The physical and mental state of healthcare professionals working with terminally ill patients

An inquiry into the well-being of those working in hospice-palliative care in Hungary, especially with regard to their satisfaction

PhD thesis

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1. INTRODUCTION

Hospice care is a humane, complex treatment for patients in the terminal stage of their serious illness, primarily cancer. Family members may find that caring for a dying person at home is more intimate, but physically and mentally taxing, while the medicalized hospital setting may be too impersonal. A multidisciplinary team of professionals can form a bridge between home and hospital in such situations. In recent decades, hospice-palliative care has developed significantly in Hungary, as in other European countries. According to data from domestic surveys, nearly 67% of patients prefer to die in their homes, with their family at their side, but only 30% of patients have the opportunity to do so. While analyzing the annual reports on hospice care at the start of our research in 2013, we found that while the number of hospice services and patients is steadily increasing, the number of doctors, nurses, and other professionals is not increasing proportionally, but rather decreasing. Hospice work is one of the most physically and mentally demanding vocations in the world. Regular exposure to human suffering, death, dying, the trauma of another person can affect the professional quality of life of workers. A reduction in active staff can contribute to an increase in their physical and mental exertion, which can lead to physical, psychological, and social symptoms developing sooner. This, in turn, can increase the

number of workers leaving the profession, which intensifies burden, perpetuating a vicious cycle.

2. OBJECTIVES

The main aim of our research, launched in 2013, was to complement the Hungarostudy initiative in assessing the physical and mental state of health workers dealing with terminally ill patients, to map changes occurring since the 2002 and 2006 study, and to develop intervention strategies to achieve a long-term positive impact.

To achieve this main goal, we carried out three research projects:

2.1. By exploring the physical and mental state of professionals and volunteers working in hospice care, as well as the degree of overburden from work, and by exploring the predictors of well-being, our aim was to identify factors that threaten and protect well-being.

- We assumed that those working in Hungarian hospices had a high over-commitment to work, as previous Hungarian studies showed; we also hypothesized that, compared to the data of the entire Hungarian population, they had a high incidence of physical symptoms and chronic disease.
- Based on previous studies, we hypothesized that unfavorable financial situation and over-commitment at work will have a positive correlation with perceived stress, as well as depressive mood, sleep disorder, vital exhaustion, and that via these

phenomena, they will have a positive correlation with psychological well-being also.

- Furthermore, we assumed that sense of coherence will be negatively correlated with perceived stress and mitigate its adverse effects as a protective factor, thereby helping to preserve psychological well-being.

2.2. With the development of the Hungarian version of the Professional Quality of Life Scale (ProQOL5) and the exploration of its psychosocial characteristics and factor structure, our aim was to introduce a questionnaire in Hungary that aids the longitudinal study of professional quality of life among those who work with dying patients and to map the benefits and disadvantages of such work.

- We assumed that the Hungarian version of ProQOL5 is suitable for measuring compassion fatigue and satisfaction among palliative care workers, that is it adequate in language and its psychometric properties, and that it appropriately separates the constructs of fatigue, secondary traumatic stress, and burnout.
- We hypothesized that professional quality of life was positively correlated with age and education level; accordingly: older, more experienced hospice workers would experience more satisfaction and less burnout, compassion-related stress, and secondary traumatic stress than their younger colleagues.

- We assumed that, compared to other nations, the Hungarian sample would exhibit higher levels of overburden from work and compassion fatigue, and lower levels of satisfaction.
- We hypothesized that those with higher levels of compassion satisfaction would experience lower vital exhaustion and depressive mood, while showing higher well-being.
- Finally, we assumed that personal, institutional, and societal difficulties resulting from their work would be balanced by compassion satisfaction, facilitating a positive perception of staying in the profession.

2.3. Through the development of a training program to improve sense of coherence and a qualitative analysis of experience via focus groups, my aim was to create a training and intervention method that can contribute to preventing burnout, compassion fatigue, while increasing workers' satisfaction, physical and mental well-being, and promoting a positive perception of staying in the profession.

- I assumed that the training program aimed at developing sense of coherence would enable hospice workers to learn about individual and group difficulties, coping, and protective factors.
- I also assumed that educative training on coherence as a protective factor and resources would contribute to raising awareness, and that practices aimed at reinforcement would enhance the coping

resources of the individual and the community, while increasing mental well-being and satisfaction with work.

– I hypothesized that participants would find the training worthy of being integrated into the training programs because of its positive effects.

3. METHODS

The research was carried out in the form of two quantitative cross-sectional questionnaire studies and a qualitative focus group analysis.

3.1. Assessing the physical and mental state of hospice workers

Sampling and administration of questionnaire

The voluntary, anonymous survey was administered in the span of fall 2013 to spring 2014. We recruited participants from member organizations of the Hungarian Hospice Palliative Association (HHPA): health workers, i.e. doctors, nurses, coordinators, physiotherapists, psychosocial and other professionals ($N \cong 1500$) and volunteers ($N \cong 200$) were included into the study. Questionnaires were administered online and in print during hospice training and conferences. Of the 207 responses received, 195 were valid; the response rate was 14%. The majority of respondents, 91.8%, were women ($n = 179$). In view of the low number of male respondents ($n = 16$), after a preliminary analysis of the initial research data, detailed

analyses were only carried out on the females in the sample. (Ethics permit no.: ETT TUKEB 274/2013.)

Employed measurement instruments

The questionnaire entitled “Assessment of the quality of life of hospice workers and volunteers” comprised four sections: 1) socio-demographic data; 2) questionnaires and survey scales; 3) further questions and survey scales aimed at mapping the physical and mental state of those dealing with terminally ill patients; 4) hospice work-related questions. The questionnaires employed in the study were selected from the test battery used in Hungarostudy 2002 and Hungarostudy 2013 (studies representative for adult Hungarian population). These questionnaires were: WHO-5 Well-Being Index, shortened version of the Life Meaning Subscale of the Brief Stress and Coping Inventory, Overcommitment Subscale ofshortened version of Effort-Reward Imbalance Questionnaire, Perceived Stress Questionnaire, Beck Depression Questionnaire, Maastricht Vital Exhaustion Questionnaire, and the Athens Insomnia Scale. In addition, we added the Multidimensional Fear of Death Scale, not included in the Hungarostudy questionnaires.

Data analysis procedures

The analyses were carried out with SPSS 21.0 and MPLUS 7.11 (Muthén & Muthén, 1998-2012). The internal reliability of the scales was estimated by calculating the Cronbach alpha indicator. For scales

measuring psychological constructs, we also calculated the 95% confidence interval of the averages and applied this to the comparison with domestic reference data. For methodological reasons, the two- and multi-variable analyses were only carried out on females in the sample. The extent of association was examined with correlation analysis (Pearson's correlation and Spearman's rank correlation).

The complex relationship between sense of coherence, work-related over-commitment, sociodemographic variables, perceived stress, depressive symptoms, sleep disorder, vital exhaustion and psychological well-being was tested with Structural Equation Modelling (SEM), namely path analysis, which enabled us to explore the relationship between predictors, mediators, and output variables.

3.2. Development of the Hungarian version of the Professional Quality of Life Scale (ProQOL5) and the exploration of its psychosocial characteristics and factor structure

Development of the Hungarian version of the Professional Quality of Life Scale (ProQOL5)

With the permission of the authors, the original 30-item version was translated into Hungarian by three independent translators, and the version co-developed by the research team was translated back into English by a translator. The developed Hungarian version was tested for language, intelligibility, and level of difficulty by thirty-nine

university students. Based on these experiences, we finalized the Hungarian version.

Sampling and administration of questionnaire

We administered the paper-based survey in the span of April – June 2016. We included individuals working in Hungarian hospice care: doctors, nurses, and other workers, e.g. physiotherapists, dietitians, social workers, and volunteers. We received 188 valid questionnaires from respondents: 162 women and 26 men.

The "Professional quality of life of hospice workers and volunteers" questionnaire

In addition to the ProQOL5 questionnaire, we used shortened versions of the measurement instruments already validated in the Hungarostudy quality of life research (Maastricht Vital Exhaustion Questionnaire, Beck Depression Inventory and the WHO Well-being Index), as well as the Center for Epidemiologic Studies Depression Scale (CES-D). Additionally, we explored the sociodemographic data.

Steps in statistical data processing

For statistical analysis, we used IBM SPSS 23.0© (International Business Machines Corporation, Armonk, NY, United States). We employed a MANCOVA analysis.

To explore the internal structure of the measurement instrument, we performed factor analysis (principle component analysis and varimax rotation); subsequently, we prepared the 4 scales that had the

appropriate Cronbach alpha values for further testing. The external validity of the scales was tested with correlation to various scales of standardized questionnaires used in Hungarostudy initiatives and the CES-D.

3.3. Positive resources: creating a training program to develop sense of coherence, and the qualitative analysis of experiences through focus groups

Development of the training program

I have developed practices to improve sense of coherence based on educational materials on occupational health promotion, specific work-related characteristics, as well as based on the recommendations of professionals with experience in this subject:

- Set goals that are worth reaching
- Consider problems as challenges rather than burdens
- Re-frame burdensome situations and transform problems into challenges
- Find and mobilize protective factors and sources of coping with stress

Identify and raise awareness of workplace characteristics that promote sense of coherence and health.

Focus group component of research

The focus group activities took place two weeks after the training programs and were an hour and a half each. We employed two

moderators. Audio and visual recordings (videos) were made during the focus group discussions; anonymity was ensured and individuals gave their verbal consent to participate. In order to stimulate participants to elaborate their opinions and experiences on the research subject, we used a semi-structured questionnaire containing several, intertwined blocks of questions.

Circumstances of sampling

The training program developing sense of coherence and the focus groups took place between 20 February and 11 April 2018 with the participation of professionals from an institutional and a home care team. Participants were: eleven nurses and one doctor from institution staff (n=12), and six nurses, one doctor, one physiotherapist, one dietitian, and one volunteer from the home care team (n=10). Participants of the focus group discussions were: six nurses from the institution, as well as one nurse, one doctor, and one dietician from the home care team (n=3).

Description of content analysis

The literal description of the focus group interviews from the audio was followed by a multi-stage coding process. After a descriptive analysis of the text, we approached the variables to be examined by forming more comprehensive categories and finally developed clear codes.

Summary of the categories and analyzed codes

Categories	Codes
Own feelings about hospice work	Negative aspects – stress factors
	Positive aspects – protective factors
Sense of coherence	Meaningfulness
	Manageability
Impact of training aimed to develop sense of coherence	Work conditions that aid sense of coherence
	Staying in the profession

4. RESULTS

According to the results of the physical and mental state evaluation, hospice workers report disturbing physical symptoms with higher frequency than does the Hungarian population. Of the slightly or very disturbing physical symptoms observed in the month prior to questionnaire completion, our respondents most often experienced fatigue, lack of energy (64.1%). Nearly half of respondents reported pains in the waist or back (63.1%) that mildly limited their everyday activities, as well as pain in the limbs or joints (51.8%) and headaches (49.2%). Sleep disorders were reported by 41% of them, and about one third had digestive problems. Illustrative of work-related over-commitment, almost half of respondents had at least three jobs, with 38.5% working 12 hours or more a day. According to our results, and

as expected, the work-related over-commitment, perceived stress level, and depressive symptoms of women working in hospice care was higher than in the national female population. However, contrary to our expectations, psychological well-being was higher and sense of coherence was lower than the domestic average. About half of respondents want to continue working in hospice care for decades or as long as they can.

According to the results of the path analysis, over-commitment at work was positively correlated with perceived stress, depressive mood, symptoms of vital exhaustion, and sleep disturbances. Furthermore, via these variables, well-being exhibits a negative correlation. Increased sense of coherence is associated with lower levels of perceived stress, depressive symptoms, and vital exhaustion, as well as higher levels of well-being. The novelty of our research is a change in approach, insofar as we have focused on a factor that contributes to the adequate coping and well-being of healthy, but stressed workers – sense of coherence –, and have demonstrated its importance.

Based on the study of the psychometric properties and factor structure of the Professional Quality of Life Scale (ProQOL5), we can conclude that the strength and direction of association between the standardized scales measuring external validity and the scales of our own measurement instrument were satisfactory; they behaved

according to what the canonic literature dictates. The questionnaire measured the phenomena we wanted to examine according to the expected values, with appropriate consistency based on internal and external indicators. The factor analysis showed a four-factor structure, differing from the three-factor structure of the original and international samples. During the assessment of the “Professional quality of life of hospice workers and volunteers” questionnaire, we found average burnout and lower secondary traumatization values compared to the Hungarian average, and satisfaction rate was higher than the average. According to the results, Hungarian hospice workers exhibited lower well-being, average mild depression, and low vital exhaustion. Higher levels of compassion satisfaction correlated with mild depression.

In the qualitative, focus group analysis of the training program that develops sense of coherence, we asked participants about the positive aspects of hospice work. They emphasized the importance of common values, a feeling of success, and employee support. The negative aspects that participants reported were mainly stress factors that are also supported by the literature, and which constituted the underlying assumptions in our research: physical exertion, difficult emotions, psychological burdens, and over-commitment to work. In terms of the two elements comprising sense of coherence, meaningfulness and manageability, participants emphasized

reframing problems as challenges concerning the former, and separation of work and life regarding the latter. In identifying and raising awareness of workplace factors that improve sense of coherence, the importance of trust, honest communication, and shared values was emphasized. Based on the content analysis of focus group activities, the protective function and resource-role of the sense of coherence helped participants to “open their mind” and feel renewed. According to participants, these have a beneficial effect on psychological well-being, job satisfaction, and can help hospice workers to have a positive perception of staying in their profession.

The strength of the mixed quantitative and qualitative research process is that, in addition to assessing the physical and mental state of health workers dealing with terminally ill patients, I have pointed out the positive aspects and protective aspects of this work, including the importance of sense of coherence. We developed the Hungarian adaptation of the tool for measuring professional quality of life, after which I developed a training program to improve sense of coherence. With the latter, I aimed to contribute to the positive perception of staying in the profession by increasing the satisfaction and well-being of hospice workers.

5. CONCLUSIONS

Based on our quantitative and qualitative studies, I have drawn the following conclusions:

1. Hospice workers involved in the research were, as in previous research, overburdened: nearly two-thirds had two or more jobs, more than a third worked twelve hours or more a day, nearly half had been active in end-of-life care for more than five years, and about half wanted to stay in the profession long-term.
2. The physical symptoms of those working in hospice care are more severe than the average in the Hungarian sample.
3. The extent of the over-commitment, perceived stress level, depressive symptoms, and well-being of our respondents, mainly women and nurses, was higher compared to the domestic female population. Yet, their sense of coherence was lower than average, which justifies the development of a training aimed at this.
4. Aforementioned paradox raises the likelihood that workers dealing with dying patients and their families ignore their symptoms of physical and psychological overload at the individual, organizational, and social level, and persist in their work. This draws attention to compassion fatigue and compassion satisfaction, which balances it.
5. Our results indicate that adverse financial situation and work-related over-commitment have a positive correlation with increased perceived stress, depressive mood, sleep disorders, and

vital exhaustion, and via these variables, low well-being exhibits a positive correlation as well.

6. We have pointed out the protective role of sense of coherence: namely, it has a negative correlation with the level of perceived stress, it mitigates its adverse effects, which ultimately helps to preserve psychological well-being.
7. The Professional Quality of Life scale (ProQOL5), commonly used to measure the effects of work with dying patients and their families, contributes to shifting our focus from the negative aspects of professional quality of life in these occupations (e.g. occurrences of burnout or compassion fatigue and their prevention) to the positive aspects, such as compassion satisfaction.
8. The validation and application of the Hungarian version of the ProQOL5 will enable the monitoring of the professional quality of life of those working with terminally ill patients, screening for compassion fatigue, and facilitating the development of appropriate personal or organizational interventions, which can increase the well-being of workers and the number of people who remain on the field.
9. The use of ProQOL promotes the comparison of results from other health professions and international data; thus, scrutinizing the professional quality of life of Hungarian hospice workers

contributes to the under-researched topic of East-Central European hospice staff.

10. The results of Hungarian hospice workers exhibiting lower well-being, average mild depression, and the high values of compassion satisfaction justify a more detailed understanding of the factors underlying the paradox. Additionally, inquiry into the work of hospice professionals and groups is also justified, as is the incorporation of interventions into education to improve satisfaction.
11. The experience of pilot trainings and focus group interviews is consistent with previous and current international research, confirming the results regarding the physical and mental state of hospice workers and their professional quality of life.
12. According to participants of the focus group discussions, the training program is suitable for increasing job satisfaction, helping to maintain well-being and staying in the profession.
13. The training program that improves sense of coherence contributes to diversifying the training and education program for hospice-palliative care workers, thereby expanding the range of interventions that can be used in their education.

6. LIST OF PUBLICATIONS

The candidate's publications related to the dissertation

International journal articles

- **Kegye A**, Czeglédi E, Zana Á, Csikai EL, Hegedűs K. (2020) Influential factors of well-being among Hungarian female hospice workers examined through structural equation modelling. Health Soc Care Community, 28: 1560–1568.

National journal articles

- **Kegye A**, Takács S, Ries B, Zana Á, Hegedűs K. (2018) A szakmai élet minőségét mérő kérdőív (Professional Quality of Life Scale) magyar változatának validálása. Orv Hetil 159: 1441–1449.
- Révay E, **Kegye A**, Zana Á, Hegedűs K. (2016) A túlélők mindennapjai. A hospice-ellátásban dolgozók életminősége. Orv Hetil, 157: 1000–1006.
- **Kegye A**, Zana Á, Révay E, Hegedűs K. (2015) A súlyos betegek ellátásának igazi ára – az együttérzésből fakadó fáradtság vagy elégedettség. LAM, 25: 129–136.

Conference abstracts

- **Kegye A**, Takács S, Zana Á, Hegedűs K. (2019) Validation of the Hungarian Version of the Professional Quality of Life Scale. An Opportunity to Improve the Well-being of Hospice Care Workers. Palliat Med, 33: 339-340.

- Zana A, Czegledi E, **Kegye A**, Hegedus K. (2018) Differences in Well-being and Fear of Death of Hospice Employees and Volunteers in Hungary. Palliat Med, 32 (Suppl 1): 265.
- **Kegye A**, Czeglédi E, Hegedűs K. Predictors of well-being among women working in hospice care. In: 15th World Congress of the European Association for Palliative Care, Abstracts. 2017: 619-619. Paper: P01-391.

The candidate's publications independent of the dissertation

International journal articles

- Zana Á, **Kegye A**, Czeglédi E, Hegedűs K. (2020) Differences in well-being and fear of death among female hospice employees and volunteers in Hungary. BMC Palliat Care, 19: 58–66. Megosztott első szerzős.
- **Kegye A,** Naszaly A. (1998) Radiotherapy for lung metastases in a patient with ewing sarcoma. Sarcoma, 2: 209–213.

National journal articles

- Farkas KR, **Kegye A.** (2015) Özvegyek és elváltak veszteségfeldolgozása. Kharón, 19: 18–32.
- **Kegye A,** Pádi. É, Hegedűs K. (2014) Rehabilitation model program for seriously ill patients. Health Psychology Report, 2: 263–268.

- **Kegye A,** Pádi É. (2013) A csoport-pszichoterápia lehetősége a hospice-palliatív ellátásban. Egy modellprogram eredményei. Orv Hetil, 154: 1102–1105.
- **Kegye A,** Pálfi Z. (2011) Befolyásoló életesemények? Az onkológiai betegek pszichoszociális támogatásáról egy kutatás tükrében. IME, 10: 19–22.
- Mayer Á, Patyánik M, **Kegye A,** Mészáros E. (2001) Rectumtumorok praeoperativ sugárkezelése saját eredményeink alapján. Magy Onkol, 45: 347–351.

Book

- **Kegye A** (szerk.), Rohánszky M, Molnár M, Boda É, Kapitány Zs. Pszichoszociális onkológia. Gyakorlati útmutató a teljeskörű betegellátáshoz. Zafír Press, Budapest, 2014.

Book chapter

- Prezenszki Zs, **Kegye A,** Molnár M. Pszichoonkológia. In: Füredi J, Németh A (szerk.), A pszichiátria magyar kézikönyve. Medicina Könyvkiadó Zrt., Budapest, 2015: 768–780.
- **Kegye A.** Pszichoszociális támogatás. In: Csikós Á (szerk.), Palliatív ellátás. Pécsi Tudományegyetem Általános Orvostudományi Kar, Pécs, 2015: 195–204.
- **Kegye A.** Gyász. In: Csikós Á (szerk.), Palliatív ellátás. Pécsi Tudományegyetem Általános Orvostudományi Kar, Pécs, 2015: 204–214

- **Kegye A.** Eszter. Onkológus. In: Campos JM (szerk.), S.O.S. Daganat! Oriold és Társai Kiadó, Budapest, 2014: 257–286.
- **Kegye A**, Schaffer J, Zana Á. Végsőkig kísérni. Tanácsadó füzet súlyos betegségben szenvedők hozzátartozóinak. Magyar Hospice-Palliatív Egyesület, Budapest, 2015.
- **Kegye A.** A pszichoszociális támogatás helye a komplex onkológiai elltásában. In: Kiss E, Polyák L (szerk.), A fogyatékossággal élők pszichológiai és társadalmi rehabilitációja: a Magyar ILCO Szövetség 2010-es konferenciájának válogatott, lektorált tanulmányai. Magyar ILCO Szövetség, Kaposvár, 2010: 35–44.
- **Kegye A,** Nemeskéri Cs. Ductus choledochus elzáródás okozta icterus. In: Mayer Á (szerk.), Sürgősségi (palliatív) onkológiai állapotok nem sebészi kezelése. Roche (Magyarország) Kft., Budapest, 2000: 21–25.
- **Kegye A,** Szabó Z, Póti Zs. Mentális szupportáció. In: Mayer Á (szerk.), Emlőrák nem sebészi kezelése: 2. módosított kiadás. Roche (Magyarország) Kft., Budapest, 1999: 61–67.