense of unfinished, incomplete, lost*".

Some participants reported that the training course enabled them to acquire competence in dealing with ambiguous loss and disenfranchised grief. In fact, some of the participants reported that they had gained more preparation and confidence in dealing with these issues, as a 46-year-old participant states: "*[Regarding loss issues], having been able to experience these issues in a protected way, from a work point of view, I think it may help me to feel a little safer in dealing with painful situations as well as recognising them, but also being able to approach them*". Regarding ambiguous loss experiences, some state that the training course will enable them to better cope with the experience of assisting people who gradually loses their identity, as reported by a 20-year-old participant: "*[Having participated to the course] let's say that it helps me to cope more with something that happens to me almost every day, when a person who maybe a month ago was in a state and day after day starts not to recognise you and to let themselves go*". Concerning the skills required to deal with disenfranchised grief, some report that the training course allowed them to understand that disenfranchised grief can be dealt with within the structure, as reported by a 24-year-old participant: "*[The course] made me realise how [being disenfranchised in one's own loss] is something that can occur and therefore is something that one does not actually have to deal with alone, but that one can easily deal with by talking about it with colleagues*".

Discussion

This study is one of the first at international level to investigate and intervene on the phenomenon of ambiguous loss and disenfranchised grief among formal caregivers working in a health care context. The initial status of the participants prior to the training intervention shows that 17% of the participants reported problems related to well-being, specifically with regard to mental and physical health, the ability to cope with everyday life, the social and interpersonal sphere and their own quality of life and emotional health. No harmful attitudes towards self and others emerged. From the literature it emerges that caring for a person with dementia affects the well-being of caregivers, who tend to report psychological distress and a lower quality of life (Pereira et al., 2021), as well as a perception of poorer physical health in general (Allen et al., 2017; Alzheimer's Association, 2021).

One of the novel aspects of the present study was that it investigated ambiguous loss within the population of formal caregivers, a phenomenon that had previously mainly been studied only in informal caregivers (Bravo-Benítez et al., 2021; Meichsner et al., 2019). The data of the present study show the importance of considering the phenomenon also in formal caregivers: the results show that, prior to the training intervention, 19% of the individuals experienced high levels of distress related to formal caregiver ambiguous loss. Of the participants, 63% reported high levels of distress regarding relational losses occurring during the course of illness, while 46% experienced high levels of painful emotions associated with the progressive loss of a loved one. Data from the present study show that formal caregivers of people with dementia experience ambiguous loss similarly to family caregivers (Gilsenan et al., 2022; Lindauer & Harvath, 2014).

The quantitative analysis of the data collected a week after participation in the psychodrama training course revealed a reduction in the suffering related to formal caregiver ambiguous loss and an improvement in the participants' well-being. With regard to the results on formal caregiver ambiguous loss, it emerged that intervening with psychodrama resulted in a general decrease in suffering due to ambiguous loss,

and specifically in the painful emotions caused by the progressive loss of a care recipient. To a lesser extent, the training course also led to a reduction in the feeling of absolute loss of the person with dementia, loss of life meaning and despair due to the loss. Indeed, according to the literature, psychodrama has proven effective in dealing with death and loss processing in other contexts as well (Testoni et al., 2019a; Testoni et al., 2018a; Testoni et al., 2019c; Testoni et al., 2018b; Testoni et al., 2020b).

As a result of the training intervention, a significant improvement in the participants' levels of well-being was also noted, especially in the sphere of mental health problems and physical disorders. Participating in psychodrama interventions can indeed lead to improvements in subjective well-being levels (Kaya, 2020). On the other hand, no significant changes in burnout levels were observed and this may be because burnout was already low prior to the training intervention.

The results from the qualitative analysis of the interviews conducted before the training course show recurrent feelings of stress and frustration caused by the sense of helplessness derived from working in contact with people with dementia, a disease that can be a cause of stress for the caregiver (Mello et al., 2017; Pearlin et al., 1990). Moreover, difficulties emerged in the management of professional and personal spheres, which is characterised at times by over-involvement, at others by the need to set limits and detach oneself. Finding a balance between these two aspects in working with people with dementia can be complex for professionals (Bailey et al., 2013). One solution that may favour the well-being and professional involvement of caregivers is to set a psychological distance from the experiences lived at work during leisure time (Sonnentag et al., 2010). With regard to the relationship with care recipients, it was found that participants often establish emotional bonds with care recipients and experience a sense of familiarity and closeness with them. Authentic involvement in the relationship, i.e. establishing a personal connection with a care recipient, is one of the key approaches in person-centred practice that can be beneficial to both caregivers and care recipients (Pratt et al., 2020). Establishing a connection with the care recipient is therefore a central aspect of care. At the same time, the caregiver must possess the necessary tools to manage it and thus avoid risks to their psychological well-being. In fact, the present study shows that during work, strategies of emotional detachment are implemented by the participants as a defence against suffering. Detachment reactions and denial of grief related to work losses are frequent and serve to protect professionals from being overwhelmed by their own emotional experiences (Papadatou, 2000).

Different experiences also emerged regarding people's relationship with illness and loss. In particular, feelings of sorrow and defeat caused by the condition of the care recipients imposed by their disease and their worsening were common among the participants. Family caregivers of people with dementia similarly reported experiencing distress due to the stress of experiencing loss slowly during the course of the illness and thus experiencing a paradox given by the separation between psychological and physical loss (Lindauer & Harvath, 2014). With regard to death-related experiences, when a care recipient passes away participants report experiencing not only a feeling of grief over the loss, but also a sense of liberation for the end of the suffering of the person under their care. Similarly, family caregivers may welcome the death of their loved one often with feelings of relief (Hovland, 2018).

The results highlighted the importance of attending funerals to say goodbye to care recipients, paying respect and bringing closure. The opportunity to say a final goodbye represents an opportunity for caregivers to support the grieving process and achieve a form of closure (Yeh et al., 2018). They find it important to be able to share their experiences with their colleagues and/or those going through similar experiences and wish to be understood and valued. Having a sense of trust and open communication with the team contributes to the ability to care for care recipients and to feeling valued and acknowledged (Sikma, 2006). The desire to be valued is relevant in people working with people with dementia, in that it satisfies the need for security, recognition and personal fulfilment (Cooke, 2018). It also emerged that participants face difficulties, lack of acknowledgment or minimisation when sharing their experiences. The lack of acknowledgement and bereavement intervention experienced by caregivers can negatively affect their job performance (Carton & Hupcey, 2014).

Regarding the contributions of the training intervention, the qualitative analysis highlighted how it led to various results. The psychodrama enabled the participants to become more aware of formal caregiver ambiguous loss and disenfranchised grief experiences by defining them. With regard to ambiguous loss, the actions of recognising and defining the experience of ambiguous loss are fundamental because they allow for an initial awareness of the grieving process, with the consequent possibility of implementing the process of managing and processing it (Blandin & Pepin, 2017). On the other hand, with regard to disenfranchised grief, recognising and defining it even at a social level, as was the case during the training intervention, is an aspect of central importance and its denial can prevent the team from identifying the need for care and moving effectively through the bereavement process (Anderson & Gaugler, 2007; Testoni et al., 2021a; Vis et al., 2016). The training course helped to bring closure to loss experiences left unresolved. Psychodrama, by giving the opportunity to "meet" and "talk" with the person, in fact allows for a closure of unresolved issues (Giacomucci, 2020), which in cases of ambiguous loss is particularly difficult to achieve (Boss, 2010; Knight & Gitterman, 2019). With the training intervention, more skills were also acquired with regard to bereavement that need to be handled in the work setting, as it provided the opportunity to deal with difficult topics such as bereavement and loss within a protected environment, thus allowing to work on potentially problematic issues in a safe and non-judgmental space (Orkibi & Feniger-Schaal, 2019).

The training course enabled the participants to gain a greater sense of confidence and preparedness to face work challenges. Psychodrama is indeed able to promote psychological empowerment in the healthcare population (Özbaş & Tel, 2015). The training course resulted in better acceptance and management of one's emotions. Psychodrama is effective in improving healthcare personnel's self-awareness in relation to their experiences and emotions, enabling them to better know and manage their emotional reactions (Oflaz et al., 2011).

As a result of the training course, the importance of the relationship with the care recipients and their family was rediscovered, along with a consequent renewed willingness to engage in one's work. It is essential to establish a good caregiver- care recipient relationship based on trust and respect to achieve a better quality of care (Pratt et al., 2020). Finally, gains were also noted in the relationship with the work team, as participants perceived greater knowledge of their colleagues, greater support and greater attention to and appreciation of the experiences of others. The training course also highlighted the importance of dialogue as a tool to better manage difficulties at work. These results confirm that building relationships based on mutual trust between colleagues enables good collaboration and improvement in the care of frail elderly people (Vrijmoeth et al., 2022).

Limitations and future directions

The limitations of this study were that it addressed a specific context with a small number of participants. These participants were selected in a non-random manner. The small numerosity can be justified by pointing out the type of sampling. In fact, the sample considered was a systematic group, as it involved all subjects in the system, that is, workers in the facility where the research was conducted. Furthermore, a control group with which to compare the results of the experimental group was not included. Regarding the questionnaires, the scale used for burnout may not have been sufficient for the exploration of the construct as it was based on a single-item scale and the subjective definition of burnout of the participants.

In the future, it will be important to continue caring for formal

caregivers, both by investigating grief and by focusing on the perception of burnout, in order to prevent and process possible problems in the workplace. There is almost no research concerning ambiguous loss and disenfranchised grief in formal caregivers and the effectiveness of psychodrama in this field. For this reason, and because of the importance of ensuring the occupational well-being of caregivers caring for persons with neurodegenerative and/or terminal illnesses, it will be crucial to provide this training intervention in multiple contexts in the future in order to assess its impact.

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Institutional Review Board Statement

The study was conducted in accordance with the Decla-ration of Helsinki, and approved by the Ethics Committee of the University of Padova (protocol code: 99AF23E57237B2922335B1B2C833337E, date of approval: 09/08/2021).

Informed Consent Statement

Informed consent was obtained from all subjects involved in the study.

CRediT authorship contribution statement

Ines Testoni: Conceptualization, Methodology, Validation, Resources, Writing – original draft preparation, Writing – review & editing, Visualization, Supervision, Project administration. **Gianmarco Biancalani:** Conceptualization, Methodology, Validation, Investigation, Data curation, Writing – original draft preparation, Writing – review & editing, Visualization, Supervision. **Lucia Ronconi:** Methodology, Validation, Formal analysis, Data curation, Writing – original draft preparation, Writing – review & editing, Visualization. **Arianna Pedrini:** Validation, Formal analysis, Investigation, Data curation, Writing – original draft preparation, Writing – review & editing, Visualization. **Sofia Romanelli:** Validation, Formal analysis, Investigation, Data curation, Writing – original draft preparation, Writing – review & editing, Visualization. **Andrea Melendugno:** Conceptualization, Methodology, Resources, Supervision. All authors have read and agreed to the published version of the manuscript.

Declaration of Competing Interest

None, the authors declare no conflict of interest.

Data Availability

Data will be made available on request.

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