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Comfort Level in Caregivers of Palliative Care Patients and Affecting Factors: What Should We Know?

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Abstract

Caregivers are an important source of support for patients in palliative care. Comfort is an important concept in nursing care for both patients and their families, and nurses aim to increase comfort. The aim of the study was to determine the comfort level and influencing factors in caregivers of palliative care patients. The research sample consisted of 102 caregivers related to palliative care patients. The data were obtained with an Individual Information Form, the Edmonton Symptom Assessment Scale (ESAS) and the End of Life Comfort Scale (Caregiver/Family). The study was conducted in the palliative care clinic of Aksaray University Training and Research Hospital between October 2018 and April 2019. There was a significant relationship between the total comfort score of the caregivers and the patient's performance status, the caregivers' age, their economic situation, the length of the caregiving period and receiving help in care (social support) ($p < 0.05$). Providing comfort is an important function and challenge for holistic nursing care, as comfort is a lifelong need in health and disease. Caregivers in the risk group should be aware of this issue and necessary precautions should be taken.

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Introduction

Recent years have seen a steady increase in the prevalence and incidence of chronic disease among people of all ages and this increase is expected to continue (World Health Organization [WHO], 2018). However, despite the increase in life expectancy with new technological developments and medical advances, patients with life-limiting diseases still suffer considerably (Chan, 2018; Gayosa et al., 2018). This transition has created new needs for healthcare, which has led to a new way of thinking about patient care (Gayoso et al., 2018). Palliative care, which emerged from this idea, emerged a half a century ago as an idea based on compassion and care to relieve patients and their families of their suffering (Chan, 2018). According to the WHO, an estimated 40 million people need palliative care each year. Palliative care improves the physical, psychological, social, or spiritual quality of life of patients and their families who encounter difficulties associated with life-threatening diseases (WHO, 2020). The quality of life of caregivers improves as well (Subih et al., 2020; WHO, 2020). Family members are often the main caregivers, and they often experience difficulties such as pain, anxiety, financial burden, lack of knowledge about care, difficulty in accessing professional care, and potential loss of loved ones (Gayoso et al., 2018; Strommen, 2020). In addition, the family members should be considered as individuals in need of comfort as they are suffering with their patients (Twohig et al., 2015). Caregivers are an important source of support for all patients, especially those in palliative care. However, caregiving is often a tiring and psychologically severe burden where caregivers may be confused between their own needs and their care role responsibilities (Thomsen et al., 2017). For this reason, it is very important to support caregivers affected by the disease, to relieve pain and to provide comfort while treating patients receiving palliative care (Gayoso et al., 2018). The caregivers are suffering from psychological problems due to the illness of a loved one, as well as the physical needs of the patient. All of these affect the four components of caregiving comfort (physical, psychological, environmental, and spiritual comfort). Changes in the comfort level directly or indirectly affect the quality of life (Kim & Kwon, 2007).

Comfort is holistic, and physical symptoms, including personal perceptions of individuals, the organization of the environment, interpersonal relationships, individual beliefs, and values are related to the experiences of patients and caregivers (Gayoso et al., 2018; de Araujo Lamino et al., 2014; Kolcaba & Steiner, 2000). Comfort is an important concept in nursing care for patients and their families, and nurses aim to increase comfort (Kim & Kwon, 2007; Kolcaba & Steiner, 2000). Although the stress and care burden of caregivers is widely reported in the literature, little is known about how their comfort is affected. Despite the

importance of this topic, there are few studies in the literature regarding the comfort of caregivers of palliative care or cancer patients (Gayoso et al., 2018; de Araujo Lamino et al., 2014; Kim & Kwon, 2007). In Turkey, no studies were found which examined the comfort levels and factors affecting them of those providing palliative care. This study was carried out to investigate the relationship between the level of comfort in the caregivers of palliative care patients, and the socio-demographic variables and the functional status of the patient.

Methods

Study Design and Sampling

The purpose of this descriptive study was to examine the comfort level and influencing factors in the caregivers of palliative care patients. The sample of the study consisted of 102 caregivers. The study was conducted in the palliative care clinics of Aksaray University Training and Research Hospital between October 2018 and April 2019. The inclusion criteria were as follows: being 18 years or older, having at least three days of patient care, being a primary caregiver (spouse, son/daughter or daughter-in-law, sister, parent), providing care voluntarily, having a physical condition and cognitive level adequate to answer forms, and agreeing to participate in the study. Caregivers who did not agree to participate in the study, who had speech or hearing difficulties, who were diagnosed with a mental disorder, or who were paid caregivers were excluded from the study.

Data Collection

The data were obtained with an Individual Information Form, the Edmonton Symptom Assessment Scale (ESAS) and the End of Life Comfort Scale (Caregiver/Family).

Individual Information Form: The individual identification form was developed by the researchers in the light of information collected from the literature (Gayoso et al., 2018; de Araújo Lamino et al., 2014; Townsend et al., 2014). The form consisted of questions on socio-demographic variables and characteristics related to the individual, both the patient and the caregiver.

Patient Characteristics: This section consisted of questions on information such as age, gender, marital status, educational status, disease name, time since diagnosis, status, and duration of hospitalization. The performance status of the patients was evaluated according to the Eastern Cooperative Oncology Group (ECOG) performance status classification (Oken et al., 1982). The ECOG performance status scale assesses the degree to which patients are affected by the disease process and the level of activity related to treatment, scored from 0 to 4 points. An increased score indicates that the activity level of patients has decreased (Pickard-Holley, 1991).

Caregiver Features: This section consisted of questions on information such as carriage return can be done age, gender, educational status, occupation, working status, economic status, marital status, proximity to the patient, duration of care, additional responsibilities, and receipt of social support while caring for a patient.

Edmonton Symptom Assessment Scale (ESAS): The Edmonton Symptom Assessment Scale (ESAS) was developed in 1991 by Bruera et al. to improve the management of care giving for cancer patients (Bruera et al., 1991). This tool was designed to assist in the assessment of nine symptoms commonly found in cancer patients: pain, fatigue, nausea, depression, anxiety, drowsiness, loss of appetite, decreased sense of well-being and shortness of breath. The validity and reliability of the ESAS were investigated by the researchers (Sadirli & Unsar, 2009; Kurt & Unsar, 2011; Yesilbalkan et al., 2008). The ESAS also includes a section entitled "other problems", to which three more symptoms that were detected by researchers and listed as additional symptoms by patients were added: skin and nail changes, stomatitis, and numbness in the hands. The severity at the time of assessment of each symptom is rated from 0 to 10 on a numerical scale, 0 meaning that the symptom is absent and 10 that it is of the worst possible severity (Bruera et al., 1991). The ESAS provides a clinical profile of symptom severity over time and the context within which symptoms can be understood.

End-of-Life Comfort Scale (Caregiver/Family): The End of Life Comfort Scale (Family) is a four-point Likert type scale. It is one-dimensional and has 49 questions. Kolcaba's Comfort Theory constitutes the theoretical framework used (Kolcaba, 1992; Kolcaba, K., & Steiner, R. (2000). Scale items were scored both positively and negatively (Novak et al., 2001). The total score obtained from the scale is minimum 49, maximum 196, and high scores show increased comfort. The validity and reliability of the End-of-Life Comfort Scale (Caregiver/Family) in Turkey was tested by Aslan et al. (2018). Cronbach's Alpha reliability coefficient for the Turkish form of the scale was calculated as 0.80 (Aslan et al., 2018).

Data Analysis

The data obtained from the research were analyzed using the program SPSS 24.0 (SPSS Inc., Chicago, IL, USA). Kolmogrov Smirnov was used to check whether the numerical variables had normal distribution. Normally distributed variables were shown as mean ± standard deviation (SD). In the analysis of the data, descriptive statistics were shown as numbers, percentages, means, and standard deviation. Kruskal Wallis and Mann Whitney U tests were used in independent samples. The relationship between comfort scores and symptoms according to ESAS was analyzed by multiple linear regression. Statistical significance was accepted as $p < 0.05$.

Ethical Considerations

The study was conducted in accordance with the principles of the Helsinki Declaration. Written permission was received from the Ethics Committee of Human Research (ref. 2018-242) and from the institution. All participants were informed about the aims and procedures of the study. Participation in the study was voluntary and privacy was guaranteed. Written and oral consent was obtained from the participants.

Results

The caregivers' ages were from 32 to 78 years, and the mean age was 50.84± 11.42 years. In the sample of 102 caregivers, most were female (84.3%) and approximately half of the caregivers were the children (46.1%) of the patients. More than half (68.6%) of the caregivers did not work. Most were primary school graduates and 72.5% were housewives. The mean period of care was 35.97±77.56 days. More than half of the caregivers stated that they did not receive support (15.7%) or received only partial support (39.2%).

The patients had different disease diagnoses. The most common were cancer (34.5%) and neurological (27.6%) and cardiovascular (20.7%) problems. The disease diagnoses of the patients are listed in Table 2. The ECOG performance status scale assesses the degree to which patients are affected by the disease process and the level of activity related to treatment from 0 to 4 points. Assessing the ECOG performance of patients, it was found that the performance of 20 patients (23%) was 2, that of 37 patients (42.6%) was 3, and that of 30 patients (34.4%) was 4. The highest scores obtained by patients related to ESAS were as follows:

Table 1. The Mean and Linear Regression of the Symptoms of Patients According to ESAS in the Comfort of Caregivers (n = 87).

Edmonton Symptom Assessment Scale (ESAS)	$\bar{X} \pm SD$	*Min–Max*	*B*[a]	***p***
Pain	3.70 ± 2.70	0–9	−.061	.931
Fatigue	4.92 ± 2.72	0–10	.035	.962
Nausea	2.88 ± 2.81	0–10	−.532	.508
Depression	2.19 ± 1.81	0–8	−2.191	.089
Anxiety	1.90 ± 1.69	0–8	−.996	.382
Drowsiness	5.27 ± 1.80	0–9	.864	.183
Appetite	5.43 ± 3.05	0–10	1.226	.059
Sense of well-being	3.56 ± 2.51	0–9	.062	.933
Shortness of breath	2.54 ± 2.73	0–9	.350	.505
Skin and nails changes	1.13 ± 1.29	0–6	−.922	.496
Stomatite or sore mouth	0.96 ± 1.34	0–7	1.067	.353
Numbness at hands	0.68 ± 1.13	0–70	.785	.543

[a]B-Regression coefficient.

appetite (5.4 points), drowsiness (5.2 points), fatigue (4.9 points) and pain (3.7 points). There was no significant relationship between caregivers' comfort score and patients' ESAS symptoms ($p > 0.05$) (Table 1).

In the End of Life Comfort Scale (Caregiver/Family), the mean scores of caregivers were found as 109.6 ± 12.49 (min: 86, max: 146). There was a significant relationship between the total comfort scores and ECOG scores of the patients ($p < 0.05$). As the ECOG performance status of the patient worsened, caregiver comfort was reduced (Table 2). Table 3 shows that there was a significant relationship between total comfort score and caregivers' age, economic situation, and the length of the caregiving period and receiving help in care ($p < 0.05$). It was found that comfort levels were higher for caregivers who were over 65 years of age, whose incomes were greater than their expenditures, who cared for the patient for 12 hours a day, and who received social support while providing care.

Table 2. Mean of *End of Life Comfort Scale* Score of Principal Caregivers According to Social Demographic and Clinical Characteristics of the Patients (n = 87).

Variables	*n (%)*	*End of Life Comfort Scale* $\bar{X} \pm SD$	*p*
Age of the patient			
Under 40	5 (5.7	103.80 ± 9.36	
Age 41–64	32 (36.8)	107.52 ± 10.35	0.267[a]
Over 65 years	50 (57.5)	111.87 ± 13.86	
Gender of the patient			
Female	40 (45.9)	110.60 ± 11.48	0.422[b]
Male	47 (54.9)	108.56 ± 13.67	
Marital status of the patient			
Married	79 (90.8)	110.24 ± 12.54	0.100[b]
Single	8 (9.2)	103.12 ± 10.34	
Categories of terminal disease			
Cancer	30 (34.5)	108.90 ± 14.59	
Neurological	24 (27.6)	111.75 ± 20.01	
Cardiovascular	18 (20.7)	112.18 ± 10.34	0.349[a]
Respiratory	6 (6.9)	110.40 ± 12.48	
Other	9 (10.3)	111.90 ± 11.43	
Time since diagnosis			
0–2 years	48 (55.2)	108.50 ± 11.52	
3–5 years	28 (32.2)	110.32 ± 13.31	0.692[a]
6 years and over	11 (12.6)	111.92 ± 13.72	
ECOG performance status			
2	20 (23.0)	116.26 ± 13.71	
3	37(42.6)	107.05 ± 10.88	**0.030**[a]
4	30 (34.4)	100.00 ± 5.65	

[a]Kruskal Wallis test.
[b]Mann Whitney-U test. Statistical signifcant values ($p < 0.05$) are given in bold.

Table 3. Mean of *End of Life Comfort Scale* Score of Principal Caregivers According to Their Social Demographic Characteristics (n = 102)

Variables	*n (%)*	*End of Life Comfort Scale* $\bar{X} \pm SD$	*p*
Age of the caregiver			
Under 40	15 (14.7)	105.00 ± 11.74	
Age 41–64	68 (66.7)	108.33 ± 10.54	**0.009**[a]
Over 65 years	19 (18.6)	118.21 ± 15.90	
Gender of caregiver			
Female	86 (84.3)	110.54 ± 12.61	0.057[b]
Male	16 (15.7)	105.06 ± 11.04	
Marital status			
Married	92 (90.2)	109.88 ± 13.05	0.944[b]
Single	10 (9.8)	108.12 ± 5.66	
Having a child			
Yes	98 (96.1)	109.76 ± 12.65	0.945[b]
No	4 (3.9)	107.75 ± 8.69	
Economic situation			
Expenditure > income	8 (7.9)	108.63 ± 12.39	
Expenditure = income	84 (82.3)	110.14 ± 11.41	**0.009**[a]
Expenditure < income	10 (9.8)	119.75 ± 10.25	
Care period (days)			
7 days and below	39 (38.2)	107.87 ± 11.77	
8–14 days	23 (22.5)	106.30 ± 10.24	0.159[a]
15–21 days	22 (21.6)	114.00 ± 13.24	
22 days and above	18 (17.6)	112.66 ± 14.45	
Length of the caregiving period			
12 hours	48 (47.1)	114.70 ± 13.81	**<0.001**[b]
24 hours	54 (52.9)	105.22 ± 9.22	
Receives help in the care (social support)			
Yes	46 (45.1)	113.52 ± 13.41	**0.003**[b]
No	56 (54.9)	106.53 ± 10.82	
Work			
Yes	32 (31.4)	107.09 ± 12.87	0.158[b]
No	70 (68.6)	110.87 ± 12.22	

[a]Kruskal Wallis test.
[b]Mann Whitney-U test. Statistical signifcant values ($p < 0.05$) are given in bold.

Discussion

Comfort is an important need in palliative care, and patients and their families also refer to it (Brent et al., 2018). Patients and their families receiving palliative care often experience physical, psycho-spiritual, socio-cultural, and

environmental discomfort (Nuraini et al., 2017). This study aims to determine the comfort level and the factors affecting the caregivers of patients receiving palliative care.

In this research, as also in the literature, the caregivers were predominantly female (84.3%) and in the age group of 41-64 years, which shows that care is still very frequently delegated to adult women (Gayoso et al., 2018; Meneguin et al., 2019; Zimmermann et al., 2016). Socio-culturally, women are generally seen as primary caregivers and women see themselves as responsible for family care (Sharma et al., 2016). Due to the influence of cultural and religious structures in this country, long-term care, especially that of the elderly and sick people, is usually carried out by family members and generally women (Oglak, 2017; Onur, 2015). Turkish social life is based on family and kinship ties. The most important feature of this is unity and solidarity among family members. This is thought to have affected our findings.

The caregivers' comfort score mean was 109.6; better comfort scores were associated with the caregiver's age, economic situation, care time, receipt of help in the care (social support), and the patient's performance (ECOG performance status). In the study by Meneguin et al. (2019), examining the association between comfort and needs of family members of intensive care patients, a positive association was found between comfort level and female sex, marital status, education status, disease severity, employment status and family relationship (Meneguin et al., 2019). Descriptions in the literature report that patients' decreased functional capacity can reduce comfort in caregivers (de Araújo Lamino et al., 2014; Gayoso et al., 2018). Although there are limited studies examining the comfort of palliative caregivers, it appears that it is particularly closely related to the functional status of the patient and the economic status of the caregiver. Since the low functional performance of the patients puts a greater burden on the caregiver, adequate support should be provided to increase caregiver comfort.

In this study, caregivers over 65 years of age had better comfort than younger ones. Younger caregivers have greater difficulty in dealing with care responsibility due to the lack of life experience. This may be because their life experiences increase their coping capacity (de Araújo Lamino et al., 2014; Gayoso et al., 2018; Rocha & Ciosak, 2014). In this case, it may have reduced the comfort of the caregiver. Besides, it is thought that the decrease in home and work responsibilities of elderly caregivers may be effective in this situation.

It was observed that the daily care period and receipt of help in care (social support) positively affected the caregivers' comfort. Comfort is a concept based on individual experience and interpretation, so it is difficult to provide

maximum comfort (Gayoso et al., 2018; Lima et al., 2017). Tao et al. (2020) stated that perceiving the financial situation as insufficient and receiving a low level of social support increases the burden on caregivers (Tao et al., 2020). It is thought that providing care for 12 hours a day and receiving social support from other family members reduces the burden of caregiving, and that psychological or emotional support has a positive effect on comfort.

Palliative care is a comprehensive care that reduces symptoms and stress and increases comfort in individuals with life-threatening or chronic diseases (Nuraini et al., 2017). There is no significant relationship between caregivers' comfort score and patients' ESAS symptoms. With the patient receiving palliative care, the comfort of the family is affected by this difficult process. However, the issue of comfort is commonly overlooked by health care professionals, including nurses (Nuraini et al., 2017). It is important to know the positive and negative aspects that affect the caregiver's comfort. In particular, nurses who are with the patient for 24 hours a day can provide better understanding and encouragement to caregivers.

Conclusion

The comfort of the caregivers was affected by the age of the caregiver, financial condition, duration of care, social support during the care process, and the patient's performance. These results show the impact of caregivers on the comfort of the palliative care patient, their effective communication and support needs, and the factors that the interventions of health care workers can change with individualized actions. In addition, the number of studies related to the difficulties, needs, and comfort experienced by the caregivers of palliative patients in Turkey is not sufficient. It is thought that because this is the first study in this field in this country, it will provide a significant contribution to the literature. It is also thought that more comprehensive and qualitative studies are needed.

Study Limitations

There are some limitations to consider in this study. First, this study was conducted in a single health center and therefore the results of the study cannot be generalized to other caregivers. Secondly, an adequate number of male caregivers could not be reached due to the cultural and social perception of care being women's responsibility. Finally, there was a sampling limitation due to the limitation of the population to a single center of 10 beds.

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References

Aslan, O., Yaranoglu, C., Tosun, B., & Bagcivan, G. (2018, March 21–25). End-of-Life Comfort Scale (caregiver/family) its validity and reliability in Turkish. 7. Turkish Medical Oncology Congress. https://slideplayer.biz.tr/slide/14873928/ (Original work published in Turkish)

Brent, L., Santy-Tomlinson, J., & Hertz, K. (2018). Family partnerships, palliative care and end of life. In: K. Hertz & J. Santy-Tomlinson (Ed.), *Fragility fracture nursing. perspectives in nursing management and care for older adults* (pp. 137–145). Springer. https://doi.org/10.1007/978-3-319-76681-2_11

Bruera, E., Kuehn, N., Miller, M. J., Selmser, P., & Macmillan, K. (1991). The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care*, *7*(2), 6–9.

Chan, K. S. (2018). Palliative care: The need of the modern era. *Hong Kong Medical Journal = Xianggang yi xue za zhi*, *24*(4), 391–399.

de Araújo Lamino, D., Turrini, R. N., & Kolcaba, K. (2014). Cancer patients caregivers comfort. *Revista da Escola de Enfermagem da U S P*, *48*(2), 278–284. https://doi.org/10.1590/s0080-623420140000200012

Gayoso, M. V., Avila, M. A. G. D., Silva, T. A. D., & Alencar, R. A. (2018). Comfort level of caregivers of cancer patients receiving palliative care. *Revista latino-americana de enfermagem*, *26*, 1–10.

Kim, K. S., & Kwon, S. H. (2007). Comfort and quality of life of cancer patients. *Asian Nursing Research*, *1*(2), 125–135. https://doi.org/10.1016/S1976-1317(08)60015-8

Kolcaba, K. Y. (1992). Holistic comfort: operationalizing the construct as a nurse-sensitive outcome. ANS. Advances in nursing science, 15(1), 1–10. https://doi.org/10.1097/00012272-199209000-00003

Kolcaba, K., & Steiner, R. (2000). Empirical evidence for the nature of holistic comfort. Journal of Holistic Nursing: official journal of the American Holistic Nurses' Association, 18(1), 46–62. https://doi.org/10.1177/089801010001800106

Kurt, S., & Unsar, S. (2011). Assessment of symptom control in patients with cancer in Northwestern Turkey. European journal of oncology nursing: the official journal of *European Oncology Nursing Society*, 15(2), 137–144. https://doi.org/10.1016/j.ejon.2010.07.0044 (Original work published in Turkish)

Lima, J. V., Guedes, M. V., Silva, L. F., Freitas, M. C., & Fialho, A. V. (2017). Usefulness of the comfort theory in the clinical nursing care of new mothers: critical analysis. Utilidade da teoria do conforto para o cuidado clínico de enfermagem à puérpera: análise crítica. *Revista gaucha de enfermagem*, *37*(4), e65022. https://doi.org/10.1590/1983-1447.2016.04.65022

Meneguin, S., de Souza Matos, T. D., Miot, H. A., & Pollo, C. F. (2019). Association between comfort and needs of ICU patients' family members: A cross-sectional study. *Journal of Clinical Nursing*, *28*(3-4), 538–544. https://doi.org/10.1111/jocn.14644

Novak, B., Kolcaba, K., Steiner, R., & Dowd, T. (2001). Measuring comfort in caregivers and patients during late end-of-life care. *American Journal of Hospice and Palliative Medicine®*, *18*(3), 170–180. https://doi.org/10.1177/104990910101800308

Nuraini, T., Gayatri, D., & Rachmawati, I. (2017). Comfort assessment of cancer patient in palliative care: A nursing perspective. *International Journal of Caring Sciences*, *1*(10), 209–215.

Oglak, S. (2017). The value of informal caregiving on elderly care: As a shadow workforce. *Istanbul Gelisim University Journal of Social Sciences*, *4*(2), 73–87. https://doi.org/10.17336/igusbd.348785 (Original work published in Turkish)

Oken, M. M., Creech, R. H., Tormey, D. C., Horton, J., Davis, T. E., Mcfadden, E. T., & Carbone, P. P. (1982). Toxicity and response criteria of the Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology*, *5*(6), 649–656.

Onur, H. T. (2015). Elderly care in axis gender. *International Journal of Social Science*, (37), 185–202. http://doi.org/10.9761/JASSS2955 (Original work published in Turkish)

Pickard-Holley, S. (1991). Fatigue in cancer patients. A descriptive study. *Cancer Nursing*, *14*(1), 13–19.

Rocha, A. C. A. L. D., & Ciosak, S. I. (2014). Chronic disease in the elderly: Spirituality and coping. *Revista da Escola de Enfermagem da USP*, *48*(SPE2), 87–93. https://doi.org/10.1590/S0080-623420140000800014

Sadirli, S. K., & Unsar, S. (2009). Edmonton symptom assessment scale for patients with cancer: Its validity and reliability in Turkish. *Firat Journal of Health Services*, *4*(11), 79–95. (In Turkish)

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family-caregivers of people with mental illnesses. *World Journal of Psychiatry*, *6*(1), 7. https://doi.org/10.5498/wjp.v6.i1.7

Strommen, J., Fuller, H., Sanders, G. F., & Elliott, D. M. (2020). Challenges faced by family caregivers: Multiple perspectives on eldercare. *Journal of Applied Gerontology*, *39*(4), 347–356.

Subih, M., AlBarmawi, M., Bashir, D. Y., Jacoub, S. M., & Sayyah, N. S. (2020). Correlation between quality of life of cardiac patients and caregiver burden. *PLoS One*, *15*(8), e0237099. https://doi.org/10.1371/journal.pone.0237099

Tao, X., Chow, S., Zhang, H., Huang, J., Gu, A., Jin, Y., He, Y., & Li, N. (2020). Family caregiver's burden and the social support for older patients undergoing peritoneal dialysis. *Journal of Renal Care*, *46*(4), 222–232. https://doi.org/10.1111/jorc.12322

Townsend, C. S., Bonham, E., Chase, L., Dunscomb, J., & McAlister, S. (2014). A comparison of still point induction to massage therapy in reducing pain and increasing

comfort in chronic pain. *Holistic Nursing Practice*, *28*(2), 78–84. https://doi:10.1097/HNP.0000000000000012

Thomsen, K. T., Guldin, M. B., Nielsen, M. K., Ollars, C. L., & Jensen, A. B. (2017). A process evaluation of systematic risk and needs assessment for caregivers in specialised palliative care. *BMC Palliative Care*, *16*(1), 23. https://doi.org/10.1186/s12904-017-0196-x

Twohig, B., Manasia, A., Bassily-Marcus, A., Oropello, J., Gayton, M., Gaffney, C., & Kohli-Seth, R. (2015). Family experience survey in the surgical intensive care unit. *Applied Nursing Research*, *28*, 281–284. https://doi.org/10.1016/j.apnr.2015.02.009

World Health Organization. (2018, June). *Noncommunicable diseases, key facts*. https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases

World Health Organization. (2020, August). *Palliative care, key facts*. https://www.who.int/news-room/fact-sheets/detail/palliative-care

Yesilbalkan, Ö. U., Özkütük, N., Karadakovan, A., Turgut, T., & Kazgan, B. (2008). Validity and reliability of the Edmonton Symptom Assessment Scale in Turkish cancer patients. *Turkish Journal of Cancer*, *38*(2), 62–67.

Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. *Canadian Medical Association Journal*, *188*(10), E217–E227. https://doi.org/10.1503/cmaj.151171

Author Biographies

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