Health & Research Journal

Vol 10, No 2 (2024)

Volume 10 Issue 2 April - June 2024

Health and Research Journal (peer review) ISSN:2459-3192

International Journal of Research and Review in Health Sciences

Volume 10 Issue 2 April - June 2024

EDITORIAL

INTENSIVE CARE UNIT: THE CONCEPT OF A SPECIAL CARE

RESEARCH ARTICLES

AN INVESTIGATION OF PARENTAL CONCERNS ABOUT THE EDUCATIONAL AND PSYCHOSOCIAL DEVELOPMENT OF THEIR CHILDREN AGED 2-6 YEARS DURING THE COVID-19 PANDEMIC

A NEGLECTED PROBLEM IN CAREGIVERS OF CANCER PATIENTS: SUPPORTIVE CARE

EXPERIENCES OF LOSS AND THEIR MANAGEMENT BY INFORMAL CAREGIVERS IN THE COMMUNITY. PERCEIVED QUALITY OF LIFE OF PEOPLE WITH CHRONIC DISEASES

THROMBOSIS IN SEVERELY ILL PATIENTS ADMITTED IN ICU DUE TO COVID-19 PNEUMONIA. DATA FROM A GREEK HOSPITAL

CASE REPORT

CUTANEOUS AMYLOIDOSIS IN A PATIENT WITH SYSTEMIC AMYLOIDOSIS DUE TO MULTIPLE MYELOMA

SPECIAL ARTICLE

HOW HAS PSYCHOLOGY IMPROVED UNDERSTANDING OF WHY PEOPLE LIE?

REVIEW

WOMEN AND FAMILIAL HYPERCHOLESTEROLEMIA

Published in cooperation with the Postgraduate Program "Intensive Care Units", the Hellenic Society of Nursing Research and Education and the Helerga

Experıences of loss and theır management by ınformal caregıvers ın the communıty. Perceıved Qualıty of Lıfe of people wıth chronıc dıseases

Helen Tsaga, Agathi Argyriadi, Alexandros Argyriadis

doi: 10.12681/healthresj.35284

To cite this article:

Tsaga, H., Argyriadi, A., & Argyriadis, A. (2024). Experıences of loss and theır management by ınformal caregıvers ın the communıty. Perceıved Qualıty of Lıfe of people wıth chronıc dıseases. *Health & Research Journal*, *10*(2), 92–104. https://doi.org/10.12681/healthresj.35284

HEALTH AND RESEARCH JOURNAL
E-ISSN:2459-3192

(2024), Volume 10, Issue 2

ORIGINAL ARTICLE

EXPERIENCES OF LOSS AND THEIR MANAGEMENT BY INFORMAL CAREGIVERS IN THE COMMUNITY. PERCEIVED QUALITY OF LIFE OF PEOPLE WITH CHRONIC DISEASES

Helen Tsaga[1], Agathi Argyriadi[2], Alexandros Argyriadis[3]

1. MSc student, Department of Nursing, Frederick University, Cyprus
2. Lecturer, Department of Psychology, Frederick University, Cyprus
3. Assistant Professor, Department of Nursing, Frederick University, Cyprus

Abstract

Background: Informal caregivers play a vital role in caring for patients with chronic illnesses, but this care can significantly affect their mental health and well-being, particularly after the loss of the patient. Due to the significance of the issue and limited research in the field, it is important to identify factors associated with the mental health of informal caregivers.

Method and Material: This study aimed to investigate the experiences of loss and their management by informal caregivers of people with chronic diseases. Specifically, it evaluated the relationship between experiences of loss and (1) mental health and (2) socio-demographic characteristics of informal caregivers.

A quantitative survey was conducted on a sample of 98 informal caregivers of patients with chronic diseases, using the Core Bereavement scales BEQ-24 and DASS-21.

Results: The data analysis revealed that 25.5% of informal caregivers were prepared to experience loss, while only 12.2% sought psychological support to manage their experiences. Informal caregivers often experienced loss with sadness, loneliness, and nostalgia while recalling memories with the deceased patient. Fewer caregivers experienced guilt, self-blame, and anger or sought to fulfill their emotional and existential needs. The study also found that experiences of loss were associated with symptoms of depression, anxiety, and stress in informal caregivers of people with chronic diseases.

Conclusions: The study underscores the impact of caring for patients with chronic illnesses on mental health and wellbeing of informal caregivers, particularly after the loss of the patient. The results highlight the need for interventions to support informal caregivers.

Keywords: Experiences of loss, informal caregivers, chronic illnesses, mental health.

Corresponding Author: Argyriadis Alexandros, Email: alexargiriadis@gmail.com

Cite as: Tsaga, H., Argyriadi, A., Argyriadis, A. (2024). Experiences of loss and their management by informal caregivers in the community. Perceived quality of life of people with chronic diseases. Health and Research Journal,10(2),92-104. https://ejournals.epublishing.ekt.gr/index.php/HealthResJ

INTRODUCTION

Supporting informal caregivers before and after bereavement and loss experiences is an important part of primary health care. Health professionals, due to their status, are in regular contact with caregivers during the care of the patient and also after the end of their life. Thus, they have the opportunity to intervene in possible predictors of loss experiences and post-loss mental disorders.[1,2]

Grieving during loss is a dynamic and individualized adjustment process.[3] The experiences, management of loss, and occurrence of mental health burden symptoms of family members and informal caregivers are heterogeneous and classified into five groups.[4] In the first group, there are individuals and informal caregivers coping with the difficulty of losing a loved one. The second group includes caregivers who have severe symptoms of depression and bereavement, but recover quickly, within three to six months after the loss. The third group is similar to the second group, but symptoms may take 7 to 12 months to resolve. The latter two groups show prolonged periods of severe depressive symptoms, mourning, guilt, and emotional reactions, which gradually improve only in the fourth group of bereaved caregivers.[4] The fifth group essentially consists of people who never get over the loss, and managing it is a very difficult and painful process.[5]

According to Schulz et al. approximately 20% of bereaved caregivers will experience a variety of psychiatric symptoms, such as depression and/or complicated grief, a disorder characterized by persistently high levels of distress that impair functioning in important life domains.[6] Also, informal caregivers report physical and emotional exhaustion, limited participation in social and recreational pursuits, difficulties preparing for the death of the person they are caring for, and strong feelings of stress and anxiety.[7] While according to Nielsen et al.,[8] a small percentage of caregivers, approximately 6%–8%, may experience persistent and pervasive distress called complicated grief or prolonged grief disorder.

AIM

The aim of this study was to investigate the experiences of loss and their management by informal caregivers of people with chronic diseases. More specifically, it evaluated the relationship of the experiences of loss with (1) mental health and (2) the socio-demographic characteristics of the informal caregivers.

MATERIALS AND METHODS

Research Tool

Data collection was performed using a questionnaire distributed to informal caregivers of deceased chronically ill persons. The survey questionnaire was divided into three sections of questions.

In the first section, demographic data of/concerning gender, age, education level, marital status and annual family income were collected, as well as data related to their relationship with the patients (e.g., husband/partner or father/mother). Furthermore, patient’s characteristics, including the category of the chronic disease the patients were dealing with, the years of care, the average hours per day that caregivers spent with the patients, and the number of years since the patient's death, were also collected. Finally, the participants were asked to state whether they had received psychological support from specialized personnel (e.g., psychiatrist, psychologist) after the loss and whether they were ready to experience the loss.

In the second section of the questionnaire, the experiences of loss of the informal caregivers of patients with chronic diseases were evaluated. For this reason, 31 questions were formulated on a Likert scale of 0=Never, 1=Rarely, 2=Sometimes, and 3=Many times/always. Questions 1, 2, 4, 7, 8, and 9 assess the extent to which informal caregivers think about patients after their death (“Thinking” variable). Questions 3, 5, 6, 10, 11, 12, 13, 14, 15, 16, and 17 assess the level of emotional reaction of informal caregivers after the death of patients (variable “Emotional Reaction”). Questions 18 to 25 assess the extent to which informal caregivers feel guilt or anger about the patient's death (“Guilt/Anger” variable). Finally, questions 26 to 31 assess whether informal caregivers feel existential loss and have emotional needs after the death of the patient (variable "Guilt/Anger"). Questions 1-17 were based on the Core scale Bereavement,[9] while questions 18-31 were based on the BEQ-24 scale.[10]

In the third section of the questionnaire, the level of mental health of informal caregivers of patients with chronic diseases was assessed. For this reason, 21 questions were formulated on a Likert scale: 0=Did not apply to me at all, 1=Applied to me to a certain extent, or for a short time, 2=Applied to me to a particular extent, or for a long time, 3=Applies to me very much, or most of the time. The questions assess the level of depression (questions 3, 5, 10, 13, 16, 17, 21), the level of stress (questions 1, 6, 8, 11, 12, 14, 18), and the stress level (questions 2, 4, 7, 9, 15, 19, 20) of informal caregivers of patients with chronic diseases. The questions were based on the DASS-21 scale of Lovibond and Lovibond[11] translated into Greek by Lyrakos et al.[12]

Research sample

The research population was defined as informal caregivers of patients with chronic diseases who died. A sample of 98 informal caregivers was selected from the entire population using the method of feasibility sampling. The distribution of the questionnaires to the sample was carried out electronically and through the Google platform Forms.

Data analysis

The statistical analysis of the primary data collected with the questionnaire was done using the data processing and analysis software, SPSS version 26. The analysis of the primary data was done through the calculation of indicators of descriptive statistics and criteria and methodologies and inductive statistics. The investigation of the experiences of loss and the mental health of informal caregivers of patients with chronic diseases was done through the calculation of descriptive statistics measures such as the Mean Value and Standard Deviation as all the questions were of the Likert type. A higher mean value on a question indicates that informal/caregivers recognize the corresponding characteristic or behavior in them to a greater extent.

In order to highlight differences in demographic characteristics of informal caregivers and to investigate the correlations between loss experiences and mental health, inductive statistics measures and controls were used at the level of statistical significance α=0.05. More specifically, (1) Pearson's correlation coefficient, (2) the multiple linear regression methodology, (3) the t-test statistic, and (4) the one-way ANOVA statistic were used.

Ethics

During the conduct of the research, all ethical measures that govern a quantitative research were applied. The informal caregivers who participated in the research were initially informed about the purpose of the research and the importance of their participation in the research. In addition, informal caregivers were informed about the confidentiality of their responses and the anonymity of their participation, both verbally and with an appropriate information form. Finally, informal caregivers were informed of their right to withdraw from the study even after completing the questionnaire. The Ethical Approval that was obtained by the Ethics Committee of Frederick University has the no E3328.

RESULTS

A total of 98 informal caregivers of patients with chronic diseases who died participated in the survey, of which, 78 (79.6%) were women and 20 (20.4%) were men. The demographic and other data are presented in Table 1.

Regarding education, 35.7% (n=35) were graduates of Primary Education, 23.5% (n=23) were graduates of Secondary Education, and 25.5% (n=25) were graduates of Tertiary Education. Additionally, 6.1% (n=6) of the sample had received no education, 6.1% (n=6) were graduates of private training centers, and 3% (n=3) had a master's or doctoral degree.

In terms of marital status, the results show that 57.1% (n=56) are married, 21.4% (n=21) are widowed, 11.2% (n=11) divorced, and 10.2% (n=10) unmarried. Furthermore, 57.1% (n=56) of the informal caregivers had a father/mother relationship with the patient (they were children of the patients), and 29.6% (n=29) were partners/spouses of the patients. A smaller percentage reported that they had another relationship (n=13, 13.2%).

Finally, the results show that 38.8% (n=38) of the informal caregivers cared for a patient with suffering from cancer, 19.4% (n=19) cared for a patient with suffering from dementia or Alzheimer's disease, and 18.4% (n=18) cared for a patient with suffering from a cardiovascular disease.

The average age of the informal caregivers in the research sample was 62.3 (SD=13.2) years and their average annual individual income was equal to 12987 (SD=10364.3) euros. Furthermore, it appears that on average they cared for the patient 4.1 (TA=3.4) years and on average they cared for him 11.9 (8.6) hours per day.

Finally, on average 8.3 (SD=7.3) years have passed since the patient's death.

As the research shows, 12.2% (n=12) of the informal caregivers reported that they had received psychological support from specialized staff (e.g. psychiatrist, psychologist) after the loss, while only 25.5% (n=25) reported that they were ready to experience the loss.

The findings of the descriptive analysis show that in all questions the mean value (M) varies between 0.1 and 2.3.

The results of the research on the experiences of loss and their management by informal caregivers of people with chronic diseases show that the average level of thoughts of informal caregivers is equal to 1.7 (SD=0.7), the average level of emotional reaction is equal to 1.6 (SD=0.8), the mean level of guilt/categorization/anger is equal to 0.4 (SD=0.4), and the mean level of existential loss/emotional needs is equal to 0.7 (SD=0.6).

Pearson's r correlation coefficient showed that "Thoughts" are positively related to "Emotional Reaction" (r=0.858, p=0.000) and "Existential Loss/Emotional Needs" (r=0.461, p=0.000). Similarly, "Existential Loss/Emotional Needs" is positively related to "Emotional Reaction" (r=0.586, p=0.000) and "Guilt/Blame/Anger" (r=0.384, p=0.000).

Relationship between the mental health of informal caregivers of people with chronic diseases and their experiences of loss.

The results of the analysis concerning the mental health of informal caregivers of people with chronic diseases and the evaluation of the relationship between their experiences of loss and mental health, as derived from the levels of anxiety, stress, and depression experienced by informal caregivers, are presented in Table 3. The analysis was conducted using the 21 questions of the DASS-21 scale. The findings of the descriptive analysis show that, in all questions, the mean value (M) varies between 0.2 and 1.1. These results indicate that informal caregivers rarely experienced the 21 reported symptoms during the period after the loss of the chronically ill patient.

The results of the research on the level of mental health of informal caregivers of people with chronic diseases show that the average depression level of informal caregivers is equal to 4.1 (SD=3.6), the average stress level of informal caregivers is equal to 5.0 (SD =4.0), and the average anxiety level of informal caregivers is equal to 3.6 (SD=3.7). Based on the fact that all three dimensions of mental health can take values between 0 and 21, the average values show that informal caregivers of people with chronic diseases have a low level of anxiety, stress, and depression.

Regarding the results about the correlation between the dimensions of the mental health of informal caregivers of people with chronic diseases, the Pearson r correlation coefficient showed that the level of depression in the informal caregivers of people with chronic diseases is positively related to the level of stress (r = 0.750, p = 0.000) and with to the level of anxiety (r = 0.794, p = 0.000). In addition, the level of stress in informal caregivers of people with chronic diseases is positively related to the level of depression (r = 0.726, p = 0.000).

The results regarding the correlation between the dimensions of mental health of informal caregivers of people with chronic diseases and the dimensions of loss experiences showed that the Pearson r correlation coefficient showed that the level of depression in informal caregivers of people with chronic diseases is positively related to the dimensions "Thoughts" (r = 0.419, p = 0.000), "Emotional reaction" (r = 0.490, p = 0.000), "Guilt/Blame/Anger" (r = 0.278, p = 0.000), and "Existential Loss/Emotional Needs" (r = 0.682, p = 0.000). Similarly, Pearson's correlation coefficient r showed that the level of stress in informal caregivers of people with chronic diseases is positively related to the dimensions "Thoughts" (r = 0.257, p = 0.011), "Emotional reaction" (r = 0.260, p = 0.010), "Guilt/Blame/Anger" (r = 0.392, p = 0.000), and "Existential Loss/Emotional Needs" (r = 0.533, p = 0.000). Finally, Pearson's r correlation coefficient showed that the stress level in informal caregivers of people with chronic diseases is positively related to the dimensions "Thoughts" (r = 0.491, p = 0.000), "Emotional reaction" (r = 0.479, p = 0.000), "Guilt/Blame/Anger" (r = 0.283, p = 0.005), and "Existential Loss/Emotional Needs" (r = 0.623, p = 0.000).

The analysis of the multiple linear regression with the dependent variable being the level of depression of informal caregivers of people with chronic diseases and the independent variables being the dimensions that evaluate the experiences of loss showed that of the four dimensions that evaluate the experiences of loss, only one is significant in predicting the depression of the informal caregivers. The dimension that is significant is "Existential Loss/Emotional Needs" (b = 4.313, t = 9.130, p = 0.000). This dimension explains 45.9% of the variability in depression experienced by informal caregivers (Adjusted R2 = 0.465, F (1, 96) = 83.

Variation in Bereavement Experiences and Mental Health of Informal Caregivers of Persons with Chronic Illnesses by Demographic Characteristics

The results of the research showed that women had a statistically significant higher level of depression (t = -1.997, p = 0.049), stress (t = -2.855, p = 0.005), and anxiety (t = -2.023, p = 0.0046) compared to male informal caregivers. Furthermore, women had a statistically significant higher level of thoughts about deceased patients (t = -3.393, p = 0.000), a higher level of emotional response to loss (t = -3.911, p = 0.000), and a higher level of existential loss/emotional needs (t = -2.734, p = 0.000) compared to male informal caregivers.

Informal caregivers with no education had a statistically significant higher level of stress compared to graduates of Primary, Secondary/private training centers, and Tertiary education (F = 5.450, p = 0.002). In addition, informal caregivers with no education had a statistically significant higher level of guilt and anger compared to graduates of Primary, Secondary/private training centers, and Tertiary education (F = 3.216, p = 0.026).

Informal caregivers who were spouses/partners of patients had a significantly higher level of depression (F = 5.541, p = 0.0005), stress (F = 6.916, p = 0.0002), and anxiety (F = 4.168, p = 0.018) compared to informal caregivers who had a father/mother relationship or other relationship. In addition, informal caregivers who had a husband/partner relationship or a father/mother relationship with the patients had a statistically significant higher level of emotional reaction to the loss (F = 4.101, p = 0.020), a higher level of existential loss/emotional needs (F = 6.020, p = 0.003), and a higher level of guilt and anger (F = 3.183, p = 0.046) compared to informal caregivers who had another relationship with the patients.

The chronic illness experienced by the patients did not significantly affect either the experiences of loss or the mental health of the informal caregivers as in all comparisons an observed level of significance above α=0.05 was obtained.

The marital status of informal caregivers did not significantly affect either their loss experiences or their mental health as in all comparisons an observed level of significance above α=0.05 was obtained.

Informal caregivers who had received psychological support had a statistically significantly higher level of depression (t = 4.286, p = 0.000) and anxiety (t = 2.891, p = 0.014) compared to those who had not received psychological support. In addition, informal caregivers who had received psychological support had a statistically significant higher level of thoughts about the deceased patients (t = 2.515, p = 0.014), a higher level of emotional reaction to the loss (t = 2.418, p = 0.018), and a higher level of existential loss/emotional needs (t = 3.252, p = 0.002) compared to those who had not received psychological support.

The results of the research also showed that whether the informal caregivers of people with chronic diseases were ready for the loss did not significantly affect either the loss experiences or their mental health as in all comparisons an observed level of significance above α=0.05 was obtained.

Finally, the results revealed only two statistically significant correlations, between the years informal caregivers cared for the patient with anxiety (r=0.228, p =0.024) and the thoughts they have about the patient after they died (r =0.206, p = 0.042). The results show that the more years they cared for the patient, the greater the anxiety and also the thoughts that the informal caregivers have about the patient.

DISCUSSION

The findings of this research indicate that informal caregivers who provide care for patients with chronic diseases often experience loss with sadness and thinking about the deceased patient, as well as feelings of loneliness. These findings are consistent with previous research[13-16] that highlights the emotional impact of caregiving.

Moreover, the study revealed that informal caregivers less often react to the loss by developing feelings of guilt, self-blame, and anger, and less frequently seek fulfillment of their emotional and existential needs. However, thoughts about the patient, emotional reactions to the loss, feelings of guilt/self-blame/anger, and existential loss and emotional needs arising after the loss were associated with an increased level of depression, anxiety, and stress. These results support the idea that the experience of loss has a significant impact on the mental health of informal caregivers.[17-21]

Regarding the role of demographic characteristics, the study showed that women and informal caregivers who were spouses/partners of patients experienced higher levels of depression, stress, and anxiety after the loss, thought more often about the patient, had greater emotional responses, and had a higher level of existential loss/emotional needs. These findings align with previous research[22-24] and highlight the importance of considering the caregiver's demographic characteristics when providing support and interventions.

Interestingly, the results did not confirm that the chronic illness experienced by the patients significantly affects the experiences of loss and the mental health of informal caregivers, contrary to most research that has reported worse levels of mental health and stronger experiences of loss in informal caregivers of patients with cancer.[16, 25-28] Further research is needed to investigate the impact of chronic illnesses on the experiences of loss and mental health of informal caregivers.

In conclusion, this study provides valuable insights into the experiences of informal caregivers of patients with chronic diseases and the impact of loss on their mental health. The findings highlight the need for tailored support and interventions for informal caregivers, taking into account their demographic characteristics and specific needs. Future research can build on these findings to develop and evaluate effective interventions for supporting the mental health and well-being of informal caregivers.

The findings of this research showed that of all informal caregivers, 12.2% sought psychological support from specialized staff, while only one in four reported that they were ready to experience the loss. Informal caregivers primarily experience loss through thinking about the deceased person (seeing images of the events surrounding their death, recalling memories of their death) and experiencing emotional reactions (their memories make them cry and make them feel lonely) and find themselves searching for the deceased person in familiar places. In contrast, informal caregivers less often react to the loss by developing feelings of guilt, self-blame, and anger (feeling guilty about things they said or did after the person's death, feeling that they contributed to the person's death, and feeling angry with themselves). Similarly, informal caregivers less often respond to loss by seeking fulfillment of their emotional and existential needs (the need to be emotionally close to someone, fear of being alone, loss of interest in work). These results confirm the findings of related research that report that informal caregivers of patients with chronic diseases often experience loss with sadness, thinking about the deceased patient, and experiencing feelings of loneliness (emotional reaction)[16, 26-28], while they often bring images of the patient to their mind trying to recall memories they have with him.[32,33]

The results regarding the mental health of informal caregivers showed that they rarely experienced symptoms of anxiety, depression, and stress. Regarding the connection between the experiences of loss and mental health, the findings of the research confirmed the existence of significant positive correlations between how they experience the loss and mental health. In more detail, the findings confirmed that thoughts about the patient, emotional reaction to the loss, feelings of guilt/self-blame/anger, and existential loss and emotional needs arising after the loss are associated with an increased level of depression, anxiety, and stress.[17,18]

Finally, the results regarding the role of demographic characteristics in loss experiences confirmed that women show a higher level of depression, stress, and anxiety after the loss, think more often about the patient, have greater emotional responses, and have a higher level of existential loss/emotional needs In addition, the results confirmed that informal caregivers who were spouses/partners of patients have a significantly higher level of depression, stress, and anxiety after loss, have greater emotional reactions, have a higher level of existential loss/emotional needs, and feel guilt and anger to a greater extent after the loss.[33] On the contrary, the results did not confirm that the chronic illness experienced by the patients significantly affects the experiences of loss and the mental health of informal caregivers, contrary to most research that has reported worse levels of mental health and stronger experiences of loss in informal caregivers of patients with cancer.[17]

CONCLUSIONS

In conclusion, this research aimed to explore the experiences of informal caregivers of patients with chronic diseases and their mental health outcomes. The findings of this study revealed that informal caregivers primarily experience loss through thinking about the deceased person and experiencing emotional reactions, such as feelings of sadness and loneliness. However, they less often react to the loss by developing feelings of guilt, self-blame, and anger, or by seeking fulfillment of their emotional and existential needs.

Regarding mental health outcomes, informal caregivers in this study rarely experienced symptoms of anxiety, depression, and stress. However, the findings confirmed the existence of significant positive correlations between how they experience the loss and their mental health, with thoughts about the patient, emotional reactions, feelings of guilt/self-blame/anger, and existential loss and emotional needs arising after the loss being associated with an increased level of depression, anxiety, and stress.

The study also found that women and spouses/partners of patients showed higher levels of depression, stress, and anxiety after the loss, and had greater emotional reactions and higher levels of existential loss/emotional needs. However, the chronic illness experienced by the patients did not significantly affect the experiences of loss and mental health of informal caregivers.

To answer the research questions posed at the beginning of this study, the findings showed that informal caregivers of patients with chronic diseases primarily experience loss through thinking about the deceased person and experiencing emotional reactions, and that their mental health outcomes are significantly correlated with how they experience the loss. Additionally, demographic characteristics such as gender and relationship to the patient play a role in their experiences of loss and mental health outcomes.

The results of this study have important implications for healthcare professionals and policymakers who work with informal caregivers of patients with chronic diseases. To support the mental health of informal caregivers, healthcare professionals should prioritize addressing the emotional reactions and needs arising after the loss. Further research should explore potential interventions to support the mental health of informal caregivers, with a focus on addressing their experiences of loss and meeting their emotional and existential needs. The present research is characterized by several limitations, mainly of a methodological nature. The main limitations of the research are (1) that the sample was selected from a specific geographical area of Greece using purposive sampling and (2) that the sample is small in relation to the size of the real population. These two limitations affect the external validity of the research as the research sample cannot be characterized as representative of the population under study. Based on these limitations, it would be good to carry out a larger nationwide survey using a sample that will result from some probability sampling technique. Such research would result in the emergence of results that can be generalized to the entire population of informal caregivers of patients with chronic diseases and give a safer picture of the factors that influence the loss experiences of informal caregivers as well as their mental health.

Limitations of the study

Although this study offers insightful information about the experiences of loss and how informal caregivers for people with chronic illnesses handle them, it must be acknowledged that it has limitations. First off, the informal caregivers in the study's sample size may restrict how broadly the results may be applied. Furthermore, the information was gathered using a quantitative survey, which might not have fully captured the range of feelings and experiences that unpaid caregivers encounter. Additionally, the primary focus of this research was on the association between caregivers' mental health and their experiences of loss; other potential influencing factors, such as the particular chronic illness or cultural factors, were not thoroughly investigated. Larger, more varied sample sizes and a more thorough examination of the complex experiences of unpaid caregivers in the community may be advantageous for future research.

REFERENCES

1. Marfil-Gómez R, Morales-Puerto M, León-Campos Á, Morales-Asencio JM, Morilla-Herrera JC, Timonet-Andreu E, Cuevas-Fernández Gallego M, Martí-García C, López-Leiva I, García-Mayor S. Quality of Life, Physical and Mental Health of Family Caregivers of Dependent People with Complex Chronic Disease: Protocol of a Cohort Study. Int J Environ Res Public Health. 2020;17(20):7489. doi:10.3390/ijerph17207489
2. Argyriadi A, Argyriadis A. Health Psychology: Psychological Adjustment to the Disease, Disability and Loss. Imperial Journal of Interdisciplinary Research. 2019;5(2):109-116.
3. Bachner YG, Guldin MB, Nielsen MK. Mortality communication and post-bereavement depression among Danish family caregivers of terminal cancer patients. Support Care Cancer. 2021;29:1951-1958.
4. Kanny D, Jeffries IV WL, Chapin-Bardales J, Denning P, Cha S, Finlayson T, et al. Racial/ethnic disparities in HIV preexposure prophylaxis among men who have sex with men—23 urban areas, 2017. Morb Mortal Wkly Rep. 2019;68(37):801.
5. Stahl ST, Schulz R. Feeling relieved after the death of a family member with dementia: Associations with postbereavement adjustment. Am J Geriatr Psychiatry. 2019;27(4):408-416.
6. Hochbaum M, Kienitz R, Rosenow F, Schulz J, Habermehl L, Langenbruch L, et al. Trends in antiseizure medication prescription patterns among all adults, women, and older adults with epilepsy: A German longitudinal analysis from 2008 to 2020. Epilepsy Behav. 2022;130:108666.
7. Constantinou A, Polychronis G, Argyriadi A, Argyriadis A. Evaluation of the quality of palliative home care for cancer patients in Cyprus: a cross-sectional study. Br J Community Nurs. 2022;27(9):454-462.
8. Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin MB. Do We Need to Change Our Understanding of Anticipatory Grief in Caregivers? A Systematic Review of Caregiver Studies during End-of-Life Caregiving and Bereavement. Clin Psychol Rev. 2016;44:75-93. doi:10.1016/j.cpr.2016.01.002
9. Vlachou C, Argyriadis A, Argyriadi A. Self-Management of Fear due to the Covid-19 Pandemic and the Changes it has brought to the Every Day Life. Review of Clinical Pharmacology and Pharmacokinetics, International Edition. 2022;17-22.
10. Kainama JV, Riasnugrahani M, Rohinsa M. The Effect of Social Support and Religiosity Against Bereavement. Al Qalam: Jurnal Ilmiah Keagamaan dan Kemasyarakatan. 2023;17(4):2763-2774.
11. Husain W. Depression, anxiety, and stress among urban and rural police officers. Journal of police and criminal psychology. 2020;35(4):443-447.
12. Alizioti A, Lyrakos G. Measuring the effectiveness of psychoeducation on adherence, depression, anxiety and stress among patients with diagnosis of schizophrenia. a control trial. Current Psychology. 2021;40(8):3639-3650.
13. Coelho A, Parola V, Cardoso D, Sandgren A, Apóstolo J. Depression and coping in heart failure patients and informal caregivers. Journal of Clinical Nursing. 2015;24:3565-3573.
14. Hovland I. The significance of cancer patients' informal caregivers' experiences of hope. European Journal of Cancer Care. 2018;27:e12941.
15. Treml J, Střeštíková M. Informal caregivers of patients with chronic diseases: Their experiences of loss and depression, anxiety and stress symptoms. Health & Social Care in the Community. 2021;29:1058-1069. doi:10.1111/hsc.13123
16. Vlachogianni A, Efthymiou A, Sgantzos M, Lianou C, Tsitsi T, Lavrentiadou A, Korkontzelos I, Hatzitheodorou E. The experiences of informal caregivers of cancer patients undergoing chemotherapy in Greece. Journal of Clinical Nursing. 2016;25:526-534. doi:10.1111/jocn.13076
17. El-Jawahri A, Temel JS. Palliative care for patients with advanced lung cancer. Journal of Thoracic Disease. 2021;13:2006-2012.
18. Große J, Rüsch N, Wiegand H-F, Nestoriuc Y, Fischer FH. Stigma and attitude towards psychological treatment in

cancer patients. Supportive Care in Cancer. 2017;25:3735-3742.

19. Oechsle K, Ullrich A, Marx G, Benze G, Aurnhammer F, Schuler M. Experiences of grief, depression and anxiety among spousal and parental caregivers of patients with multiple myeloma. Supportive Care in Cancer. 2019;27:2403-2409.
20. Treml J, Střeštíková M. Informal caregivers of patients with chronic diseases: Their experiences of loss and depression, anxiety and stress symptoms. Health & Social Care in the Community. 2021;29:1058-1069. doi:10.1111/hsc.13123
21. Shimizu H, Hotta K, Uchitomi Y, Miyashita M, Morita T. Grief reaction and depression among primary caregivers of terminally ill patients with cancer: A longitudinal analysis. Palliative and Supportive Care. 2021;19:201-206.
22. Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin M-B. Do We Need to Change Our Understanding of Anticipatory Grief in Caregivers? A Systematic Review of Caregiver Studies during End-of-Life Caregiving and Bereavement. Clinical Psychology Review. 2016;44:75-93. doi:10.1016/j.cpr.2016.01.002.
23. Pérez-González A, Chacón-Cuberos R, Zurita-Ortega F, Castro-Sánchez M, Ruiz-Rico J. Gender differences in psychological well-being and perception of caregiver burden in informal caregivers of dependent people: A meta-analytic study. Health & Social Care in the Community. 2021;29:1315-1332. doi:10.1111/hsc.13202
24. Pérez-González A, Olivares-Faúndez VE, Forero-Castro M. Caregiver burden, depression, anxiety and quality of life in informal caregivers of advanced cancer patients: A comparative study. European Journal of Cancer Care. 2021;30:e13348.
25. Pérez-González R, Maseda-Garrido E, Martínez-Cengotitabengoa M, Guillén-Solvas J, Barbeito S, Gutiérrez-Rojas L, García-Alberca JM. Risk factors for caregiver grief, depression, and burden in dementia: A systematic review and meta-analysis. Journal of Affective Disorders. 2021;291:109-120.
26. Treml J, Střeštíková M. Informal caregivers of patients with chronic diseases: Their experiences of loss and depression, anxiety and stress symptoms. Health & Social Care in the Community. 2021;29:1058-1069. doi:10.1111/hsc.13123
27. Breen LJ, Aoun SM, O'Connor M, Halkett GK. "I just take each day as it comes": A qualitative study exploring the experiences of informal caregivers of patients with advanced cancer. Palliative & Supportive Care. 2020;18:577-587.
28. Caserta MS, Lund DA, Rice CA. Long-term care of the dying: Experiences of spousal caregivers. The Gerontologist. 2019;59:e325-e334.
29. Coelho A, Parola V, Cardoso D, Sandgren A, Apóstolo J. Depression and coping in heart failure patients and informal caregivers. Journal of Clinical Nursing. 2015;24:3565-3573.
30. Hovland I. The significance of cancer patients' informal caregivers' experiences of hope. European Journal of Cancer Care. 2018;27:e12941.
31. Treml J, Střeštíková M. Informal caregivers of patients with chronic diseases: Their experiences of loss and depression, anxiety and stress symptoms. Health & Social Care in the Community. 2021;29(4):1058-1069. doi:10.1111/hsc.13123
32. Breen LJ, Aoun SM, O'Connor M, Halkett GK. "I just take each day as it comes": A qualitative study exploring the experiences of informal caregivers of patients with advanced cancer. Palliative & Supportive Care. 2020;18(5):577-587.
33. Mah L, Cummings I, Lobb EA. "It's just one of those things you do": Exploring informal caregivers' experiences of maintaining hope in advanced cancer. European Journal of Oncology Nursing. 2022;54:101980.

ANNEX

TABLE 1. Participant demographics

		n	%
Sex	Man	20	20.4
	Woman	78	79.6
Education level	None	6	6.1
	Primary	35	35.7
	Secondary	23	23.5
	Post-secondary education (PRIVATE TRAINING CENTERS)	6	6.1
	Higher education	25	25.5
	Postgraduate	2	2.0
	Ph.D	1	1.0
Marital status	Single	10	10.2
	Married	56	57.1
	Divorced	11	11.2
	Widower	21	21.4
Relationship with the patient	Spouse/Partner	29	29.6
	Son daughter	2	2.0
	Father mother	56	57.1
	Other	11	11.2
Chronic diseases that the patient was dealing with	Cancer (any type)	38	38.8
	Alzheimer's disease	19	19.4
	Cardiovascular disease	18	18.4
	Chronic lung disease	4	4.1
	Chronic kidney disease	2	2.0
	Arterial hypertension	1	1.0
	Other	16	16.3

TABLE 2. Descriptive results for questions assessing bereavement experiences of informal caregiverspeople with chronic diseases

	M	SD
1. Experience images of the events surrounding the death of "X"	1.7	0.9
2. Thoughts of 'X' enter your mind whether you want it or not	1.8	0.9
3. Thoughts about "X" make you feel distressed	2.1	0.9
4. Did you think of "X"	0.6	0.9
5. Images of "X" make you feel distressed	2.0	1.0
6. You find yourself having memories of "X"	2.2	0.9
7. Thinking of reuniting with 'X'?	2.1	0.9
8. Did you feel you were missing "X"	1.9	1.0
9. Familiar objects (photos, possessions, rooms, etc.) remind you of "X"	2.3	0.9
10. Feel like you're missing "X"	2.1	1.0
11. You find yourself looking for "X" in familiar places	1.6	1.1
12. You feel anguish/pain at the idea that "X" will not return	1.3	1.1
13. The memories of "X" make you long for him	1.5	0.9
14. Memories of "X" make you feel lonely	1.4	1.0
15. Memories of "X" make you cry	1.3	1.1
16. Memories of "X" make you feel sad	1.5	1.1
17. Memories of "X" make you not enjoy the moments	1.1	0.9
18. You thought you contributed to the death of "X"	0.1	0.4
19. You felt guilty about things you said or did after 'X' died	0.3	0.7
20. I thought there were some very real reasons why you felt guilty about 'X's death'	0.2	0.4
21. You felt guilty about things you said or did before his death	0.4	0.7
22. You felt angry with yourself	0.4	0.7
23. You felt guilty about small, insignificant things	0.5	0.7
24. You felt angry about "X"	0.5	0.9
25. You felt unable to remember the picture of "X"	0.7	1.1
26. You felt the need to be emotionally close to someone	1.4	0.9
27. You felt emotionally distant from people	0.9	0.8
28. You felt afraid of being alone	1.0	1.0
29. You have experienced a loss of interest in activities that previously interested you	0.6	0.8
30. You felt like you were losing your mind	0.2	0.4
31. You have lost interest in your work	0.4	0.7

0=Never, 1=Rarely, 2=Sometimes, 3=Many times/always

TABLE 3. Descriptive results for questions assessing informal caregivers' stress, depression, and anxietypeople with chronic diseases

	M	SD
1. I couldn't calm myself down	0.7	0.7
2. My mouth felt dry	0.5	0.7
3. I could not experience any positive emotion	0.7	0.8
4. I had trouble breathing (eg, breathing too fast, holding my breath without physical exertion)	1.1	1.1
5. I found it difficult to take the initiative to do some things	0.6	0.7
6. I had a tendency to overreact to the situations I was faced with	0.3	0.6
7. I felt tremors (eg in the hands)	0.2	0.5
8. I often felt nervous	0.8	0.9
9. I worried about situations where I might panic and look foolish to others	0.7	0.6
10. I felt like I had nothing to look forward to	0.8	0.8
11. I found myself feeling annoyed	0.6	0.8
12. It was hard for me to relax	0.9	0.8
13. I felt depressed and disappointed	0.6	0.7
14. I couldn't stand anything that kept me from going on with what I was doing	0.6	0.7
15. I felt very close to panic	0.4	0.7
16. Nothing could make me feel excited	0.4	0.8
17. I felt like I wasn't worth much as a person	0.6	0.9
18. I felt that I was quite irritable	0.3	0.7
19. I could feel my heart beating without physical exertion (palpitations, arrhythmia)	0.5	0.7
20. I felt scared for no reason	0.8	1.0
21. I felt that life had no meaning	0.5	0.8

0=Did not apply to me at all, 1=Applied to me to a certain extent, or for a short time, 2=Applied to me to a particular extent, or for a long time, 3=Applied to me very much, or the more times.

TABLE 4. Association of bereavement experiences and mental health of chronically ill caregivers with age, annual personal income, years of caregiving, daily hours of caregiving, and years since patient death

		Age	Annual personal income	How many years have you cared for the patient?	How many hours per day on average did you care for the patient during this time period?	How many years have passed since the patient's death?
Depression	Pearson r	-.086	-.077	.086	.042	-.124
	p	.402	.453	.399	.686	.224
	n	98	98	98	97	98
Stress	Pearson r	-.010	-.076	.095	-.038	-.155
	p	.921	.455	.351	.709	.129
	n	98	98	98	97	98
Anxiety	Pearson r	-.023	-.064	**.228** *	.139	-.103
	p	.824	.532	**.024**	.176	.311
	n	98	98	**98**	97	98
Thoughts	Pearson r	-.125	.095	**.206** *	.108	-.182
	p	.220	.352	**.042**	.294	.072
	n	98	98	**98**	97	98
Emotional reaction	Pearson r	-.095	.094	.197	.079	-.142
	p	.354	.357	.051	.442	.162
	n	98	98	98	97	98
Guilt/Blame/Anger	Pearson r	.189	-.163	-.045	.029	-.019
	p	.062	.109	.658	.780	.853
	n	98	98	98	97	98
Existential Loss/Emotional Needs	Pearson r	.060	.042	.136	.090	-.095
	p	.555	.684	.181	.383	.350
	n	98	98	98	97	98