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Including: Social Work, Humanitary Health Intervention, Nursing, Missionary Work

# CLINICAL SOCIAL WORK AND HEALTH INTERVENTION

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## *Issue: Social and Health Palliative Care* Original Articles

- ✓ PSYCHOSOCIAL AND SPIRITUAL NEEDS OF DYING PATIENTS FROM THE PERSPECTIVE OF THE NURSE AND LENGTH OF PROFESSIONAL PRACTICE (ORIGINAL RESEARCH)
- ✓ TUBEROUS SCLEROSIS COMPLEX: RARE DISEASE WITH SIGNIFICANT SOCIAL IMPACT (CASE SERIES)
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    - ✓ RISKS OF PROFESSIONAL PARENTING (ORIGINAL RESEARCH)
- ✓ HOW DO HOSPICE PATIENTS FEEL ABOUT HOSPICE CARE - AND IS IT IMPORTANT? EXPLORING THE RELATIONSHIP BETWEEN PATIENT ATTITUDE TO HOSPICE CARE, SURVIVAL AND OTHER PATIENT CHARACTERISTICS IN THE SETTING OF FIRST CROATIAN HOSPICE (ORIGINAL PAPER)
  - ✓ PREDICTS THE FACTORS INFLUENCING ON BEHAVIOR OF BODY MANAGEMENT IN FEMALE STUDENTS (ORIGINAL RESEARCH)
- ✓ CULTURAL PERCEPTIONS ON THE ROLE OF PALLIATIVE MEDICINE AIN CENTRAL AND EASTERN EUROPE (REVIEW)
- ✓ A COMPARATIVE LITERATURE REVIEW ON CONTRIBUTIONS OF SOCIAL WORKERS IN KENYA AND SLOVAKIA TO PALLIATIVE CARE MULTIDISCIPLINARY TEAM (REVIEW)
- ✓ REPLENISHING THE SPIRITUAL NEEDS IN PATIENTS WITH INFAUST PROGNOSIS IN PRAGUEAN AND THE CENTRAL BOHEMIAN REGION'S HOSPITALS (RESEARCH NOTE)
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- ✓ TOWARDS A COMPREHENSIVE HEALTH CARE: HUMAN RIGHTS APPROACH (LETTER)
  - ✓ HOW AN AGING POPULATION IN SLOVAKIA IMPACTS THE UTILIZATION OF THE CURRENT ARRAY OF LONG-TERM CARE SERVICES (REVIEW)
- ✓ HOW PALLIATIVE AND HOSPICE CARE ARE ORGANIZED IN UKRAINE (REVIEW)



**European Association for Palliative Care**  
Non-governmental organisation (NGO) recognised by the Council of Europe

...A message from the European Association for Palliative Care (EAPC)...  
The European Association for Palliative Care is a European membership organisation for all of those working or with an interest in palliative care. The EAPC looks forward to working more closely with our colleagues, and welcomes initiatives, from the palliative care movement in Eastern, Southern and Central Europe. Globally, palliative and hospice care aims to modernise and humanise health care and improve quality of life.

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Issue 3/2017: Perception of Health Sciences by Consumers

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## Editorial

In this issue, we have tried to focus on medical, psychosocial, organizational and other components of the Palliative and Hospice Care (PHC). This so far should reflect the fact that the PHC is very broad social reality which consists of and affects many social components and institutions - civic society, public health, human rights, education, spirituality, economy etc.

This is the intersectoral and multidisciplinary approach which unites representatives of different disciplines as well as researchers, spiritual leaders, volunteers, NGO activists etc. with one aim: improve the life quality of those who finish their lives. Ideally, PHC aims to underline and announce the dignity of each human being and declare that each human matters. The slogan of one of the Polish Children's Hospice is "Yet it is possible to help them". This means that notwithstanding the physical and mental weakness of hospice clients', the support should be provided.

The PHC approach as a modern ideology is relatively new: 2017 marks the 50th anniversary of the Hospice Movement. The first modern hospice, St Christopher's, was founded by Nurse Cicely Saunders who established the discipline of palliative care. She introduced the idea that dying people need dignity, compassion and respect. Since then, the PHC Movement developed and strengthened. Nonetheless, in many countries of the world there are no hospices or palliative care teams or other capacities to support those facing the problem of incurable disease. The Hospice movement is not well developed in countries of the former Soviet Union. So, one of this Issue's goals is to advocate for PHC. This means, that we have tried to collect papers that reflect different components of PHC and represent them from the scientific point of view. In the Ukraine, for example, the advocacy of PHC among researchers and the medical establishment has encouraged the sustainable development of this type of care.

Of course, the grass-roots initiatives started by patients, medical or Social Workers, Psychologists, Chaplains etc. are also very important. It is crucial that PHC is being supported locally, from beneath. Human rights of those who face incurable disease is the key element of development of the system of PHC.

In conclusion, PHC is currently one of the most actual elements and needs in our society and for this reason it is extremely important to devote this Issue of Clinical Social Work and Health Intervention to this topic.

**Alexander Wolf**

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## Few words from the Editors-In-Chief

This journal brings authentic experiences of our social workers, doctors and teachers working for the International Scientific Group of Applied Preventive Medicine I-GAP Vienna in Austria, where we have been preparing students for the social practise over a number of years. Our goal is to create an appropriate studying programme for social workers, a programme which would help them to fully develop their knowledge, skills and qualification. The quality level in social work studying programme is increasing along with the growing demand for social workers.

Students want to grasp both: theoretical knowledge and also the practical models used in social work. And it is our obligation to present and help students understand the theory of social work as well as showing them how to use these theoretical findings in evaluating the current social situation, setting the right goals and planning their projects.

This is a multidimensional process including integration on many levels. Students must respect client's individuality, value the social work and ethics. They must be attentive to their client's problems and do their best in applying their theoretical knowledge into practice.

It is a challenge to deliver all this to our students. That is also why we have decided to start publishing our journal. We prefer to use the term 'clinical social work' rather than social work even though the second term mentioned is more common. There is some tension in the profession of a social worker coming from the incongruity about the aim of the actual social work practice. The question is whether its mission is a global change of society or an individual change within families. What we can agree on, is that our commitment is to help people reducing and solving the problems which result from their unfortunate social conditions. We believe that it is not only our professional but also ethical responsibility to provide therapeutic help to individual and families whose lives have been marked with serious social difficulties.

Finding answers and solutions to these problems should be a part of a free and independent discussion forum within this journal. We would like to encourage you – social workers, students, teachers and all who are interested, to express your opinions and ideas by publishing in our journal. Also, there is an individual category for students' projects.

In the past few years there have been a lot of talks about the language suitable for use in the field of the social work. According to Freud, a client may be understood as a patient and a therapist is to be seen as a doctor. Terminology used to describe the relationship between the two also depends on theoretical approach. Different theories use different vocabulary as you can see also on the pages of our journal.

Specialization of clinical social work programmes provides a wide range of education. We are determined to pass our knowledge to the students and train their skills so they can one day become professionals in the field of social work. Lately, we have been witnessing some crisis in the development of theories and methods used in clinical social work. All the contributions in this journal are expressing efforts to improve the current state. This issue of CWS Journal brings articles about social work, psychology and other social sciences.

Michael Olah  
Peter G. Fedor-Freybergh  
*Edition of the journal*





# Psychosocial and Spiritual Needs of Dying Patients from the Perspective of the Nurse and Length of Professional Practice (Original Research)

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Original Article

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## Abstract:

**Objective:** The aim of our research was to find out correlation between length of practice in Nurses and Midwives and length of practice in satisfaction of spiritual needs of dying patients.

**Design:** Project study.

**Participants:** 433 respondents (43 were men and 390 women). In terms of jobs the majority was of Nurses and Midwives 385 (86.6%). The most numerous age group was between 35-44 years (40.9%), 25 to 34 years (24%), 45-54 years (23.6%), under 20 (4.6%) and above 55 30 participants (6.9%). Length of experience: The largest group 10-21 years of practice (32.8%), 22-31 years (25.9%), 5-9 (15.5%), under 5 (12.7%) and over 32 years practice (13.2%).

**Methods:** Standardized questionnaires SNAP (Spiritual Needs Assessment for Patients) and SCCS (Spiritual Care Competence Scale) analyzed by descriptive characteristics for variables and subsequent testing of normality. Due to the sample size was used the Kolmogorov-Smirnov test (KS-test). We evaluated the correlation by using SPSS 22 Parametric Pearson Correlation Coefficient with a significance level of  $p < 0.01$  and  $p < 0.05$ .

**Results:** We evaluated the intrinsic reliability of SNAP using the Cronbach Alpha coefficient for SNAP - Spiritual needs is  $> 0.900$  in the whole set, which we interpret as a high degree of elemental credibility, respectively internal consistency of the questionnaire. In the SNAP - Psychosocial needs  $> 0.750$ , which also interferes with the high level of reliability at the item level. As for inter-polar correlations and also the correlation between individual items and the total SNAP subtracted score, we found that the Spearman correlation coefficient between items and SNAP scores are in the range of 0.608 - 0.787 which is a strong to very strong correlation. The correlation is significant at a level of Sig.  $p < 0.01$ . Length of practice - The correlation of the value (Spearman's correlation coefficient)  $\rho = 0.105$  (Sig.  $p < 0.05$ ) is directly related to attitudes of Nurses and Midwives. There is a statistically significant relationship between the length of practice and SCCS subclass - professionalization and quality improvement of spiritual care ( $p = 0.121$ ; Sig.  $p < 0.05$ ).

**Conclusion:** The project study shows that important role in the approach to dying patients and their spiritual needs plays not only to good preparation in school, but also personal experience that Nurses and Midwives acquire during their professional practice.

## Introduction and Aim

The Nurse has an irreplaceable role in nursing processes during the dying period of the patient. She/he is part of a multidisciplinary team requiring high professionalism, professional maturity and good communication ability (Kelnarova, 2007). An important prerequisite for the work of Nurses in the field of palliative nursing care is personal

maturity and certain features of character, of which the most important are ability of self-control and patience. The essence of nursing care for a dying patient is to ensure an adequate quality of life that greatly affects the understanding of human existence and the meaning of human life. The Nurse in a process of caring for the dying patient

is the person who provides care and treatment. Her/his main task is to saturate the patient's needs according to priorities. Usually we say that it should be a priority to satisfy the biological needs which we consider to be primary; without which it is impossible to effectively meet the psychosocial and spiritual needs. However, this is not always the case. In the dying, it could be the higher needs including spiritual needs. Experience from practice plays an important role in care for a dying patient. Positive death experiences are associated with absence of patient pain, dyspnea, anxiety, or agitation and the presence of spiritual, psychological, and culturally appropriate care for the patient and family (Bennett, Proudfoot, 2016).

From time immemorial, spiritual care has played an important role in the care of the sick and subsequently in nursing care. In the past, the development of the company influenced by certain ideology has come to a halt for a period; but not forever. We can assume that spirituality is a general characteristic of a person (Rican, 2010). Spirituality and spiritual needs have a particular importance in the terminal stage of disease. Satisfying spiritual needs helps patients to be more tolerable to cope with suffering. Satisfying spiritual needs is of great importance for the sick person (Zrubakova, Herinkova, 2015).

With regard to all the needs of the dying, we should not forget to integrate them into a holistic view of a human. On the other hand, we should not forget the fact that each person is a specific identity which from a psychological point of view can be understood as self-perception and self-awareness; perception of one's own uniqueness and difference from others (Hartl, Hartlova, 2004).

Through an interview with the patient, the Nurse has the opportunity to know the patient's spiritual needs and then to set the goal of meeting these needs. The assessment of spiritual needs must be very gentle,

which is one of the most important principles of their satisfaction. Spiritual care must be planned as well as satisfying other needs of the patient. The most important in meeting the spiritual needs is the quality of interpersonal relations. The Sister often becomes the main person in the process of establishing such relationships in the workplace (Kelnarova, 2007).

In current practice, there have been developed standards for the satisfaction of biological needs but there is a lack of standards for the satisfaction of spiritual needs (Prasilova, 2009). The spiritual needs of the dying patient are related especially with his/her accompanying spiritual experience. Spiritual care can be perceived by such a patient as a need for understanding their own lives, suffering and death. The spirituality is perceived by the dying patient as the acceptance of the afterlife; the forgiveness, the communication with God; but also the hope.

Kelnarova (2007) defined important principles for practice in the satisfaction of spiritual needs:

- Spiritual care requires trust and mutual support.
- Spiritual care is part of all the activities we do for and with the dying.
- Spiritual care requires an assessment of the current dying situation.
- We do not press on a dying person; during conversation we will show interest in him.

Modern nursing perceives dying as a whole range of medical problems that need to be identified and need to be dealt with. The idea of a good dying comes as alien to many people because they do not realize that death can involve more than physical pain and tragedy. The real experience of dying cannot be perceived purely from the medical point of view. As long

as we support the human dimension of the dying, the process of dying can become as deep and intimate as the birth of a child (Byock, 2013).

Spiritual needs have a close relationship with the search for meaning of life and death; they cannot be limited to religiosity, although in most cases we understand them in this sense. We can define spiritual needs as a means of achieving welfare (Cicha, 2010).

Howard Clinebell believed that humans have seven spiritual hungers in common. As you read through them, consider whether you recognize any of these spiritual needs in yourself. Are there particular areas of “spiritual hunger” in your life that need more attention than others?

Specifically, Clinebell felt that human beings long for seven spiritual needs:

- Experience the healing and empowerment of love-from others, self, and an ultimate source.
- Experience renewing times of transcendence; expansive moments beyond immediate sensory spheres.
- Have vital beliefs that lend meaning and hope in the midst of losses, tragedies, and failures.
- Have values, priorities, and life commitments centered in issues of justice, integrity, and love to provide guidance for personally and socially responsible living.
- Discover and develop inner wisdom, creativity, and love of self.
- Develop a deepening awareness of oneness with other people, the natural world, and all living things.
- Have spiritual resources to help heal grief, guilt, resentment, unforgiveness, self-rejection, and shame and deepen experiences of trust, self-esteem, hope, joy and love of life. (Clinebell, 2012).

Satisfaction of spiritual needs involves salvaging not only the sick part of the human body, but also with the sick/dying human and subsequently with relatives/survivors. Nurses act on them by their professional interventions, as well as all their personality; relationship; degree of professional qualities; level of competence; professional adaptation (Moraucikova, 2015).

The aim of our research was to find any correlation between the length of practice in Nurses and Midwives and the length of practice in satisfaction of spiritual needs of dying patients. We have worked on this project for three years in Slovakia.

**Research sample** consisted of a total 433 respondents, of which 43 were men (9.9%) and 390 were women (90.1%). In terms of jobs, the majority were Nurses 375 (86.6%); other positions are represented several times lower: paramedics 28 (6.5%); medical assistants 14 (3.2%); Midwives 10 (2.3%); sanitarians-caregivers 6 (1.4%). The most numerous age group was between 35-44 years (40.9%); 25 to 34 years (24%); 45-54 years (23.6%); under 20 20 (4 , 6%) and above 55 30 participants (6.9%). Length of experience was also similarly represented. The largest group 10-21 years of practice (32.8%); 22-31 years (25.9%); 5-9 (15.5%); under 5 (12.7%) and over 32 years practice (13.2%). In terms of work most respondents were working at standard treatment unit/wards at the hospital (36.5%); in outpatient casualty treatment departments (24.5%); independent ICU (18%); social facilities and HNCA - home nursing care agency (15.2%); Department of Anesthesiology; IM; operating theaters 5 (1,2%); education and management 5 respondents (1.2%); other workplaces reported 2.2% of respondents. Research output as variable is also the religion represented. No religion is a set of 15%; 77.4% of respondents are believers; others - 7.6% did not care about religion (**Table 1**).

**Table 1:** Frequency table of categorical variables: gender, age, position, workplace, length of practice, faith in the whole sample.

		Absolute number	%
Gender	Masculine	43	9.9
	Feminine	390	90;1
Age	< 25 years	20	4.6
	25 - 34 years	104	24
	35 - 44 years	177	40.9
	45 - 54 years	102	23.6
	55 - 64 years	30	6.9
Work position	Nurse	375	86.6
	Midwife	10	2.3
	Paramedics	28	6.5
	Sanitarists-caregivers	6	1.4
	Healthcare assistant	14	3.2
Work place	Standard treatment unit / the wards at the hospital	158	36.5
	ICU	78	18
	Operating theaters	5	1,2
	Anesthesiology and IM	5	1,2
	Casualty treatment departments	106	24.5
	Social facilities and HNCA	66	15.2
	Others	10	2.2
	Education and Management	5	1.2
Length of practice	< 5 years	55	12.7
	5 - 9 years	67	15.5
	10 - 21 years	142	32.8
	22 - 31 years	112	25.9
	>32 years	57	13.2
Faith	Believers	335	77.4
	No religion	65	15
	Not given	33	7.6

In **Table 2**, is information of categorical variables in the groups of Nurses and Midwives, which are the most numerous - 367 respondents formed of 95.3% women and

4.7% men. Other evaluated variables are similarly represented as in the entire file, so we will not interpret them in the text (**Table 2**).

**Table 2:** Frequency table of categorical variables: gender, age, position, workplace, length of practice, faith in Nurses and Midwives.

		Absolute number	%
Sex	Masculine	18	4.7
	Feminine	367	95.3
Age	< 25 years	7	1.8
	25 - 34 years	87	22.6
	35 - 44 years	162	42.1
	45 - 54 years	99	25.7
	55 - 64 years	30	7.8
Work position	Nurse	375	97.4
	Midwife	10	2.6
Work Place	Standard treatment unit / the wards at the hospital	142	36.9
	ICU	75	19.5
	Operating theaters	5	1.3
	Anesthesiology and IM	5	1.3
	Casualty treatment departments	82	21.3
	Social facilities and HNCA	65	16.9
	Others	7	1.8
	Education and Management	4	1
Length of practice	< 5 years	41	10.6
	5 - 9 years	49	12.7
	10 - 21 years	129	33.5
	22 - 31 years	110	28.6
	>32 years	56	14.5
Faith	Believers	298	77.4
	No religion	59	15.3
	Not given	28	7.3

## Methods

To obtain relevant data, we used standardized questionnaires SNAP (Spiritual Needs Assessment for Patients) and SCCS (Spiritual Care Competence Scale). The obtained data were analyzed by descriptive characteristic for variables and subsequent testing of normality. Due to the sample size was used the Kolmogorov-Smirnov test (KS-test). We

evaluated the correlation by using SPSS 22 Parametric Pearson Correlation Coefficient with a significance level of  $p < 0.01$  and  $p < 0.05$ .

## Results

In our survey, we achieved the following results: characteristics for variables obtained

through the SNAP questionnaires (Psychosocial needs and Spiritual needs) and the SCCS.

**Table 3** gives descriptive characteristics for SNAP variables - Psychosocial needs, SNAP - Spiritual needs and SCCS for Nurses and Midwives. For the interpretation of values, the same expressions apply as for the whole research file. We would only

point to the minimum value in SCCS, which is 45 points for Nurses and Midwives, and 31 points for the whole sample.

In interpreting Kolmogor-Smirnov's normality test, in the group of Nurses and Midwives, we can notice that even in the SCCS variable significance was achieved Sig.  $p < 0.05$ , thus rejecting the supposition of normal distribution in this variable (Table 4).

**Table 3:** Descriptive characteristic scales SNAP - Psychosocial needs, SNAP Spiritual needs and SCCS in Nurses and Midwives.

	SNAP Psychosocial needs	SNAP Spiritual needs	SCCS
N	385	385	385
Average	16,29	42,02	101,45
Median	17	42	102
Modus	17	47	95
Standard Deviation	2,78	7,09	16,95
Obliquity	-0,58	-0,71	-0,33
Sharpness	-0,15	0,42	-0,27
Minimum	7	15	45
Maximum	20	52	135
1 <sup>st</sup> quartile	14	37,5	90
3 <sup>rd</sup> quartile	19	48	115

**Table 4:** Results of normality testing of the SNAP and SCCS (Kolmogorov-Smirnov's test) in Nurses and Midwives.

	Kolmogorov-Smirnov		
	Statistic	df	Sig.
SNAP – Psychosocial needs	.120	385	.000
SNAP – Spiritual needs	.091	385	.000
SCCS	.048	385	.035

We evaluated the intrinsic reliability of SNAP - Psychosocial needs and SNAP - Spiritual needs using the Cronbach Alpha coefficient. As can be seen in **Table 5**, the value of the coefficient for SNAP - Spiritual needs is greater than 0.900 in the whole set, which we interpret as a high degree of elemental credibility, respectively internal consistency of the questionnaire. None of the 13 items reduces this value, so we consider the items to be consistently saturation to that sub-scale. In the SNAP - Psychosocial needs, the calculated coefficient is higher than 0.750, which also interferes with the high level of reliability at the item level. None of the 5 items alter the Alpha coefficient value and all share the same score on the overall score of the sub-scale.

**Table 5:** Cronbach Alpha coefficient for SNAP.

	SNAP – Spiritual needs	SNAP – Psychosocial needs
Whole sample (N = 433)	0.921	0.780

As for inter-polar correlations and also the correlation between individual items and the total SNAP subtracted score, we found that the Spearman correlation coefficient between items and SNAP scores - Psychosocial needs are in the range of 0.684 - 0.787, which is a strong to very strong correlation. The correlation is significant at a level of Sig.  $p < 0.01$ . Relationships between items and SNAP scores - Spiritual needs reach Spearman's correlation coefficient from 0.608 - 0.778, which we interpret as strong to very strong correlations. The

correlation is significant at a level of Sig.  $p < 0.01$ . Inter-polar correlations representing item relationships have a statistical significance of Sig.  $p < 0.001$ .

We have evaluated the correlation between used methodologies and the sub-scales. Because of the sample size, we used the parametric Pearson correlation coefficient (although SCCS and SNAP sub-scales do not have normal distribution). In **Table 6** we can see that there is a weak positive relationship between the SCCS score and the SNAP - Psychosocial needs ( $r = 0.270$ , Sig.  $p < 0.001$ ), and between the SCCS score and the SNAP - Spiritual needs is a moderate positive relationship ( $r = 0.366$ ; Sig.  $p < 0.001$ ).

Further data in **Table 6** tells about the relationships between SNAP - Psychosocial needs, SNAP - Spiritual needs and SCCS sub-scales. All identified relationships can be interpreted as weak positive correlations (in the range of 0.1 to 0.3) except for the relationship between SNAP - Spiritual needs and SCCS - Professionalization and quality improvement of spirituality care ( $r = 0.321$ ; Sig.  $p < 0.001$ ) and SNAP - Spiritual needs and SCCS - Personal support and advice to the patient ( $r = 0.301$ , Sig.  $p < 0.001$ ), which we formally consider to be moderate.

**Table 6:** Correlations between SNAP sub-scales and SCCS sub-scales (Pearson correlation coefficients).

		SNAP – Psychosocial needs	SNAP – Spiritual needs
SCCS	r	.270**	.366**
	Sig.	0.000	0.000
	N	433	433



Attitude to patient's spirituality	r	.170**	.151**
	Sig.	0.000	0.002
	N	433	433
Communication	r	.208**	.213**
	Sig.	0.000	0.000
	N	433	433
Assessment and implementation of spiritual care	r	.212**	.282**
	Sig.	0.000	0.000
	N	433	433
Request for consent	r	.232**	.299**
	Sig.	0.000	0.000
	N	433	433
Personal support and advice to the patient	r	.193**	.301**
	Sig.	0.000	0.000
	N	433	433
Professionalization and quality improvement of spirituality care	r	.217**	.321**
	Sig.	0.000	0.000
	N	433	433

\*\* The correlation is significant at a level of  $p < 0.01$

**Length of practice** - The correlation of the value (Spearman's correlation coefficient)  $\rho = 0.105$  (Sig.  $p < 0.05$ ) is directly related to attitudes of Nurses and Midwives (the longer the practice, the slightly higher the attitude toward patient spirituality). With longer practice, healthcare professionals are increasing their ability to communicate with patients (SCCS). There is a statistically significant relationship between the length of practice and SCCS subclass - professionalization and quality improvement of spiritual care ( $p = 0.121$ ; Sig.  $p < 0.05$ ). With the increasing length of practice, the professionalization and the improvement of the quality of care for spirituality are increasing.

Age slightly correlates with the SCCS score ( $p = 0.137$ , Sig.  $p < 0.01$ ), and its subscales - Communication ( $p = 0.104$ , Sig.,  $p < 0.05$ ), Assessment and Implementation of Spiritual Care ( $p = 0.165$ ;  $p < 0.01$ ). Also

important are the relationship between Age and Attitude to Patient Spirituality and Age and Personal Support and Counseling to a patient with a value of  $\rho = 0.100$ , but this is interpreted as a very weak correlation and therefore no relevant context can be discussed.

**Length of practice**, in addition to the above results, correlates significantly and positively with the overall SCCS score ( $p = 0.185$ ; Sig.  $p < 0.001$ ) and with all other SCCS subclasses.

## Conclusion

Nurses and Midwives are commonly confronted with death, and their perception of death should be on a professional level. In the process of disease and dying, staff and patients are brought into interaction. In today's modern nursing care, high emphasis

is placed on the quality of care provision and humanization, so the Nurse must be flexible and have full responsibility for her work, which stems from her competencies.

An important role in the approach to dying patients and their spiritual needs plays not only to good preparation in school, but also personal experience that Nurses and Midwives acquire during their professional practice. It is important that professionals be properly prepared when patients need this communication. An evidence-based training intervention could provide such preparation (Henoach et al., 2015)

Care of dying patients is one of the hardest jobs in the healthcare sector, as it is not only the physical site of the Nurses, but especially their psyche. The spiritual needs of a dying person can sometimes be overlooked in the busyness of physical care. However, for those experiencing it, spiritual distress is very real (Hlinkova, Moraučíková, 2014). While Nurses most often find a deficiency in the area of biological needs that are primary for humans, we are increasingly confronted with the fact that the dying patient has as priority his spiritual needs.

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# Tuberous Sclerosis Complex: Rare Disease with Significant Social Impact (Case Series)

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Original Article

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## Abstract:

The disease called the *tuberous sclerosis complex* has, besides its medical impact, also a significant social impact. It negatively affects the quality of life not only of the affected patients but also of their families, as this disease also occurs in a familial form. The social aspects of this disease are also reflected in the need to create specific conditions for

the upbringing, education and care of the patients suffering from the tuberous sclerosis complex.

In clinical practice we only rarely come upon patients affected by the tuberous sclerosis complex. Therefore, the experience in the diagnostics and management of these patients is quite limited. Diagnostics of the *tuberous sclerosis complex* is more difficult due to the fact that subjective symptoms and objective signs are not specific for the *tuberous sclerosis complex*, but can be the signs of other diseases.

*Tuberous sclerosis complex* is an autosomal dominant hereditary disease that is the result of mutations of two tumor suppressor genes and is characterized by the formation of benign tumors, *hamartomas*, in several organ systems. In about 80% of cases the mutations are acquired, the cause of mutation is unknown. Autosomal dominant gene mutations are the cause of about 20% of cases of *tuberous sclerosis complex*, and affliction of more family members is found. Most commonly, in patients with *tuberous sclerosis*, neurological and psychiatric symptoms are present in the central nervous system. *Renal hamartomas* are called *angiomyolipomas*. After neurological and skin changes, *renal angiomyolipomas* are ranked third in the incidence rate in patients with *tuberous sclerosis*.

The authors analyze their own clinical experience with the diagnostics and treatment of children and adult patients with the *tuberous sclerosis complex*. The study includes 14 children (8 girls and 6 boys aged 7 to 15 years) and 12 adult patients (9 women and 3 males aged 17 to 42 years). The girls and women predominated (66.7%) over male patients (33.3%).

All patients were *polysymptomatic*, symptomatology was highly complex and polymorphic. In every patient the signs of simultaneous affliction of at least two organ systems were found. There was no common symptom to all patients, and no symptom was absolutely pathognomonic for the *tuberous sclerosis complex*. Neurological symptomatology was the dominant finding in children. Very significant is the recognition that affliction of the brain resulted in almost all children, besides topical symptomatology, also in epilepsy, intellectual impairment disorders in the form of mental retardation of various degrees and autism.

In adult patients, affliction of the kidneys by *angiomyolipomas* was the predominant form of the tuberous sclerosis complex. In most of them simultaneous signs of affected skin and nails was observed.

Since virtually in all cases of impairment of the brain, kidneys and also of the heart, the disease is life-threatening and surgically incurable, it is reasonable to consider the alternative treatment by administration of an inhibitor of the mTOR signaling pathway.

### **Conflict of interests:**

None.

## Introduction

The complex of tuberous sclerosis is an autosomal dominant hereditary neuro-cutaneous disease characterized by pleomorphic features and affecting several organ systems. It is manifested by the formation of benign tumors, hamartomas, in the brain, kidneys, heart, liver, eyes, mouth and on the skin.

The incidence of the tuberous sclerosis complex is 1:6,000 to 1:10,000 of births. The population prevalence is estimated at 1:20,000. Globally, about one and half million patients are affected by *tuberous sclerosis* (Osborne *et al.* 1991, O'Callaghan *et al.* 1998, Northrup and Krueger, 2013).

Two gene mutations, TSC1 on chromosome 9 (9q34) and TSC2 on chromosome 16 (16p13) are responsible for tuberous sclerosis development. TSC1 and TSC2 belong to tumor suppressor genes that play an important role in inhibiting the mTOR signaling pathway responsible for cell proliferation (Jozwiak *et al.*, 2005, Au *et al.*, 2007). These genes encode the information responsible for the synthesis of two proteins – hamartin and tuberin – which together form an intracellular complex blocking excessive cell proliferation and differentiation. If a mutation of one of the genes results in a loss of the blockade, the affected cell are propagated uncontrollably and tumors develop. Since hamartin and tuberin are formed in most tissues, the complex of tuberous sclerosis can be manifested by the formation of tumors in several organs (Crino, 2013). Typical manifestation of tuberous sclerosis complex includes tumors, hamartomas in the brain and in the kidneys. Since clinical experience with patients suffering from these tumors within the *tuberous sclerosis complex* is rare, the knowledge on the diagnostics and management of these patients is quite limited (Novotna, 2013).

## Patients

The study included 14 children (8 girls and 6 boys aged 7 to 15 years) and 12 adult patients (9 women and 3 men aged 17 to 42 years) who suffered from various symptoms of *tuberous sclerosis*. All of these patients complied with the main or secondary criteria formulated by the *National Association of Tuberous Sclerosis* in 2012 and published in year 2013. The female patients predominated (66.7%) over male patients (33.3%).

All patients underwent a complete clinical evaluation. All the subjective symptoms were taken into account, similarly the objective features and circumstances in which the tuberous sclerosis complex was diagnosed. Emphasis was put on the family history of the *tuberous sclerosis complex* in genetically related family members.

The mental condition of the patients and the level of intelligence in children were assessed using special questionnaires and standardized psychological examination. Based on IQ, the patients were categorized into three categories, from mental retardation with IQ of less than 70 to the age-appropriate intelligence with IQ of more than 85.

Imaging and functional examinations of individual organ systems followed with particular emphasis on the brain and the kidneys visualized by CT and/or MRI examinations.

## Results

The familial incidence was found in 18.1% of cases. The category of cases of *familial tuberous sclerosis complex* includes 7 and 9 year old girls, cousins who inherited mutation of TSC2 gene from their fathers and from the grandmother. The third case was an 11 year old girl whose father had exhibited a symptomatology of the *tuberous sclerosis complex* at the mutation of the TSC2 gene. Another patient, 42 year old woman has a 13-year-old son who suffers

from the same difficulties as his mother but this patient has not been examined and included in the study.

Symptomatology of the *tuberous sclerosis complex* in children was complex and markedly polymorphic. Symptomatology of the central nervous system disorder characterized by epilepsy and mental retardation was dominant. This affects 7 out of 8 girls and 5 out of 6 boys (**Table 1**).

all cases was in the structural changes in the brain. In all girls and in 5 out of the 6 boys, numerous *subependymal nodules*, *subcortical* and *cortical tubers*, and *lesions* of the white matter of the brain were proven.

The second most common symptom of *tuberous sclerosis* in children was heart affliction. *Hamartomas* in the heart were found echocardiographically in 3 out of 8 girls (37.5%) and in all 6 boys. In all cases,

**Table 1:** Affliction of organ systems in children with tuberous sclerosis complex.

	Girls n = 8	Boys n = 6
Affliction of the brain	7/8 87.5%	5/6 83.3%
Affliction of the heart	3/8 37.5%	6/6 100%
Affliction of the kidneys	4/8 50%	4/6 66.7%
Affliction of the skin, including the nails	6/8 75%	4/6 66.7%

Epilepsy and mental retardation in *tuberous sclerosis complex* diagnosis are not among the main or secondary diagnostic criteria. However, the incidence of epilepsy and mental retardation was surprisingly high in patients diagnosed with *tuberous sclerosis* (**Table 2**).

these were one or more *hamartomas* (1 to 6) of low hemodynamic severity. In adult patients, heart affliction was not observed. Multiple *renal angiomyolipomas* occurred in 50% of girls and 67% of boys. *Angiomyolipomas* in children were mostly small, with a diameter of up to 8mm, greater in

**Table 2:** IQ values in patients with tuberous sclerosis complex.

IQ	Girls n = 7	Boys n = 5
less than 70	4/7 57.1%	4/5 80%
70 – 85	1/7 14.3%	–
more than 85	2/7 28.6%	1/5 20%

Epilepsy occurred in all patients with mental retardation. Epilepsy, however, occurred also in one girl and one boy of age-adquate intelligence. The cause of epilepsy in

only two children. *Angiomyolipomas* were asymptomatic in all children.

In the group of 12 adult patients, renal involvement was the dominant sign (**Table 3**).

**Table 3:** Impairment of organ systems with tuberous sclerosis complex in adult patients.

	Women n = 9	Men n = 3
Affliction of the kidneys	9/9 100%	2/3 66.7%
Affliction of the brain	2/9 22.2%	2/3 66.7%
Affliction of the skin and nails	8/9 88.9%	1/3 33.3%
Affliction of the lungs (LAM)	2/9 22.2%	–

*Renal angiomyolipomas* were demonstrated in all adult patients with *tuberous sclerosis complex*. In all cases, multiple tumors were presented; in 10 patients *angiomyolipomas* occurred on both sides. All patients complained of intermittent blunt pain in the lumbar region. In three women, *angiomyolipomas* manifested dramatically through so-called *Wunderlich syndrome*, *hemorrhagic shock* due to massive retroperitoneal bleeding from the ruptured large *angiomyolipoma* of the kidney.

In two female patients we diagnosed an *incipient stage of chronic renal insufficiency* due to destruction of the *renal parenchyma* by *angiomyolipomas*.

Especially from an aesthetic point of view, 8 of 9 women and 2 adolescent girls were very uncomfortable with the lesions of the skin of the face and nails. The affected patients had extensive changes in the face due to numerous *perioral* and *perinasal angiobromas*. In two female patients, the disease was manifested also by *paraungual fibromas* on the fingers of hands and feet.

Genetic tests were performed in 19 patients (**Table 4**)

Patients with the TSC2 gene mutation had more severe clinical manifestations of the disease with a higher incidence of epilepsy, more severe kidney impairment and more pronounced *facial angiobromas*.

In five adult women, diagnosis of the tuberous sclerosis complex was determined without genetic examination only on the basis of clinical examination, meeting the baseline criteria recommended by the *International TSC Consensus Conference* in 2012. In three adult patients, genetic examination was performed because of family counseling, the current testing methods, however, failed to prove any mutation in the TSC1 or TSC2 gene.

## Discussion

The *complex of tuberous sclerosis* is a disease very variable in its manifestations. The expression of the specific genotype are different phenotypic manifestations of the disease manifesting in different ages of the patients at the onset of the disease, different severity of the disease and various subjective symptoms

**Table 4:** Mutations of the TSC2 gene in patients with tuberous sclerosis complex.

	Girls n = 8	Boys n = 6	Adults n = 10
no changes	1/8	1/6	3/10
mutation de novo	4/8	5/6	2/10
congenital mutation	3/8	–	–

as well as objective signs. In addition, patients with *tuberous sclerosis complex* have a higher risk of developing malignancies. All these aspects have to be taken into consideration when planning treatment (Rakowski *et al.* 2006).

In most cases, the treatment of the tuberous sclerosis complex is only palliative, depending on the extent of affliction of single organ systems.

More than 80% of patients with *tuberous sclerosis* experience changes in their kidneys during their lifetime. The first symptoms indicative of renal involvement are most often manifested in the second or third decade of life. However, we have observed also young children in whom kidneys have been afflicted by *angiomyolipomas*. Renal involvement is the second most common cause of death of patients with *tuberous sclerosis complex* (Shepherd *et al.*, 1991). The most common form of renal involvement in *tuberous sclerosis* patients is *angiomyolipoma*. These are the tumors formed by abnormal thick-walled vessels, smooth muscle fibers and fat tissue. They are mostly found on the kidney surface, they are small (a few centimeters in diameter), usually grow slowly, but they can get bigger. Up to 70 - 90% of patients with *tuberous sclerosis* have multiple *angiomyolipomas*. They occur on both sides, and usually grow slowly. Tumor growth or an increased number of tumors occur in 60% of patients. The growth often results in an aneurysm of the arterial blood vessels of *angiomyolipomas* and in a formation of so-called pirated blood vessel bed. The growth appears to depend on the hormonal status of the affected patients, as evidenced by the prevalence of these tumors in women and virtually zero in prepubertal patients.

Diagnostics of *tuberous sclerosis complex* is based on targeted history; on the

basis of clinical criteria; and/or the results of genetic testing (Rose *et al.*, 1991). Genetic testing is not required to establish the diagnosis in patients who meet the clinical criteria for a definitive diagnosis. According to the *Consensus Guidelines for Diagnosis of TSC, renal angiomyolipomas* are among the major diagnostic criteria for *tuberous sclerosis complex*. In addition to numerous and bilateral *renal angiomyolipomas*, in our patients we also found other major diagnostic criteria – *face angiofibromas, ungual fibromas, and lymphangiioleiomyomatosis* of the lung.

Kidney involvement with *angiomyolipomas* was the dominant symptom of the *tuberous sclerosis complex* in our group of patients. Women are affected by *renal angiomyolipomas* more often than men. In the studied patients, we observed both subjective symptoms as well as objective signs of renal disease. Clinical manifestations of *renal angiomyolipomas* include anorexia, pain, palpitations, hematuria, hypertension, anemia. In three female patients, we urgently addressed a life-threatening situation, *hemorrhagic shock* from massive bleeding to the retroperitoneum due to a rupture of dysplastic aneurysmal vascular vessels in the tumor. The risk of rupture is particularly threatening to patients with large *angiomyolipomas* (diameter greater than 4-6 cm) and *aneurysmal vessels* with a diameter of more than 5 mm (Breza *et al.*, 2010).

The number and size of *angiomyolipomas* as well as their relationship to *renal parenchyma* and the *renal excretory system* can be monitored by ultrasonography of the kidneys, and/or by CT and MR examinations. CT and MR examinations allow obtaining information not only about the kidneys, but also about other abdominal or retroperitoneal organs, on the vascular supply of the kidneys and *angiomyolipomas* and on



the nature and extent of their pathological disability.

In some patients with *tuberous sclerosis complex*, most commonly in women after the menarche, *pulmonary lymph-angioliomyomatosis* can occur with benign metastases of smooth muscle cells of *angiomyolipomas*. The most accurate diagnostics of this complication is achieved by the so-called high resolution lung CT. The treatment is a palliative use of everolimus. Terminal stages of respiratory insufficiency include lung transplantation (Hancock and Osborne, 2002, Northrup and Krueger, 2013).

The treatment of *renal angiomyolipomas* must maintain as much functional parenchyma as possible. In asymptomatic patients the procedure is conservative, the patients are followed by the described biochemical and visualization methods. Preventive surgical treatment is considered for rapidly growing *angiomyolipomas* and large *angiomyolipomas* (with a diameter of 5 or more cm) with a risk of tumor rupture. Preference is given to nephron sparing surgery in which only the pathological focus is removed from the kidney but the kidney is retained. In the case of bleeding *angiomyolipomas*, targeted selective embolization may be used as the first treatment step. A ruptured *angiomyolipoma* with severe *retroperitoneal hemorrhage* and *hemorrhagic shock* is indicative of urgent surgical revision, usually ending with nephrectomy of the affected kidney. In exceptional cases, also in such a situation a kidney saving operation can be performed.

Causal treatment with the mTOR inhibitor is preferred in patients with growing but still asymptomatic multiple *angiomyolipomas* (Novotna 2013).

In case of *chronic renal insufficiency* caused by destruction of *renal parenchyma* by *angiomyolipomas* the possibility of kidney transplantation from a dead donor may be considered in appropriate patients with

*tuberous sclerosis complex*. Everolimus, the mTOR signaling pathway inhibitor, becomes part of *basal immunosuppression* in these patients.

## Conclusion

In clinical practice, Urologists only rarely meet patients suffering from the *tuberous sclerosis complex*. Therefore, experience with the management of this disease is very limited in affected patients. Diagnostics of *tuberous sclerosis complex* is all the more demanding because the patients are usually poly-symptomatic, subjective but also objective symptoms are not specific to the *complex of tuberous sclerosis* but can also be the signs of other diseases. In all patients, we found the signs of simultaneous involvement of at least two organ systems. There were no symptom common to all patients, and no symptom was absolutely pathognomonic for the *tuberous sclerosis complex*.

Patients with kidney disease affected by *tuberous sclerosis complex* should be monitored on a long-term and systematic basis, in a timely and robust manner, while at the same time complications resulting from *kidney angiomyolipomas* must be resolved sparingly.

The complex of tuberous sclerosis is a disease that cannot be prevented. However, based on knowledge and experience, it is possible to modify the course of the disease, improve the quality of life and extend the survival of some patients.

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# Stigmatization of People with Mental Illness in Students of Clinical Social Worker Branch (Original Research)

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## Abstract:

**Objective:** The objective is to determine the degree of stigmatization of people with mental illness in the Clinical Social Worker students.

**Design:** Pilot study.

**Participants:** 32 students of College of Polytechnics Jihlava. 12 students were taught with and 20 without peer lecturers.

**Methods:** Stigmatization was measured by the RIBS questionnaire. An additional question focused on work with clients with a psychiatric

illness. The data were processed in MS Excel and IBM SPSS Statistics 22. For comparing the probability distribution of categorical variables the chi square goodness of fit test and semantic differential were used.

**Results:** It is not possible to clearly describe statistically significant differences between the groups. However, it is evident that lessons with peer lecturers reduce stigmatization.

**Conclusion:** Instruction with peer lecturers has been justified. Destigmatization-oriented teaching and further research into the stigmatization of the mentally ill will continue.

## Introduction

The number of people with mental illness is steadily increasing. One of the major problems they face is stigmatization. This situation is to a large extent caused by media that present these people as dangerous not only to themselves but also to their environment. However, people with mental illness are faced with stigmatization not only when in contact with people around them but also in communication with Health and Social Workers. Destigmatization of psychiatric clients is one of the objectives of the project *Deepening of Cooperation with the Application Sphere for the Purposes of Profile Subjects Innovation*, which is being realized by the *Department of Social Work of the College of Polytechnics Jihlava* in 2017. One of the innovated subjects is *the Basics of Psychiatry and Psychopathology*, the innovation of which is being carried out in cooperation with *FOKUS Vysocina* and the *Center for the Development of Mental Health Care*. The key activity is the participation of peer lecturers, i.e. people with their own experience of mental illness, in teaching. Engaging peer lecturers directly into mental health education has had a long tradition in many developed countries (e.g. Great Britain, the Netherlands). In the Czech Republic, the use of this important destigmatization tool in the context of the professional training of helping professionals is only in its beginnings. Its development is attended to by the *Center for the Development of Mental*

*Health Care* which developed the necessary methodology and training modules (recovery; stigma and discrimination; peer programs; self-management) with the participation of foreign experts in 2013 and 2014, and carried out historically the first lessons with the participation of peer lecturers within an optional subject in cooperation with the *Department of Social Work at the Philosophical Faculty of the Charles University* and the *Prague University of Psychosocial Studies*. The *College of Polytechnics Jihlava*, the *Department of Social Work*, is thus the first university in the Czech Republic to introduce this instrument into teaching and to test its efficiency in compulsory education.

## Objective

The aim of this paper is to present the results of a quantitative survey carried out after the pilot training with peer lecturers in the form of a questionnaire survey in which the level of stigmatization of people with mental illness was determined in *Clinical Social Worker* students. One group of these students were trained with the participation of peer lecturers while the other one completed *the Basics of Psychiatry and Psychopathology* subject without peer lecturers. The paper explains the concept of stigmatization; describes the methodology used; presents interpretation of the results.

Due to the small number of students taking part in the pilot phase, the purpose of this survey was to find out whether training with peer lecturers had an impact on the degree of stigmatization. The exact degree of stigmatization will be determined and analyzed in detail on a larger sample of informants in a more extensive qualitative and quantitative survey.

## Design

The above-mentioned project was being implemented at the *College of Polytechnics Jihlava* in 2017. The pilot phase took place in the Summer Semester of 2016/2017 Academic Year. The results of the pilot phase are now being evaluated and further instruction with peer lecturers is being planned. The degree of stigmatization in students is assessed by both the quantitative methods presented in this paper and qualitative methods. Psychiatric illnesses are understood as diseases in accordance with the *International Classification of Diseases* ([www.uzis.cz](http://www.uzis.cz)).

The word stigma from the historical point of view designates the signs burned on the bodies of slaves in ancient Greece. Stigma is often perceived as a convincing trace; in medicine it is a sign of disease in humans. The stigmatized person is thus impaired by an obvious disorder in the sense of the birth or acquired defect. According to Hartl and Hartl (2010, p. 553), it is a condemning social attitude for alleged mental, physical or social inferiority, subsequently leading to the rejection and exclusion of an individual, group or organization from the surrounding society. Stigmatization of the mentally ill is the topic of research papers, e.g. Winkler (2015), Pechova (2013), graduate theses, e.g. Wohlinova (2015) and texts by psychiatric patients, e.g. Bednarova, Horka (2013).

## Participants

The questionnaire survey in the pilot phase was participated in by 32 *Clinical Social Worker* students of the 4th Semester within the compulsory subject of *the Basics of Psychiatry and Psychopathology* at the *College of Polytechnics Jihlava*. 12 of the students were taught with peer lecturers, 20 without peer lecturers. This is a relatively small group and, given the unequal number of students, it is problematic to compare the results. But for practical reasons, it was not possible to implement the pilot phase for more students. On the other hand, we consider the number of students to be sufficient for piloting purposes. The lessons were attended by 8 peer lecturers and 2 academic staff members of VŠPJ.

## Methods

An international *RIBS questionnaire* (Evans-Lacko, S., 2011) was used as a data collection tool for both groups. This questionnaire was supplemented by one question about stigmatization when dealing with a client.

The questionnaire evaluation procedure was identical to that used by the author of the questionnaire (Evans-Lacko, S., 2011). In Questions 1 to 4, the respondents who answered the question “I do not know” were excluded from some statistical processing.

In Questions 5-9, the answers were encoded by the five-point ordination 1-5, from “I strongly disagree” with the value 1 to “I definitely agree” with the value 5. For the purposes of determining the overall score, the “I do not know” answer as well as the neutral answer “I neither agree or disagree” were encoded with value 3.

To compare the probability distribution of categorical variables, we can use *Chi square goodness of fit* test (e.g.

Hendl, 2004, p. 304 or Rehak, 2015, p. 123) The output is the p-value and, in the case of significance, also the contingency coefficient (CC), in the case of the association table, the coefficient of association (Cramer’s V).

A semantic differential was created to measure the intensity of the psychological and sociological attitudes of respondents. These attitudes were measured separately for the group of students without a peer lecturer and for the group of students with a peer lecturer. The semantic differential

(Hayes, 2004, p. 112). It is the difference in connotation which assigns importance to the language structure of individual respondents. The connotation of every individual person is based on their subjective, inherently vague internal psychological cognitive model. Data processed in MS Excel, IBM SPSS Statistics 22.

**Results**

**Table 1** summarizes the frequency of responses to the first four questionnaire questions.

**Table 1:** Number of answers to the questions concerning living with a person with mental illness, working with such a person, living in their neighborhood, and maintaining friendship.

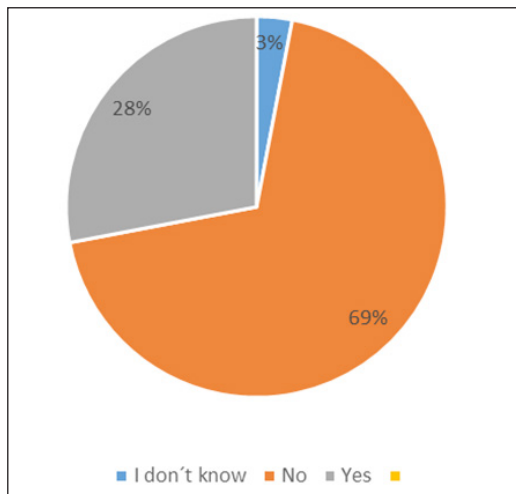
Question	Yes n (%)	No n (%)	I don’t know n (%)
1. Are you currently living or have you ever lived with a person with a mental illness?	9 (28.1%)	<b>22 (68.8%)</b>	1 (3.1%)
2. Are you currently working or have you ever worked with a person with a mental illness?	<b>19 (59.4%)</b>	12 (37.5%)	1 (3.1%)
3. Is a person with a mental illness currently living or has such a person ever lived in your neighborhood?	10 (31.3%)	<b>16 (50.0%)</b>	6 (18.8%)
4. Do you have at present or have you ever had a person with a mental illness as a close friend, boyfriend, girlfriend?	9 (28%)	<b>22 (68.8%)</b>	1 (3.1%)

Source: Own Research, 2017

was introduced in the work of Osgood, Suci, Tannenbaum (1957) and identifies the nuances peculiar to individual attitudes. A *Likert scale* can reveal only one dimension of the respondent’s response to the attitude - whether they agree with it or not. However, a semantic differential uses several different dimensions to determine the respondent’s responses to the target word

**Graphs 1-4** show the percentage share of answers to questions concerning living with a person with mental illness (**Graph 1**); working with such a person (**Graph 2**); living in their neighborhood (**Graph 3**); maintaining friendship with person with mental illness (**Graph 4**).

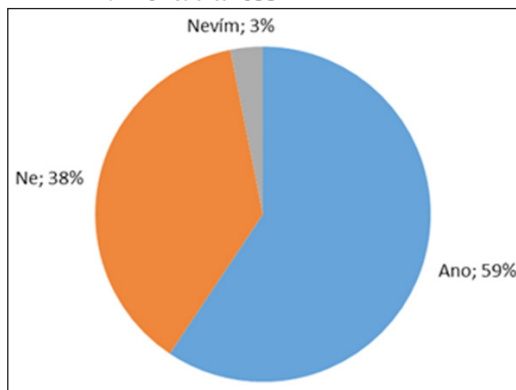
**Graph 1:** Are you currently living or have you ever lived with a person with a mental illness?



Source: Own Research, 2017

We cannot compare the structure of respondents taught with and without peer lecturers, the *Chi square goodness of fit* test conditions are not met (25% expected values lower than 5).

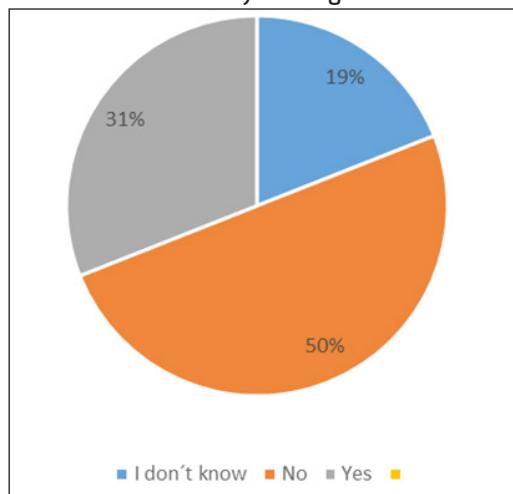
**Graph 2:** Are you currently working or have you ever worked with a person with a mental illness?



Source: Own Research, 2017

We cannot compare the structure of respondents taught with and without peer lecturers, the chi square goodness of fit test conditions are not met (25% expected values are lower than 5).

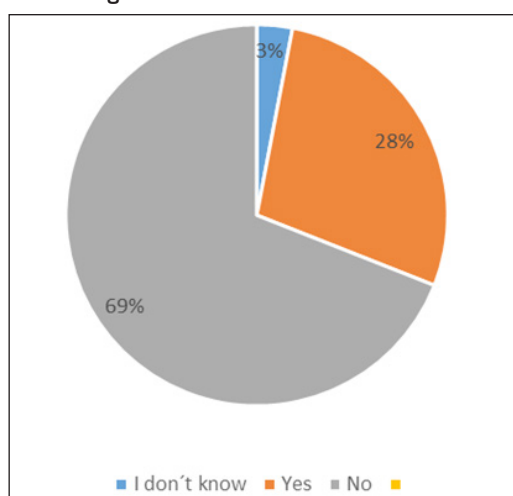
**Graph 3:** Is a person with a mental illness currently living or has such a person ever lived in your neighborhood?



Source: Own Research, 2017

We cannot compare the structure of respondents taught with and without peer lecturers, the *Chi square goodness of fit* test conditions aren't met (25% expected values lower than 5).

**Graph 4:** Do you have at present or have you ever had a person with a mental illness as a close friend, boyfriend, girlfriend?



Source: Own Research, 2017

We cannot compare the structure of respondents taught with and without peer lecturers, the *Chi square goodness of fit* test conditions are not met (25% of the expected values are lower than 5).

**Table 2** shows the absolute and relative frequency of answers to Questions 5–9.

**Table 2:** The number of responses to questions related to the willingness to live with a person with a mental illness in the future, to work with them, to live in their neighborhood and to maintain friendship, and the willingness to professionally deal with these people.

Question	I definitely agree n (%)	I rather agree n (%)	I neither agree nor disagree n (%)	I rather disagree n (%)	I definitely disagree n (%)	I do not know n (%)
5. In the future, I would be willing to live with a person with a mental illness.	1 (3.1)	<b>16 (50.0)</b>	9 (28.1)	4 (12.5)	1 (3.1)	1 (3.1)
Instruction without peer lecturers	1 (5.0)	<b>10 (50.0)</b>	4 (20.0)	4 (20.0)		1 (5.0)
Instruction with peer lecturers		<b>6 (50.0)</b>	5 (41.7)		1 (8.3)	
6. In the future, I would be willing to work with a person with a mental illness.	13 (40.6)	<b>17 (53.1)</b>		2 (6.3)		
Instruction without peer lecturers	5 (25.0)	<b>13 (65.0)</b>		2 (10.0)		
Instruction with peer lecturers	<b>8 (66.7)</b>	4 (33.3)				
7. In the future, I would be willing to live in the neighborhood of a person with a mental illness.	8 (25.0)	<b>18 (56.3)</b>	3 (9.4)	2 (6.3)		1 (3.1)



Instruction without peer lecturers	4 (20.0)	<b>11 (55.0)</b>	2 (10.0)	2 (10.0)		1 (5.0)
Instruction with peer lecturers	4 (33.3)	<b>7 (58.3)</b>	1 (8.3)			
<b>8. In the future, I would be willing to maintain my relationship with a friend with a mental illness.</b>						
	<b>24 (75.0)</b>	7 (21.9)	1 (3.1)			
Instruction without peer lecturers	<b>14 (70.0)</b>	5 (25.0)	1 (5.0)			
Instruction with peer lecturers	<b>10 (83.3)</b>	2 (16.7)				
<b>9. In the future, I would be willing to deal professionally with people with a mental illness.</b>						
	<b>13 (40.6)</b>	8 (25.0)	5 (15.6)	5 (15.6)		1 (3.1)
Instruction without peer lecturers	6 (30.0)	<b>7 (35.0)</b>	2 (10.0)	4 (20.0)		1 (5.0)
Instruction with peer lecturers	<b>7 (58.3)</b>	1 (8.3)	3 (25.0)	1 (8.3)		

Source: Own Research, 2017

Like in the previous questions, we cannot compare the structure of the participants in terms of instruction conducted with a peer lecturer or without, the requirements of the *Chi square goodness of fit* test are not met (the number of cells with the expected frequency of less than 5 is higher than 20%).

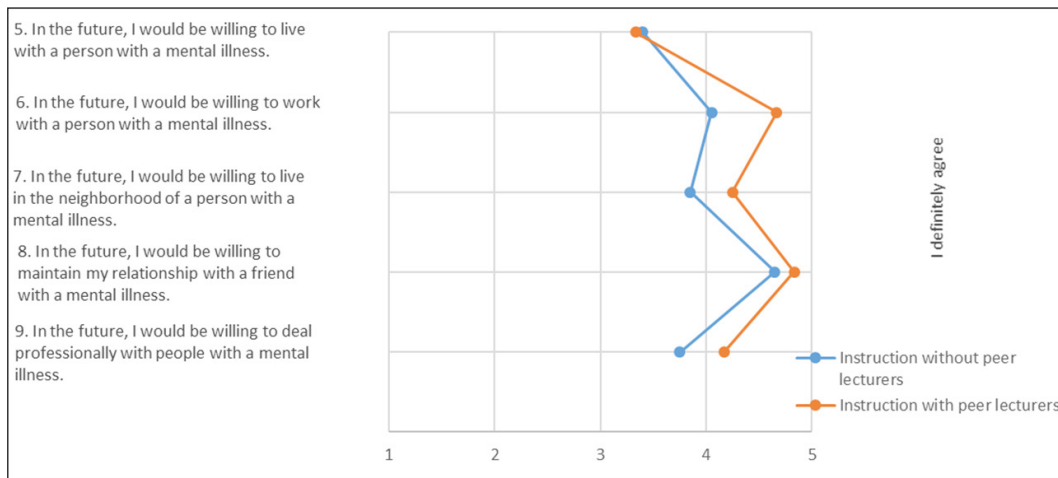
Due to a small sample of participants, testing of statistical hypotheses is impossible. In all the cases where we compare the

current attitude with the willingness to live, work, live in the neighborhood, or become friends with a person with mental illness, the number of cells with the low expected frequencies of the respective variations of the two variables is always higher than 20%. If we simplify the output only to a positive, neutral and negative attitude, the situation with the number of cells with the expected frequencies does not improve significantly.

For better illustration of questions 5-9, a semantic differential was used. Its graphical form is shown in **Graph 5**.

with a person with a mental illness) the average score is 3.40 in the group without peer lecturers and 3.33 in the group with

**Graph 5: Semantic differential for questions 5 – 9.**



Source: Own Research, 2017

It is clear from the graph that the students instructed by peer lecturers demonstrate on the average, with just one exception, a more positive attitude. Only in the fifth question (In the future, I would be willing to live

peer lecturers. In the other questions, the average score in the group with peer lecturers is higher than in the one without peer lecturers. The average values for questions 5-9 are shown in Table 3.

**Table 3: Average score.**

Question	Instruction without peer lecturers	Instruction with peer lecturers	Total average
5. In the future, I would be willing to live with a person with a mental illness.	3.40	3.33	3.38
6. In the future, I would be willing to work with a person with a mental illness.	4.05	4.67	4.28
7. In the future, I would be willing to live in the neighborhood of a person with a mental illness.	3.85	4.25	4.00
8. In the future, I would be willing to maintain my relationship with a friend with a mental illness.	4.65	4.83	4.72
9. In the future, I would be willing to deal professionally with people with a mental illness.	3.75	4.17	3.91

Source: Own Research, 2017

The most frequent answers are that the respondents are not currently living or have never lived with a person with a mental illness (less than 70%). Less than 60% are working or have worked with them, half (50%) of the respondents is living with or in the neighborhood of a person with a mental illness and less than 70% (68.8%) do not have or have not had a close friend with a mental illness. In the group with peer lecturers, the “I do not know” answer occurred only in two cases (one answer in **Question 3**: living in the neighborhood of a person with a mental illness, and one answer in **Question 4**: a friend with a mental illness). In the group without peer lecturers, there were a total of seven responses where respondents did not know. Due to the sample size, it is not possible to determine whether these numbers differ (statistically) significantly.

Positive attitudes are in the majority in all the questions related to the willingness to live with people with a mental illness (53.1%), to work with them (93.7%), to live in their neighborhood (81.3%), to be friends with them (96.9%), and to deal with them professionally (65.6%) in the future. The brackets show the sum of the percentages of positively rated questions (I definitely agree and I rather agree).

## Discussion

As mentioned above, in view of the number of respondents, the results of this survey cannot be generalized. Nevertheless, it is necessary to show the results of other studies focused on stigmatization of mentally ill people. This problem is not peculiar only to the Czech Republic, other countries are also faced with this issue. According to the results, however, the stigmatization in the Czech Republic, for example compared to Great Britain, is more significant (Winkler, 2015). 56% of the British respondents

would not almost mind or would not mind at all living with the mentally ill in comparison to only less than 15% of the respondents in the Czech Republic. Working with a person with a mental illness would not bother 68% of the British, but only one fifth of the Czechs. 72% of the British, but only one quarter of the Czechs, would not mind living in the neighborhood of the mentally ill. Mental illness would be the reason for ending friendship for 2% of the British and for more than 12% of the Czechs, while 56% of the British and less than 8% of the Czechs would definitely continue in friendship.

## Conclusion

Given the low number of respondents in the pilot phase, it was not possible to test hypotheses and to look for more significant differences between the two groups of students. However, the pilot phase showed that instruction with peer lecturers is justifiable and has an impact on the degree of stigmatization of mentally ill people. Now it is important to continue the activities **leading to destigmatization**.

## Acknowledgement

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## Multicultural Aspects of Palliative Care (Original Research)

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Original Article

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### Abstract:

**Aim:** This paper deals with terminal care from the aspect of multiculturality. Our aim was to assess the satisfaction of the culture-specific needs of dying patients by Nurses in selected health care institutions.

**Methodology:** In the research, we used a quantitative method for data collection and processing. We constructed and used a questionnaire, which was voluntary and anonymous.

**Sample:** The target group of the research consisted of 175 Nurses working in health care institutions in Slovakia, Germany and Sweden.

**Results:** We processed the collected data quantitatively, and are presenting them in their absolute and relative frequency. We processed the results of the research statistically by the *Chi-square goodness of fit* test, the *Mann-Whitney U* test, and the *Shapiro-Wilk test of normality*. We arranged the results into tables and charts.

**Conclusion:** The contribution of the paper is to call attention to the subject matter and make the provision of nursing care to patients of different cultures more efficient.

## Introduction

Multiculturality with respect to health is a new focus of the attention of the society, of the health care system, and of health professionals. It is becoming an increasingly large reality not only for patients but also for health care providers. One of the most important aspects of caring for a dying person is to provide her/him with qualified help, so that the last moments of life could be spent in accordance with their own social and cultural background and religious beliefs since, in the terminal stage of an illness, besides a need to cope with pain, spiritual needs are almost always in the foreground,.

In our research, we sought to assess whether Nurses are aware of the specifics of the various cultures, and to what extent they respect the spiritual needs and specific rituals of patients of varying cultures. Also, we sought to assess to what extent the conditions for providing culture-specific care are ensured in health care institutions.

## Method

We used a quantitative method of data collection. We constructed a questionnaire, which was voluntary and anonymous. The questionnaire was aimed at Nurses and their

attitudes to satisfying and respecting the culture-specific needs of patients of other cultures. Before carrying out the research, we performed a pilot testing of the questionnaire, and a preliminary research. The research took place from September 2016 to June 2017. The selection of the health care institutions, as well as of the respondents, was intentional. The target group of the research consisted of Nurses working in health care institutions in Slovakia, Germany, and Sweden. The total number of the respondents was 175. We gained approval for carrying out the research in all the respective health care institutions. We processed the collected data quantitatively, and presented them in tables and charts, using Microsoft Excel. We presented the data in their absolute and relative frequency. For cardinal variables, we presented also the values of the arithmetic mean and the respective standard deviation, the values of the median, of the mode, and the minimum and maximum values.

## We used the following statistical tests

*Chi-square goodness of fit* test – used for categorical variables for a comparison of the observed and the expected frequencies;

*Mann-Whitney U* test – non-parametric test for comparing the differences between two independent groups, provided that the dependent variable is at least ordinal, or, if it is cardinal, then not normally distributed, *Shapiro-Wilk* test of normality – for testing the distribution of the normality of the data.

The revealed statistical significance of the results was compared in relation to a 0.05 significance level. In the case of statistically significant results, we determined the substantive significance as well, expressed by effect size  $r$  and effect size  $w$ . Effect size  $r$  was calculated by the *Mann-Whitney U* test with the formula , with  $Z = z$ -score (result from the *Mann-Whitney U* test), and  $N =$  size of the investigation set (total). Effect size  $w$  was calculated by the *Chi-square goodness of fit* test with the formula , with  $\chi^2 =$  the value of the Chi-square, and  $N =$  size of the investigation set. The interpretation of the effect size was governed by classic recommendations: small effect size ca. 0.1, medium effect size ca. 0.3, and large effect size above 0.5.

## The Results of the Research

After collecting the data through the questionnaire, we analyzed them.

We assessed whether, when admitting a patient, the Nurses surveyed what her/his religion was. In the said item, 78.90% of the Nurses stated that they did not enquire what the patient's religion was when admitting; 21.10% of the Nurses said they enquired what the patient's religion was.

We assessed whether the Nurses respected the use of alternative forms of pain management, such as herbs; tea; acupuncture; music therapy; incense sticks; or prayers.

In the said item, 44.00% of the Nurses stated that they respected the use of alternative forms of pain management 13.70% said they did not respect the use of alternative forms of pain management.

We assessed whether the Nurses respected the specific rituals connected with dying and death, such as ritual objects; prayers; calling a cleric to the dying person; incense sticks; chants or songs. In the said item, 73.70% of the Nurses stated that they respected the specific rituals connected with dying and death; 5.70% of the Nurses said they did not respect the specific rituals connected with dying and death.

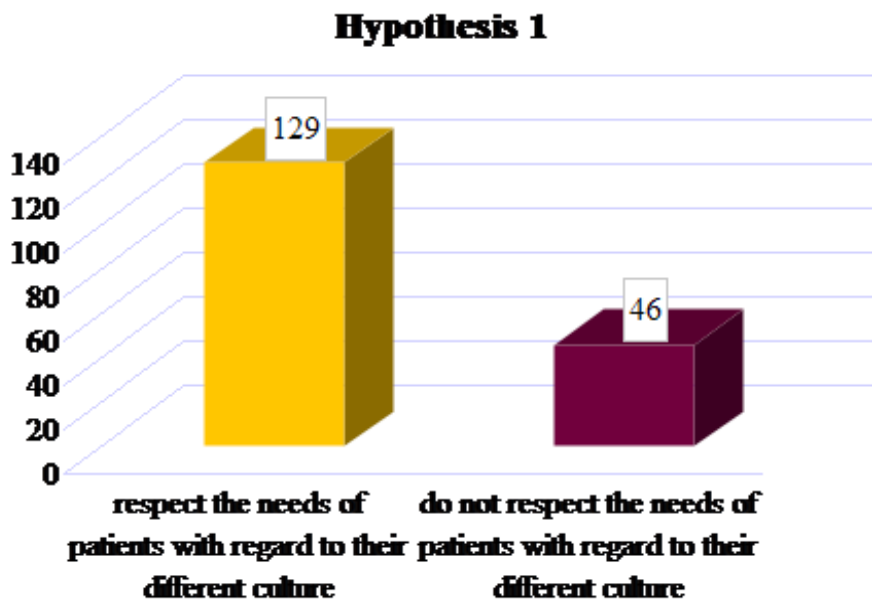
We assessed whether the Nurses respected the use of religious items, such as prayer books; pictures of saints; prayer rugs; rosaries; or other sacred items of a given culture. In the said item, 78.30% of the Nurses stated that they respected the use of religious items, and 1.10% of the Nurses said they did not respect the use of religious items.

## Interpretation of the Results and Discussion

We analyzed the depicted data statistically, and verified the hypotheses we had formed.

In **Hypothesis 1**, we assumed that the Nurses respected the needs of patients with regard to their different culture.

129 Nurses (73.70%) respect the needs of patients with regard to their different culture, and 46 Nurses (26.30%) do not respect their needs. The findings are presented in **Chart A**.

**Chart A:** Respecting vs. not respecting the needs of patients with regard to their different culture.

We verified the result statistically, using the *Chi-square goodness of fit* test, whose value equaled 39.366 at 1 degree of freedom. The value of statistical significance was lower than the value of 0.05 (**Table A1**). There is a statistically significant difference in the Nurses' responses with a medium effect size. More than 70.00% of the Nurses respect the needs of patients with regard to their different culture.

In a research conducted in 2013, Nurses stated a need to take into account and respect the cultural differences in caring for patients, although they admitted that few of them really did so in practice. In spite of this attitude, the Nurses felt that they were providing adequate and high-quality care to the patients (Franková, 2017). Anita Berlin (2010) presents different attitudes of the Nurses in her Swedish study, where the majority of the Nurses express their fears of failing professionally for not having adequate knowledge of the cultures they come into contact with.

A research conducted by a team of American authors in a Californian institution of long-term care confirms the significance of satisfying the needs of patients in the terminal stage of their disease. The research focused on severely ill, dying patients. The aim was to analyse to what extent their needs are met. The result was a finding that the patients' dignity was compromised especially by the inability to comply with rituals and by not respecting their wishes (Periyakoil *et al.*, 2013).

**Table A1:** Comparison of respecting vs. not respecting the needs of patients with regard to their different culture.

Chi-square	39.366
degrees of freedom	1
statistical significance	0.000
effect size W	0.474



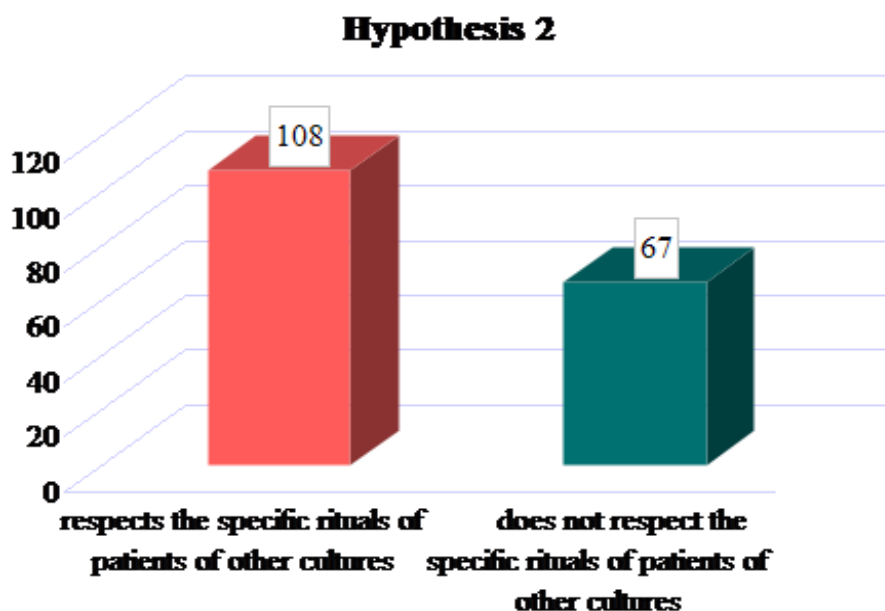
**Conclusion:** Based on the results of the statistical analyzes, we found that more than 70% of Nurses respected the needs of patients with regard to their different culture ( $\chi^2(1) = 39.366$ ;  $p < 0.05$ ). **Hypothesis 1** was confirmed by the research we conducted.

**In hypothesis 2**, we assumed that the Nurses respected the specific rituals of patients of other cultures. We found that 108 Nurses (61.70%) respected the specific rituals of patients of other cultures, and 67 Nurses (38.30%) did not respect them (at least one response to the 3 questions was negative). We present the findings in **Chart B**.

with a low effect size. More than 60.00% of the Nurses respect the specific rituals of patients of other cultures.

A common feature of all religions is the use of symbols connected to religious rites. Chants; hymns; prayers; services; fasts are all considered to be ritual acts (Davie, 2013). In her research conducted in Bosnia and Herzegovina, Aida Bešić (2012) surveyed the respondents' attitudes to respecting the religious and cultural needs of patients. Based on the Nurses' responses, she established that the Nurses were ready to meet the patients' specific needs with respect to using religious items and rituals connected

**Chart B:** Respecting vs. not respecting the specific rituals of patients of other cultures.



We used the *Chi-square goodness of fit* test to find out the statistical difference. Its value equalled 9.606 at 1 degree of freedom. The statistical significance was lower than the value of 0.05 (**Table B1**), so we conclude that there is a statistically significant difference between the Nurses' responses

with dying and death. A research conducted in the Czech Republic (2008) also arrived at the same conclusion, with 85.47% of the Nurses considering it important to be informed about the customs, needs and values of other ethnic and religious groups (Franková, 2017).

**Table B1:** Comparison of respecting vs. not respecting the specific rituals of patients of other cultures.

Chi-square	9.606
degrees of freedom	1
statistical significance	0.002
effect size W	0.02

**Conclusion:** Based on the results ( $\chi^2(1) = 9.606$ ;  $p < 0.05$ ), we conclude that more than 60.00% of Nurses respect the specific rituals of patients of other cultures, and confirm **Hypothesis 2**.

In **Hypothesis 3**, we assumed that the Nurses were familiar with the specifics of various cultures.

The results we gained by the investigation, with the use of questionnaires meant to verify the given hypothesis, show that more than half of the answers given by Nurses were correct in the case of 59 Nurses (33.70%), whereas we recorded fewer than 4 of the answers correct in the case of 116 Nurses (66.30%). We present the findings in **Chart C**.

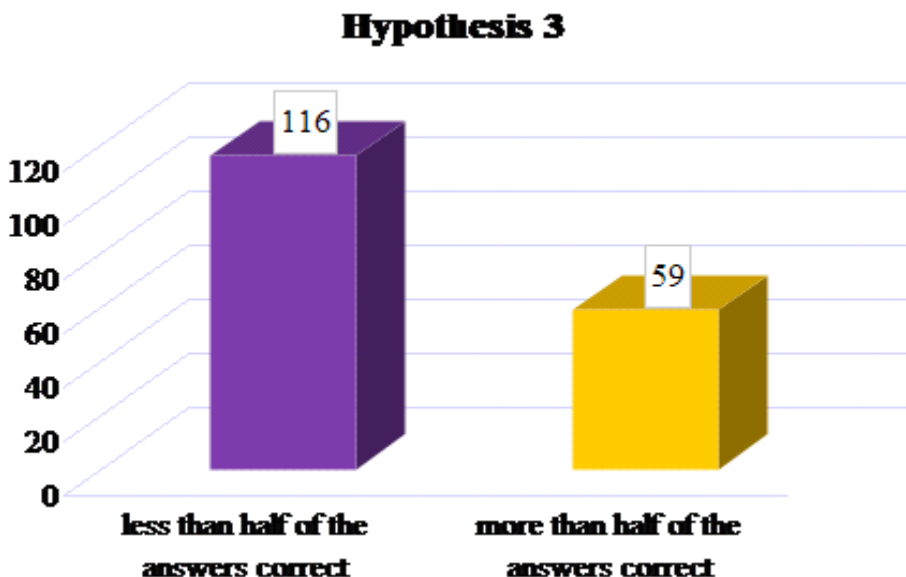
We compared these answers using the *Chi-square goodness of fit* test whose value equaled 18.566 at 1 degree of freedom. The resulting statistical significance was lower than 0.05, so we may conclude that there is a statistically significant difference between the Nurses' responses with a low effect size (**Table. C1**).

Similar results were revealed by a study in Iran whose aim was to investigate the experience of health care professionals providing care for migrants in Mashhad. The research found inadequate knowledge in the given field, and an inability of the health care professionals to satisfy the emotional and mental needs of the patients (Amiri *et al.*, 2016).

**Table C1:** Comparison of correct answers by the Nurses about the specifics of the various cultures.

Chi-square	18.566
degrees of freedom	1
statistical significance	0.000
effect size W	0.02

**Chart C:** Correct answers by the Nurses about the specifics of the various cultures.



**Conclusion:** Based on the findings, we may establish that more than 60.00% of the Nurses are unfamiliar with the specifics of the various cultures ( $\chi^2(1) = 18.566$ ;  $p < 0.05$ ) and, consequently, we do not confirm **Hypothesis 3** in the research we conducted.

In **Hypothesis 4**, we assumed that the conditions for providing culture-specific care were ensured to a greater extent in health care institutions abroad than in those in Slovakia.

We verified this hypothesis by questions regarding the possibilities to communicate with foreign-language patients; the possibility to provide food to the patients while taking into account their culture; by the question whether the health care institution has a prayer room for patients of various

religions (at least for two religions); whether it is possible for the staff of the department to provide care by a female member of the staff on the patient's request.

In the said items, we coded the positive answers by the value of 1, and the negative answers, or the "do not know" answers by the value of 0. In this way, we got a scale from 0 to 4, where the higher the value, the greater the extent to which the conditions for providing culture-specific care in health care institutions are met.

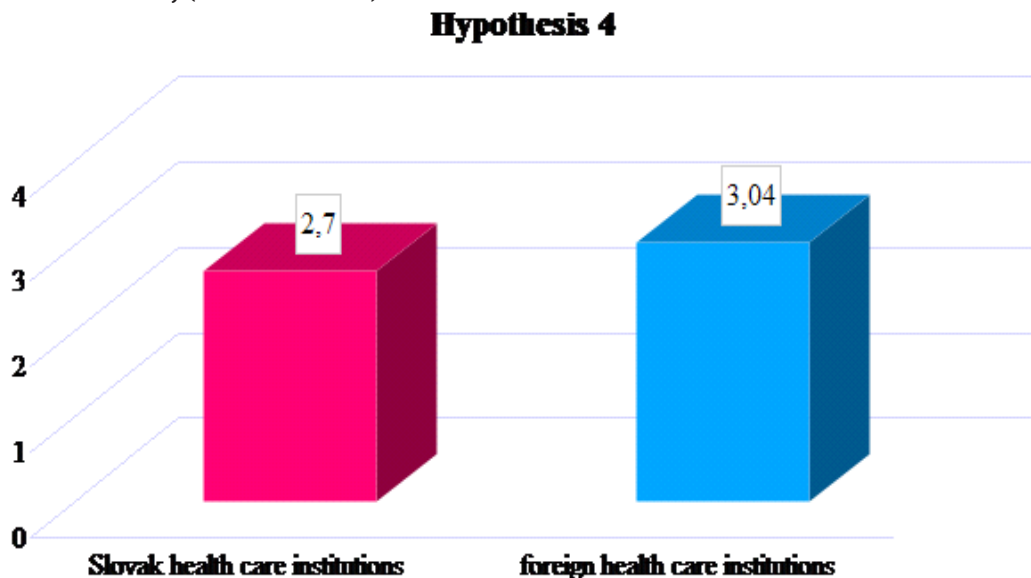
In Slovak health care institutions, the arithmetic mean was  $AM = 2.7$  with a standard deviation of 0.89 and, abroad, the arithmetic mean was  $AM = 3.04$  with a standard deviation of 0.64. The results are shown in **Table D1** as well as in **Chart D**.

**Table D1:** Ensuring conditions for providing culture-specific care in health care institutions by country.

	n	AM	SD	median	mode	min	max
Nurses from Slovakia	125	2.7	0.89	3	3	0	4
Nurses from abroad	50	3.04	0.64	3	3	1	4

Legend: AM – arithmetic mean, SD – standard deviation, min – minimum, max – maximum

**Chart D:** Ensuring conditions for providing culture-specific care in health care institutions by country (arithmetic mean).



Prior to comparing Slovak and foreign health care institutions, we verified the normality of the data distribution, which we rejected based on the results of the *Shapiro-Wilk* test and, therefore, we used the nonparametric *Mann-Whitney U* test. Its value equalled 2,466.5, and the statistical significance was lower than the value of 0.05 (**Table D2**). There is a statistically significant difference between health care institutions in Slovakia and abroad in terms of ensuring conditions for providing culture-specific care with a low effect size. These conditions are ensured to a greater extent in foreign health care institutions (based on values of average order).

**Table D2:** Comparison of ensuring conditions for providing culture-specific care in health care institutions by country.

Slovakia – average order (n = 125)	82.73
abroad – average order (n = 50)	101.17
Mann-Whitney U test	2,466.5
statistical significance	0.017
effect size r	0.18

The results of foreign researches confirm inadequacies mainly in the field of communication.

In an American study, the authors focused on multicultural care for women of various ethnicities. The research found negative experiences of the patients in the field of communication (Wheatley *et al.* 2008).

**Conclusion:** Based on the results, we found that the conditions for providing culture-specific care are ensured to a greater extent in health care institutions abroad than in those in Slovakia ( $U = 2,466.5, p < 0.05$ ). The results of our research confirmed **Hypothesis 5**.

## Recommendations for Practice

Based on the analyzes of the results of the research, we arrived at a conclusion that, to achieve efficient nursing care for patients of different cultures, it is necessary to motivate the Nurses to participate in training activities on an international level, aimed at providing nursing care while respecting and meeting the culture-specific needs of patients. It is important to create training programs and training material to educate the Nurses in the field of nursing care, and of communication with patients from different cultural environments.

## Conclusion

With the increasing globalization of the world, cultures, customs, and traditions are blending into a homogenized global culture. This current phenomenon has an impact also on caring for patients in the terminal stage of their illnesses. Therefore, it is important to devote attention to this phenomenon; to improve the efficiency of the provision of nursing care; and to increase the standard of the Nurses' familiarity with the topic of multicultural care.

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## Risks of Professional Parenting (Original Research)

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Original Article

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### Abstract:

**Objective:** The research aims to identify perceived risks of professional parenting from the viewpoint of professional parents, children's home employees cooperating with professional parents, and Educators.

**Design:** Comparative, quantitative and exploratory research

**Participants:** The research sample consisted of 115 participants - 56

professional parents, 27 children's home employees and 32 Educators. **Methods:** To identify perceived risks of professional parenting, our self-constructed questionnaire containing 32 items describing potential risks of professional parenting was used. These items were assessed by participants using a *5-point Likert Scale*.

**Results:** The results suggested statistically significant differences in perceiving the risks of performing the tasks of professional parenting among children's home employees, professional parents, and Educators.

**Conclusion:** All the identified results favoured children's home employees and Educators, in the sense that they perceived higher risks in comparison to professional parents. In terms of effect size, observed differences in perceiving the risks from the viewpoint of employees and Educators were small ( $\eta^2=.27-.31$ ).

## Introduction

The provision of care to children who are removed from their biological families and placed into children's homes based on a court's order of institutional care or a provisional measure is regulated by the Act No. 305/2005 Coll. on Social and Legal Protection of Children and on Social Guardianship. Currently, it defines a form of provision of care to children in professional families as an option to provide care to a child in a domestic environment of a professional parent who is an employee of a children's home. Child care in a professional family primarily presupposes meeting of a child's individual needs in an environment as close as possible to the model of a family upbringing. The upbringing of a child in an environment where there is no staff rotation and where, instead, the permanent presence of a professional parent is ensured and a child is able to go through a certain period of their life in a family environment has a significant impact on the fulfillment of their psychosocial needs and positively affects their social functioning in their interpersonal relationships later in life (1).

The focus of the present study is on a specific area within the issue being discussed, namely on perceiving the risks of

performing the tasks of professional parenting. Specific attention is being paid to comparing risks perceived by professional parents, children's home employees and Educators. As the authors are unaware of any satisfactory empirical starting points for this specific area, the study could be considered an exploratory study introducing the issue in the context of the Slovak Republic.

## Methodology and Results

### Research sample

The research sample consisted of 27 children's home employees, 56 professional parents and 32 Educators.

Of professional parents, 52 were female (92.9%) and 4 male (7.1%). 38 professional parents (67.9%) completed secondary education with a school-leaving exam, 2 completed first-degree university education (3.6%) and 16 (28.6%) completed second-degree university education. As for the marital status, 5 (9.1%) professional parents were single, 36 (65.5%) were married, 6 (10.9%) lived in a partnership, 7 (12.7%) were divorced and one professional parent was widowed (1.8%).

There were 26 female and one male children's home employee. As for occupational position, our sample contained 10 Psychologists (37%), 8 Social Workers (29.6%), 6 children's home managers (22.2%), two Special Pedagogues (7.4%) and one Assistant Social Pedagogue (3.7%).

Of Educators, 30 were female and two male. There were 18 (56.3%) Social Workers, 12 Psychologists (37.5%) and two reported other positions. 31 Educators worked at the *Office of Labor, Social Affairs and Family* and only one was an employee of an accredited body.

## Research methods

To identify perceived risks of performing the tasks of professional parenting, our self-constructed questionnaire was used. The questionnaire contains 32 items describing potential risks related to the performance of professional parenting which were assessed by respondents using a 5-point Likert scale (1-not at all risky, 5-completely risky). Risks were assessed by professional parents, children's home employees, and Educators. The questionnaire used enabled a quantitative assessment of perceived risks and an application of comparative analysis of obtained data.

## Statistical analysis

SPSS 21 Software was used to statistically process the results. Descriptive analysis and procedures of statistical inference

were employed. With regard to the ordinal level of measurement of examined variables, descriptive statistics were calculated (average order, median and, considering small differences between median values, also average and standard deviation). The *Mann-Whitney U Test* was used to identify differences in perceiving the risks among groups of respondents. To determine the effect size, a correlation measure was calculated, the values of which were interpreted as follows:  $\eta=0.00-0.30$  - small effect,  $\eta=0.30-0.50$  - medium effect,  $\eta=0.51$  and more - large effect of a difference (2).

## Results

The results pointed out statistically significant differences in perceiving the risks of performing the tasks of professional parenting between children's home employees and professional parents. Significant differences were found in 12 of 32 observed risks of performing the tasks of professional parenting. These 12 areas are shown in **Table 1**.

All the identified results favored children's home employees and Educators, in the sense that they perceived higher risks in comparison to professional parents. In terms of the effect size, small to medium differences were found ( $\eta=.23-.41$ ). There were no significant differences between the two groups of respondents in the other 20 risk areas.

**Table 1:** Perceiving the risks of performing the tasks of professional parenting: a comparison between children's home employees and professional parents.

Issue	Informant	n	mR	Md	M	SD	U	p	$\eta$
Insufficient preparation for the performance of professional parenting	Employee	27	53.89	4	4.19	.92	408	.001	.38
	Professional parent	55	35.42	3	3.07	1.41			



Completed education of a professional parent in fields other than human and social sciences	Employee	27	49.70	2	2.56	1.28	521	.022	.26
	Professional parent	55	37.47	2	1.89	1.01			
“Us” vs. “them” distinction (biological family vs. a child in a professional family)	Employee	27	50.74	4	3.96	0.90	493	.011	.28
	Professional parent	55	36.96	3	3.16	1.29			
Insufficient support from one’s own family	Employee	27	49.67	4	3.93	1.07	549	.037	.23
	Professional parent	56	38.30	3	3.25	1.37			
Anxiety of a professional parent	Employee	27	53.17	4	4.33	0.68	454.5	.002	.34
	Professional parent	56	36.62	4	3.57	1.13			
Conflict between a biological child and a child in a professional family	Employee	27	50.80	4	3.96	1.13	518.5	.017	.27
	Professional parent	56	37.76	3	3.30	1.22			
High demands on a child, undue expectations on the part of a professional parent	Employee	27	51.19	4	4.07	.92	508	.012	.28
	Professional parent	56	37.57	3	3.48	.99			
Adopting a child into a professional family shortly after losing a child	Employee	27	55.13	4	3.93	.78	401.5	.000	.40
	Professional parent	56	35.67	3	2.89	1.34			
Adopting a child into a professional family shortly after losing a partner	Employee	27	53.63	4	3.81	.88	442	.002	.35
	Professional parent	56	36.39	3	2.86	1.35			
Age of a professional parent under 25	Employee	27	53.28	4	3.63	1.11	451.5	.002	.34
	Professional parent	56	36.56	3	2.69	1.29			
Age of a professional parent over 55	Employee	27	53.13	3	2.96	1.16	455.5	.002	.34
	Professional parent	56	36.63	2	2.14	1.07			
Conflicts between professional parents and children in a professional family	Employee	27	55.78	4	4.15	.86	384	.000	.41
	Professional parent	56	35.36	3	3.13	1.18			

Notes: mR- mean Rank, Md – median, M – mean, SD – standard deviation, U – Mann-Whitney U Test, p – significance,  $\eta$  - effect size

The comparison between children's home employees and Educators has shown statistically significant differences in three areas of perceived risks of performing the tasks of professional parenting (Table 2). Children's home employees perceived

"Insufficient preparation for the performance of professional parenting" statistically significantly more risky than Educators. "Adopting a child into a professional family shortly after losing a child" and "after losing a partner" was perceived statistically significantly more risky by Educators in comparison to children's home employees. In terms of effect size, the observed differences were small ( $\eta=.27-.31$ ).

significant differences in perceiving the risks in other 19 areas between the respondents.

## Discussion

Following the results, the most notable differences between professional parents and professional Parenting Educators in perceiving the risks could be observed in three questionnaire items (Table 3).

In terms of effect size, the largest difference ( $\eta=.59$ ) was found in perceiving the risk of the *age of a professional parent over 55*. Professional parents perceive the age over 55 as less risky in comparison to

**Table 2:** Perceiving the risks of performing the tasks of professional parenting: a comparison between children's home employees and Educators.

Issue	Informant	n	mRank	Md	M	SD	U	p	$\eta$
Insufficient preparation for the performance of professional parenting	Employee	27	34.85	4	4.19	.92	301	.037	.27
	Educator	32	25.91	4	3.66	.97			
Adopting a child into a professional family shortly after losing a child	Employee	27	24.72	4	3.93	.78	289.5	.019	.31
	Educator	32	34.45	5	4.38	.79			
Adopting a child into a professional family shortly after losing a partner	Employee	27	25.15	4	3.81	.88	301	.034	.28
	Educator	32	34.09	4	4.28	.81			

Notes: mR- mean Rank, Md – median, M – mean, SD – standard deviation, U – Mann-Whitney U test, p – significance,  $\eta$  - effect size

The comparison between Educators and professional parents in perceiving risks pointed out 13 statistically significant differences. Differences favored Educators in all 13 areas – they perceived these 13 areas (Table 3) as more risky in comparison to professional parents. In terms of effect size, differences between Educators and professional parents were medium to large ( $\eta=.31-.59$ ) in ten areas. There were no statistically

Educators (Table 3). There were also professional parents aged over 55 among our respondents. The reason why they didn't consider this item risky could be the fact that a professional parent at this age has rich experience in the area of parenting and, in many cases, also their own adult children who are already relatively independent. Hence, they are able to devote themselves to a child in professional care more thoroughly

and effectively. It is very important for a professional parent to know that the performance of professional substitute care does not consist only of basic knowledge that they had acquired as a parent (3). The *age of a professional parent under 25* was also assessed by Educators as risky. The age under

25 is generally considered risky because of insufficient experience in the area of child care. Young people are one of the most disadvantaged and vulnerable; their behavior is often the most challenging. In such cases, professional parents are expected to be able to provide professional care (4).

**Table 3:** Perceiving the risks of performing the tasks of professional parenting: a comparison between Educators and professional parents.

Issue	Informant	n	mRank	Md	M	SD	U	p	$\eta$
Completed education of a professional parent in fields other than human and social sciences	Educator	32	51.53	3	2.38	0.94	639	.025	.24
	Professional parent	55	39.62	2	1.89	1.01			
Inappropriate treatment of a child on the part of a professional parent	Educator	32	55.59	5	4.47	0.88	541	.001	.35
	Professional parent	55	38.16	4	3.59	1.29			
“Us” vs. “them” distinction (biological family vs. a child in a professional family)	Educator	32	54.95	4	4.06	1.01	529.5	.001	.34
	Professional parent	55	37.63	3	3.16	1.29			
A large age difference between children in a professional family	Educator	32	55.83	3	3.16	0.88	533.5	.001	.35
	Professional parent	55	38.03	2	2.30	1.17			
Anxiety of a professional parent	Educator	32	52	4	4.09	0.89	565	.030	.23
	Professional parent	55	40.21	4	3.57	1.13			
Conflict between a biological child and a child in a professional family	Educator	32	52.83	4	3.94	0.88	629.5	.016	.26
	Professional parent	55	39.74	3	3.30	1.22			
Child of different ethnicity	Educator	32	54.24	3	3.03	0.84	550.5	.004	.31
	Professional parent	55	38.33	2	2.35	1.24			
High demands on a child, undue expectations on the part of a professional parent	Educator	32	57.50	4	4.28	0.63	480	.000	.41
	Professional parent	55	37.07	3	3.48	0.99			
Adopting a child into a professional family shortly after losing a child	Educator	32	61.84	5	4.38	0.79	341	.000	.54
	Professional parent	55	34.59	3	2.89	1.34			

Adopting a child into a professional family shortly after losing a partner	Educator	32	61.33	4	4.28	0.81	357.5	.000	.52
	Professional parent	55	34.88	3	2.86	1.35			
Age of a professional parent under 25	Educator	32	56.55	4	3.66	0.94	510.5	.001	.37
	Professional parent	55	37.62	3	2.69	1.29			
Age of a professional parent over 55	Educator	32	63.45	3.5	3.59	0.84	289.5	.000	.59
	Professional parent	55	33.67	2	2.14	1.07			
Conflicts between professional parents and children in a professional family	Educator	32	55.50	4	3.94	0.91	544	.002	.34
	Professional parent	55	38.21	3	3.13	1.18			

Notes: mR- mean Rank, Md – median, M – mean, SD – standard deviation, U – Mann-Whitney U Test, p – significance,  $\eta$  - effect size

Another large difference in terms of effect size was the perception of

*adopting a child into a professional family shortly after losing a child* ( $\eta=.54$ ) and of *adopting a child into a professional family shortly after losing a partner* ( $\eta=.52$ ).

Professional parents perceived both areas as less risky than Educators (**Table 3**). In such cases, it is important for Educators to assess the interest and motivation of a person to perform professional care. If the desire to compensate for the loss of a close person primarily prevailed the main purpose of performing the tasks of professional parenting would disappear. The comparison between children's home employees and Educators has shown statistically significant differences in three areas, with the difference in perception of *adopting a child into a professional family shortly after losing a child* (**Table 2**) being the most notable of them.

An interesting finding was related to the perception of risks by professional parents and Educators in the case of "Us vs. them" distinction (*biological family vs. a child in*

*a professional family*) (**Table 3**). One of the main reasons why a child is placed into a professional family is to teach them how a family works. Many children don't have the opportunity to imagine how a "healthy" family works. That is why professional parenting giving a child the opportunity to grow up in an environment that gives them enough incentives for their healthy development and the ability to form new family and social relationships is important. The essence of professional parenting lies in ensuring such a family environment where children can feel accepted (5). It is impossible for a child to feel accepted when making "us vs. them" distinctions, as they perceive differences in the way professional parents bring them up. This area was perceived as less risky by professional parents in comparison to Educators.

This area is closely associated with *inappropriate treatment of a child on the part of a professional parent* and with *high demands on a child, undue expectations on the part of a professional parent* (**Table 3**). It is assumed that a professional parent

is suitably selected based on their competences and experience, is well prepared for performing the role of a professional parent, and that there are no undiscovered pathological problems in their personality (4).

Perceiving risks by professional parents and children's home employees has shown statistically significant differences in perceiving the risks of performing the tasks of professional parenting. Most interesting were the results regarding perceiving the risk of *insufficient preparation for the performance of professional parenting* (Table 1). Children's home employees perceived this area as more risky in comparison to professional parents ( $\eta=.38$ ). Knowledge, experience, and education - a professional parent needs to have all of those to be a true professional and to be able to perform their job in the best possible way (3). Unless a professional parent has sufficient preparation, also other risks may become evident during the performance of the tasks of professional parenting - *inappropriate treatment of a child on the part of a professional parent, high demands on a child, undue expectations on the part of a professional parent, conflicts between professional parents and children in a professional family* and numerous others.

## Conclusion

All the identified results favored children's home employees and Educators, in the sense that they perceived higher risks in comparison to professional parents. In terms of effect size, observed differences in perceiving the risks from the viewpoint of employees and Educators were small ( $\eta=.27-.31$ ).

Perceived risks of performing the tasks of professional parenting from the viewpoint of professional parents, children's home employees and Educators overlap to a substantial extent. All three groups reported

similar risk areas – *adopting a child into a professional family shortly after losing a child; adopting a child into a professional family shortly after losing a partner; the age of a professional parent under 25; the age of a professional parent over 55; “us vs. them” distinction (biological family vs. a child in a professional family); high demands on a child; undue expectations on the part of a professional parent.*

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# How do Hospice Patients Feel about Hospice Care - and is It Important? Exploring the Relationship between Patient Attitude to Hospice Care, Survival and other Patient Characteristics in the Setting of First Croatian Hospice (Original paper)

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Original Article

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**Abstract:**

**Objective:** To research the relationship between the initial attitude of hospice patients towards hospice care and different patient characteristics.

**Design:** Retrospective chart review.

**Participants:** 433 consecutive patients with the determined attitude towards hospice care, in the first Croatian hospice, the Marija K. Kozulić from March 2013 to March 2016.

**Methods:** We evaluated the relationship between patient attitude towards hospice care and characteristics such as age, gender, marital status, level of education, the presence of cancer, performance status, initial and final opioid dose, the use of anxiolytics and antipsychotics, fluid intakes, participation in physiotherapy, discharge status and survival in hospice.

**Results:** Patients were divided into four different groups based on their attitude towards hospice care: acceptance, rejection or anger, depression, bargaining or adapting, and uninformed or partially informed. Our research shows that the majority of patients (69%) has a positive attitude towards hospice. There were no significant differences regarding age, gender, marital status, as well as survival and discharge status between the groups. However, patients exhibiting depression, bargaining or adapting had significantly higher opioid doses in therapy (on average, 145.8 mg OME/day), and the highest elevation of opioid doses during their stay (on average, 52 mg OME/day) compared to other groups.

**Conclusion:** Most patients have a positive attitude towards hospice care. However, the differences in attitude might not influence the length of survival or discharge percentage. However, patients exhibiting depression, bargaining or adapting might be in risk of over-treatment with opioids and could potentially gain significant benefits from the addition of anti-depressants, or sessions with a psychologist.

**Conflict of interest:**

The authors declare no conflict of interest.

**Statement of Informed Consent and Human Rights** The study is a retrospective chart review and does not in any way offer any identifying information regarding patients and offers complete anonymity and does not require informed consent. The

study was performed only after approval from the Ethics Committee of the Marija K. Kozulić Hospice and was conducted by the ethical standards and with the Helsinki Declaration.



## Introduction

Hospice is an institution where terminal patients are provided with palliative care with the primary goal of enhancing the quality of life as much as possible. Enrolling into a hospice is a stressful and potentially traumatic choice for both, patients and their families. Among other issues regarding hospice care, it is important to examine the attitudes of the patients entering hospice as such information might be used to assess the need for a Psychologist or Spiritual Guide in terminal care and to help in prescribing different medications.

However, to the best of our knowledge, there is a scarcity of data on such topic, and no such information for the Eastern European region. Adenipekun *et al.* showed that the majority of Nigerian patients did not have any knowledge about hospice and palliative care which might be responsible for different expectations when entering the hospice, although 87% of patients agreed that establishing a hospice is necessary (1).

A study by Azami-Aghdash (2) *et al.* described a similar percentage of patients and health care providers with a positive outlook towards hospice care (79%). Catt *et al.* found that attitude to hospice is unaffected by the position in society or fears from death, with similar views between different age groups (3).

We aimed to determine whether patients who are more receptive towards hospice care live longer on average and whether, there is a higher percentage of discharge among patients who are not receptive of hospice care.

## Patients and methods

Our study is a retrospective analysis of 433 consecutive patients at the Marija K. Kozulić Hospice in Rijeka, Croatia,

for whom an attitude towards hospice care was noted and described. The study includes patients who were hospitalized in the only Croatian hospice from March 2013 to March 2016. The hospice offers 14 beds divided into single and double rooms. Patient groups were divided into four main subgroups with a similar attitude, to prevent splitting into too few groups which would make statistical analysis more difficult.

Opioid doses were based on McPherson's Guide (4) and expressed as oral morphine equivalent (OME). Performance status (PS) is based on the *Croatian Patient Categorization System* and upon the level a patient requires, with PS 1 meaning patients with low level of dependency, and PS 4 describing the bedridden patient. The system resembles the *Eastern Cooperative Oncology Group Classification*, with 0, 1 and four being the same (5,6).

Statistical analysis was performed using Statistica 12 Software (StatSoft, USA). A p-value of less than  $<0.05$  was considered statistically significant. The study was performed after permission was obtained from the Ethics Committee of the Marija K. Kozulić Hospice.

## Results

A total of 433 hospice patients from March 2013 to March 2016 were examined. Genders were equally represented, with 218 female patients (50%), while the average age was 70.9 years ( $\pm 12.7$  years), and the average performance status was 3.25 out of 4. A majority of patients had cancer as the reason for admittance (90%).

A total of 58 (13%) of patients were discharged due to various reasons, which were not explicitly mentioned. Active physiotherapy was performed in 149 (34%) patients. Patients used, on average, 6.2 different

medications, while anxiolytics and antipsychotics were used by 224 (52%) and 129 (30%) respectively. Average opioid dose on admittance was 94.9mg OME/day rising to an average final dose of 124.3mg OME / day.

We have divided patients into five different categories based on their attitude towards hospice care: acceptance group; rejection/anger group; depression; bargaining or adapting (DBA) group; and uninformed or partially informed (UPI) patients.

We found no significant difference between the groups regarding age, gender, cancer percentage, marital status, the highest level of education, number of medications and fluid intake on day 1, 7 or night 1 (**Table 1**). There was a difference in performance status with, unsurprisingly, the UPI group exhibiting the lowest scores among all groups.

Between the two largest groups, patients who are in acceptance towards hospice care, and patients who expressed rejection and anger, there are no significant differences among any of the explored characteristics. A difference exists among patients exhibiting DBA and acceptance. There is a notable difference in opioid use between the DBA and the acceptance group, with the DBA group using a significantly higher opioid dose, both initially and finally. Also, a difference was seen in elevation of opioid doses during the hospice stay between DAB (on average, elevation of 52 mg OME/day) and all other groups (elevation ranged, on average, from 23-34mg OME/day). On the other hand, the DBA group used fewer antipsychotics and anxiolytics than any other group. We have also noted a possibility that uninformed patients might be under-dosed with opioids before entering the hospice (**Figure 1**).

**Table 1:** Patients characteristics in different attitude groups, N=433.

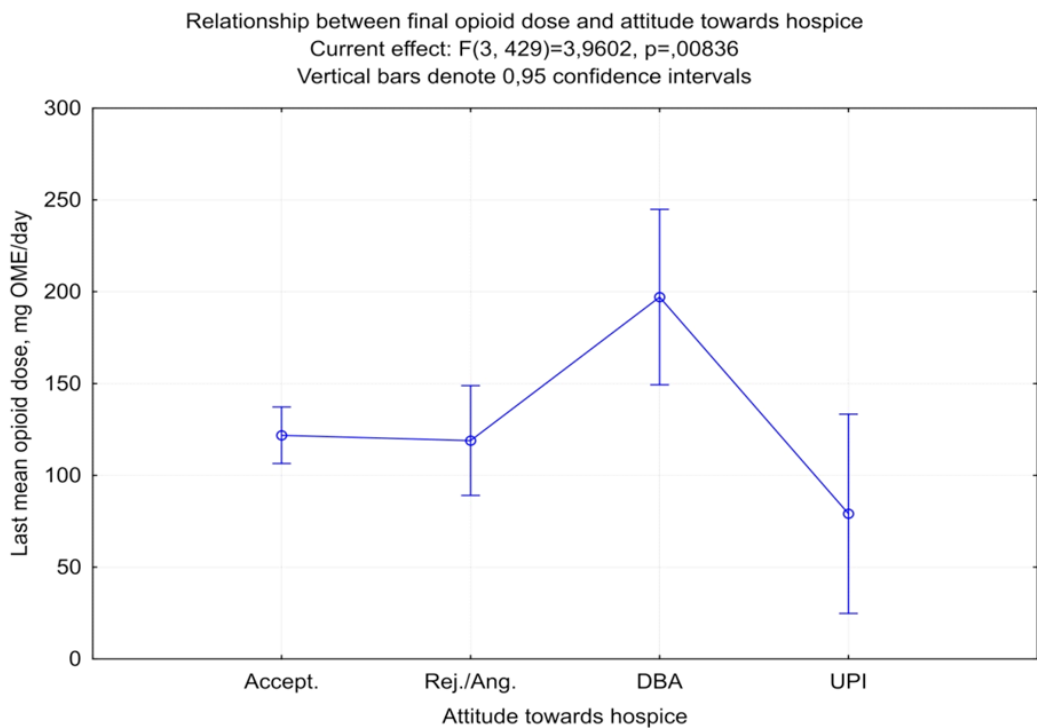
Characteristics	Initial attitude toward hospice care			
	Acceptance	Rejection or Anger	Depression, bargaining or adapting	Uninformed / partially informed
Total number	299	79	31	24
Average age (years)	70.7	71.1	69.6	74.7
Females (%)	152 (51)	40 (51)	14 (45)	12 (50)
Cancer patients (%)	273 (91)	68 (86)	27 (87)	21 (88)
Married (%)	142 (47)	40 (51)	14 (45)	10 (42)
College highest level of education (%)	64 (21)	15 (19)	4 (13)	6 (25)
<b>Initial opioid dose (OME / day)</b>	<b>93.5</b>	<b>95.4</b>	<b>145.8</b>	<b>44.9</b>
<b>Final opioid dose (OME / day)</b>	<b>121.8</b>	<b>118.9</b>	<b>197.1</b>	<b>79.06</b>
Antipsychotic use	90 (30)	26 (33)	6 (19)	7 (29)
Anxiolytic use	155 (52)	43 (54)	13 (42)	13 (54)
Number of medications	6.2	6.4	5.6	5.7

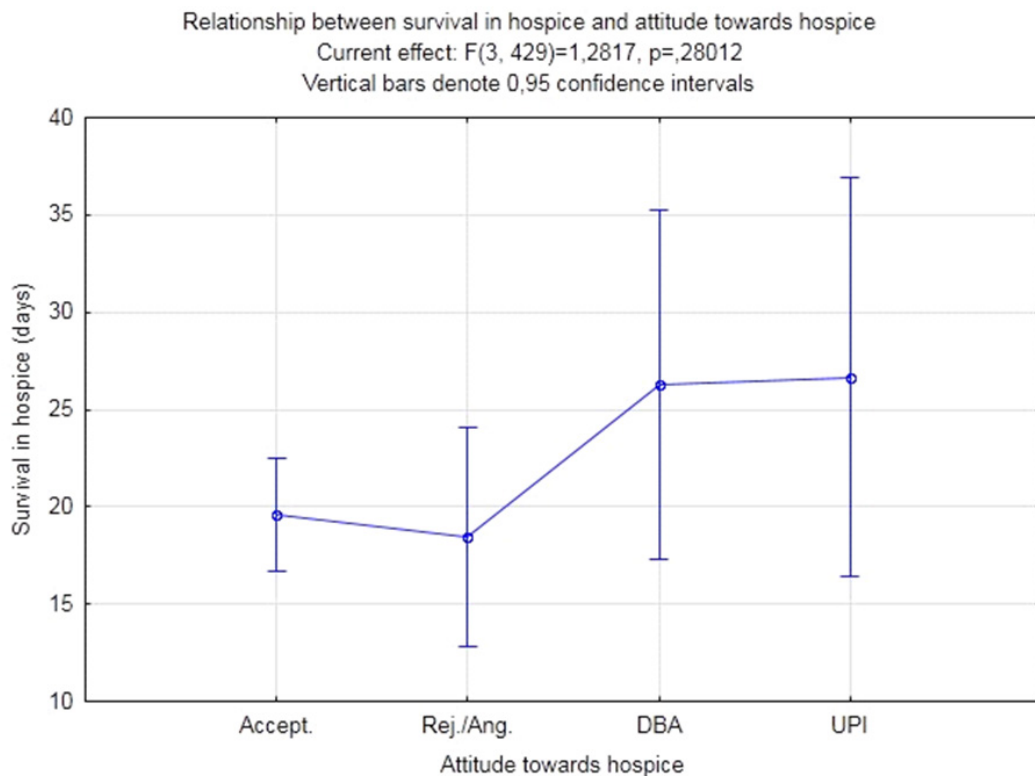
Intake day 1 (ml)	670	597	606	708
Intake night 1 (ml)	361	270	347	354
Intake day 7 (ml)	858	808	796	1092
<b>Performance scale</b>	<b>3.2</b>	<b>3.4</b>	<b>2.9</b>	<b>3.8</b>
Active physio-therapy sessions (%)	112 (37)	21 (27)	10 (32)	6 (25)
Discharged (%)	40 (13)	8 (10)	5 (16)	5 (21)
Length of stay (days)*	15.8	15.7	18.8	18.9

**Bolded** text signifies p value < 0.05. OME = Oral Morphine Equivalent.  
 Ml = milliliter. \*Only deceased patients were analyzed, N= 373.

Our results also show that patients who are in acceptance towards palliative care might perform active physiotherapeutic exercises more often (37% vs. 25-32%).

Surprisingly, however, there was no difference in survival between the four groups (**Figure 2**). There was a trend towards a higher number of discharges among uninformed or depressed patients, but the result did not reach statistical significance.





## Discussion

The study is one of largest retrospective studies examining attitudes of actual hospice patients towards hospice care and is part of a larger study examining the effects of different medications on the same, but larger population (7).

Most patients who arrive at hospice are reconciled with themselves and accept palliative care in hospice with a positive standpoint. However, at least a third of the patients are in different stages of grief, signifying the need for a Psychologist or Spiritual Guide along with medication and supportive care.

Our research shows that acceptance and rejection/anger group did not significantly differ in any of the analyzed characteristics. However, the DBA group exhibited a significantly higher average opioid dose than other groups - both initially and finally. This

group also had the highest elevation of opioid dose during the hospice stay. However, the same effect was not present in antipsychotic and anxiolytic use. It is known that depression and related conditions might emphasize pain (8), and we propose a hypothesis that screening for attitude towards hospice care might identify patients in which adjuvant treatment with medications such as antidepressants and psychologist sessions might achieve success and consequently lower opioid dose (9).

Age, marital status, level of education or cancer diagnosis did not significantly affect attitudes towards hospice care. Also, we did not confirm our primary hypothesis as different attitudes were not associated with a shorter stay in hospice. Although UPI and DBA patients were more likely than average to be discharged from hospice, the trend did

not reach statistical significance, but this result is intriguing and offers valuable insight for further research.

The shortcoming of this research is the lack of information for almost a quarter of total patients, which were in many cases comatose or somnolent; therefore no clear data can be concluded. Also, this study suffers the critique standard for all retrospective studies, offering correlations without causality. We should also note that only initial attitude of patients was described. We did not note whether there was a change in initial attitude which might also be very important for a more accurate analysis. Also, the attitude described is a subjective analysis of the interviewer, and may also depend on the current mood of the patients, which might not represent a correct attitude.

However, this is one of the largest retrospective analysis published so far in the hospice setting which analyzes attitude and different patient characteristics, and to the best of our knowledge, the first of its kind in the eastern European countries. It provides new insight into patient position; describes differences in opioid use between patient groups; offers plausible hypotheses for further studies.

## Conclusion

Placing a higher emphasis on patient attitude when entering hospice might be useful as patients who exhibit signs of depression, bargaining or adapting suffer the risk of over-treatment with opioids. Such patients should be offered psychological and spiritual support, and they could potentially have the highest gain in using adjuvant analgesic therapy and antidepressants, which could lower the need for high opioid dose and thus avoid opioid side-effects. Our research also notes that the attitude towards hospice care might also influence a percentage of patients included into active physiotherapeutic

exercises. However, no difference in survival or discharge rates between the groups with a different attitude towards hospice care was observed.

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# Predicts the Factors Influencing on Behavior of Body Management in Female Students (Original Research)

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Original Article

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## Abstract:

This study aimed to investigate the relation between body management and body satisfaction, diversityism, modernity, attention-drawing and distinction-seeking and sought to identify the predictability degree of these variables through quantitative and survey methods as well as questionnaire tool. Their effects on body management are considerable since they play an important role in society and in family.

The tendency of young girls to control their weight, to be in shape; to consume cosmetics increases day-to-day. Theoretical framework of research was a compilation of theories of Sociology and Psychology. The statistical population consisted of female students of *Payame Noor University* of Abade in the academic year 2014-2015. In this study, 150 questionnaires were distributed among the students and 130 samples were selected, which were thirty times more than the main variables of the study. Pearson Correlation was used for data analysis and stepwise multiple regression was used to predict. Previous studies were reviewed for determining different dimensions of body management, which finally were summarized in characteristics: personal and health care ( $\alpha=0.81$ ); interest in fitness ( $\alpha=0.70$ ); weight control ( $\alpha=0.80$ ). Totally, body management was assessed by 36 items in which Cronbach's Alpha was 0.79. The results showed that diversityism ( $t=4.182$ ), distinction-seeking ( $t=3.866$ ) and modernity ( $t=3.879$ ) were related to body management directly and positively and were not related to body satisfaction and attention-drawing. Finlay Stepwise regression results showed that there was Correlation between diversityism and body management in female students. At this stage, the coefficient of determination ( $R^2$ ) was 0.120 and in the second stage, with the introduction of modernity, the coefficient of determination ( $R^2$ ) was equal to 0.164, which explained about 17% of body management changes. Despite the primary assumption, body satisfaction and drawing attention were not in significant relationship with body management.

A new attention to the body and recirculation of its issues in sociological texts in two recent decades have revived debates over subject matters such as identity; social movements; consumer culture; lifestyle; ethics, to the extent one can apply the metaphor of "social body" (21) or "body age" (8) in line with metaphors like return to culture or return to language in this regard (pointing to prevalence of postmodern or post-structural thoughts and theories). Several processes are about youth in regard to importance and promoted status of body and body culture, both on structural and ethical levels, such as: growth in health technology; sports and nourishment; fashion and cosmetic industries; ever-increasing interests in juvenility; priority of consumption; individualism; attention to differences in lifestyle;

mass media and mass culture 'with special emphasis on fresh and attractive body'; popular culture.

With modernity, globalization, and development of technologies relevant to body, body management has become more significant than the past (5). In fact, consumer-oriented identity and body-oriented consumption in this new and globalized society have made body managements such as makeup, diet, cosmetic surgery, etc. dominant practices and behaviors among women (16; 4). Body and its management are cultural issues connected to social values and norms, in a way members modify their behavior with the changes in cultural elements and components. Self-presentation and self-ornamentation are important issues for women. Women are psychologically heterosexual



so that they are inclined into self-ornamentation more than men (18). The need for self-presentation in human being causes tendencies to different kinds of ornamentation and for fashion and making distinctions as well. In classifying needs, Alexander Mary concerns with 'self-presentation' as a need and defines it: "the need for self-presentation is to draw attention, to influence, to attract, to arouse curiosity, to entertain" (3). The study entitled "Does It Make Me More Beautiful? A Discussion over Cosmetic Surgery" by Zare et al. (2014), indicated that positive attitude toward cosmetic surgery confirms human agency for self-control and independence. Nonetheless, ever-increasing tendency of men for cosmetic surgery in Iran approves the fact that lack of confidence in transsexual and patriarchal system has found its new men victims to whom new standards of beauty have imposed. In addition, imitating cultural standards of beauty is inevitable since individuals who do not follow may be abandoned from communities (22).

Siti Zulaikha et al. (2015), in their study entitled "Dangerous Raw Material in Cosmetics, Personal Care, and Safety" concluded that with global increases in demands for cosmetics among adolescences and adults, the awareness and responsiveness for their safety have increased as well. They aimed to show hygienic and harmless materials can be used in cosmetics or other personal care productions. Cosmetics are composed of preservatives, perfumes, and heavy metal impurities. Their study in fact suggested people should be more informed about materials used in cosmetics and their side effects (20).

Khosheghbal et al. (2015), in their paper "Analyzing Relationship between Perfectionism and Body Image Dissatisfaction among Demanders of Cosmetic Surgery, The Role of Primary Incompatible Scheme" concluded that there is a significant relationship

between demands for nose cosmetic surgery with body image dissatisfaction, perfectionism, and primary incompatible schemas (14). The results of the study "Body Management and Social Acceptance (Case Study: Students of Islamic Azad and Payame Noor University of Zanjan, Iran)" by Shekarbeigi and Amiri specified the mean of body management for female students is 83.46 and it is 72.66 for male students, that confirm female students manage their body more than male students. Totally, 89.7 percent of variance or spread of body management variable were determined through independent variables (19). The results of the study "Lifestyle and Body Management" by Khajeh Noori, et al. (2011), indicated that modern lifestyles influenced by sport, music, leisure, new participations, religious, traditional music all together define 45 percent of women's body management and 30.3 percent of their shape change management (13). Having considered body management as an element in lifestyle, Karami Qehi and Zadsar, (2013), in their study "Assessing the Relationship between Religiosity and Lifestyle (Case Study: 20 years-old or older females living in Tehran) concluded that there is high Correlation between religiosity and lifestyle and there is also a weak relationship between age and religiosity (11). Ghaderzadeh, et al. (2012), in their study "Tattoo and Reflexive Individual Construction" considered tattoo as body management and design that has obtained social and signifying function through which individuals express their individual, mental, and sexual identity (7).

Results of the study by Heidarkhani et al. (2013), in *The Relationship between Elements of Cultural Capital and Body Management in Women* indicated that cultural capital (behaviors and appearances, objectified, and internal knowledge), economic and marital status have a positive and direct relationship with body management in women (9). The findings of the

study *Similar Members in Similar worlds: Analyzing the Effect of Globalization in Body Management* by Fathi and Rashtiani, (2013), designated a direct and significant relationship between globalized media and communicative technologies through implication of sender's culture (acculturation of addressee); spread of consumer culture; variety and renovation; globalized western popular culture; spread of individualism and self-education; education from and to others; and mutual feedbacks have a direct and significant relationship with body management, but there is not any relationship between body management and theorizing (6). The findings of the study *Analyzing Effective Social Factors on Women's Tendency toward Body Management in Recent Three Decades* by Mirzai et al. (2013), indicated that there is a significant relationship between marital status; job and occupation; media; spiritual growth and self-actualization; eating habits; responsibility for healthiness; intersubjective relationships; fashion; management of stress; sports and exercises with tendency to be in shape; but a significant relationship was not observed between age; education; socio-economic status with the tendency to be in shape (17).

The findings of by Khajeh Norri and Parnian, (2014), indicated that variables of rethinking, modern lifestyle new technologies in the domains of communication and information; sociable lifestyle; awareness of globalization; sexuality have positive and significant relationship with body management (12). New technologies in the domains of communication and information; modern lifestyle; sociable lifestyle; and rethinking totally defined 52.2% of the changes in body management. Adibi Sedeh and Jalali Akordi, (2015), in their study *Body Management and National Identity in Youth (Case Study: The Young in Sari)* concluded that there is a negative and inverse relationship between body management and national identity in

youth. The results of regression analysis indicated that independent variables totally define 23.4% of changes in national identity (1).

## Hypothetical Framework of the Study

A synthesis of psychological and sociological theories are considered for the hypothetical framework of the present study. Maslow's hierarchy of needs is firstly considered for a psychological approach. In this theory, human needs are categorized in five levels that respectively are:

- *Physiological needs*: that are necessary for living: food, clothing, sex, health, and housing.
- *Safety needs*: non-violence, security, and non-deprivation are essential needs in this regard; in other words, this level is concerned with protection in the present and future.
- *Social needs*: or love and belonging; human being as a socially-oriented person who attempts to operate in relationships with other human beings.
- *Esteem*: this is firstly from the individual to himself/herself; then it is achieved by others in respect to a person. If a person cannot obtain respect and esteem by proper manners, he/she may tend to draw attention through violation from cultural and social norms.
- *Self-actualization*: it is the actualization of potential talents and abilities, as Maslow states what a human being can be must be attained (2).

If an individual is not satisfied with his physical and health condition in the first level of needs, he/she may attempt to draw attention in order to stimulate their respect and admiration toward himself/herself (15). On the other hand, this study relies on sociological

theories introduced by Goffman, Bourdieu, and Weber. Max Weber widened class distinction and its relevant issues. His distinction between status and class along with related issues on production; life chance; consumption; and lifestyle have been influential in further development of theories pertinent to consumption and lifestyle.

A significant point is the role of sex in attention to body. Women have been concerned with their body and physicality more than men. Bourdieu believes body is a physical capital that concerns with social status and forms of distinction. Considering body as a physical capital, Bourdieu connects identities with social values in regard to size, shape, and appearance (3).

On the other hand, Goffman reflects on face as a significant issue in social and face-to-face dealings and interactions. Social face is a public face which is required to continuous changes in the masks it represents. Makeup is a mean for attaining this mask. It is just in severe emotional states, loneliness, and among friends that this mask or makeup disappears, and the person is in his/her real state.

This study aims to analyze the effects and predicting abilities of variables variety-seeking, body satisfaction; individuation; modernity; and drawing attention on body management among female students. Their effects on body management are considerable since they play an important role in society and in family. The tendency of young girls to control their weight, to be in shape, to consume cosmetics increases day-to-day. Unlike Europe, women in Iran tend to consume cosmetics and do makeups. Women in Iran spend nearly 1,630 million euros annually for imported or smuggled cosmetics. Consuming cosmetics is not related to special class or for specific age; women in Iran consider it part of their essential life. On the other hand, the age of using cosmetics is now 15 in Iran, in contrast

to developed societies in which older women tend to cosmetics since they have lost their fresh and young skin and body.

## Research hypothesis

Diversityism of female students has a significant effect on their body management. The body satisfaction of female students has a significant effect on their body management. Distinction-seeking of female students has a significant effect on their body management. Modernism of female students has a significant effect on their body management. Drawing attention by female students has a significant effect on their body management.

## Methodology

The methodology of this study is quantitative that applies Correlation analysis, and it utilizes survey research technique. The statistical population of this study are female students in *Payame Noor University* of Abadeh during the year 2014-2015: it is 120 persons, thirty times more than principal variables of the study that for assurance increased to 130 persons.

## Tools for Analysis

A questionnaire was used for collecting data; its validity is nominal. What is meant by nominal is realizing the validity of questionnaire's factors and characteristics through referring to reviewers. Acceptable reliability was accomplished by a pre-test (50 questionnaire). The harmony of items and the internal compatibility of the questionnaire were provided by *Cronbach's Alpha*. Each effective variable was assessed by six items that *Cronbach's Alpha* for all is 0.75. A dependent variable is body management which covers continuous observation and changes in the physical body. In other words, all characteristics and behaviors that

cause distinction in an individual's physical appearance in contemporary life are considered as body management. It is analyzed through weight control; surgery; personal and health care. Previous studies were reviewed for determining different dimensions of body management that finally were summarized in characteristics: personal and health care (Alpha: 0.81); interests in fitness (0.70); weight control (0.80). Totally, body management was assessed by 36 items that *Cronbach's Alpha* was 0.79.

## Data Analysis

For this purpose, 150 questionnaires were distributed among the students of *Payame Noor University* of Abade. After analyzing 130 questionnaires, *SPSS software* were used for data entering and coding. *Pearson Correlation* was used for data analysis and step-wise multiple regression was used to predict.

## Results

Descriptive statistics revealed, 15.4% considered themselves to the lower class;

amount of makeup was in the wedding ceremony and subsequent party and university.

Pearson Correlations were used to assess the relationships between variables. Hypothesis test results is shown in **Table 1**.

In the first hypothesis test, Pearson Correlation coefficient for diversityism and body management was 0.347, which this relationship was significant ( $p < 0.01$ ).

In the second hypothesis test, Pearson Correlation coefficient for body satisfaction and body management was 0.071, which this relationship was not significant.

In the third hypothesis test, Pearson Correlation coefficient for distinction-seeking and body management was 0.323, which this relationship was significant ( $p < 0.01$ ).

In the fourth hypothesis test, Pearson Correlation coefficient for modernism and body management was 0.324, which this relationship was significant ( $p < 0.01$ ).

In the fifth hypothesis test, Pearson Correlation coefficient for draw attention and body management was 0.114, which this relationship was not significant.

**Table 1:** Pearson Correlation test and body management.

Variables	The Correlation coefficient	Significance level
Diversityism	0.347**	0.000
Body satisfaction	0.071	0.421
Distinction-seeking	0.323**	0.000
Modernism	0.324**	0.000
Draw attention	0.114	0.197

\*\* =  $p < 0.01$

80% to middle class; 4.6% to high-class. Based on the results 22.3% at the time of purchasing; 45.4% in the party; 83.1% in the wedding party; 18.5% in the recreation and pilgrimage; and 32.3% attending university were self-make-up. Generally, the most

## Statistical Analysis

*Multiple Regression Analysis* of step by step was utilized in this study. The regression model of body management for female students indicates that regression analysis followed two steps.

The first variable involved in regressed equation in variety-seeking. The results showed that there was correlation between diversityism and body management in female students. At this stage, the coefficient of determination ( $R^2$ ) was 0.120 and in the second stage, with the introduction of modernity, the coefficient of determination ( $R^2$ ) was equal to 0.164, which explained about 17% of body management changes. Variables of body satisfaction, distinction-seeking, drawing attentions were not included into the equation. The value and measure of F are significant (12.481), and this indicates at least one of the independent variables is effective in predicting a dependent variable (Table 2).

The results of this study indicated that variables of variety-seeking, individuation, and modernity are in significant relationship with body management that are in line with findings by Khajeh Noori and Parnian (2014) (12), Ghaderzadeh *et al.* (2012) (7), Khajeh Noori *et al.* (2011) (13), Heidarkhani *et al.* (2013) (9), Fathi and Rashtiani (2013) (6), Mirzai *et al.* (2013) (17), and Khoshedgbal (2015) (14), but the results of this study are not in line with findings by Zare *et al.* (2014) (22) and Shekarbeigi and Amiri, (2011) (19). Despite primary assumption, body satisfaction and drawing attention are not in significant relationship with body management.

**Table 2:** Elements and variables within the equation to predict the managing body.

The level	Variable	B	Beta	t	p	$R^2$
1	Diversityism	0.319	0.262	2.996	0.003	0.120
2	Modernism	0.236	0.226	2.587	0.011	0.164
					p = 0.000	F = 12.481

## Dissection and Conclusion

In this study, several variables were studied in relation to body management in female students. Dramaturgical Theories by Goffman, Bourdieu, and Weber provided the hypothetical framework of the study on body management. In dramaturgical theory of Goffman, individuals are in role play, and their physical appearance is determining for their roles. On the other hand, body capital, in terms of Bourdieu, is the result of interaction among social status; habitus and taste, which provides individuals with symbolic capital, subculture possibilities and distinctions. Bourdieu analyzed different groups in society that are distinctive through consumption patterns that determine lifestyle.

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# Cultural Perceptions on the Role of Palliative Medicine in Central and Eastern Europe (Review)

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Original Article

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## Abstract:

**Objective:** The aim of this study was to understand how palliative care is integrated into the cultural and healthcare systems of Central and Eastern Europe.

**Design:** This study was conducted through the use of secondary research sources and was augmented by Róbert Dul'a, Trnava University, by conversation and review.

**Results:** The study indicates that although there appears to be a lack of regulation, palliative care is making progress by reducing the uncertain social stigma.

**Conclusion:** There remains opportunities to educate the population on the benefits of palliative care, therefore, helping citizens achieve a better possible quality of life.

## Introduction

Palliative care is a type of care that can be beneficial to anyone with a life-limiting illness.

The World Health Organization (WHO) defines palliative care as: an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO Definition of Palliative Care, 2017).

Palliative care is important because it is able to look at the patient in a holistic way. During this care, health care workers look at the patients' needs beyond physical pain. By providing this type of care, the patient can live as comfortable as possible receiving the proper pain management, communication, and access to family and spiritual needs. All these aspects allow patients to live with this illness in ways that provide a better quality of life.

Palliative care in Central and Eastern Europe is still developing. There are opportunities for a more uniform platform that will help train clinicians, as well as use government policies and regulations. With a growing population of older people, experts see more people living with morbidities, co-morbidities, and chronic conditions, thus showing the need for palliative care.

By developing of a stronger palliative care system, citizens can increase their quality of life.

## The Importance of Palliative Care

According to the *Health and Human Resource Guide*, palliative care is a human rights issue. The United Nations Committee on Economic, Social and Cultural Rights explained that, "States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, and curative and palliative health services" (Health and Human Resource Guide 2017 para. 2).

This raises awareness to how important providing palliative care is to the patients with a life-limiting illness. More than half of the people who are dying annually can benefit for end-of-life patients. International states have an obligation to their citizens to provide the appropriate needed care.

Not only is it important to provide palliative care, but it is important to initiate palliative care at the start of curative treatment. To get the most benefit out of this non-curative treatment, Palliative Medicine should be provided in tandem with curative treatment. This can be seen in **Figure 1**. By providing these treatments together, the family, patient, and clinicians can make sure that all necessary steps are put into place to ensure a better quality of life. When the patient's disease transitions everyone is ready for the next step and understands the best approach to care.



Palliative care is a service that many citizens can and should use throughout this region. The European Health Committee took initiatives after the reports of *Problems Related to Death: Care For The Dying* in 1990 and *The Protection of the Human Rights and Dignity of The Terminally Ill and The Dying in 1999* (Clark and Centeno, 2006).

These reports raised awareness of the importance of palliative care and how it is a basic essential service for its citizens. By receiving the most appropriate care, which perhaps is palliative care, it can reduce the high cost of end-of-life care. The European Health Committee noticed that there are many variances amongst the countries in Europe. This Committee has realized that addressing a more level palliative care system will increase cooperation and the quality of palliative care given amongst the region. These reports also raise the issue of informal care and the wishes of many patients to spend their last days in the comfort of their home. There is a great need to provide uniform care to all citizens regardless of race, gender, or ethnicity.

Roque and Cleary (2013) state that a majority of patients in the last six months of life prefer care to primarily focus on pain relief and discomfort, yet more than half of the patients are hospitalized, and almost 10 percent undergo life-sustaining procedures during their last month.

In addition, 54% spend their last days in the hospital, 30% spend it at home, 12% spend their last days in other places, and 3% spend their last days in long term care facilities. (See **Figure 2**.) Even though a majority of patients would rather spend their last days in their home, only 30% are actually able to do so. Palliative care is a type of care that can be delivered in multiple settings; in hospitals, clinics, and perhaps most importantly a home-based setting. It is vital that there be coordination amongst patients and care givers, so that each party understands

the desires and expectations of the patient. There is a great need and value to palliative care. It is important that patients with a life-limiting illness get not only the physical, but the mental, spiritual, and family needs as well. All these aspects help patients increase quality of life and pass away with dignity.

## History

The Slovak Republic has inherited a *Socialist Healthcare System*. This system is very good at providing acute care and curative treatment. Because of this healthcare style, a lot of death and dying took place in hospitals.

“Slovakia is a country with no tradition of home care services and a long history of regarding death and dying as taboos therefore institutionalizing them” (Sadovská, 1997, p.1).

Due to this history, in 1995 the *Department of Palliative Care* was created. It is the mission of this organization to raise awareness about palliative care and how it can benefit many suffering patients at the end of life. During this period of time, the Slovak Republic wanted to provide slow releasing Opioid medications; create a network of home care agencies; continue to promote the value of palliative care. This region of Central and Eastern Europe has an opportunity to shift its focus with patients who have a life limiting illness from an aggressive curative treatment plan to a non-curative comfort treatment plan. This change of focus allows patients to increase their quality of life by receiving appropriate care in appropriate locations.

This history makes it difficult to adapt and fully understand how to implement Palliative care. Sadovská (1997) studies showed that terminally ill patients spent 70 days in institutional care and 49.9 days in acute care hospitals, 61% of patients had

complex social needs that led them to spend their last days in an acute care setting. This setting is not appropriate for patients who need non-curative treatment. These patients suffered from inadequate symptom control and excessive instrumental activities, i.e. daily blood tests; invasive diagnostic procedures; intravenous hydration; and antibiotics. Sadovska (1997) also noted that in the Slovak Republic about 12,000 cancer patients die each year. This is a large portion of the population that shows the importance of palliative care in this region.

*The Department of Palliative Care* is helping to provide palliative care to help those suffering to live a better quality of life. This organization under the *Cancer Institute*, strives to deliver excellent palliative care by developing and providing a consistent network of facilities throughout the region; supports ideas of patient and families to obtain the proper form of care. This organization is vital to improving the teaching and research of palliative care in the Slovak Republic. In 2005, the *European Association for Palliative Care* helped identify the barriers to Palliative care in Central and Eastern Europe. Throughout their studies they found that the development of Palliative Care throughout this region remained uneven, uncoordinated, and poorly integrated.

## Education and Training

Each country in this region educates and trains their Clinicians in different ways. However, this study looks closely into Czech Republic and Slovak Republic which allows a broad understanding of education and training in this region. In 2001, the Czech Republic had 6 in-patient hospices (148 beds) (Luczak, Kluziak, Hunter, 2001). These beds are run by a non-governmental organization that provides a certain level of palliative care. Besides textbooks, undergraduates receive a three hour

palliative care instruction, while postgrads receive 8-10 hour instruction. Beyond this initial training there is no further training to help Clinicians understand how to provide better palliative care.

In 1994, the Slovak Republic, established a professional *Palliative Care Department* part of the *National Oncology Centre* in Bratislava. This 20 bed institution cooperates with the *Slovak Society for Study and Treatment of Pain*. Led by Dr. Kulichova, this organization organizes annual international conferences on chronic pain, cancer pain, and palliative care. Some professionals even attend training courses in Puszczykowo, Poland (Luczak, Kluziak, Hunter, 2001). The Slovak Republic holds courses and conferences on palliative care where Clinicians and caregivers can come for further education. Due to lack of institutional care, there are little or no funds available for this type of care (Luczak, Kluziak, Hunter, 2001).

## Barriers

One of the most significant barriers we see with palliative care is the lack of financial and material resources. Many countries in this region blame lack of funding on unstable governments; while some countries blame a smaller budget which only covers the basic hospice needs. Other countries have difficulties with the distribution of palliative care services. In countries like Czech Republic and Poland there are still many areas with no access to palliative care.

European policies are still underdeveloped however; both non-government and inter-government groups have been collaborating to find a policy that fits the need of not only the country but the regions of Central and Eastern Europe. According to Clark and Centeno (2006), palliative care policies should be based on human rights; patient rights and dignity; social cohesion;

equality; solidarity; freedom of choice. End-of-life care is a special topic because everyone deals with it differently. Caregivers and policy makers need to be sensitive to how they approach palliative care. It is important to follow proper policies as well as enhance the quality of life.

## Conclusion

Although there is a lack of regulation and education, palliative care is making progress. To further enhance progress, local and national leaders should have a greater focus on the need for palliative care. Due to the history of this area and ideas that care should not be provided for the terminally ill, palliative care still maintains a stigma of uncertainty. With events such as the *Forum for Cancer Pain Treatment* and *European Association for Palliative Care Conference*, governments can get involved to help educate populations about the benefits of palliative care and to reduce stigma. By initiating this care early, Clinician and the patient can have a mutual understanding of the course of treatment to enable patients to receive all the services they need for a better quality of life end.

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## Appendix

Figure 1:

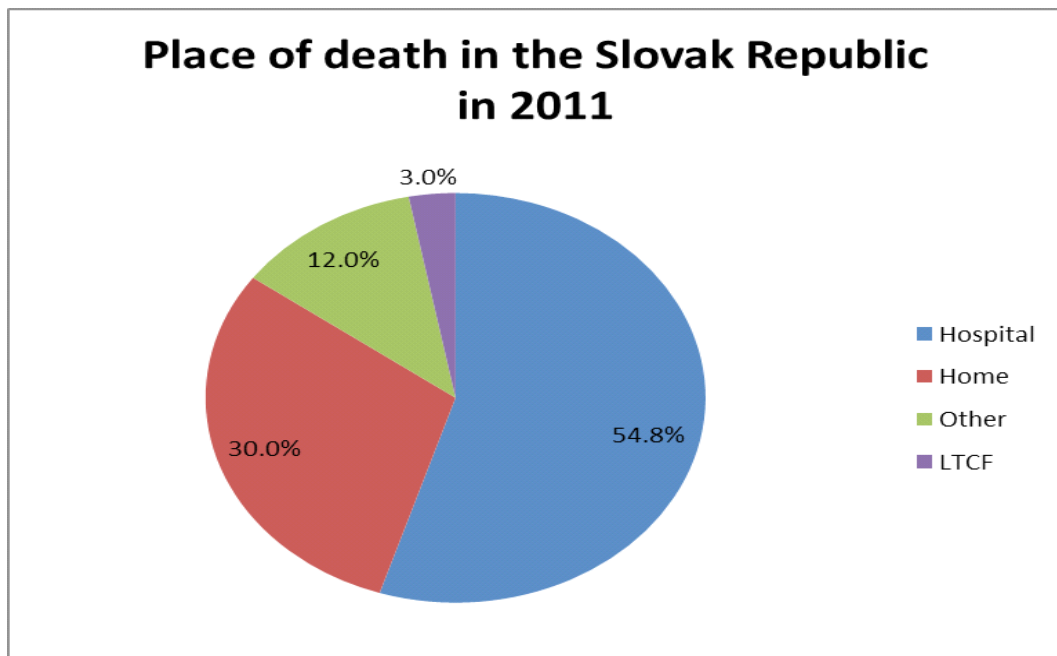
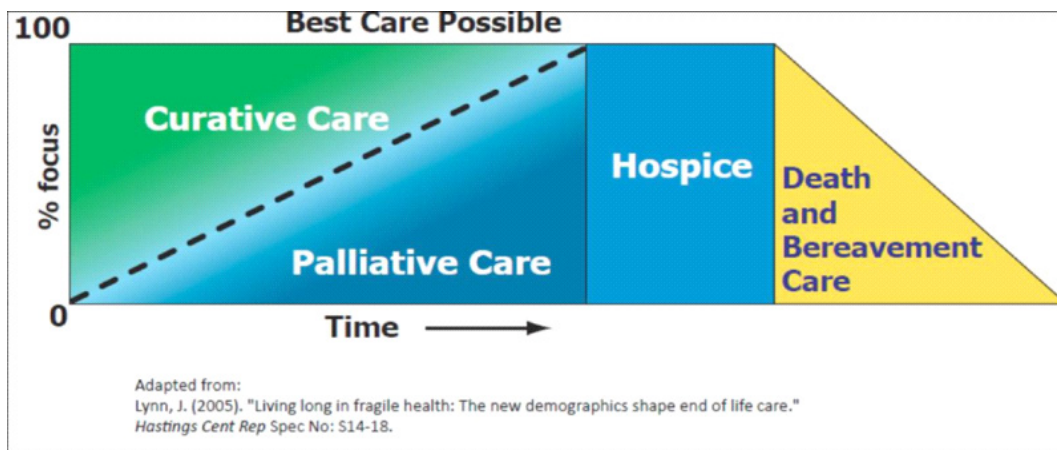


Figure 2:



# A Comparative Literature Review on Contributions of Social workers in Kenya and Slovakia to Palliative Care Multidisciplinary Team (Review)

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Original Article

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## Abstract:

**Introduction:** Effective Management of terminally ill patients involves a multidisciplinary team. Social Work is one of the professions that contributes to this team. Objective of this review is to compare how Social Workers in Kenya and Slovakia contribute to the palliative care team.

**Methods:** A traditional type of literature review was employed in writing this article. It involved search of articles published in online databases such as ProQuest Central, Oxford Journals, Science Direct, Springer Link and Wiley Online Library. Some of the key words used were: Palliative Care and Multidisciplinary Team.

**Results:** Social Workers in both countries contribute to a multidisciplinary team with slight differences. For instance, Slovak Social Workers focus more on social advocacy such as seeking powers of the attorney to represent their clients in state offices unlike to their counterparts in Kenya who only come into contact with the legal system when summoned by Courts of law.

**Conclusion:** In both countries, Kenya and Slovakia, Social Workers immensely contribute to the multidisciplinary team which goes a long way in addressing factors that may hamper effectiveness of palliative care.

## Introduction

Cancer is the 3<sup>rd</sup> leading cause of death and sickness in Kenya after infectious and cardiovascular diseases. It causes 7% of the total national mortality each year. The leading types of cancer in women are breast and cervical cancers while in men is prostate and oesophageal cancers (MoH, Kenya, 2013; Korir *et al*, 2015). Most patients in Kenya (over 80%) have their first cancer diagnosis at an advanced stage of the disease, making curative approach not to be an option in managing it. Factors that contribute to this late diagnosis range from inadequate or long travel distances to diagnostic centers; long waiting time that may run into months before one is seen by an oncologist; prohibitive costs of diagnosis and treatment, to lack of cancer awareness among patients (Malloy *et al*, 2017; Muttunga *et al*, 2015; Kimani *et al*, 2017; MoH, Kenya 2013).

In Slovakia, Cancer is the second leading cause of death after cardiovascular diseases. This rise is attributed to sedentary life and gradual increase in life expectancy witnessed over past few years. Most cancers (70%) are diagnosed among patients older than 60 years. In Slovakia, Colorectal and

prostrate are the leading types of cancers in men; in female breast and colorectal cancer. In addition, 10 years survival rate for cancer are currently at 75% for children and 59% for adults (Vilinová *et al*, 2015; Ferlay *et al*, 2013).

## Methods

A traditional style of literature review was adopted in writing this article (Green *et al*. 2006). It involved search of articles published in online databases. Key words that were used in conducting the search were: 'palliative care', 'Hospice care', 'Multidisciplinary team', 'cancer care' and 'palliative social work. The databases used for electronic searches of the literature were (1975-2017): Ebook Central (ebrary Academic Complete), EBSCO, ProQuest Central, Oxford Journals, Science Direct, Springer Link and Wiley Online Library. Objective of this review was to compare how Social Workers in Kenya and Slovakia contribute to multidisciplinary team involved in providing palliative care to terminally ill patients.

## Roles and Responsibilities of Social Workers

In working with terminally ill patients, Social Workers strive in helping patients fulfill four kinds of wishes they would like addressed before they die: these wishes are: Social Wish i.e. they don't die in isolation but be surrounded by their closest friends and relatives, wish for their body, i.e. to die a painless death without difficulties, Psychological Wish, i.e. to have reconciled with all their unfinished businesses before their time of death, Spiritual wish, i.e. all their questions answered about life after death (Munn, 2010; Student *et al*, 2006).

In Kenya, roles and responsibilities of Social Workers in Public palliative and hospice facilities include: conducting group or individual counseling with patients or families whose members have been diagnosed with cancer, reconnecting or reintegrating abandoned patients in the hospital with their relatives, recommending to the hospital administration for bill waivers to those who are not able to pay, connecting patients with resources such as linking patients from needy families with agencies that may help them in buying medical equipment required of them.

In Slovakia, day to day duties of Social Workers in Palliative and Hospice care are:

1. taking social anamnesis, making diagnosis and developing work plan for social therapies;
2. helping clients overcome social, economic or moral barriers that may interfere with success of treatment;
3. participates in the process of reintegrating patients back into their communities;
4. holding consultations with doctors on duties on how to realize social interventions for the clients;
5. representing clients when they are needed by police, courts or doing paperwork;
6. performing psychotherapies, and
7. working with families, judges/magistrates and probation officers.

## Discussion

Our general findings were that Social Workers in both countries contributes with some slight differences to multidisciplinary teams tasked with responsibilities of providing palliative care to terminally ill patients. Social Workers in Slovakia focus more on advocacy compared to their counterparts in Kenya who only come into contact with the legal system when summoned by the Courts of Law. This difference can be attributed in the legal systems used in both countries i.e. Common Law vs. Civil Law.

## Conclusion

We conclude that there are some slight differences in how Social Workers in Kenya and Slovakia contribute to their multidisciplinary team. This makes it necessary for members of their team to be knowledgeable of cross-cultural practices, especially now that air travel has advanced, making patients able to move from one part of the globe to another in pursuit of medical care. We also conclude that Social Workers bring to the multidisciplinary team particular skills in working with families and children. These skills play key roles in determining outcomes of palliative care.

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# Replenishing the Spiritual Needs in Patients with Infaust Prognosis in Praguean and the Central Bohemian Region's Hospitals (Research Note)

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Original Article

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## Abstract:

**Objective:** The aim of our research was to determine the current situation at Praguean hospitals and hospitals of the Central Bohemia Region regarding the replenishing of spiritual needs in patients with infaust (unfavorable) prognosis.

**Design:** Pilot study.

**Participants:** The criteria for selection of respondents were age (people over the age of 65), diagnosed with chronic disease with complications, infaust prognosis of their health condition and hospitalization in a healthcare facility in Prague and the Central Bohemia Region.

**Methods:** Investigation and evaluation of the current situation regarding this research problem was conducted using the FICA questionnaire, a tool of spiritual assessment that helps to discover personal spiritual history and provides guidelines for pastoral care in clinical practice. The research was conducted in hospitals in Prague and the Central Bohemia Region.

**Results:** During the research, we identified that the satisfaction of spiritual needs is at an insufficient level, and this deficit leads to a deterioration of the mental state of the patients.

**Conclusion:** In line with the research, the authors describe the appropriate forms of spiritual care that can be provided in the context of health care.

### **Conflict of interest:**

The authors of this article certify that they have NO affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, or other equity interest), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

## **Introduction**

The multi-dimensional constitution of humans includes also spirituality. Replenishing their spiritual needs is at high demand in different kinds of personal struggles especially in patients with infaust prognosis. It is found, that many people experience spirituality as an important support aid while trying to cope with a chronic or life-threatening disease (1).

Palliative Medicine should not only be used to suppress physical pain, but also discomfort, anxiety, and other disease-related problems. Individually perceived loss of personal dignity; sense of life or hope can be reasons for giving up and the desire to die soon. Awareness of finitude; of one's mortality does not inevitably have to lead to minimization of the meaning of remaining

life. According to Baars, it relativizes cultural idols and poses the question of what life as a whole is really about (2). Ensuring the best possible quality of life for infaust patients is mainly helped by psychological, social and spiritual support (3). Keenan states, that by enhancing spiritual security, the professional can reduce the patient's/service user's spiritual vulnerability, risk and distress (4). Border issues in both Christian Pastoral Care and Clinical Psychology are concerned with in Pastoral Psychology (5).

The National Health Service Scotland has differentiated between spiritual care and religious care suggesting that, "spiritual care is usually given in a one to one relationship, is completely person-centered and makes no assumptions about personal conviction

or life orientation”; it could be provided by all health care staff, by carers, families, and other patients. In contrast, “religious care is given in the context of shared religious beliefs, values, liturgies and life style of a faith community“ (6).

Academic Medical Centers, Medical and Nursing Schools, residency programs, and hospitals in the USA began to recognize the role of spiritual care as a dimension of palliative care in the early 1990s. Puchalski *et al.* came to a conclusion, that principles of spiritual care can be applicable across all phases and settings for seriously ill, without regard to culture, religious tradition, or spiritual frames of reference. They have defined spirituality as the aspect of humanity that refers to the way individuals seek and express meaning and purpose; the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred. The most recognized models of spiritual care were considered as a bio-psycho-social-spiritual model of care and an inter-professional spiritual care model (7).

However, so far, attention for the spiritual needs of patients and dying in the Czech Republic has been implemented in health care facilities unsystematically and very diversely (8). In order to satisfy the spiritual care in the conditions of the Czech health care system, we refer to the Act on Health Services: Act No. 372/2011 Coll., where it is stated in detail that the patient is entitled in the provision of health services: “To receive spiritual care and spiritual support in medical facility at the patient department or daycare facilities from spiritual leaders of churches and religious societies registered in the Czech Republic or from persons charged with performing spiritual activities in accordance with the internal order and in a way that does not violate the rights of other patients and regarding their health status“ (9).

As we can see, there is no distinction between the spiritual and the religious care in Czech legislation, as mentioned above regarding Scotland.

## Patients and Methods

Investigation and evaluation of the current situation regarding our research issue was made upon the questionnaire FICA, spiritual assessment tool developed by Dr. Christina Puchalski and a group of Primary Care Physicians. It helps to discover any personal spiritual history and the guidelines for the Pastoral Care in clinical praxis. The FICA questionnaire is the only validated screening questionnaire, which was also described in the Czech Republic. Health professionals can, using this tool deal with patients with spiritual issues that are important to them. According to the author of the Puchalski Questionnaire, the method of asking FICA questions is applicable across different cultures.

In all, 318 respondents aged 65 to 91 were involved in the survey. To comply with ethical considerations and to protect the rights of participants, the authors obtained permission; introduced themselves to participants; explained objectives of the study; obtained their informed consent; assured them of confidentiality of data; emphasized that they could withdraw from study as and when they wished. They were also assured that their names w not be disclosed.

## Results

Based on this review of the literature, this paper addresses two research questions:

- Does infaust prognosis affect spiritual needs?
- Are the spiritual needs in hospitals sufficiently replenished?

**Question 1a:** From the following variants of answers choose the one that characterizes your spirituality the most. Respondents could choose only one answer.

**Table 1:** Variants of answers regarding the spirituality of patients.

variant of answer	n <sub>i</sub>	f <sub>i</sub>
practicing believer	120	37.7%
believer	82	25.8%
atheist	97	30.5%
I do not want to answer	19	6%
<b>Total</b>	<b>318</b>	<b>100%</b>

**Question 1b:** In the case you have stated that you are a believer, did your infaust prognosis affect this fact? Respondents could choose only one answer.

The total number of respondents (based on the question number 1a) is 202.

**Table 2:** Variants of answers on influence of infaust prognosis on spirituality of patients.

variant of answer	n <sub>i</sub>	f <sub>i</sub>
I have been believer since my childhood	72	35.6%
my disease has brought me faith	94	46.5%
some other factors brought me faith	35	17.4%
I do not want to answer	1	0.5%
<b>Total</b>	<b>202</b>	<b>100%</b>

**Question 1c:** In the case you have stated that you are an atheist, did your infaust prognosis affect this fact? The total number of respondents (based on the question number 1a) is 97.

**Table 3:** Variants of answers on influence of infaust prognosis on their atheistic approach.

variant of answer	n <sub>i</sub>	f <sub>i</sub>
I have an atheistic approach since birth	59	60.8%
I have an atheistic approach based on the other factors	15	15.5%
I have an atheistic approach based on an infaust prognosis	14	14.4%
I do not want to answer	9	9.3%
<b>Total</b>	<b>97</b>	<b>100%</b>

**Question 2:** What does the collocation of spiritual need mean to you? Respondents have chosen from the below-listed variants of responses (Table 4) all of those, which they consider important for the replenishing of their spiritual needs (they could have multiple answers).

**Table 4:** Variants of answers on comprehending the spiritual needs.

variant of answer	n <sub>i</sub>	f <sub>i</sub>
interview with chaplain or priest	136	42.8%
the need for faith	172	54.1%
securing the life safety	144	45.3%
satisfaction of religious needs	64	83%
care for the soul and the feelings	86	58.5%
the need for well-being	259	81.4%
the need for love	32	73%
the need for consolation	25	39.3%
reconciliation with death	245	77%

**Question 3:** To what extent have you been satisfied with replenishing your spiritual needs during hospitalization at the health

facility? Respondents have chosen from the following variants of responses (**Table 5**) the one that characterizes the most the degree of replenishing their spiritual needs during hospitalization (they could choose only one).

**Table 5:** Variants of respondents' answers regarding satisfaction with replenishing the spiritual needs in the health facility.

variant of answer	n <sub>i</sub>	f <sub>i</sub>
absolutely satisfied	29	9.1%
rather satisfied	36	11.3%
satisfied	67	21.%
rather dissatisfied	39	12.2%
dissatisfied	45	14.2%
I did not feel the need to replenish my spiritual needs	102	32.1%
<b>Total</b>	<b>318</b>	<b>100%</b>

Evaluation of the first research question:  
*Does infaust prognosis affect spiritual needs?*

On the basis of the results of our research, we can state that the influence of the infaust prognosis on the assumption of faith and spirituality was demonstrated in 94, ergo **46.5%** of the respondents (**Table 2**).

Evaluation of the second research question:

*Are the spiritual needs in hospitals sufficiently replenished?*

On the basis of the evaluation of the results of our research, we can state that of the 216 respondents (the total number of respondents was 318 and 102 of them did not have the need to replenish their spiritual needs - that is to say 216), 132 (61.1%) respondents were satisfied and 84 (38.9%) of respondents were dissatisfied with replenishing

their spiritual needs during hospitalization at the health care facility (**Table 5**).

## Discussion

In this part of the article we will focus on comparing our findings with the results of other authors. We were wondering if an infaust prognosis had an impact on the development of spiritual needs. Our results affirm the results of the group of authors Samson *et al.* (2003). In the article titled, *The experience of spirituality in hospitalized patients*, they concluded that more than 93% of patients with cancer believed spirituality helped them to strengthen their hope. Researchers emphasized the importance of the relationship with God as an aspect of spirituality that may provide some hope, optimism, and inner strength in adapting to stress (10). According to Samson *et al.* experiences of cancer patients also indicated that their transformation led to changes in their value system and priorities and they found a new perspective on life. All of these matters lead the individual to a position where life is meaningful and useful (11). The existence of a strong relationship between overall patient satisfaction and spiritual needs confirms the findings of the authors Ong *et al.* (12).

The authors Narayanasamy *et al.* dealt with the issue of satisfaction and the importance of spiritual needs. They reported correlation between the satisfaction of the spiritual needs and the satisfaction of the patient. In providing health care, they recommended interventions to meet the spiritual needs of the patient; including respect for privacy; helping patients connect with medical personnel; listening to their concerns; comforting and reassuring; using personal religious beliefs to assist patients; observation of their religious beliefs and practices (13).

Spirituality plays a significant role in the life of both the believer and the atheist.

Especially in the occurrence of complications of chronic disease or infaust prognosis, the spiritual aspect of human personality is of great importance. Insufficient care for patients' spiritual needs may have a significant effect on the quality of life and well-being of the patient but may also cause a deterioration in overall health.

## Conclusion

The results of this research study on a sample of 318 respondents (people over the age of 65), diagnosed with chronic complications or infaust prognosis clearly indicate that the following recommendations are needed to improve the state of care in the health care sector. These proposals mainly relate to attitudes of Doctors and General Nurses:

- Get acquainted with the Pastoral Care of the given hospital by healthcare professionals as part of the adaptation process.
- Inform patients (family) about the possibility of using spiritual services during reception and hospitalization.
- Create a unified recording system to identify the patient's spiritual needs in Nursing documentation.
- Establish the assessment of the patient's spiritual needs by an objective method - a questionnaire (for example FICA or HOPE).
- Improve communication between Medical Staff and Hospital Chaplains, and Pastoral Assistants.

It is also desirable to continue with a discussion of this issue.

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## Analysis of the Palliative Care Need for the Population of the Precarpathion Region (Letter)

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Original Article

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### Abstract:

**Objective:** The need for palliative care around the world will increase at least three times by 2040. So, it is crucial to predict which forms of palliative caregiving will be needed; how will this need grow in the next 3-5 years. That was our task.



**Methods:** Analysis of statistical reporting data for the last 5 years (Pre-carpathion Region).

**Results:** We have rationed the acute need of residents of the city and region in expanding the availability of palliative care for patients with chronic incurable diseases; especially at home; a visiting mobile team; the need to establish nursing homes care; with various forms of palliative caregiving and education for these.

## Background

The aim of the study. Within the framework of the last XVI EAPC Congress (Madrid, May 18-20, 2017), the need for palliative care around the world will increase at least three times by 2040. Therefore, assessing and analyzing such a need in our region is an urgent task for planning the proportion of different types of settings, such assistance, necessary human resources and facilities [1].

It is crucial to predict which forms of palliative care giving will be needed; which of them will be the most comfortable for the patient; will provide him and his family members with quality and affordable palliative care from the moment of diagnosis of incurable illness until the end of life in any place where the palliative patient is located [1]. And how will this need grow in the next 3-5 years. That was our task.

## Research methods

Analysis of statistical reporting data for the last 5 years (statistical materials of the *Regional Information-analytical Center of Medical Statistics for 2012-2016 years*) - where do the residents of the Region die and why do they pass away by? Analysis of the data of the population survey of Ivano-Frankivsk and the Region concerning palliative care.

## Main results

We performed an analysis of the 5-year trends in mortality and morbidity for the Precarpathion population in order to understand the changes in the number and causes of deaths in our Region. Attention was focused on the adult population (as an object of research), because there are more definite age and nosological groups.

The main trends of morbidity and mortality in the three most important nosological groups were analyzed, namely: *cardiovascular*, *oncological* and *cerebrovascular* diseases. The most significant was the increase in the morbidity of cancer (from 2,050.6 to 2,218.7 per 100 thousand us.) [2]. This also indicates an improvement in diagnostics.

In terms of mortality rates, a clear increase was observed in the *cardiovascular* groups (from 441, 89 to 493.71 per 100 thousand) and *cerebrovascular* (from 56.07 to 60.31 per 100 thousand), but non-cancerous diseases (in this group, mortality even decreased from 179.10 to 168.86 per 100 thousand us) [2].

In parallel, a survey was conducted among the inhabitants of Precarpathion Region (969 people were interviewed). It has been established that 72.4% of residents do not know at all what such palliative care is and where it is provided. 80.6% of the residents of Region indicated that in the event of a severe incurable illness, they would like to pass away complete at home, but with the help of doctors of the mobile specialized hospice team.

86.2% of residents who care for palliative relatives at home need help of the mobile specialized hospice team.

30.4% of such caregivers for seriously ill relatives would like and need a transfer of such a patient to a hospital (hospice).

## Conclusions

Detected trends of mortality and morbidity show:

1. The acute need of residents of the city and Region in expanding the availability of palliative care for patients with chronic incurable diseases, especially at home, visiting mobile team;
2. The need to establish nursing homes care, both in Ivano-Frankivsk and in future hospital districts;

3. The creating of mobile palliative teams in Precarpathion Region.

It is also important to expand the informing of the Precarpathion community about the possibility of providing such care and various forms of its provision.

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# Towards a Comprehensive Health Care: Human Rights Approach (Letter)

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## Abstract:

Health needs (in all points of this notion) should be identified as previously listed vitally important human needs and/or a vice versa. The right to life is equal to the person's right to being included in society; to being protected and supported; to have access to collective goods. Human rights concept should be seen as a key point of Public Health and must play the role of methodological platform for comprehensive healthcare.

## To the Editors

The aim of our research was to analyze, in what measure, is the Human Rights Approach a methodological basis for providing of comprehensive health care: A pilot study using an analysis of web-sites, articles, experts, interviews.

It is well-known that illness affects a person mentally and socially in no less degree than it affects his/her physiological nature. It is also known that the biological, psychosocial and cultural domain of human beings influence each other in a strong interrelated manner. This notion leads to understanding of the social environment as an active agent of health forming and health-illness relationships. Moreover, society turns out to be the only system which is capable of satisfying a wide range of vitally important human needs corresponding with maintaining homeostasis and including feeding; clothing; housing; life protected artificial means and social infrastructure to provide, support and facilitate health, and which have been created and utilized on a collective base.

Besides that, according to numerous studies in the same arena of fundamental human needs are placed psychosocial needs. These are belongingness needs (attachment needs) (J. Bowlby); safety needs (the need for ordered, properly ruled and predictable course of life and social relationships); the esteem needs; the needs in self-actualization (A. Maslow) which are also, as it was shown, facilitate homeostasis or biopsychosocial equilibrium in a wider social and cultural context; that actually means that biological adaptation and social (norms-values) adaptation go together (E. Durkheim, R. Merton, R. Fogel, R. Wilkinson).

Such a vision opens a new dimension for analyses of health-illness relations with respect to human rights; as well as quality of life concepts in Public Health discourse.

Indeed, from these above mentioned, derives the concept that health needs (in all

points of this notion) should be identified, as previously listed, vitally important human needs and/or a vice versa. Hence, the health care might to be seen as a care which is addressed to basic human needs. Nevertheless, health care is still associated with medical care and meets basic human needs (health needs) only partially making stress predominantly on disease and its somatic issues.

At the same time, human rights, namely the right to life, is essentially the right to satisfy vitally important needs which are directly related with social relationships; social inclusion; social norms and values. In other words, the right to life is equal to the person's right to being included in society; to being protected and supported; to have access to collective goods. From another side it means for a person to be attached; to be loved; to have the possibility to unfold his/her own personality in social roles performing, doing what he or she is fitted for. In turn, it means that poverty; low living standards; psychosocial stresses caused by inequalities of all kinds; as well as anomy (little moral guidance); social exclusion; lack of social cohesion carries permanent health risks and must be considered in the context of human rights violations.

In case of disease a person faces similar risks. Even innocent disorder is able to unsettle a person's life course; not to mention the more serious cases threatening death; irreversible functional disabilities; social exclusion which as it already has been noted contains the same hazards and provokes further development of disease.

For this reason, the qualitative and quantitative evaluation impact of disease and a person's health status measurements denote the set of variables describing the physical, social and mental functioning of a person with reference to quality of life and wellbeing, and which could be interpreted as one may conclude in the human rights framework.

Therefore, the concepts of human rights; quality of life; health needs should be considered in one functional plan.

Namely, the rights of the needy person must be analyzed in light of the quality of life and efficiency of care received by him; undertaken medical and social measures; its efficiency should be evaluated under the eye of human rights and to what extent it contributes to improving of quality of life; evaluation of the quality of life requires appealing to the person's capacity to realize his/her own rights.

In practice, such an approach could be represented with the follow procedures:

- A) Evaluation of a person's actual health status.
- B) Identification of disease/social environment impact, namely unsatisfied basic vital needs articulated due to disease and/or external circumstances, or subjected to its influence.
- C) Identification of activities/measures which have to be undertaken in order to protect a person from negative somatic and psychosocial influences of disease; or which are able to compensate them.
- D) Revealing the links between activities should to be undertaken and institutional tools in providing of human rights referred with particular vital needs. This point should make a clear distinction between human rights and patient rights concepts. The "patient's rights" is an important but institutionally restricted notion which must not

be a substitute for the generalized and universal concept of human rights.

The above considerations could be summarizing with the following conclusion:

Human rights concept should be seen as a key point of Public Health and must play the role of methodological platform for comprehensive health care.

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# How an Aging Population in Slovakia Impacts the Utilization of the Current Array of Long-Term Care Services (Review)

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Original Article

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## Abstract:

**Objective:** The aim of this research is to analyze aging population demographics compared to the current demand of long-term care services available in the Slovak Republic.

**Methods:** This paper is a secondary source research study augmented by person to person conversation with Slovak Doctoral Students at Trnava University.

**Results:** The Slovak government should increase efforts to integrate both the social and medical healthcare spheres.

**Conclusion:** The study indicated that the Slovak Republic is experiencing an aging population and may not be able to accommodate elders in the future due to an increased demand for services. There is opportunity for growth within the informal caregiving sector by increasing support and education. Increasing preventative and ambulatory care services can ensure accessibility and more medical staff educated in the field of Geriatrics. There is an opportunity to conduct more research on future long-term care trends.

## Introduction

Almost every country in the world is experiencing an aging population. The increasing share and proportion of people aged 65 years or older is drastically changing the social sphere of every country. Population aging includes implications for nearly all sectors of society. Preparing for a dramatic social change is essential to ensure a country's continuous development. This causes a need to identify specific impacts and propose solutions to respond to the changes.

Countries all over the world are experiencing shifts in long-term care due to an aging population. This shift is inevitable and known as a "demographic revolution, characterized by low birth and death rates respectively to prolong human life" (Pavelek, Eidenmueller, 924). Aside from an aging population, technological and scientific advancements have also contributed to mortality decline, ultimately influencing better health and longevity. The elderly population as a whole is defined as persons aged 65 years or older. People aged 65-74 are known as "young-old," while those aged 75 or older are known as "old-old" (Pavelek, Eidenmueller, 925). This is causing long-term care to become one of the fastest growing sectors in healthcare today.

## Demographics

The Slovak Republic, like many Central European countries, is experiencing an aging population. Currently, there are approximately 5,433,381 people living in the Slovak Republic. According to *Eurostat: Population Structure and Aging*, in 2015, persons aged 65 years or older accounted for approximately 14% of the total population. By 2025, that %age will rise to 18.1%, and by 2050, 24.8% of the population. Currently among the top five youngest countries in Europe, the Slovak Republic will become the oldest country in Europe by 2080. According to *Eurostat: Population Structure and Aging*, the median age of the Slovak Republic in 2016 was 40.1 years old, while in 2080, the median age is expected to rise to 53.7 years, a 13.6-year difference.

An old age dependency ratio is a ratio of elders, or those not currently active in the workforce, to the working age population, which is often defined as ages 15-64. This ratio is defined as the amount of persons aged 65 years or older for every 100 working age persons in a given population. According to *Eurostat*, in 2010, persons aged 15-64 accounted for approximately 73% of the population. By 2050, that %age is expected to decrease to 57% of the population, a 16%age point decline. As of 2015, there were 19.8 persons aged 65 years or older per 100 working age persons, or a 1 to 5

ratio. By 2060, there will be 57.2 persons aged 65 or older per every 100 working age people, or a 1 to 2 ratio. With this increase, there will be greater pressure placed on the productive part of the population to provide goods for themselves and also the older portion of the population (*Eurostat*).

Currently, out of the Slovak Republic's population, approximately 770,000 people are aged 65 and older. Of those 770,000 people, approximately 200,000 people require long term care services. Of those, approximately 38,000 receive formal, institutional medical care, 70,000 receive formal, home-based social services, and 61,000 receive informal care provided by informal caregivers. Thus, approximately 31,000 elders, or 15.5% do not receive the proper care they need (The Long-Term Care System for the Elderly in Slovakia, 11).

## Long-Term Care Services

The current array of long-term care services in the Slovak Republic is represented by two main spheres - social care services and healthcare services. Social care services aim to rehabilitate a dependent person to live a more independent life. These services are concerned with alleviating unfavorable social situations for a dependent person. Social care services consist of outpatient, inpatient, and home care, including supported living facilities, nursing care facilities, facilities for seniors, social housing, day care facilities, community care, social rehabilitation, retirement homes, and informal home care (The Long-Term Care System for the Elderly in Slovakia, 6-7).

Healthcare, also known as institutional medical care, is provided for people who need care for twenty-four hours per day or longer. These services include inpatient and outpatient care such as medical facilities, ambulatory care, mobile hospice care, nursing homes, hospitals, long-term care departments,

and sanatoriums (The Long-Term Care System for the Elderly in Slovakia, 4-5).

Another category, which stems from social care services, is known as informal care. Informal care is provided by informal caregivers who are typically relatives, close friends, or neighbors of a dependent person. These services are paid on a monthly basis depending the elder's level of dependency. There are approximately 59,000 informal caregivers caring for 61,000 elders receiving informal care. 52% of informal caregivers are between the ages of 51 to 64. Women account for about 84% of caregivers, while men only account for a mere 16%. There is a lack of men in informal caregiving (The Long-Term Care System for the Elderly in Slovakia, 3).

To determine which services are provided to a dependent person, an assessment of their level of dependency and level of needs is addressed. Their level of disability is determined by their activities of daily living (ADL). A six-grade scale is assessed by an advisory committee comprised of Physicians and Social Workers. Act No. 448/2008 defines 12 criteria for ADLs, such as eating, drinking, sitting, walking, personal hygiene, washing, and orientation. The dependent person is then scored from zero to ten on their assessment of needs. The higher the degree of dependency, the more likely a person will be provided with institutional medical care. Due to limited capacity, the preferred outcome is providing the dependent person with social service needs or informal caregiving (Long Term Care of the Elderly, 96).

## Barriers to Long-Term Care

There are four potential barriers to the long-term care system in the Slovak Republic. There are governmental barriers, organizational barriers, financial pressures, and increasing pressure on informal caregivers.



There are governmental barriers to long-term care. There are legislative issues that arise when elders are using both spheres - social care and healthcare - in long-term care. Both systems are regulated by different acts, regulations, and legislature, which may not always be linked together, nor cover all services provided. Some acts have been prepared to combine both systems, but these acts were not approved (The Long-Term Care System for the Elderly in Slovakia, 17). Several acts have been put in place, however, social care and healthcare is not systematically regulated.

Since 2000, the Slovak Government has made efforts towards improving the legislature for long-term care. In August 2000, the National Action Program for the Protection of Elderly People, or NAPPEP, was approved (OHCHR). The aims of this program were to help elders live an independent life, inclusion in social participation, integration into society, and autonomy. The goal of the program was to prepare society for an aging population. This program addressed five key principles for elders—the principle of independence, participation, caring, self-realization, and dignity (OHCHR). In November 2000, the State Policy of Health in the Slovak Republic was approved. This policy defined three long-term care priorities: enhancing healthy aging, developing and increasing palliative care, and improving mental health (Government of the Slovak Republic, 2000).

Although improvement efforts were gaining headway in the early 2000s, much of the government's success efforts ended by 2005. A legislative act to support long-term care and disabled persons was prepared in 2004 but was never approved by the government. In 2005, the Slovak government approved the Strategy on Healthcare for Geriatric Patients and Long-term Patients and the Conception of Social and long-term Care in the Slovak Republic, but the proposals for

the acts stopped by the end of 2005 (The Long-Term Care System for the Elderly in Slovakia, 16). There are also efforts to create “amendments and reparations that aim to equalize providers of Social Services, but lack of financial resources in budgets of self-governing regions and municipalities creates a non-equal environment for private social care providers” (Long-Term Care of the Elderly, 88).

There are also organizational barriers within the long-term care system. With two separate sectors providing care to elders, there is little coordination between the two. In the early 2000s, the Slovak Republic's Government began efforts to integrate both sectors to create one integrated model of social and long-term medical care. However, in 2005, these integration efforts were stopped. To integrate these models, both sectors should first be improved (The Long-Term Care System for the Elderly in Slovakia, 16).

There are financial pressures on the long-term care system in the Slovak Republic. With the increase in services needed in the near future to accommodate the aging population, there is a demand on revenues from the working age population. However, revenues are expected to decrease due to a decline in the working age population over the next fifty years. The reduction of the working age population is expected to also cause a decline in the average annual GDP (OECD, 2012). This decline will add additional pressure to the health system and may need to create measures to keep people in the work force longer (WHO, 2009).

## **Solutions and Opportunities**

With a lack of information, there is an opportunity to conduct more research on future long-term care trends in the Slovak Republic. The long-term care system is in need of simplification and unification. Current future

needs are not well-defined and should be further addressed to accommodate future trends in an aging population. Since the *Velvet Revolution*, healthcare, especially long-term care, has been in a transitional period. Tasks and priorities need to be addressed for future needs (The Long-Term Care System for the Elderly in Slovakia, 14). Some possible solutions to address the expanding need are providing additional support, information, and education for informal caregivers, creating an integrated model of care, focusing on additional needs in preventative, ambulatory, geriatric care, and increasing additional institutional capacities.

Additional support, information, and education should be provided to those providing care to their loved one. Currently, informal caregivers are not required to have any special qualifications or training to provide care. Measures should be put in place to provide assistance to those providing care, such as training, counseling, or coaching from healthcare professionals. Classes can be held at local healthcare organizations to teach caregivers the most efficient ways of providing care. In addition, men should be encouraged to participate in caregiving (OECD).

The Slovak Republic should work towards integrating both the social and medical sector under one joint model. There is currently a wide variety of services offered within the social sector, but these services will need to be simplified to fit with the institutional, medical sector (The Long-Term Care System for the Elderly in Slovakia, 6). To integrate these models, both sectors need improvements under the authority of both ministries. The social care sector will require additional resources in the future to accommodate the increasing elder population. The institutional, medical care sector should aim to reduce the supply of medical care. There is opportunity to provide integrated services, but, currently, the Slovak

Republic's long-term care facilities do not fulfil the criteria to do so (The Long-Term Care System for the Elderly in Slovakia, 16).

There is also an opportunity to provide additional needs in preventative care, ambulatory care, and institutional, geriatric healthcare, as stated in the *Conception of Social and Long-Term Care* (Government of the Slovak Republic, 2005b) and *Strategy of Health Care for Geriatric Patients and Long-Term Patients in the Slovak Republic* (Government of the Slovak Republic, 2005a).

In these needs, additional institutional capacities should be met. Preventative care puts an emphasis on preventative programs such as The National Cardiovascular Program, Oncologic Program, and free vaccinations for people 65 years of age or older. These programs should be continued based on needs, and there should be increased knowledge about the importance of taking preventative action. This could ultimately reduce the number of elders using institutional, medical care in the future if their illnesses are prevented. From a global perspective, increased attention should be placed on preventing infectious disease (Skolnik, 26).

Ambulatory care also requires an additional focus. According to page 15 of *The Long-Term Care System for the Elderly in Slovakia*, Practitioners should place an emphasis on improving the care and maintenance of chronic diseases, while working closely with nursing care agencies and other social care facilities. There should also be increased availability of ambulatory care services in all 79 counties of the Slovak Republic. This will ensure accessibility to care and increased medical staff educated in the field of Geriatrics (The Long-Term Care System for the Elderly in Slovakia, 15).

For those who have chronic conditions and need prolonged medical care, there is institutional and geriatric medical care, which is provided in geriatric departments

of hospitals and sanatoriums. Increased bed capacity and facilities for palliative care and hospice are needed to address the increase in demand. According to the Ministry of Health, there should be at least one geriatric department in each region in the Slovak Republic, along with an increase in Geriatric Specialists (The Long-Term Care System for the Elderly in Slovakia, 16).

## Conclusion

An aging population presents challenges within the Slovak Republic's long-term care system and will have a major impact on the delivery of care in the future. Population aging presents new philosophies on the relationships between the delivery of social and medical care. While there had been legislative changes in the past, the long-term care system has not been an established concept and is currently integrated into different sectors of healthcare. Knowledge is limited on good practice policies and future trends. This fragmentation hinders the development of the healthcare system, the communication between sectors, and limits the opportunity to measure and evaluate long-term care trends.

These demographic changes present opportunities for improvement within the Slovak Republic's long-term care system. There is a greater need to recognize and prepare for the integration of the social care and medical care sectors. This integration could reduce the need for medical care and provide the social care system with additional resources. It is important to recognize the role of caregivers within the social care sector. The increase of informal care givers through awareness and support will run parallel with the increase of the population. Lastly, an increased emphasis on preventative programs, ambulatory care, and geriatric health could increase the capacity of services and may prevent elders from needing care.

An aging population, the need for an integrated model, and the need for greater availability of service capacities will further place pressure on the Slovak Republic's long-term care system. This provides greater opportunity to respond to these needs and prepare for increasing population trends.

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# How Palliative and Hospice Care are Organized in Ukraine (Review)

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Original Article

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**Abstract:**

In the world, *Palliative and Hospice Care* (PHC) are approaches conceived to improve the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical; psychosocial; spiritual. In Ukraine, the first efforts to develop PHC already have been made 20 years ago. In 2006-2017 the breakthrough

was made. In our research, we have analyzed the activities of both governmental bodies and non-governmental organizations in the field of development of PHC. Our main conclusions are that PHC in Ukraine is just starting to develop; the philosophy of PHC just forming. Organizations which develop PHC are very young. As Ukraine is the former Soviet country, paternalistic traditions are very alive here so that many directives, orders and other documents go from above (from Ministry of Health mostly) and the grass-roots are rather rare. As many organizations have not yet undergone training yet, the main directions of the work to develop PHC are advocacy; improvement of the legislation; training for civic leaders, specialists and other stake-holders.

## Introduction

PHC is a modern approach developing globally. The level of its development is defined by many factors - state of humanity, civil society, economics etc. Ukraine is one of the post-Soviet countries which accepts different models and approaches, and PHC is one of them.

## Objective

The aim of our research was to analyze the organizational patterns of the development of PHC in Ukraine: the activities of both governmental bodies and non-governmental organizations in the field of development of PHC.

## Methods

This is a pilot study. Analysis of web-sites, papers and reviews.

## Results

**Results** The last research funded by the *International Renaissance Foundation* in Ukraine declares that in the documents which regulate palliative care for people with HIV / AIDS, there are no detailed mechanisms for collecting data on needs in palliative care. The collection of detailed statistics on palliative care in the sphere of tuberculosis is not foreseen. In the cancer

sphere, an electronic register of patients in Ukraine exists which contains detailed data on more than 3 million patients; where the nature of treatment (radical or palliative) is recorded. The experience of implementing and completing the cancer registry can be useful for the development of palliative data collection systems. No other valid statistics on palliative and hospice care exists (Guzij, 2017). According to statistical data of the Association of Palliative and Hospice Care (APHC) and considering WHO recommendations about PHC, at least 500,000 end-of-life patients and nearly 2 million members of their families in Ukraine need supportive care every year (Wolf, 2013). Accordingly to the last official statistics, there are around 42 million people living in Ukraine.

Because this problem was very actual, the first palliative and hospice care initiatives appeared in Ukraine in the first years of independence, after USSR break-down.

In 1990s, the basic governmental organizations in Ukraine which developed palliative and hospice care included those within the structure of Ministry of Health. In 1990s, the basic health care establishments, which provided palliative care in Ukraine, were the hospices; palliative care departments in regional or city hospitals; hospitals of oncological, tuberculosis and

geriatric profiles; HIV/AIDS centers. Inpatient PHC institutions provided then (and provide now) the medical care and elements of psychosocial and spiritual support. The first formal in-patient hospices in Ukraine were established in Lwiw, Korosten and Ivano-Frankivsk in 1996-1997. Notable, that Lwiw and Ivano-Frankivsk Hospices have been organized by the local health care administrations as the “special” facilities which have been (and remain now) in the structure of these administrations with the relevant reporting, financing, educational, logistics and other procedures. As one of the founders, The Korosten Hospice had been organized in the form of a charity, with health administration.

Civic society initiatives have been rather weak then and did not play an evident role in the development of PHC.

The National State Program *Oncology 2002-2006* (which had aimed at the prevention of cancer and improvement of life quality of those with cancer) have mentioned palliative and hospice care, and noted the need of establishing the hospices, but it did not provide the budget for this activity. Anyway, some regions have created hospice (palliative care wards), for example in Kyiv and Lutsk.

In this time some hospices for patients with tuberculosis have been established within the base of some TB hospitals.

In that period (2000s) the activity of NGOs in Ukraine became more evident and encouraged some changes. Advocacy, mobilization and capacity building helped PHC start to be on the agenda for governmental organizations.

Notably, the *All-Ukrainian Association of Palliative Care* during its monitoring of existing PHC services received formal answers from local health care administrations like:

“Our region has no hospice because the dying patients die at their homes accordingly

to the Order of the local health care authority”.

PHC services for dying patients at home have not been provided.

Patients’ general rights and especially their right to get comprehensive care in the end-of-life have been used as the main message helping to advocate PHC among Ministry of Health Policy-makers. On 11<sup>th</sup> September, 2008, at the Ministry of Health with the participation of the Minister and representatives of various Churches, a round table was held on the topic *Rights of patients in Ukraine. Palliative care: spiritual aspects. Pastoral care for severely ill and dying persons*. It was a step towards dialogue to coordinate joint actions of physicians and Churches for the sake of health and good for people. For the first time in the history of Ukraine, the Central Executive Authority met with representatives of different denominations not for the sake of politics, but to do something specific for people. As a result of another joint meeting, which discussed the issue of reducing the practice of abortion, a working group on the study of this issue was initiated at the Ministry of Health. In September 2008, a working group elaborated on *the Concept of Counter-action to Abortion in Ukraine* and conducted the Symposium *Moral and ethical aspects of artificial abortion* (Bratsun, 2011). Messages considering human rights and humanization /modernization of medical/health care in Ukraine have been used by non-governmental organizations to advocate and encourage PHC development.

## Discussion

As a result, changes to basic Ukrainian Law on organization of health care have been made and PHC was mentioned as a separate level of medical care. The Law became activated on the 1st of January 2012. Thus the PHC have been legalized as

in fact no Ukrainian Laws had mentioned or regulated it up to now.

On December 1, 2009, the *Department of Palliative and Hospice Medicine of the National Medical Academy of Postgraduate Education* was established. A member of the *National Academy of Medical Sciences of Ukraine, Doctor of Medical Sciences*, Professor Yuri Ivanovich Gubsky was appointed as Head of the Department and continues to be its head in 2017.

From 2015 to 2017, the transformation of hospitals and HIV/AIDS centers into facilities which provide palliative care continued. For example, the regional HIV/AIDS center in Mykolaiv was transformed into the regional center of palliative support and integrated services. Accordingly, to information of the Regional Health Care Administration, the center provides only the medical component of palliative care.

As we easily can see, the establishing of hospices went from above, mostly from Ministry of Health, and depended on the wish and possibilities of authorities.

As a result, it should be noted that most people still do not have access to comprehensive PHC. In accordance with the data of All-Ukrainian Association of Palliative and Hospice Care as of January 1, 2013 there are 5 inpatient hospices and 13 palliative care departments, which have 521 inpatient beds, and 7 HIV/AIDS centers (up to 50 beds) in Ukraine established by governmental organizations. Also 3 PHC institutions (about 65 inpatient beds) are charitable and are established by NGOs, and the Local Health Authorities as Co-founders. Also, bed capacity covers only about 20% of demands for inpatient hospice care (at a rate of 10 beds for palliative patients per 100 thousand population, that is 4,600 beds for Ukraine). Thus, PHC is provided mainly at home by relatives or carers of patients. These data have shown a significant deficiency of specialized medical institutions in

providing PHC to patients and psychological support for their families after the loss of relatives (9, 10).

In 2013, International donors and local authorities supported by local non-governmental organizations have initiated a local fundraiser to support creation of the first Children's Hospice in Ukraine. The institution should be created in Nadwirna in Western Ukraine within the structure of the Ministry of Health Institution (so called "Child's hHome"). In 2015, the First Children's Hospice received this criticism from the *President's High Commissioner on Children Rights*:

"The Nadwirna Child's Home almost does not provide a social component of care; has no social worker, psychologist, lawyer in the staff; any mechanism for interdisciplinary cooperation is absent. Together with small financing, this means that no services could be provided for the ill person and his/her family" (8).

In 2017, the Institution reduced its *Palliative Unit* to 10-15 respite beds where severely ill children for several days during their parents short "vacations".

With the support of the *United Nations Children's Fund (UNICEF)* and in partnership with the *Ukrainian-German Medical Association*, the law firm *ILF* and the *Kharkiv National Medical University*, the *Perspective Agency* have begun transforming Child's Homes into Rehabilitation, Palliative Care and Early Intervention Centers to provide social-medical services not only for children, but also for families. The purpose of the project, implemented from November 2016 - May 2017, was to create and develop a mechanism for the transformation of residential institutions into centers providing family-oriented services for children with special needs.



As mentioned above on 1<sup>st</sup> January 2012, the Law where PHC have been included have been activated. Then in 2013 the former Health Minister Vasyl Knyazevich and his group (League for the support of palliative and hospice care in Ukraine) developed and encouraged implementation of Minister Order # 41. Upon analysis, we have concluded that the document has rather negative effect on the PHC. The document supports the Ministry of Health as a leading body in the PHC field: underlining that only those organizations which shall have pain management and relevant licenses on medical clinical practice shall be the PHC facilities. The Order encourages the paternalistic approach; non-governmental organizations which face corruption barriers in obtaining state licenses, lose the possibilities to provide PHC.

Notably that the National strategy of health care reform in 2015-2020 (4), elaborated in 2012-2014, mention palliative care just one time and did not regulate it. Anyway, the Law on state financial guarantees of medical services voted by Parliament in the frameworks of the medical reform of 2017 does not mention palliative medical care. It is declared as a free of charge service. The service shall consist of pain evaluation; prescription of drugs; pain syndrome treatment (3).

In the process of analysis of the activities of governmental organizations in PHC development, we have noted that Ministry of Social Policy noted the problem for PHC as well.

In 2008, the Ministry of Social Policy supported an innovative project initiated by the Association of Palliative and Hospice Care for development of PHC in the structure controlled by this Ministry. Also elaboration of methodical recommendations on its development have been done (Wolf, 2011). An innovative project on provision of palliative care for the elderly at home, informs

the Ministry of Social Policy, has been successfully implemented for two years. As a result of approbation, since March 1, 2012, a Palliative Care Unit has been established at home. There are more than 100 people in the service at this Department. The Department has Social Workers, a Psychologist, a Physician, a Nurse. All clients are provided with auxiliary medical equipment upon request. Palliative care is carried out in close cooperation with health care facilities. The list of social services includes Palliative/Hospice Care, providing self-service (personal hygiene, medication, feeding); monitoring of health status; assistance in the provision of medical services; assistance in providing technical rehabilitation equipment, training in their use skills; training of the family caregivers; psychological support of a person and family members; assistance in obtaining free legal aid; organization and support of self-help groups (6).

Notably that the Ministry issued another Order which approves the standards for *Social Service Home Palliative Care* and this document has no allusions to Ministry of Health Orders on PHC. This official document allows various organizations (for example, businesses) to develop this type of care. The State Standard of Palliative Care (the Order of the Ministry of Social Policy of January 29, 2016, № 58) defines the content, norms, conditions and procedure for the provision of social care services in the frameworks of the palliative care. Some institutions in the structure of the Ministry – in Uman, Kyiv, Krasny Kut and other towns and cities have established *palliative care units* and other similar institutions but multidisciplinary team work and pain management remain rarities here as well. For example, in Uman, within the framework of the social care center offer just 10 palliative care beds (7). Non-governmental organizations (NGOs) activities have been analyzed as well.

The *All-Ukrainian Council for Patients' Rights and Safety* in cooperation with the *All-Ukrainian Association of palliative and hospice care* initiated the development of PHC in 2006. Mostly, it was within the framework of international grants of donors affiliated to *Soros's Open Society Institute*. It was NGOs which have encouraged the development of new documentation, orders, and standards on PHC. In 2006-2009 the *All-Ukrainian Association* has united and started the advocacy. 2008 was the year of a breakthrough in the field of palliative care. With the support of the Program, the *All-Ukrainian Palliative Care Association* and the *All-Ukrainian Council for the Patient's Rights and Safety*, prompted the creation of the Coordination Council for the Development of Palliative Care in Ukraine, the composition and powers of which were approved by a relevant *Order of the Ministry of Health*. According to the *Order of the Ministry of Health*, the Council developed and submitted for Ministerial approval the *National Program for the Development of Palliative and Hospice Care for 2010-2014*. The creation of the National Program allowed not only the introduction of palliative care in Ukraine as part of the General Health Care System, but would also oblige the government to allocate a budget for financing palliative needs and services for the population. The financial and expert support of the Program and the *International Palliative Care Initiative* also resulted in a 3-week training for health professionals (Doctors, Nurses) providing palliative care. Given the critical shortage of health professionals in this area, the training has significantly contributed to the training of 30 specialists who will further train their colleagues in the regions. The training provided a powerful impact to the implementation of palliative care in Ukraine and the development of a network of facilities providing palliative care services (5, 2).

In 2011, the new *National League for Support of PHC Development in Ukraine* was created. This NGO was founded by the former Minister of Health V.Knyazevich who is its Head of the Board since then. After analysis of news and other posts of the *League*, we can conclude that the *League* is rather medically oriented, and regards other elements (psychosocial, spiritual) as additional ones. For example, the Heads of the *League* in their article state:

"The medical and social analysis of the development of the Provision of PHC to the population of Ukraine has shown that the unsatisfactory state of the PHC system development is largely caused by the insufficient population provision by the specialized PHC facilities homecare teams; lack of staff in PHC facilities; lack of proper motivation for health workers; the need to improve the regulatory framework regulating the provision of PHC to the population; unsatisfactory interdisciplinary collaboration of healthcare workers, both in inpatient and outpatient settings and at home. So that the key problem of PHC in Ukraine is that there are no palliative units" (Gojda *et al.*, 2015).

The *Association of Palliative and Hospice Care* believes that the key problem for PHC in Ukraine is a weak civic society which should develop the PHC from the grassroots. And, during the development of PHC in Ukraine, the moving force should be not representatives of the health care which need the reform themselves, but civic activists.

Since 2013, after the release of *Pain Management Procedures*, NGOs provide advocacy and capacity building of Healthcare Workers. Also, NGOs have initiated some positive changes in the formal education on the issue of care for the incurably ill. The *Association of Palliative and Hospice Care*, for example, cooperates with different medical facilities; organizes study visits;

clinical placements; other events. This organization pays the greater funding for the development and supporting of grass-roots initiatives and capacity building. Such were the local initiatives on elaboration and implementation of local programs on development of PHC in Cherkassy, Kharkiw, Irpin, Vasylkiw and other cities; conducting the numerous trainings on project management and human rights etc. In its trainings, the *Association of PHC* pays great attention to the explanation of the sense of PHC.

The great efforts in advocacy of PHC development belongs to the *International Renaissance Foundation* which has supported the PHC since 2000s.

In 2016, the *Association of Palliative and Hospice Care* started a program of education of civic leaders from different regions of Ukraine. Up to 15 trainings and workshops were done in 2016 and 2017.

Notwithstanding the efforts, until now, regional hospices have not been established in Vinnytsia, Dnipropetrovsk, Transcarpathian, Kyiv, Odessa, Poltava, Sumy, Ternopil, Khmelnytsky, Cherkassy, Chernihiv Regions and the City Hospice in Kyiv. In Ukraine there is almost no PHC at home. Only in a few regions, in particular, in the cities of Ivano-Frankivsk, Lutsk, Kharkiv, Kiev, Lwiw, Vynohradiv (Transcarpathian region), at hospices and PHC departments, there were established mobile home care teams of palliative care, both in public health care institutions, as well as charitable and public organizations.

## Conclusion

The pilot study shows that PHC in Ukraine is just starting to develop. The philosophy of PHC is forming and sometimes it is misunderstood, especially in governmental structures, and non-governmental organizations work to influence better standards of PHC. Organizations which develop PHC

are very young. As Ukraine is the former Soviet country, the paternalistic traditions are very alive here so that many directives, orders and other documents go from above and the grass roots are rather rare. As many organizations does not underwent the training yet, the main directions of the work to develop PHC are advocacy, improvement of the legislation, and trainings for civic leaders, specialists, and other stake-holders. Institutes (and PHC is an social institute) are the people and their culture. Sometimes these people are outdated. And we can create the most modern institutes with the best ideas, but if they shall consist of the same outdated people with the same outdated ideas, we shall get the same outdated result. So, to develop PHC in Ukraine, we should develop the culture and civic society, especially, grass-roots initiatives. We believe that NGOs will be the driving force of changes in how we care for incurably ill people in Ukraine. Otherwise, PHC shall become the cargo-cult.

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