

General

Dehumanization and burden of care among caregivers of terminally ill patients

Ines Testoni¹, Giulia Sicari², Lucia Ronconi³, Gianmarco Biancalani², Chiara Franco², Paolo Cottone², Robert Crupi⁴

¹ Department of Philosophy, Sociology, Education and Applied Psychology (FISPPA), University of Padova; Emili Sagol Creative Arts Therapies Research Center, University of Haifa, ² Department of Philosophy, Sociology, Education and Applied Psychology (FISPPA), University of Padova, ³ IT and Statistical Services, Multifunctional Pole of Psychology, University of Padua, ⁴ NewYork-Presbyterian Queens

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This article considers the relationship between dehumanization, ontological representation of death, trust in physicians, and burden of care on the part of caregivers of terminally ill patients. One hundred informal caregivers (relatives and friends) of patients hospitalized in four hospice facilities in northern Italy were involved. Of these, 77% were primary caregivers (those who mostly helped the patient). All of the participants were given a questionnaire comprising the Caregiver Burden Inventory (CBI) to determine caregivers' burden in their roles, the *questionario post mortem (QPM)* (post mortem questionnaire) for the effectiveness of and their trust in the medical nursing team of palliative care services, the Testoni death representation scale (TDRS) to detect their ontological representations of death and the humanity attribution test (HAT) to investigate their attributions of humanity to terminally ill patients. Per the literature, the present results demonstrated higher burden levels for female caregivers and primary caregivers. In informal caregiving, the dehumanization of patients does not have any advantage in reducing the burden of care. Further studies are required to compare formal and informal caregivers concerning the effect of dehumanization.

1. INTRODUCTION

The last 30 years have seen a significant increase in family members' involvement in managing patients' needs within the context of healthcare systems.^{1,2} Unlike their professional counterparts, informal caregivers are usually relatives who assist people with physical, cognitive, or emotional impairments without being financially compensated.^{3,4} This burden of care can adversely affect them, as they often lack adequate resources and are not sufficiently prepared for this role.^{2,5} The concept of 'caregiver burden' is a multidimensional construct that is generally used to refer to the physical, psychological, social and/or financial conditions that affect caregivers during the period they are engaged in caring.^{3,6} The burden develops as the disease progresses because worsening the patient's disease entails increased physical care and emotional support. The limitations in their social life and relationships, the heightened demands of terminal care, and the emotional strain often leave caregivers physically and psychologically exhausted.^{1,2,7} In addition, studies have shown that their social difficulties are often related to their need to avoid conversations about the disease to protect themselves and their loved ones.⁸ In the end-of-life field, a low level of communication between patients and caregivers can lead to several adverse consequences that influence important decisions about treatment and plan of care and undermine the time for affirming meaningful relationships and saying final goodbyes.⁷ The literature suggests that sociodemo-

graphic differences among caregivers can affect the caregiving experience. Indeed, it has been observed that women and young caregivers are more likely to be at risk of developing psychological distress.^{2,9,10}

The burden of care also affects healthcare professionals, who suffer higher psychiatric comorbidity and stress levels than the general population due to their heavy workload and exposure to patients' physical, emotional, and psychosocial needs. This difficulty can cause dysfunctional behaviors that offend patients' dignity and are related to an implicit attribution of lower human status.¹¹ Starting with the sociological idea that dominant groups often preserve the attribution of humanity for themselves (ingroup), social psychology coined the expression dehumanization to indicate the idea that other groups (outgroup) are denied their proper 'humanness.' This concept recognizes an asymmetry between those who share typically human qualities and those who are considered less human.^{12,13} A particular form of dehumanization is 'infrahumanization'; it consists of the latent attribution of emotional characteristics.¹⁴ Some emotions are considered unique to humans ('secondary emotions' such as love, regret, and nostalgia), whereas others are considered common to humans and animals ('primary emotions' such as joy, anger, and sadness). The prejudicial bias consists in the attribution of the primary emotions to the outgroup.¹⁵⁻¹⁷ Studying a sample of health professionals, Vaes and Muratore¹⁸ observed that the attribution of primary emotions to the patient was negatively associated with burnout. On the contrary, the attributions

of secondary emotions to the patient were positively associated with burnout, particularly in professionals with more direct contact with patients. Therefore, dehumanization can provide functional effects for healthcare professionals and clinical practice as a strategy to cope with stress and avoid emotional overload of the direct exposure to the pain, suffering, and death of the patient (see also Capozza, Falvo, Testoni, & Visintin¹⁹; Trifiletti, Di Bernardo, Falvo, & Capozza²⁰). However, dehumanization can adversely affect communication processes, particularly the exchange of information and the relationship between patients and healthcare professionals.¹¹

Taking into consideration that the aging population is leading to a growing increase in the need for informal caregiving in Western societies,² the present study has investigated the experience of informal caregivers of terminal ill patients first considering which sociodemographic variables play an essential role to determine high levels of caregivers' burden. Secondly, the possible attributions of not-human traits to terminally ill patients were analyzed to understand whether these strategies of dehumanization generally reported informal caregiving activities could be detected as a protective factor to manage the burden of care even in informal caregiving. Moreover, since some scholars have observed that ontological representations of death are related to humanness attribution to patients in health professionals,²¹ we wanted to test whether representations of death might also affect the infrahumanization processes (e.g., perceiving patients as not fully human) among informal caregivers.

2. MATERIALS AND METHODS

2.1 AIMS AND HYPOTHESES

The literature emphasizes how dehumanization and infrahumanization can be protective strategies professional caregivers use to diminish the stress they experience from direct contact with patients.^{11,18,19} This study examined whether this same protective function might be present in informal caregivers (relatives and friends). It hypothesized that in informal caregiving, this effect does not exist because patients cannot be dehumanized. When considering the closer relationship between informal caregivers and patients, it is expected that attributing not-human traits to the patient might increase the care burden. The study also surveyed if and how dehumanization was related to the ontological representation of death, as this aspect was already investigated among healthcare professionals.²¹ In particular, this study asks whether dehumanization is related to the representation of death as an absolute annihilation because it can be considered, as the literature suggests,^{22,23} that it is a characteristic depiction of animal beings. Finally, the study considered which variables most significantly affected the care burden.

The research followed the 'APA Ethical Principles of Psychologists and Code of Conduct and the principles of the Declaration of Helsinki. Participants were given a detailed explanation of all the research objectives and the methodology that was used. The Ethics Committee approved the study for Experimentation of the University of Padova

(Number 9C49C2350586C57DCCD6FFBB1AC1CE38).

2.2 PARTICIPANTS

The participants were selected at random from all those who frequented one of four hospices in northern Italy. These four hospices illustrated the research to the caregivers of the patients who attended the facility, asking them if they would like to participate and providing contact details for the researchers. Through this collaboration, researchers received contacts from 95 caregivers who offer, or have offered in the past, a network of support and assistance to the terminally ill hospitalized in one of the four hospices. Primary caregivers, in our research, were caring for a friend or family member with a terminal illness or who requires assistance with daily activities. One hundred caregivers were initially involved in the research project. The inclusion criterion included having friends or family members hospitalized in hospice due to an incurable disease and participating in the survey. Once selected, the participants were asked to fill out a questionnaire. Our research excluded caregivers of those about to die to not further stress the participants who were experiencing a burdensome situation. Five subjects were excluded because they did not fully complete the questionnaire. The caregivers' characteristics are reported in [Table 1](#).

2.3 MEASUREMENTS

The self-reported questionnaire administered to the caregivers consisted of the following instruments:

The caregiver burden inventory (CBI)²⁴ is a 24-item, 5-point Likert scale investigating the subjective care burden caregivers experience across five different dimensions. The total index has a very good internal consistency (Cronbach's alpha .91). The CBI has been used for burden measurement studies in adult caregivers caring for patients with severe degenerative diseases such as Parkinson's, Alzheimer's, and amyotrophic lateral sclerosis (ALS).²⁵⁻²⁷ The five dimensions are as follows:

- The time-dependence (TD) burden measures the burden due to the caregiver's time restrictions because of the amount of time dedicated to the patient (Cronbach's alpha .94).
- The developmental (D) burden refers to the possible sense of failure experienced and the feeling of being cut off from the average experience of peers (Cronbach's alpha .81).
- The physical (P) burden assesses the caregiver's physical stress, perceived chronic fatigue, and psychosomatic health problems (Cronbach's alpha .88).
- The social (S) burden detects the caregiver's feelings of role conflict when they argue about how to manage the care-receiver's needs when they feel unappreciated and neglected by others, or when they have to limit the time and energy invested in relationships or jobs (Cronbach's alpha .83).
- The emotional (E) burden evaluates the possible presence of negative emotions and feelings the caregiver may have toward the patient and their guilt about

these socially unacceptable feelings (Cronbach's alpha .75).

Questionario post mortem (post-mortem questionnaire) (QPM)²⁸ evaluates the effectiveness and caregivers' trust in the medical nursing team in charge of a patient's palliative care services. The QPM was administered to 91 caregivers of cancer patients to examine their satisfaction with palliative care service.²⁸ The post-mortem questionnaire-short form (QPM-SF)²⁹ is also available. The QPM is a 24-item, 5-point Likert scale divided into four different factors with very good internal consistency:

- Relational modality concerns the medical nursing staff's availability, the modality of informing, the ability to listen, the availability in case of need, and the frequency of visits (Cronbach's alpha .92).
- Control of symptoms and needs explores the team's specificity in managing pain and other symptoms related to the disease through six specific items. This factor includes items pertaining to psychological and bureaucratic needs (Cronbach's alpha .91).
- The assistance of the general practitioner measures the care provider's work through a willingness to inform, willingness to listen, availability in case of need, and the frequency of home visits (Cronbach's alpha .95).
- Information investigates the information received regarding the diagnosis, therapy, and course of the patient's pathology (Cronbach's alpha .96).

The Testoni death representation scale (TDRS)³⁰ is a 6-item, 5-point Likert scale measuring the ontological representations of death either as annihilation or as a passage into an afterlife. Lower scores indicate that the individual represents death as a passage, whereas higher scores represent death as total annihilation. The TDRS has very good reliability (Cronbach's alpha .82). The instrument shows that the representation of death as an absolute annihilation is related to depression and difficulties in coping with loss,^{22,30} whereas the representation of death as a passage helps both caregivers to better manage their support of a dying person³¹ and in general any person who is closely experiencing their death or that of a loved one.³²

Finally, the humanity attribution test (HAT)³³ is an 8-item, 5-point Likert scale that measures how participants assign uniquely human characteristics to the patients for which they care. It is divided into two different factors, both with good internal consistency: high scores in this measurement scale, with the necessary inversions for the negative items, indicate that the person (the caregiver) attributes greater humanity (toward the patient); in contrast, low scores indicate that the caregiver humanizes to a lesser extent. The HAT has been used to examine dehumanization strategies used by nurses to cope with stress²⁰ and dehumanizing perceptions of stigmatized groups, namely, LGBTQ people and individuals with intellectual disabilities.^{34,35}

- Attribution of human traits to the patient (Cronbach's

Table 1. Characteristics of caregivers (N = 95)

Variable	N (%)
Gender	
Female	62 (65%)
Male	33 (35%)
Age	
<50 years	35 (37%)
>50 years	60 (63%)
Marital status	
Married/cohabiting	56 (59%)
Other (single/separated/divorced/widower)	38 (40%)
Missing	1 (1%)
Education status	
Lower education	40 (42%)
Medium/higher education	55 (58%)
Employment status	
Employed	43 (45%)
Other (homemaker/retired)	47 (50%)
Missing	5 (5%)
Primary caregiver	
No	22 (23%)
Yes	73 (77%)
Relationship with the patient	
Partner	18 (19%)
Parent (of the patient)	10 (10%)
Son/daughter (of the patient)	49 (52%)
Brother/sister	5 (5%)
Other	13 (14%)

alpha .75).

- Attribution of no-human traits to the patient (Cronbach's alpha .72).

2.4 STATISTICAL ANALYSES

A preliminary analysis to check the distribution of the study variables was conducted by inspecting skewness and kurtosis. All measures, except the E subscale of the CBI, showed skewness and kurtosis values ≤ 2 . To evaluate the intensity of the caregiver's burden, quality of the relationship with the medical team, and death representation, the study compared the mean of the total score of each variable with the central position score using the Student's t-test.

A Pearson's correlation coefficient was used to assess associations between two continuous variables; a t-test was used to compare the means of continuous variables by caregiver characteristics. Moreover, the predictive effects of a caregiver's characteristics, quality of their relationship with the medical team, and death representation for their burden were summarized using regression analysis. Assumptions for regression were checked by multicollinearity diagnostics and residual plots examination. All the measures had tol-

erance values over .80, indicating the total absence of multicollinearity. Further, all the standardized residual scores ranged from -3 to 3, except for subscale E of the CBI, which indicated a residual distribution close to the normal distribution. All the analyses were conducted with an alpha level set at .05. Finally, the analyses were carried out using SPSS 25 (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. IBM Corp, Armonk, NY, USA).

3. RESULTS

Table 2 shows the descriptive statistics and correlations between the study variables. The results revealed significantly lower intensity scores for caregivers' burden ($t = -10.84$, $df = 94$, $p < .001$ for the total CBI score; $t = -31.38$, $df = 94$, $p < .001$ for the E subscale; $t = -8.81$, $df = 94$, $p < .001$ for the S subscale; $t = -7.06$, $df = 94$, $p < .001$ for the D subscale; $t = -5.25$, $df = 94$, $p < .001$ for the P subscale) except for the TD subscale, which showed significantly high intensity values ($t = 2.07$, $df = 94$, $p = .041$). Moreover, significantly high intensity values for the quality of caregivers' relationships with medical teams were found ($t = 17.14$, $df = 94$, $p < .001$ for Factor 1; $t = 13.57$, $df = 94$, $p < .001$ for Factor 2; $t = 2.06$, $df = 94$, $p = .042$ for Factor 3; $t = 13.01$, $df = 94$, $p < .001$ for Factor 4). No differences between the two opposite death representations, passage versus annihilation, were found ($t = -0.84$, $df = 94$, $p = .405$). Regarding the attribution of human and not-human traits to the patient, there were significantly high intensity values for human traits attribution ($t = 9.37$, $df = 94$, $p < .001$), and on the contrary, significantly low intensity values were found for not-human traits attribution ($t = -3.51$, $df = 94$, $p = .001$).

A negative correlation between Factor 2 of the QPM and caregivers' burden was found ($r = -.22$, $p = .029$ for the S subscale and $r = -.18$, $p = .088$ for the P subscale). The opposite of this was found regarding the correlation between Factor 3 of the QPM and caregivers' burden; there was a negative correlation with the S subscale ($r = -.22$, $p = .029$) and a positive correlation with the E subscale ($r = .18$, $p = .084$). No correlation between Factor 1 and Factor 4 of the QPM and caregivers' burden was found. No correlation between death representation and caregivers' burden was found. Finally, attribution of not-human traits to the patient positively correlated with caregivers' burden ($r = .20$, $p = .050$ for the total CBI score). No correlation between attribution of human traits to the patient and caregivers' burden was found.

No correlation between dehumanization - attribution of no-human traits to the patient - and death representation was found ($r = .15$, $p = .142$).

Moreover, a significant relationship between caregivers' burden and some caregivers' characteristics was found: gender ($t = 2.41$, $df = 93$, $p = .018$ for the total CBI score), age ($t = -3.42$, $df = 93$, $p = .001$ for subscale S of the CBI) and being the primary caregiver ($t = 2.98$, $df = 93$, $p = .004$ for the total CBI score). Females showed a higher level of burden than males ($M = 31.89$, $SD = 16.98$ vs $M = 23.19$,

$SD = 16.41$, respectively). Caregivers younger than 50 years showed higher scores than those older than 50 years on subscale D ($M = 5.42$, $SD = 4.95$ vs $M = 2.35$, $SD = 3.72$, respectively). Finally, caregivers who were the primary caregiver showed higher levels of burden than those who were not the primary caregivers ($M = 31.64$, $SD = 16.46$ vs $M = 19.66$, $SD = 16.75$, respectively).

Finally, the study evaluated a regression model for caregivers' burden that only included the variables with a significant bivariate association with caregivers' burden. The regression analysis results (**Table 3**) showed that caregivers' burden was significantly predicted in a positive way by female gender ($\beta = .24$, $p = .017$ for the total CBI score; $\beta = .33$, $p = .001$ for subscale D; $\beta = .29$, $p = .003$ for subscale P), being the primary caregiver ($\beta = .28$, $p = .006$ for the total CBI score; $\beta = .25$, $p = .012$ for subscale P; $\beta = .23$, $p = .034$ for subscale TD and $\beta = .17$, $p = .080$ for subscale S), attribution of not-human traits to the patient ($\beta = .18$, $p = .072$ for the total CBI score; $\beta = .22$, $p = .030$ for subscale D; $\beta = .16$, $p = .096$ for subscale P). Caregivers' burden was significantly predicted in a negative way by age ($\beta = -.31$, $p = .002$ for subscale S) and Factor 2 of QPM ($\beta = -.22$, $p = .028$ of the subscale P). Globally, the predictors explained a significant proportion of the variance in caregiver's burden scores, excepting the subscales TD and E (R^2 ranged from .06–.23).

4. DISCUSSION

The research only partially confirmed the study's assumptions. Although the literature has highlighted how representations of death as a passage help caregivers' to better manage distress and their relationship with the dying³¹ – and how representations of death as annihilation in totality are related to processes of dehumanization in healthcare²¹ – in this study, neither of these relationships appeared. This result suggests that death-related factors do not intervene in informal caregivers' processes of humanization and dehumanization.

Furthermore, representations of death did not appear to affect the distress, neither reducing nor increasing it. This study found that other factors affected the burden. In particular, being female and being a primary caregiver were the two most significant predictors of the caregiver's level of exhaustion. This is consistent with the literature, which has reported that women usually spend more time caring for the sick and experience greater stress levels in their caregiver activities.^{9,10} In addition, being the primary caregiver is another significant predictor of burden levels. The literature has already shown that this factor is affected by the severe limitations of time and freedom that caregivers suffer. The primary caregiver is responsible for the full-time care of the patient and, therefore, can suffer most from limitations to personal existential experiences.³⁶

Table 2. Descriptive statistics and correlations between measures (N = 95)

Measure	Range	M (SD)	1	2	3	4	5	6	7	8	9	10	11	12
1.CBI-TD	0-20	11.49 (6.99)	-											
2.CBI-D	0-20	6.29 (5.11)	.38***	-										
3.CBI-P	0-20	6.95 (5.67)	.43***	.62***	-									
4.CBI-S	0-15	3.48 (4.44)	.22*	.33**	.45***	-								
5.CBI-E	0-15	0.66 (2.12)	.02	.30**	.20*	.29**	-							
6. CBI-Total	0-96	28.87 (17.21)	.72***	.78***	.83***	.63***	.36***	-						
7.QPM-Factor1	1-5	4.22 (0.70)	-.02	-.15	-.08	-.12	.10	-.10	-					
8.QPM-Factor2	1-5	4.09 (0.78)	-.02	-.14	-.18~	-.22*	.04	-.16	.79***	-				
9.QPM-Factor3	1-5	3.27 (1.28)	-.12	-.01	-.09	-.22*	.18~	-.12	.33**	.27**	-			
10.QPM-Factor4	1-5	4.13 (0.84)	-.07	-.16	-.16	-.09	.02	-.14	.76***	.71***	.29**	-		
11.TDRS-Total	1-5	2.91 (1.02)	.00	.00	-.10	.01	-.16	-.05	.00	.08	.08	.01	-	
12.Attribution of human traits to the patient	1-5	3.83 (0.86)	-.04	-.14	-.14	-.17	-.08	-.16	.12	.15	-.07	.16	-.11	-
13.Attribution of no-human traits to the patient	1-5	2.66 (0.93)	.09	.20~	.19~	.19~	-.02	.20~	-.08	-.05	-.17	.01	.15	-.09

-p < .10; *p < .05; **p < .01; ***p < .001

Table 3. Regression analysis results of the CBI (N = 95)

Predictor	CBI					
	TD	D	P	S	E	Total
Gender caregiver (1=Female, 0=Male)	.09	.33**	.29**	.00	.07	.24*
Age caregiver (1=Over 50 years, 0=Under 50 years)	-.02	-.03	.11	-.31**	-.07	-.07
Primary caregiver (1=Yes, 0=No)	.23*	.15	.25*	.17~	.11	.28**
QPM-Factor2	.00	-.17	-.22*	-.12	.00	-.16
QPM-Factor3	-.13	.04	-.04	-.16	.18	-.07
Attribution of no-human traits to the patient	.05	.22*	.16~	.15	.01	.18~
R-square	.09	.20**	.23**	.23**	.06	.22**

Values reported in the table are standardized regression coefficients.

~p < .10; *p < .05; **p < .01

Regarding chronic fatigue and damage to physical health, women suffered more than men (as did primary caregivers, as they spent the most time with the patient); this was confirmed in previous studies.^{9,10,37} Furthermore, the present study found that adequate control of symptoms and needs – thus supporting the patient physically in managing pain and other symptoms and providing psychological support to the family caregiver – promotes the caregiver's health, reducing physical damage. The burden that the caregiver experiences in the event of a conflict in their role (e.g., a discussion with other family members on how to manage the needs of the sick patient or feeling unappreciated and neglected by others) were increased in caregivers <50. Other family members may think a younger age equates to a lack of experience inadequately caring for the patient, fuelling judgments that can negatively affect the well-being of the young caregiver, who may feel inadequate in their role despite that the literature shows that younger caregivers have more excellent resistance to stress.⁵⁸

Concerning dehumanization, no advantage in terms of reducing stress appeared. The hypothesis that dehumanization/infrahumanization is not useful for informal caregivers is therefore confirmed. As the literature already indicates, what moves people to help those who die is a deep sense of humanity. More precisely, being female and attributing not-human traits to the patient increased caregivers' exhaustion due to losing out on life compared to their peers (i.e., feeling left out). Patient dehumanization is a dysfunctional strategy to cope with stress.¹¹ From the results of this study, it is clear that those who implement this strategy suffer most from feeling they are losing time out of their lives due to their commitment to caregiver activities.

5. CONCLUSIONS

This research aligns with previous literature highlighting that primary caregivers suffer most from the burden of their

role and that being a woman increases the risk of exhaustion in caregiving activities. However, it is also important to underline that adequate medical and psychological support greatly helps caregivers in their role (i.e., not feeling abandoned and carrying the full responsibility for treating a terminally ill family member or friend). Implementing medical support services for patients and psychological support for caregivers could significantly increase caregivers' well-being. This study confirms that informal caregivers do not benefit from dehumanizing patients in reducing the burden of care, unlike their medical professional counterparts. This specific result requires further investigation to compare professional and informal caregivers concerning the effect of dehumanization.

STUDY LIMITATIONS AND FUTURE DEVELOPMENTS

The most important limitation of this research is the small sample size, which prevented more in-depth analysis. The patient's primary illness and time involved in caring could also impact the experience of burden in caregivers. In addition, aspects related to religiosity should be considered in future studies since other differences among participants can be drawn from the relation between dehumanization and faith.

CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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