Challenges of the current medicine

Krajewska-Kułak Elżbieta, Kułak Wojciech, Łukaszuk Cecylia, Lewko Jolanta, Sarnacka Emilia

vol.5

Challenges of the current medicine

Volume V

Medical University of Białystok Faculty of Health Sciences

Challenges of the current medicine Vol. 5

Edited by Elżbieta Krajewska-Kułak Wojciech Kułak Cecylia Łukaszuk Jolanta Lewko Emilia Sarnacka

Białystok 2016

Reviewers

Wrońska, Irena Faculty of Nursing and Health Sciences, Medical University of Lublin, Lublin

Kędziora-Kornatowska, Kornelia Departments of Geriatrics, Nicolaus Copernicus University, Collegium Medicum, Bydgoszcz

> Grochans, Elżbieta Department of Nursing, Pomeranian Medical University, Szczecin

> > ISBN-978-83-940670-2-1

The first Edition Białystok 2015

Graphic Design: Agnieszka Kułak

Published by: "Duchno" Piotr Duchnowski, 15–548 Białystok, Zaściańska 6

Medicine will always remain an art, because the doctors will have to deal with an individual, different a human and not the generalized model Antoni Kępiński

Dear Colleagues

The monograph periodical "*Challenges of the Current Medicine - 5 Edition*" is a collection of works written by authors from many different medical centers.

The leading theme of the monograph applies patient, mainly the dying patient. Eveny Even Leonardo da Vinci said that 'Doctors who deal with patients, they should be sure to understand what man is, what life is and what health is, and how the balance and harmony of these elements support them'.

In the particular chapters are discussed various problems therapeutic care problems occurring in modern medicine, selected sociological threads of the dying person, approach to transplantation, euthanasia, genetic diagnostics of cancer and the role of support groups in the process of grieving child. We discussed the role of the therapeutic team in improving the quality of life of patients and problems associated with miscarriage and morbidity in doctors.

We hope that the subject the monograph allows demonstrate that respect for the dignity of the patient, regardless of his state of health.

As the authors we believe in the truth from words of Elizabeth Kübler Ross. 'With care and love you can heal many suffering people I do not want to say that medical knowledge is not necessary, but only knowledge will not help anyone. You will not help anyone, if you do not involve your head, hearth and soul. In my work with patient I learnt that life has its value, does not matter if patient with schizophrenic, mental dysfunction or just dying. All of them can not only learn from you, take help from your, but also can be your teachers'.

> Prof. Elżbieta Krajewska-Kułak MD, PhD Prof. Wojciech Kułak MD, PhD Cecylia Łukaszuk PhD Jolanta Lewko PhD Emilia Sarnacka PhD

Social worlds of the dying person - selected sociological threads

Social worlds of the dying person - selected sociological threads

Piątkowski Włodzimierz¹, Majchrowska Anita^{1,2}

- 1. Independent Medical Sociology Unit, Medical University of Lublin, Poland
- Department of Medical Sociology and Sociology of Family, Institute of Sociology, Maria Curie Skłodowska University in Lublin, Poland

Introduction

From the sociological perspective death is a peculiar social phenomenon constructed by communities and culture, influenced by sociocultural factors and with attitudes differentiated historically and geographically. The fact of death itself is not the central point of sociomedical analysis but a complex process of 'slow dying' with the time frame from an unfavourable diagnosis to decease. From the sociomedical point of view death constitutes a multidimentional phenomenon encompassing a range of social situations that accompany the process of dying. The process involves a lot of "actors" collaborating on the social world of a dying person. Among them there are family members, friends and acquaintances of the dying, staff of the institution where the process takes place, and last but not least the dying person. The awareness of inevitable death changes both the character and specificity of the interaction between the environment and the dying, affects forms and ways of communication as well as the social situation in which the participants of the process take part.

Sociological concept of the social world derives from the inspiration of humanistic sociology and sociological theory of symbolic interactionism. Studies by Strauss, Becker and Clarke were the basis for A. Kacperczyk to define social worlds as some "social wholes" which are engaged a particular activity, equipped with the competences for performance, have proper technology which enables action, and share resources which allow for achievement of intended goals. Participants of "the social world" are obliged to proceed the action. They also create common ideology referring to the fashion of dealing with the action and pursuing world's interests as the entirety [1].

As K. Konecki quotes the term "social world" was used for the first time by P. Cressey concerning participants of "dance schools". He defined their social environment as "a distinct social world with its own ways of acting, talking and thinking" which has" its own

vocabulary, activities and interests, its own conception of what is significant in life, and to a certain extent its own scheme of life" [2].

According to K. Konecki, "the conception of social worlds also relates to certain phenomena defining the reality by the participants [...]. Although social world can be defined in the singular, the phenomenon of multitude for social worlds always occurs and they never exist without connections with other worlds with which they often cut across, combine or cooperate"[2].

The aim of the study is to attempt to present social worlds of the dying person, distinguish actors playing in it and specific schemes of action which are characteristic for individual areas the world is identified with. In spite of the fact that the definition of the social world is a point of departure, the authors highlight that they do not refer to the established theory and what they do is merely interpretation of characteristic features for individual worlds on the basis of selected literature.

Selected issues of death and dying in classical medical sociology

In Western medical sociology, sociothanatological problems are present, though they have occurred with different intensity since emergence of the subdiscipline. However, it is worth mentioning that these issues have been marginalized and avoided in the main trend of sociomedical topics since the 1970s. First of all, sociodemographic perspective has been dominant and refers to the phenomena of mortality and mortality rate. Researchers tend to focus on statistical aspects related to death, describe standardization of mortality rates, their economic, racial or ethnic conditions as well as socio-etiology of infant mortality [3].

Later sociothanatological publications refer to the influence of new medical techniques on 'scenarios of dying", the necessity of developing socially accepted death criteria: biomedical, cultural, religious [4], but they also evolve towards deinstitutionalization, description of forms of care and support provided outside the hospital. However, little concern is still devoted to individual and personal perspective in the reception of phenomena and phenomena themselves which are related to the process of dying. There are few studies of social reactions to dying. Topics of a family in a "situation of death" and of "social phobias" surrounding the phenomena in consumerist societies, etc. are rarely raised. Only in the 1990s social researchers spotted qualitative changes linked to the prolonging process of dying and consequently, they noticed new needs and expectations of people with terminal diseases (communication, techniques of support, diagnosis of needs). A "critical trend" occurs in "sociology of dying" and refers to inter alia "formatting and technologisation of death" in large clinical hospitals "death in the culture of biomedicine"[5]. The subject of the discussion is the fact that modern hospitals with their personnel are not prepared for communicating with terminal patients and their relatives [6]. Opinions have occurred on the necessity of further analyses of "awareness of dying", stages of dying, limits and rules that guarantee the patient's passing away in privacy and dignity, respect for religious practices in public hospitals, etc. Furthermore, research projects were also suggested concerning sociological analyses of rites accompanying mourning [7]. H. Bradby points out that in the first decade of the 21st century, death and dying were included in public discourse connected with the necessity of redefining the limits of life in the context of revolutionary changes in medical technologies, transplantology, genetics and intensive therapy [8].

Thanatological themes in Polish sociomedical literature have been clearly discernible since the 1980s. Earlier studies were mainly publications by doctors who noticed the psychosocial aspects of death and dying [9,10]. The first Polish sociomedical studies of that time also contained thanatological texts often reprinted from Western publications [11,12, 13,14] showing the psychosocial perspective of the dying process; their common characteristic was that they were focused on the dying person, their problems and expectations, the special role of the medical personnel, and on ethical and procedural aspects associated with the fact of death. In sociomedical literature of the time problems of social attitudes towards death constituted a separate thread. Then M. Sokołowska was the first to raise the topic and highlighted changes of attitudes towards death in contemporary societies with the range from visibility, naturalness and "familiarizing" with death to treating it as "a technical error" and "taboo topic" [15]. This theme, a prominent one in sociothanatology, was proceeded by many authors [15-22]. A. Ostrowska points out numerous social processes which contributed to changes in social attitudes to death. The most significant ones are secularization, urbanization, a change of the family structure from extended to nuclear as well as dynamic development and progress of medicine. They caused death 'to become distant" from the mainstream of life [16]. One can risk of stating that death has undergone the process of marginalization and pushed on the fringes of social life. Medical technology development [17] has led to significant redefinition of understanding what death is. It blurred the line between life and death, offered the possibility of sustaining life in an artificial way to provide the illusion that it still lasts "deceiving death" and deferring the final moment of its occurrence. According to Z. Bauman, both modernity and post-modernity "evicted" death from their consciousness and field of vision of mankind [18]. This statement refers merely to social private space in which it is hard to talk about death. It is difficult to talk about death directly experienced (the phenomenon of privatization of death and mourning). However, "mediated" death shown in the media, usually sudden and "spectacular" becomes common. In the public and media space the sight of death is more frequently used to increase audience of programmes. M. Ogryzko-Wiewiórowska states that "mass culture specialists have noticed the mediagenic appeal of the phenomenon of death. Business technopoly commercializes everything related to death" [23].

The concept of institutionalization of death is frequently discussed in sociomedical literature and M. Sokołowska calls it hospitalization of death [15]. The processes of medicine development, progress of medical specialization and technologisation contributed to transferring death to the institution of hospital. Medicalization of social life has not missed death because death has been influenced by supremacy of medicine, subordinated to medical procedures and encompassed by the institutional frames. The process is criticized in sociological analyses of institutionalization of death [15,17,23]. Although, hospital is a place where people most frequently die, it provides neither conditions nor procedures which would guarantee "passing away with dignity."

Dying at home – social contexts

Home seems to be the best place to spend the last moments of life being surrounded by the family in the space where a person feels safe [25]. However, as the statistical data indicate, decade by decade fewer and fewer people die in home environment whereas more and more people die in institutions (hospitals, hospices and other health care institutions). Still in 1980 home was a place of death for almost every second Pole (49.1%), but in 2013 for only 36.5 % of the dying [26]. The survey carried out by the Public Opinion Research Centre reveals that although Poles think about death less and less often, most of them admit that ideal termination of life is natural death in sleep at home. As many as 66% of Poles would like to die at home being surrounded by their family whereas only 8% in hospital [27]. These preferences, though, do not coincide with the reality because according to the data of the Central Statistical Office of Poland in 2013 every second Pole died in sleep in hospital [26].

It is interesting that sociological analyses of death and dying substantially less frequently take into consideration "home context" of the process. Critical sociology paid more attention to hospital underlying its lack of adaptation to the process of dying rather than home

environment with the way of adapting it to the requirements of the process of dying, family relationship and communication with the dying person.

A. Kacperczyk cited A. Strauss to enumerate key challenges a terminal patient's family has to face. They come down to both prevention of medical crises and dealing with them as well as acquiring means for treatment. The family have to tackle care of the ill, comply with doctor's instructions and monitor them but also cope with a number of emotional, marital and family problems caused by a terminal disease [28].

One of the first studies of the problem of death in the view of family life was put forward by M. Ogryzko-Wiewiórowska [29]. She analyses changes of the ways of functioning of the family confronting with death of a relative. Anticipation of death from the diagnosis to decease is one of the most significant processes a family has to take part in. Moreover, its course and specificity depend on a multitude of mediating variables (length of dying, who the dying person is, hospital stays, etc.). Death that approaches gradually and is preceded by a long illness is easier to be accepted [29].

Authors pay attention to numerous social changes a family in a crisis situation of a terminal disease ended with death has to deal with. Among other things there is deterioration in the family's financial situation caused by both loss of income of a dying person (in particular if the income was considerable in the family budget) and an increase in expenditure on care in the last months or weeks of life [17,29,30]. The family's time budget also becomes different. With the progress of disease greater need for care and nursing of the person occurs, the family try to spend every possible moment with them, which leads to family time deficit. It is also connected with substantial limitation of family recreational and social functions because such a family is depressed and burdened by duties. Thus, they are not eager to realize social and leisure needs. In addition, as A. Ostrowska [31] points out, social norms linked to behaviour in situations of death and dying do not assume active participation in social life for families affected by death of a relative.

In the case of a disease, particularly of a terminal one, when the ill person stays at home, their family is the most important and the only social world and point of reference for an individual person. The family creates the physical space and conditions suitable for the ill person and the situation of being ill (of dying), it controls the course of a disease, observes symptoms, performs care and nursing duties, supervises the behaviour of the ill person, acts according to professionals' guidelines, offers social and emotional support. Furthermore, it should be especially highlighted that a family is a link between the world of disease and the world of everyday life. It reminds of existence of the reality different from this associated with disease, provides information from the "different reality", thus helping the ill (the dying) participate in it even symbolically and so supporting (or not) their social identity [32]. To tackle all the problems families have to work out some strategies of action, techniques and methods which influence effectiveness of activities. The strategies require a certain form of organized actions, existence of an organization structure in the character of family or neighbour system or a different configuration of people who fulfill certain roles within the structure (rescuing, supporting, protecting). Maintenance of such a system requires confidence, interactional competences as well as other resources (e.g. financial, medical, emotional). Whether the system is stable or functional largely depends on its quality of functioning before the occurrence of disease. If it is previously disturbed, it may collapse in the crisis situation caused by terminal illness. A Kacperczyk focuses on an additional problem occurring in the situation of stigmatized illnesses – family social isolation and erosion of natural support networks [28].

Those situations require rebuilding and reinforcing support networks and fulfilling gaps in the helping networks. These roles are assigned to personnel and volunteers of palliative or hospice care who support the family organization by being with them and providing professional help (medical, nursing and psychological). Creating a new interactional system with the supporting character causes that the ill/dying rejoin the social network of assistance, relationship and support [28].

It should be added that the character of relationship among hospice staff/volunteers depends on the knowledge of the ill of their condition. The family is always informed about the actual prognosis while the ill happen to be kept in ignorance. Only in the case of patient's full awareness, a hospice worker can take complete hospice and palliative care including spiritual one. They become "death companions" fulfilling not only nursing and doctor's roles but also supporting psychologically, thus becoming confidants and comforters for the dying [33]. Sometimes a hospice worker is an actual companion in the moment of death when the patient is in agony. Acceptance of death is extremely difficult for the family. Górecki notices that "peculiarity of the situation and lack of experience in how to behave trigger escape mechanisms. This leads to avoidance of contacts with the dying or "taking" death away from home to hospital or hospice" [33].

Hospital as a social world of the dying person

Technical hospital equipment, the presence of medical staff, implemented technologies and procedures but also the ideology of the hospital are all aimed at diagnosing, intensive treatment, saving life and regaining health. There is not a proper place for death in hospital, it is treated as a defeat, the result of helplessness of medicine, failure in treatment, when there is nothing that could be done. Hospital as a social institution is supposed to attain goals different from providing care for the dying person, however, as it was mentioned before currently every second death occurs in hospital.

As M. Sokołowksa points out in one of the first sociomedical analyses concerning dying in hospital, Sudnov distinguished 'biological death' from 'social death'. 'Social death', which precedes biological one, is, according to Sudnov, a way in which organizations cope with death and dying. Death in hospital means progressive isolation of the patient and treating them as "not alive," though they have not passed away yet [34]. Glaser and Strauss, the authors of one of the most renowned sociological dissertations on death and dying in hospital, distinguish seven "critical moments" in the process of dying which determine the specificity of relationship among the staff, family and dying person. The first stage involves defining a patient as "a dying one," and the course of the following two stages depends on the patient. In the second stage, the staff and family begin preparations on account of the patient's death (which the patient would make themselves if they knew that they were dying). Next, the time when "there is nothing else to be done" followed by the final stage which can last for months, weeks but also hours. The fifth episode is "the last hours" of the patient's life which leads to awaiting death, whereas the last stage is death itself. [35]. Sokołowska notices that "when the critical moments come as expected, as if planned, everyone including the patient are prepared for them. However, when they are not expected, they can evoke even more dramatic situations both for the family and staff, when for instance the patient is expected to die soon but they do not or when they die although nobody expected it" [35]. Trajectories of death [36] determine ways of dealing with the patient, their position in the structure of hospital and the character of actions undertaken for them.

The awareness of death also affects significantly the specificity of the relationship with the patient. Interaction with the environment, ways of communicating with the family and staff vary depending on the patient's knowledge about their condition and prognosis. A classic study by Glaser and Strauss [37] led to distinguishing four types of awareness of death and dying which constituted a framework for some specific forms of conduct of all actors participating in this situation. A. Ostrowska emphasises that in all these contexts actors work out certain methods, tactics and strategies typical of dying with some specific awareness. [17,37]. It is worth quoting briefly the interpretation of these awareness contexts.

In the model of closed awareness, in which the patient is not aware of dying, the effort of the environment is aimed at maintaining the secret of their actual condition and convincing them about positive prognosis. The statements of both the physicians and family are controlled and test results are kept secret. For the patient's comfort their future biography is created, future events are planned which is supposed to help them believe that they will recover or the treatment and procedures will work. Both the family and hospital staff (doctors, nurses) participate in creating this unreal atmosphere. The atmosphere of conspiracy of silence is created around the patient which is to improve their well-being. This game requires self-control, reason and well-practised ability to convey "illusion" as a fact [38].

- 1. In the model of suspected awareness, on the basis of both deliberate and unintended signals the patient begins to suspect to be terminally ill or dying. The suspecting patient begins to behave in a certain way: pays attention to the family's or doctors' behaviour, more carefully observes what and how they talk about them, tries to find out additional information from the lower status medical staff and get access to their medical history and test results. People who look after them try to (similarly to closed awareness model) maintain "fictional reality of positive prognosis" and particularly care that the patient will not reveal the truth. Research shows that this approach negatively affects the relationship with the patient since the environment (both the family and medical staff) avoids embarrassing questions by limiting contacts to caring and manual actions and by reducing the time spent talking.
- 2. Mutual pretence according to Glaser and Strauss, it is the most common model in contemporary hospitals. It occurs when the patients who are aware of their condition do not disturb the family in maintaining the fictional reality of favourable prognosis. Both sides do know the truth but participate in a peculiar game in which nobody says anything about death and the patient does not ask about the diagnosis. Also the personnel in the relationship with the patient have a range of requisites at their disposal which let them maintain the context of mutual pretence. The patient undergoes various procedures like other recovering patients, which helps to make a pretence of treatment process.
- 3. Open awareness results in unalike patterns of interaction. Both sides behave differently the definition of the patient's role alters, one can talk openly about death,

there is no need to pretend, the patient can prepare for death or share their fears or grief with the family [17]. According to Anna Wiatr "participation in the ceremony of preparation for death becomes an essential experience for the family and staff" [39].

Every above presented awareness context evokes different behaviour of the actors participating in "ars moriendi". Nevertheless, the most challenging roles are the ones acted in the context of open awareness since there are no fixed patterns of behaviour and everybody acts under pressure of stress. As Ostrowska observes, this can lead to two different types of conduct – avoiding and limiting the relations with the dying person or "officiousness" and too intensive relation which can be tiring for the patient [17]. Not everybody has to, wants and can participate in this ceremony of preparation for death. Other patients do not want to be the audience in this performance. It often happens that the staff and even families do not find enough strength to cope with death openly, talk about it and accept its inevitability. It is confirmed by the survey conducted among the nursing staff which refers to their attitude towards dying and the patient's death. As much as 35.8% of the surveyed nurses feel uncomfortable and helpless when confronted with the dying person and every tenth nurse is afraid of potential questions, requests or even glances from the patient [40]. Hospital, in its organization and ideology typical of the reductionist-mechanical paradigm with the pressure of prolonging life, is in opposition to the concept of dignified dying marked by the moment when "there is nothing left to be done" [39].

Social world of hospice

Although there are numerous arguments for the terminally ill to pass away at home, surrounded by their families, it is worth remembering that it is not always possible and a multitude of tasks connected with the technical aspect of care can exceed abilities of the family and threaten its functioning [41]. An optimum solution to this dilemma is hospice which provides comprehensive care and socio-psychological support both for the dying and their family. A patient is treated as a subject, an autonomous individual capable of making decisions and is considered as a whole in terms of their relationship with the family [28].

"Visibility" and awareness of death which affect the specificity of interaction between the patient and environment are the specific qualities of a hospice and differentiate it from other institutions. Hospice patients are aware of their condition so death is treated openly and overtly [31]. Accepting "the reality of death" opens the space for broader and authentic being together both for the patient and the people accompanying them [42]. Talking about death, sharing fear, grief and regret is allowed which enables being authentic in the last moments with the closest people. A hospice patient is in the centre of interest, their needs and expectations are the most essential which allows to attain the main aim of a hospice to provide dignified dying when any treatment becomes unjustifiable. Controlling the symptoms of an illness enables the patient to live the last moments of their life in optimum conditions and maintain the necessary relations with the family and friends [43]. Palliative care is not aimed at curing people but merely "curing" their situation through improving the standards of living and caring for the favourable relations with their relatives. As A. Kacperczyk notices, in an extremely wide range of hospice care activities, it is sometimes difficult to distinguish between what is done for the patient and for their family. The family and patient constitute one functional system and it is what "holistic" care involves which treats the patient in a systemic way in terms of their relations with the closest social environment in its natural communication setting [28].

The issues of building patient's trust to the staff/volunteers as well as creating the sense of common responsibility for the treatment is absolutely essential and builds the relationship of subjectivity in which the patient remains in the centre of actions and at the same time is a person who acts and makes decisions [28]. As C. Saunders, the founder of hospice movement, claims, hospices can offer something unique – the atmosphere of community and lack of external control which is so necessary for patients [44].

T. Paklepa presented a remarkably interesting sociological analysis of hospice functioning from the perspective of "a theatre of everyday life" [45]. According to him, every performance in this theatre is unique and finishes with the death of a person who was assigned a certain role. He believes that it is a theatre of a single actor and a few people who constitute "the audience". Transience and uniqueness of this performance result from the specific character of every situation, individuality of every patient and their experiences as well as the way each role is played by "the actors". It is worth considering the fact that in hospice there are no clear boundaries between "the stage" and "the audience", it is a mutual exchange of experiences. People, who are called the audience, are in fact active participants of the events and become actors [45]. The space of a hospice is the stage prepared by the members of the hospice movement for people who will play their roles there. It should be equipped with some special decorations and requisites that would give the performance, namely the main character's death, both a proper significance as well as setting [45]. Paklepa tries to present the specificity of such a "theatre' with the example of a hospice Lublin. The audience should be suitable, empathic and understanding, ideally, the family members whose presence makes

the life of the dying person meaningful. Incompetent audience that do not know how to behave can ruin the 'performance''. Comments of the care home staff can be a good example: *"we haven't slept the whole night because she is dying. When does she finally die?"* (T. Paklepa quotes the president of *"Hospicjum" Lublin Association of Friends of the III, who comments on the the behaviour of social care home staff who accompany the patients' death). Sometimes the family of the dying is such an audience that do not know how to behave and feel uncomfortable in this role. They happen to call an ambulance when they expect that the patient would die soon so that the moment of death would happen in hospital.*

Hospice is a place with suitable conditions for the optimum course of death performance. It provides the audience that know the rules, the script and their roles. It cares for the performance to run smoothly without any disturbances, in a proper setting with appropriate requisites [45].

As Rev. Jan Kaczkowski, the president of the hospice in Puck who has been struggling with brain cancer for years, claims that: " a hospice is like a drop of water which reflects the whole truth about man – his sainthood and meanness. People do not only pass away here, they also propose to each other, meet with people with whom they broke all relations years ago and reconcile with them, they also fight for the properties and accuse of the worst things" [46]. It is the uniqueness of every performance, its individual script, actors' play of both the main character and other participants.

Summary

The introduction defines social worlds as some "social wholes" engaged in a specific activity, equipped with the competences necessary to conduct it and share resources that enable to attain the goals. Participants of the social world feel committed to do this, they create their common ideology concerning how they should do certain things and how to pursue the interests of the world as a whole. Can this term be used with regard to dying? It seems it can be used, since regardless of where the process occurs, the actions of the participants of this world focus on the dying person, though they undoubtedly vary depending on whether the process of dying takes place at home, in hospital or hospice. The context of awareness of death has immense significance because it affects the character of the relations and communication processes among the dying person and their closest environment, actors and audience participating in this special "performance of death." The term performance happens to be understood directly without any metaphorical meaning. In the case of closed

awareness of death or mutual pretence - all actors wear masks and play their roles according to the script of positive prognosis and the most frequently repeated line is: "everything will be all right". As A. Wiatr claims – the ensuing awareness context, regardless of whether death occurs at home, in hospital or hospice, is the type of matrix, which is filled with experiences, feelings and emotions of the dying person. They eventually affect the character of integration between the dying and their closest environment. Everything happens in a certain social context: institutional, organizational, connected with the roles they perform and social setting [39], which additionally varies the performances of dying.

Social worlds of the dying person merge depending on the character and course of illness – using the term by K. Konecki – the worlds do not exist without any relation with other worlds, with which they cut across, combine or cooperate [2]. A prolonged process of dying, hospital stays, comebacks home, hospice care at home, and finally hospice stay determine the multitude of these social worlds of the dying. In all these worlds, although there appear new actors/spectators, one motive is dominant – it is the experience of death. The way of exposing this experience significantly determines alternating factors: the context of awareness of death and trajectories of this process. "Actors" taking place in the process of dying engage their behaviour and modify the character of mutual interactions.

References

- Kacperczyk A. Od redakcji [in:] Świat społeczny hodowców gołębi pocztowych. Przegląd Socjologii Jakościowej. Słotwińska A. Seria Światy Społeczne, 2010, 6, 3, 1-6.
- Konecki K.T.: W stronę socjologii jakościowej: badanie kultur, subkultur i światów społecznych [in:] Kultury, subkultury i światy społeczne w badaniach jakościowych. Leoński J, Fiternicka-Gorzko M. (eds.). Szczecin, 2010, 29.
- Mumford E.: Medical Sociology. Patients, Providers and Policies. Random House, N. York, 1983, 200-203.
- 4. Twaddle A.C., Hessler R.M.: A Sociology of Health. S. Louis, Mosby, 1977, 73-74.
- 5. Fox R.C. The Sociology of Medicine, a participant observers view, Prentice Hall, Upper Saddle River, 1989, 239-240.
- Senior M., Viveash B.; Health and Illness. Palgrave- Macmillan, N. York, 1989, 207-208.

- Scambler G.: Dying, Death and Bereavement [in:] Sociology as Applied to Medicine.
 Fifth ed. Scambler G. (ed.). Edinburgh, London, Sauders, N. York, 2003, 92-104.
- 8. Bradby H.: Medical Sociology. An Introduction. Sage, London, 2009, 44-45.
- 9. Blicharski J.: Postępowanie z nieuleczalnie chorym. PZWL, Warszawa, 1959.
- Kucab B.Ł.: Człowiek w obliczu śmierci, z uwzględnieniem etyki marksistowskiej, granic i praw reanimacji. Krajowa Konferencja Lekarzy i Humanistów. Krajowa Agencja Wydawnicza, Gdańsk, 1978.
- Pearson L.: Śmierć i umieranie. Postępowanie z człowiekiem umierającym. PZWL, Warszawa, 1973.
- Saunders C.: Chwila prawdy opieka nad człowiekiem umierającym [in:] Socjologia medycyny. Wybór tekstów. Chodkowska M, Piątkowski W. (eds.). Akademia Medyczna w Lublinie, Lublin, 1983, 287-318.
- Engelhardt K.: Umieranie [in:] Socjologia medycyny. Wybór tekstów. Chodkowska M, Piątkowski W. (eds.). Akademia Medyczna w Lublinie, Lublin, 1983, 319-325.
- Morison R.S.: Śmierć i umieranie [in:] Socjologia medycyny. Wybór tekstów. Chodkowska M, Piątkowski W. (eds.). Akademia Medyczna w Lublinie, Lublin, 1983, 102-117.
- 15. Sokołowska M.: Socjologia medycyny, Chapter 4, Śmierć i umieranie. PZWL, Warszawa, 1986, 119-138.
- 16. Ostrowska A.: Śmierć i umieranie. Oficyna Wydawnicza, Warszawa, 1991.
- Ostrowska A.: Śmierć w doświadczeniu jednostki i społeczeństwa. Polska Akademia Nauk, Warszawa, 1997.
- Bauman Z.: Śmierć i nieśmiertelność. O wielości strategii życia. Wydawnictwo Naukowe PWN, Warszawa, 1998, 166.
- Komorska M.: Postawy wobec śmierci. Wybrane zagadnienia [in:] Szkice z socjologii medycyny. Libiszowska-Żółtkowska M, Ogryzko-Wiewiórowska M, Piątkowski W. (eds.). Wyd. UMCS, Lublin, 1998, 207-219.
- 20. Libiszowska-Żółtkowska M.: Religia wobec fenomenu śmierci. Wierzenia i postawy.
 [in:] Szkice z socjologii medycyny. Libiszowska-Żółtkowska M, Ogryzko-Wiewiórowska M, Piątkowski W. (eds.). Wyd. UMCS, Lublin, 1998, 137-150.
- 21. Kolbuszewski J.: Problemy współczesnej tanatologii. T. I-XV. Wrocławskie Towarzystwo Naukowe, Wrocław, 1997-2011.
- 22. Furdał A.: Problemy współczesnej tanatologii. T. XVI. Wrocławskie Towarzystwo Naukowe, Wrocław, 2012.

- 23. Ogryzko-Wiewiórowska M.: Szaleństwa ponowoczesności ze śmiercią w tle [in:] Socjologia z medycyną. W kręgu myśli naukowej Magdaleny Sokołowskiej. Piątkowski W. (ed.). Wydawnictwo IFiS PAN, Warszawa, 2010, 110-130.
- 24. Maksymowicz A.: Jakość życia z ciężkimi chorobami przewlekłymi i terminalnymi oraz jakość umierania w Polsce z perspektywy badań socjologicznych dyskusja wokół literatury przedmiotowej. Studia Humanistyczne AGH, 2012, 11/14, 223-229.
- 25. Seale C.: Dying alone. Sociol. Health Ill., 1995, 17, 3, 376-392.
- 26. Główny Urząd Statystyczny. Rocznik Demograficzny. Warszawa, 2014.
- 27. Centrum Badania Opinii Społecznej. W obliczu śmierci. Warszawa, 2012.
- Kacperczyk A.Ł.: Wsparcie społeczne w instytucjach opieki paliatywnej i hospicyjnej.
 Wyd. Uniwersytetu Łódzkiego, Łódź, 2006, 84 240.
- 29. Ogryzko-Wiewiórowska M.: Rodzina w obliczu śmierci. Studium socjologiczne. Wydawnictwo UMCS, Lublin, 1992.
- Guenther E.: Reorganizacja życia rodziny z przewlekle chorym [in:] Człowiek nieuleczalnie chory. Block B.L., Otrębski W. (eds.). Wydział Nauk Społecznych KUL, Lublin, 1997, 295-300.
- 31. Ostrowska A.: Śmierć w doświadczeniu jednostki i społeczeństwa. Wyd. III uzupełnione. Wydawnictwo IFiS PAN, Warszawa, 2005.
- Taranowicz I.: Rodzina a problemy zdrowia i choroby [in:] Zdrowie i choroba.
 Wybrane problemy socjologii medycyny. Barański J, Piatkowski W. (eds.). Wyd.
 ATUT, Wrocław, 2002, 109-111.
- Górecki M.: Przesłanie ideowe i instytucjonalizacja wspomagania umierających [in:] Prawda umierania i tajemnica śmierci. Górecki M. (ed.). Wyd. Akademickie Żak, Warszawa, 2010, 203-225.
- 34. Sokołowska M.: Wzory umierania w szpitalu. Pielęg. Poł., 1986, 11, 326, 21-23.
- 35. Sokołowska M.: Śmierć i umieranie. Studia Socjologiczne, 1985, 2, 97, 61-81.
- 36. Kemp A.R.: Death, Dying and Bereavement in a Changing World. Pearson Education, Inc., London, N. York, 2014, 162-163.
- 37. Glaser B.G., Strauss A.L.: Awareness of dying. Aldine Pub. Co, Chicago, 1965.
- 38. Górecki M.: Kres życia [In:] Prawda umierania i tajemnica śmierci. M. Górecki (ed.).
 Wyd. Akademickie Żak, Warszawa, 2010, 13-36.
- Wiatr A.: Pomiędzy życiem a śmiercią. Opowieść o tożsamości i umieraniu. Wyd. Nomos, Kraków, 2013, 65-69.

- 40. Śleziona M., Krzyżanowski D.: Postawy pielęgniarek wobec umierania i śmierci pacjenta. Piel. Zdr. Publ., 2011, 1, 3, 217-223.
- 41. Broom A., Kirby E.: The end of life and the family: hospice patients' views on dying as relational. Sociol. Health Illn., 2013, 35, 4, 499-513.
- 42. Olszewska M.: Hospicjum jako miejsce holistycznej opieki. Piel. Zdr. Publ., 2014, 4, 2, 177-182.
- 43. Ogryzko-Wiewiórowska M.: Umieranie i śmierć. Perspektywa socjomedyczna [in:]
 W stronę socjologii zdrowia. Piątkowski W., Titkow A. (ed.). Wydawnictwo UMCS, Lublin, 2000, 94-115.
- 44. du Boulay S., Rankin M.: Okno nadziei. Cicely Saunders założycielka ruchu hospicyjnego. Wyd. Znak, Kraków, 2009, 249.
- 45. Paklepa T. Hospicjum jako teatr [in:] Szkice z socjologii medycyny. Libiszowska-Żółtkowska M., Ogryzko-Wiewiórowska M., Piątkowski W. (eds.). Wyd. UMCS, Lublin, 1998, 181-198.
- 46. Szału nie ma, jest rak. Z ks. Janem Kaczkowskim rozmawia Katarzyna Jabłońska. Wyd. Biblioteka Więzi, Warszawa, 2013, 71.

Live vs. cadaveric donation - two approaches to kidney and liver transplantation. Analysis and evaluation of methods

Gnus Jan^{1,2,3}, Antczykowski Maurycy¹, Maślanka Paulina¹, Kasperczak Michał¹, Dawidczyk Piotr¹, Pfanhauser Monika¹, Winter Paweł¹, Dorna Krzysztof³, Blok Katarzyna¹, Paprocka-Borowicz Malgorzata²

- 1. Regional Specialist Hospital in Wrocław Department of General and Vascular Surgery
- 2. Wroclaw Medical University
- 3. Papal theological University in Wroclaw

Introduction

Organ transplantation over the last fifty years has gone from experimental therapy, arouses a lot of controversy as ethical as medical, to well recognized and widely accepted treatment of many diseases. Nowadays, with the improvement of methods of collecting and storage of organs, the biggest problem is not a way of carrying out the procedure but the insufficient number of organs available to physicians and patients. For example, there are 18,000 patients waiting in the United States on the liver transplantation, while the number of deceased donors per year in last years was approximately 6000 [1]. This prompted doctors to attempt taking organs from deceased but also from living people. Now the question is what is the difference between these two methods of transplantation? Does any has an advantage? To answer for these questions, let us compare transplants of the liver and kidney.

Liver transplantation

History of Live Donor Liver Transplantation, LDLT (compared to transplants from deceased persons, Deceased Donor Liver Transplantation, DDLT) began in 1987, when prof. Raia performed the first attempt to transplantation in children [2]. Initially segments II and III, parts of the left hepatic lobe were collected (Left Lateral segment Graft LLSG, cutting is performed to the right of venous ligament [3]), which was well tolerated by donors. After the first successes in pediatrics transplantation, it was decided to use this method in adult surgery. The left lobe was used, but the mismatch between the size of organ from donor and recipient's needs caused complications as impaired secretory function, elevated transaminase levels or

prolonged cholestasis [4]. This phenomenon is called small-for-size syndrome (SFSS), and the main reasons are, apart of organ size, donor's diseases (steatosis), the rate of lobe regeneration, the inflow of blood and on the other side recipient cirrhosis and portal hypertension. SFSS is not strictly defined, is recognized by symptoms, these mentioned and also hyperbilirubinemia, the appearance of ascites or patient prolonged stay in intensive care units [5].

Because of rising number of transplanted organs failure, it was started to collect the right lobe, splitting the organ to the right of the middle hepatic vein trying to increase the weight of the gaft (segments V-VIII, Right Hemiliver, RH) [1,3], but it did not bring the expected result. It drew doctor's attention to hemodynamic disturbances in transplanted organ [1]. It turned out that destructive role of the organ congestion by inadequate for the parenchyma volume blood inflow from the portal vein was underestimated, and ensure proper drain (and thus perfusion) is crucial factor in proper graft function. However, still to ensure a favorable postoperative course, recovered lobe must be big enough so that Graft Recipient Weight Ratio, GRWR (the weight of the graft to the patient's weight) is greater than 1% [6]. Therefore for adult segments V, VI, VII, VIII are collected.

What are the advantages of collecting splited livers from living people? Undoubtedly, donor's good health determines high quality of the transplant. Surgical procedure can be scheduled, and the time of destroying ischemia and hypoxia can be reduced to a minimum [1]. In addition, the number of potential living donors is greater than the deceased and no matter where donors lives, because there is no need to provide specialized graft transport when it is possible to transport the donor.

But it necessary to mention the drawbacks and dangers associated with the recovering organs from a living person. For simultaneous recovering segments II and III, the estimated mortality rate is 0.1%, and for collecting the right lobe is higher and rises to 0.4-0.5% [7]. Time of donor's liver regeneration is important, it depends on the age, portal hypertension and steatosis [1]. After collecting the left lobe, in case of donor, after 3 months, the rest of the organ grows and reaches 80% of the average (target) size (SLV, Standard Liver Volume). It is interesting, that the part received by patient grows quicker, after that time reaches 100% SLV, however, causes of a faster organ growth in the recipient stays unclear [8]. Despite the liver high potential of healing, cases where the donor as result of complications needed a transplantation was reported. Additionally, the disadvantage of such treatments is that the whole liver transplantation from a deceased donor is technically simpler. There is also less complications of biliary system, it does not require the involvement of two surgical teams,

and it is less expensive [1].

What's more, LDLT is not the only way to increase the number of transplantations. In 2002, at the Congress in Crystal City, Virginia, the American Society of Transplantation and the American Society of Transplant Surgeons pointed several ways to maximize the use of organs from the deceased. The final report [3] mentioned: increasing the use of organs from non-heart-baeting donors, more frequent use of marginal transplants, more effective placement of organs, wider application of innovative technologies and maximizing the amount of Split Liver Transplantation, SLT, what aroused interest most. Partial transplantations for adult and child was considered to be a rule, by dividing a liver for trisegmental right transplant (adult, right Trisegmental graft, RTSG or right Extended graft, REG, segments I + IV-VIII) and left lateral transplant (for the child, as one mentioned earlier, LLSG, II and III), accepted to be equal to whole organ transplantation. It was a change, because earlier during taking parts of children, the second half of liver was unused. It was estimated if the technique expand for 20% of the livers qualifiable for procedure, the number of recipients in United States will increase by 1,000 people per year. Nowadays, SLT adult / child is 6% of all transplantation in Europe (that is 6000 operations [9]), and 1% in the United States (also 6000 [1]) [10]. SLT for 2 adults was considered to be not enough understood, to become a standard. In this case caution was justified, by the end of 2015, this technique is still not popular, and the number of operations carried out does not exceed two hundred [10].

But the question is, which type of graft is better? Analysis of transplantation performed in the period of 2002-2012, when 2,103 transplantations from living donors and 46,674 transplantations from deceased (what is 4.3% and 95.7%) took place, showed a higher survival rate for grafts from living donors, but one remark, when the operation was carried out in experienced centres (i.e. in which at least 15 transplants were created). 1-, 3-, and 5- years survival rate for patients with livers from deceased donors and from alive were respectively 87.3%, 77.9%, 71.0% against 89.6% 82.7% 77.8%. Graft survival in the equal periods, from cadaveric donors and the alive, was respectively 85.3%, 75.5% 68.5% vs. 85.8% 78.9% 73.8%. It is also necessary to note, that the survival rate for patients transplanted with liver from living donors continues to rise, for a 3-years period for transplantations performed in 1999 was 64%, for performed between 2002 and 2004 increased to 75% and reached 82% after 2008 [11].

To compare, in Poland the percentage of transplantations from living persons for 2014 was 8.2%, when 336 liver from deceased donors and 30 parts of the liver from living persons were transplanted. In 2015 (until December), the percentage was 6.6% (283 cadaveric and 20

parts) [12,13].

Conclusion is, though the indications for transplantations from living person are constantly expanded and the technique is improved, while techniques of collecting organs from cadavers are improved too (such as marginal transplant, transplant from a deceased after the circulation stop, or split transplantation), its performing become ethically questionable [1,14].

Kidney transplantation

On the other hand, collecting organ from living donors in case of kidney transplantation is much more popular- in the world almost 50% of all procedures was performed this way, but there are observed significant differences in the percentage depending on the country. In countries like Spain, Germany, France, it is a dozen or so percent (high developed donation from the deceased), in the United States, Britain, Canada, it is 26- 42%. In the next group, due to various reasons are included Brazil (lack of infrastructure), Japan (cultural problems- the people unwillingness to violate the cadaver), Turkey and Korea, the percentage of living donors is 55-80%. Finally, there are countries like Oman, Yemen, Egypt and Iceland, where the grafts come only from living [15]. In Poland in 2014, the percentage of kidneys from living people was 5% when reported 1,064 kidneys from deceased donors and 55 kidneys from living persons, and in 2015 (until December), 6.2% (respectively 896 and 59 kidneys) [12,14].

Is the origin of the organ important for the recipients? It is proved, that patients who received a kidney from a living donors live longer than those who received a graft from a deceased person; it does not matter whether the donor was related with that donor or not. The same situation is with kidney survival [16]. There are several reasons of such results, and it is hard to choose the most important. First of all, the transplanted kidneys come from healthy people and are optimally balanced in histocompatibility. The procedure can be planned so that both recipient and donor are in good health, i.e. before the dialysis starts or lasts short time, what is highly important- 10-year graft survival when recipient is on dialysis over 2 years is two times lower, than patient is in on dialysis less than 6 months [17]. The operation and ischemic time may be reduced to a minimum, which obviously influences on prognosis [18,19]. What is next, patients are selected according to vessels topography, to prevent graft mutilation [20].

In the United States also a simulation of demand for kidneys was created, and it

became clear that the number of organs obtained from deceased never cover the whole demand and it is necessary to develop the donation of living [21].

Refer of safety of living donation for donors, the mortality rate for 2010 was estimated at 0.02-0.03% [16,22]. What is interesting, all the deaths in the US in the period 1991-2001 (2 in group of 10,828 collecting) were complication of laparoscopic surgery, in addition to this one person is in a persistent vegetative state [23].

Severe open nephrectomy complications (bleeding, infection) in the experienced centers occurs in approximately 1.5% of donors, less severe in 8.5% [16]. However, in most hospitals in the world collecting kidneys from living people is performing laparoscopically [16], and the first such operation took place in 1996 [24]. A study comparing 100 open and 100 laparoscopic operation shows that the open surgery complications occur in 27% and in 21% laparoscopic [25]. Also, a large meta-analysis of 2004, based on 44 publications about classic and laparoscopic approach did not show any advantage one over the other techniques [26], however, faster postoperative course and significantly less pain after surgery is important for donors.

In case of long-term complications, literature is sparing than this describing perioperative complications, what appears to be natural. The full analysis should counts the impact of the kidneys collecting not only for donors survival rate, but also diseases, as kidney as the other- hypertension, cardiovascular disease [16]. The available results are: a study in Sweden on a group of donors who were operated in the years 1964-1994 (430 people) showed a higher survival rate in this group than in the general population, which is associated with an strict selection of donors (they were healthier than the general population) and more careful medical care [27]. Another study on a group of 3,698 people, who donated organs in the period since 1963 to 2007 shows, that the treatment and control groups (matched for sex, age, race and ethnicity) did not differ in survival, but a group of not-donors was not selected for the absence of diseases [28].

Long-term risk of kidney failure in the donors groups is the same as in the general population, what proves a minimal impact of the GFR reduction on the second kidney function [28], however there are opinions that it is impossible to compare very healthy group of donors to a randomly selected control group. Postulated solution would be to refer the results to a group of people classified as potential donors, but who did not donor the kidney [27]. Race group may also be not without significance impact.

In the last decade, it was noted that a high level of creatinine in the blood (by reduced GFR in donors) is a cardiovascular disease risk factor, but real importance of this fact requires

further studies [16].

Conclusions

In the case of kidney transplantation from living donation is the best option for the recipient, and the short- and long-term prognosis are incomparably better than when it would receive organ from a deceased person [20]. In addition, bearing in mind that the procedure has not significant (known) impact on the health of donors, and the number of cadaveric donation will not cover the demand, it is obvious that this way of transplantation development is a good way. In case of liver transplantation, the conclusions are not unambiguous- collection mortality rate is an order of magnitude greater than in the case of collecting kidneys. The prognosis for graft recipients are admittedly better, but can we expose donor's health? Remember, primum non nocere. Conclusions from Crystal City are still actual.

References

- Florman S., Miller C. M.: Live donor liver transplantation. Liver. Transpl., 2006, 12, 499–510.
- 2. Raia S., Nery J., Mies S.: Liver transplantation from live donors. Lancet, 1989, 2, 497.
- Rosengard B.R., Feng S., Alfrey E.J., et al.: Report of the Crystal City meeting to maximize the use of organs recovered from the cadaver donor. Am. J. Transplant., 2002, 2, 8, 701-711.
- 4. Tucker O.N., Heaton N.: The 'small-for-size' liver syndrome. Curr. Opin. Crit. Care, 2005, 11, 2, 150-155.
- Dahm F., Georgiev P., Clavien P.A.: Small-for-Size Syndrome After Partial Liver Transplantation: Definition, Mechanisms of Disease and Clinical Implications. Am. J. Transplant., 2005, 5, 11, 2605-2610.
- Kiuchi T., Kasahara M., Uryuhara K. et al. Impact of graft size mismatching on graft prognosis in liver transplantation from living donors. Transplantation, 1999, 67, 321– 327.
- Renz J.F., Kin C.J., Saggi B.H., Emond J.C.: Chapter 47: Outcomes of living donor liver transplantation [in:] Transplantation of the Liver, Busuttil RW, Klintmalm GB, eds, Philadelphia, Elsevier, 2005, 713-724.
- 8. Humar A., Kosari K., Sielaff T. D., et al: Liver regeneration after adult living donor

and deceased donor split-liver transplants. Liver Transpl, 2004, 10, 374–378.

- 9. European Liver Transplant Registry, Evolution of LTs in Europe, http://www.eltr.org /Evolution-of-LTs-in-Europe.html, edited 7.03.2016.
- 10. Lauterio A., Di Sandro S., Concone G., et al: Current status and perspectives in split liver transplantation. WJG, 2015, 21, 39, 11003-11015,
- Goldberg D.S., French B., Abt P.L., Olthoff K., Shaked A.: Superior Survival Using Living Donors and Donor-Recipient Matching Using a Novel Living Donor Risk Index. Hepatology, 2014, 60(5), 1717-1726.
- 12. Poltransplant, Statystyka pobierania i przeszczepiania narządów, http://www.poltransplant.org.pl/statystyka_2014.html, edited 07.03.2016.
- 13. Poltransplant, Statystyka pobierania i przeszczepiania narządów http://www.poltransplant.org.pl/statystyka_2015.html, edited 7.03.2016.
- Emond J. C., Freeman R. B., Renz J. F., et al.: Optimizing the use of donated cadaver livers: Analysis and policy development to increase the application of split-liver transplantation. Liver Transpl, 2002, 8, 863–872.
- 15. Horvat L.D., Shariff S.Z., Garg A.X.: Global trends in the rates of living kidney donation. Kidney Int., 2009, 75, 1088-1098.
- Ghods A. J.: Living Kidney Donation: The Outcomes for Donors. Int. J. Organ Transplant. Med., 2010, 1,2, 63–71.
- Davis C,L,, Cooper M.: Long-term consequences of kidney donation. N. Engl. J. Med., 2009, 360, 2370.
- 18. Perico N., Cattaneo D., Sayegh M., Remuzzi G.: Delayed graft function in kidney transplantation. Lancet, 2004, 364,1814.
- 19. Meier-kriesche H.U., Kaplan B.: Waiting time on dialysis as the strongest modifiable risk factor for renal transplant outcomes. Transplantation, 2002, 74, 1377.
- 20. Weitz J., Koch M., Mehrabi A., et al.: Living-donor kidney transplantation: risks of the donor- benefits of the recipient. Clin. Transplant., 2006, 20, Suppl 17, 13-16.
- 21. Sheehy E., Conrad S.L., Brigham L.E., et al. Estimating the number of potential organ donors in the United States. N. Engl. J. Med., 2003, 349, 667-674.
- 22. Segev D.L., Muzaale A.D., Caffo B.S., et al.: Perioperative mortality and long-term survival following live kidney donation. JAMA , 2010, 303, 959-966.
- Matas A.J., Bartlett A.T., Leichtman A.B., et al.: Morbidity and mortality after living kidney donation in 1999-2001: A survey of United States transplant centers. Am. J. Transplant., 2003, 3, 830-834.

- 24. Ratner L.E., Ciseck L.J., Moore R.G., ET AL: Laparoscopic live donor nephrectomy. Transplantation, 1995, 60, 9, 1047-1049.
- 25. Simforoosh N., Basiri A., Tabibi A., et al.: Comparison of laparoscopic and open donor nephrectomy: A randomized controlled trial. BJU Int., 2005, 95, 851-855.
- 26. Tooher R.L., Rao M.M., Scott D.R., et al. A systematic review of laparoscopic live donor nephrectomy. Transplantation 2004, 78, 404-414.
- 27. Fehrman-Ekholm I., Elinder C.G., Stenbeck M., et al.: Kidney donors live longer. Transplantation, 1997, 64, 976-978.
- Ibrahim H.N., Foley R., Tan L.P., et al.: Long-term consequences of kidney donation.
 N. Engl. J. Med., 2009, 360, 459-469.

Deontological problems of euthanasia

Sivakova Svetlana, Naumov Igar, Shpakau Andrej, Smirnova Galina, Lisok Alena

Grodno State Medical University, Grodno, Republic of Belarus

Introduction

The human right to life and health - is one of the basic provisions of the Constitution of the Republic of Belarus, it is also enshrined in the national official documents of most countries [1,2].

Euthanasia – this is the action or inaction of a doctor, which is carried out at the request of a patient experiencing unbearable suffering and which results in the death of the patient – it is increasingly attracting the attention of scientists and the general public [3,4].

The phenomenon of euthanasia is a very complex and diverse and it exists in different forms [5,6].

It can't have neutral emotional value and, as a rule, during the discussions it is defined as a negative phenomenon which has the following synonymous terms «murder», «suicide», «mercy killing» [7,8].The ambiguity of medical-social aspects of euthanasia as one of the most important and most discussed problems of bioethics in medicine, assessment of the moral attitudes of medical staff in the society and in the medical environment is not manifested only in the form of categorical rejection of active and passive forms, but also in recognition of the legality and the possibility of its implementation by doctors [9,10].Church completely condemns euthanasia in all its manifestations [11,12].

In some countries, euthanasia is considered as a human right: it equated to a dignified death. In many countries, euthanasia is practiced illegally because of state authorities are tolerant to this problem [13].

Undoubtedly, medical-social aspects of this problem and moral values of medical staff are important. Issue of euthanasia is associated with the implementation of the interests, needs and rights of patients. The main purpose of medicine is to preserve the health, cure disease and, therefore, this can't be realized for patients. Medical staff usually try to keep the information about euthanasia in secret and only 2.59% of medical staff in the Netherlands, 0.3% – in Belgium, 0.27% – in Switzerland recognize it [6,14]. However, in the community and among medical students attitude to euthanasia is ambiguous: from the categorical rejection of both active and passive forms of euthanasia to the recognition of the legality and the possibility of its implementation by doctors. Undoubtedly, the bioethical aspects of this problem and the moral values of students and medical staff have great practical importance [8].

Objective of research: to study the priorities of medical-social aspects related to the issue of euthanasia among medical students and medical stuff of the Republic of Belarus and the Republic of Poland and to assess medical-social reasons for its existence.

Material and methods

During the research were surveyed 495 respondents: students of Grodno State Medical College, students of Grodno State Medical University, as well as nurses which worked in health care organizations of Grodno, the Grodno region and the Republic of Poland with the usage of social-diagnostic method.

Results and discussion

As studies have shown, the concept of euthanasia had only 1/3 of respondents in all groups. Age also has a big impact on attitudes to euthanasia: 1/3 of nurses under the age of 50 years didn't have a sufficiently precise idea of euthanasia. The attitude of medical students to this problem varies with age in side of the supporters of euthanasia. In general, in all the surveyed groups, the number of adherents of euthanasia is much higher than the number of opponents. Results of the study showed that the problem of euthanasia is a challenging, relevant and controversial. Attitude to euthanasia is conditioned by the medical profession, age, religion and education. Therefore, in the course of training in medical colleges and universities need to pay more attention to the study of the problem of euthanasia.

It was found that 69.7% of respondents in all groups didn't know the meaning of the concept of euthanasia or gave the wrong answer. Paradoxically, the nurses who had experience with patients often gave wrong answers or recognized in their ignorance (62.2%) in comparison to students (48.3%) (Figure 1).

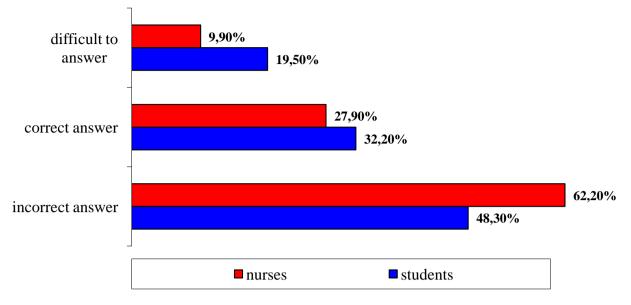


Fig. 1. The results of the survey respondents about the meaning of the concept of euthanasia

Proper understanding about passive euthanasia had only 7.7% of respondents in all groups, about active euthanasia – 26.1% of students, 38.9% of medical staff of the Republic of Belarus and 48.3% of medical staff of the Republic of Poland.

It was found that in the group of medical staff attitude to euthanasia depends on the profile of the chosen specialty. The less medical staff faced with the problem of dying during their professional activities, the more they had tolerance to euthanasia: percentage of negation of euthanasia among medical stuff of the ambulance, nurses of general departments was slightly higher (45.7%) than among nurses of anesthesiology, resuscitation and intensive therapy department and oncology departments (32.6%). Negative attitude to the problem of euthanasia had 43.8% of respondents.

Among medical staff, who has expressed a positive attitude to euthanasia, Red Cross workers amounted to 68.9%, nurses of anesthesiology, resuscitation and intensive therapy department– 49.7% and oncology departments – 12.4%.

No one religion recognizes euthanasia. Religious views among 74.3% of the respondents of the Republic of Belarus, who identified themselves as believers, didn't admit the possibility of euthanasia. Nurses of the Republic of Poland of the catholic religion (95.3%) considered that euthanasia is unacceptable in any cases.

The question about the permissibility of euthanasia as a social phenomenon and as a possible choice of medical staff who work with terminally patients among students revealed controversial feature of the responses.

The contradictory worldview consisted in the fact that 68.9% of students reported that they were believers, but a meaningful analysis of questionnaires showed that 73.3% of «believers» accepted euthanasia, considering it an act of charity to a seriously ill person.

Unfortunately, the majority of respondents received information about this problem from popular TV shows, magazines, newspapers, so their view about it largely shaped by the media (Figure 2).

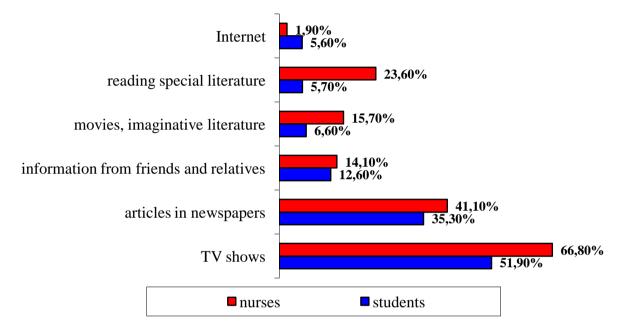


Fig. 2. The main sources of information about euthanasia

Lack of awareness about the ethical, clinical and legal aspects related to euthanasia was found among 68.9% of all respondents. According to opinion of 56.8% of respondents, euthanasia is not an urgent problem for our society and for the Republic of Poland. In terms of importance, it can't compete with other, more «urgent» questions.

During the discussion respondents noted that there are many other problems (poverty, alcoholism, drug addiction, etc.), which require priority decisions and state interference. The majority of respondents didn't think about issues related to euthanasia or about the rights of seriously ill people that was the result oflow legal culture (36.9%), social-economic problems (23.8%) and many other reasons. But this problem can be relevant for each person, while it is not a priority for the whole society.

Evaluation of the emotional state of the respondents during the survey and the discussion and after usage of the method SAM (state of health, activity and mood) showed that although age and affect the health, activity and mood, but in all groups of respondents results decreased after the survey (Table I).

Results of the survey before and after discussion			Nurses				
		Students M±m	length of service < 10 years M±m	length of service > 10 years M±m			
		max = 9 points					
state of health	before	7.5 ± 0.03	6.9 ± 0.01	6.3 ± 0.09			
	after	7.4 ± 0.04	6.7 ± 0.04	6.2 ± 0.08			
activity	before	7.2 ± 0.02	6.8 ± 0.09	5.7 ± 0.08			
	after	7.0 ± 0.01	6.6 ±0.01	5.6 ± 0.01			
mood	before	8.0 ± 0.1	6.9 ± 0.03	6.3 ± 0.07			
	after	7.6 ± 0.03	6.5 ±0.01	5.9 ± 0.01			

Tab. I. Evaluation of the emotional state by method SAM

The internal state of the respondents, which implies the recognition of their individual values and respect of the personality of others – it is confidence in their actions – the quality of much needed medical staff. Evaluation of the results of the test «How much are you confident in yourself?» (Table II) showed that these qualities are affected by age and length of service. Most of students in the group were confident in themselves– for them it is more a manifestation of youthful extremism, which allows to express themselves and show their individuality. Almost half of nurses with experience more than 10 years were quite confident in themselves– it probably a stereotype of their behavior, result of self-control in different situations, and finally, some experience. Nurses with experience less than 10 years distributed almost evenly in all groups. This indicates that they have a middle degree of confidence in themselves.

Evaluation of confidence	«Inconfident» 0-10 points		«Middle confident» 10-20 points		«Confident» > 20 points	
	M±m	%	M±m	%	M±m	%
students	6.9 ± 0.01	18.4	16.2 ± 0.06	19.4	26.8 ± 0.03	63.2
nurses with length of service < 10 years	5.5 ± 0.02	31.2	17.1 ± 0.06	36.1	26.1 ± 0.01	32.7
nurses with length of service > 10 years	6.3 ± 0.01	13.2	15.9 ± 0.02	37.2	26.4 ± 0.01	49.6

Tab. II. Evaluation of confidence

Individually-psychological characteristics of medical staff determine daily therapeutic activities with the psychological and emotional factors and interpersonal communication.

The evaluation of results of depression (Table III) showed that the level of subjective sensations of person's loneliness and depression depend on age.

	Students		Nurses					
Type of depression			with lengtl service < 10		with length of service > 10 years			
	M±m	%	M±m	%	M±m	%		
absent <50 points	37.5 ± 0.02	55.1	46.9 ± 0.05	34.5	46.3 ± 0.04	25.5		
light 50-59 points	54.4 ± 0.06	38.9	56.3 ± 0.09	45.6	56.9 ± 0.07	47.8		
masked 60-69 points	67.8 ± 0.03	6.0	66.8 ± 0.05	14.3	68.7 ± 0.05	19.6		
real > 70 points	-	-	76.6 ±0.09	5.6	75.6 ± 0.08	7.1		

Tab. III. Evaluation of the level of depression

Medicine, with all its humanity, - it is very hard sphere of activity, so medical staff are increasingly expressing a willingness to resort to euthanasia when the patient asks about the death and this criterion was the most important among all medical staff (Figure 3).

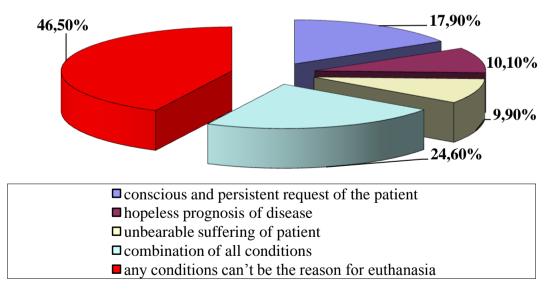


Fig. 3. Priorities in the choice of euthanasia among nurses

Next criterion for the priority of euthanasia was a hopeless prognosis or precise and undeniable proof that it is impossible to save the patient which has unbearable suffering, and 24.6% of respondents said that these joint conditions should be the main arguments for euthanasia. However, 46.5% of medical staff noted that these conditions are not cause for euthanasia.

It was found that 65.2% of medical staff took the patient's right to dignified death. But they noted that euthanasia can be applied only taking into account the legal protection of the patientsas an exception to the rule, and can be performed only under strict control of this process.15.6% of medical staff hasn't determined their attitude to euthanasia. Although euthanasia is prohibited by law in our country, the possibility of its implementation allowed 5.1%.

Students noted incurable and long-term disease as a primary medical-biological prerequisite for the existence of euthanasia (Figure 4).

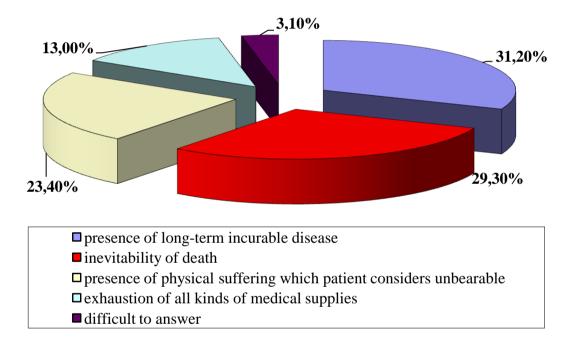


Fig. 4. Medical-biological preconditions to euthanasia among students

Students didn't give a definite answer in the determination of the rights of patients to a voluntary withdrawal from life, and 9.1% of students didn't respond to this question (Figure 5).

Choosing the answer to the question: «What is euthanasia: mercy or crime?» – 1/5 respondent (20.1%) didn't answer, 34.3% – gave a vague answer, and 1/5 of all respondents (22.9%) considered that euthanasia is necessary in some cases, but they never would not do it. We have found that 25.5% of respondents recognized the euthanasia as a mercy, because it relieves the patient from suffering, but 35.7% - noted euthanasia as a crime (among medical

stuff of the Republic of Poland this percentage is higher (56.8%)). Part of medical staff (43.7%) believed that euthanasia – is a mercy for the terminally ill person and a crime against God, that it is contrary to the religious and ethical norms.

The act of euthanasia involves both medical actions and actions of the patient (his request). So should medical staff to perform such actions? More than half of respondents (73.4%) expressed the view that medical stuff should never help patients to die, 14.5% responded that the health worker has the right to terminate the patient's life, and 8.8% were undecided, 3, 3% considered that it is necessary to create a law that will solve the problem of euthanasia.

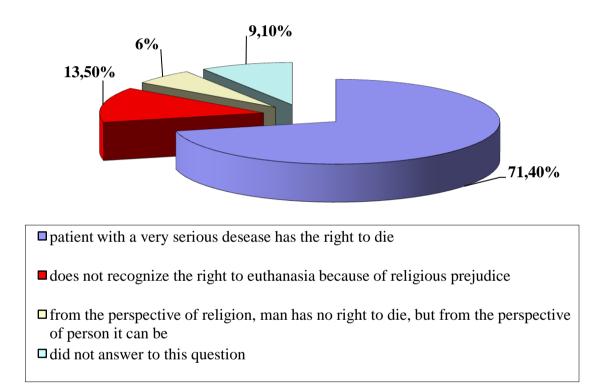


Fig. 5. The attitude of students to the right of patients to a voluntary withdrawal from life

Contradictory and harm of ideas about euthanasia, belongs to the category of phenomena that can't be resolved in moral way. Arguing about the moral of this term, we should proceed from the fact that the murder can't be humane. Society, if it wants to be humane, shouldn't impose to medical staff these ideas, which are contrary to the essence of their profession.

The results showed that belonging to the medical profession, age and education of respondents changed the attitude to euthanasia.

The attitude of nurses to euthanasia changes with age in favor of opponents of euthanasia: the youngest nurses often supported euthanasia. In the age group over 50 years, most respondents opposed its implementation. Although the overall number of nurses which supported euthanasia is slightly higher than the number of opponents. This is mainly due to the predominance of the supporters of euthanasia in the age group up to 29 years. Almost 1/5 of respondents tried to avoid answering the majority of questions, referring to the insufficient level of preparedness on this issue. Distinguish between passive and active euthanasia in the majority of the respondents caused difficulties. Results of the research suggest that euthanasia is complex and ambiguous representation in the public consciousness.

Therefore it is necessary in the course of training in medical educational institutions to form among the future medical staff civic responsibility and understanding of high value human life, and create psychological and pedagogical conditions for the development of communicative competence; motivation to the correct choices in life and serious attitude towards their chosen profession. Due to the revival of spirituality in society it is necessary to include this issue in the teaching programs of medical educational institutions and adopt relevant legislation in health care.

Conclusion

Introspection of moral attitudes to the problem of euthanasia among young people contributed to the development of mercy, humanism, medical duty to the patient and allowed to understand that any form of euthanasia is contrary to the very essence of the medical profession. It is necessary to attract the attention of young people to the importance of alternative of medical euthanasia – to the organization and development of hospice palliative care, whose purpose should be to ensure an acceptable quality of life of hopeless patient and his family. Materials were used during the practical and educational lessons among future medical staff for the formation civil liability concept of high value human life, ideological and cultural education, motivation to the correct choices in life and serious attitude towards their chosen medical profession.

References

1. About public health services: Law Rep. Belarus from 20.06.2000 №363-z // the Adviser Plus: Belarus. Technology 3000 [The electron resource]/Open Company

«UrSpectr», Nat. The centre a legal inform. Resp. Belarus. - Minsk, 2006.

- Declaration on the Promotion of Patient's Rights in Europe. Copenhagen, WHO. Regional Officefor Europe, 1994 (document ICP HLE 121).
- Salnikov V.P. Euthanasia: pro and contra [in:] The Legal world. Salnikov V.P., Starovojtova O.E., 2005, 3, 42–48.
- 4. Tchernyshev J.A.: Euthanasia: the past, present, future [in:] The law and the right. Tchernyshev J.A., 2008, 5, 54–59.
- 5. Kurtts. P.: Ethics of humanism. Rus. Human. Society, 2002, 189.
- 6. Millard D.U.: Euthanasia: debate in Britain. Soc. Clin. Psychiatr., 1996, 4, 107–109.
- Isaev J.S., Voropayev, A.S., Dilis A.S.: Medico-legal aspects of a euthanasia. Sib. Medical Jour., 2004, 8, 100–102.
- 8. Kapinus O.S.: Euthanasia as the socially legal phenomenon. Bukvoved, 2006.
- 9. Agievets S.V.: Theoretical of a problem of legal adjustment of medical aid: Monographies, GrStU, Grodno, 2002.
- Bogomjagkova E.S.: Euthanasia as a social problem. Jour. Invest. Soc. Politics, 2010, 2010, 8, 1, 32–34.
- Kapinus O.S.: Light death or soul salvage? Theology and euthanasia problems. The Law, 2005, 6, 106–113.
- 12. Krylov N.E.: Euthanasia: criminally-legal aspect, Vest. Moscow State University, 2002, 2, 17–36.
- Sabirov V.Sh.: About world outlook bases of modern western thanatology. Person, 2002, 5, 99–111.
- 14. Palkina T.N.: Problem of realization of the right to a life. Soc. Pens. Provision, 2008, 4, 5–11.

Euthanasia as legal considerations in the world over the years

Gnus Jan^{1,2,3}, Maślanka Paulina¹, Antczykowski Maurycy¹, Kasperczak Michał¹, Gnus Emilia¹, Ferenc Stanisław¹, Gonet Martyna¹, Sebzda Tadeusz², Uruska Paulina⁴, Paprocka-Borowicz Małgorzata²

- 1. Regional Specialist Hospital in Wroclaw Department of General and Vascular Surgery
- 2. Wroclaw Medical University
- 3. Papal theological University in Wroclaw
- 4. University of Environmental and Life Sciences in Wroclaw

Introduction

The problem of euthanasia was sooner or later judged by each country in the world. There are acts legalizing or prohibiting this procedure everywhere. These acts affect life of the entire society. Despite the fact that they impact the individual concerned, the decision is common for all. The decision for the entire country often is influenced by religion professed by the ruling. That was the main factor that shaped the way of thinking and value system of the people living in the area for centuries. Priorities, however, can quickly change up against the incessant and impossible to relieve pain or mental suffering. Currently, the acts concerning euthanasia are in the dynamic change process towards being more and more dependent to the will of the patient.

Definitions

The term "euthanasia" in is defined as "*deliberate deprivation of life or death acceleration of a seriously ill person in order to liberate him/her from physical suffering*" [1]. As an alternative, there are also such terms as mercy killing, murder on demand or euthanasia homicide used [2]. The procedure can be further divided into two most famous variants:

- active euthanasia [3] deliberate and thoughtful action taken by a doctor under the influence of sympathy for a patient and at his request in order to cause his death, which occurs earlier than from natural causes.
- passive euthanasia deliberate and thoughtful action taken by the physician under the influence of compassion for the patient and at his request, involving the discontinuation

of the measures and life sustaining procedures, death occurs earlier than from natural causes.

Apart from this basic division there are also the notions of dysthanasia, orthanasia and cryptonasia distinguished. Dysthanasia means the use of technological treatments aimed to keep alive a person in the state of dying whose brain is in an irreversible state of biological death, whereas orthanasia is a suspension of the invasive treatments that prolong life [4]. In other words orthanasia can be understood as an suspension of the use or turning off of artificial devices by the doctor [5]. Therefore, some sources qualify orthanasia as a variant of passive euthanasia [6], whereas cryptonasia is described as secret taking lives of sick people without their consent and knowledge (from the Greek *kryptos* - secret, hidden and *thanatos* - death) [7].

In addition, the concept of assisted suicide and the "DNR" procedure are worth mentioning. Assisted suicide involves a doctor "knowingly and intentionally providing a person with the knowledge or means or both required to commit suicide, including counseling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs" to end life sooner than it would happen from natural causes. The "DNR" (*do not resuscitate*) procedure is acceptable when, in accordance with the medical state of knowledge, the cause of life-threatening condition cannot be treated and is irreversible, i.e. the patient has no chance to come back to normal vital signs, do not show progress toward recovery, constantly requires the use intensive care methods and remains unconscious. In such a situation, the physician is exempted from the emergency measures of treatment [8].

How does the law looks like nowadays over the world?

Albania was the first European country which legalized euthanasia. The bill was passed already in 1999. Any form of active euthanasia with the consent of the patient is permitted. In the case of passive euthanasia it is required to obtain a consent of three family members of the patient.

In 2002 euthanasia was legalized in **Belgium** by means of thiopental injection for fully mentally competent patients but considered incurable, including mental illness that is causing continuous physical and mental suffering, which the patient cannot bear any longer [9]. In 2014 the law was extended "giving the right to die" to children, with no age limits, only with parental consent. The conditions that must be met for the procedure are similar to those in the Netherlands, but if the patient is in terminal stage of the disease, the doctor must consult a

second independent specialist. Between the written applications for euthanasia and the act of euthanasia itself there must be at least one month break.

In February 2015 year, **Canada** rejected the accusation of a doctor for helping mentally healthy but seriously sick patient in committing suicide. Nevertheless, both active euthanasia and assisted suicide (though here under discussion) remain illegal. An exception is passive euthanasia, which is fully admissible. Life-sustaining procedures can be withdrawn with the patient's family member consent.

In 2010, the Constitutional Court in **Colombia** ruled that "no person can be held criminally responsible for taking the life of a terminally ill patient who has given clear authorization to do so". A patient's life is terminated with a lethal dose of intravenous drugs. However, such procedure can be performed only on adult patients with severe disease in the terminal stage, causing constant pain, which can no longer be reduced. The patient must consciously express his/her consent, under the supervision of not only medical specialists in a particular field, but also a lawyer and a psychiatrist or clinical psychologist.

Although euthanasia itself is not legal in **Germany**, since 25 June 2010 assisted suicide has been legalized. The German Federal Court of Justice issued a ruling which stated that assisted suicide is legal for people who do not want to be artificially kept alive.

Euthanasia and assisted suicide in the **Netherlands** have been legal procedures since 2002. From that time doctors shortening the suffering of the sick who meet specific requirements will not be punished. The law allows euthanasia only if the following conditions are satisfied [10]:

- 1. Suffering of the sick person must be unbearable, with no chance of improvement in the patient's condition.
- 2. The request of euthanasia by the patient must be voluntary and should persist for a predetermined time, it may not be satisfied if the person is under the influence of drugs, suffers from a mental disorder or is under the influence of others.
- 3. The patient must be fully aware of his rights, prognosis of his illness and medical condition.
- 4. It is necessary to consult the decision concerning euthanasia with at least one independent doctor, who must confirm the patient's health status and the conditions referred to above.
- 5. Euthanasia must be performed through administering medically appropriate procedure by a physician or by a patient in the presence of a doctor.

6. The patient must be at least 12 years of age (patients aged 12 to 16 years must obtain parental consent).

Both passive as well as active euthanasia are allowed in **Japan**. In the case of passive euthanasia certain conditions must be met, such as the fact that the patient is suffering from an incurable disease and the will of the patient must be expressed clearly (in the form of a prewritten consent, if the patient is unconscious or the testimony of the family). However, in the case of active euthanasia there are other additional requirements such as suffering from unbearable pain, the proximity of death, which cannot be prevented, the patient must be aware when giving consent (living wills and family consent will not suffice). In addition, it is important that doctors must have ineffectively exhausted all other measures of pain relief.

Euthanasia and assisted suicide was legalized in **Luxembourg** in 2009. Only fully sane adult in the final stages of disease, from which he/she is unlikely to make a recovery, which is a source of constant mental or physical suffering can meet the legal conditions. The patient must repeatedly express the will to stop the treatment. There is also required the consent of two doctors and a panel of experts. Each individual case is reviewed by a committee of physicians and trustworthy person, which had previously been designated by the patient. When the law came into force it has been criticized not only by the Catholic Church, which has a large influence on society of Luxembourg but also by the ruling Christian-Social Party. Also, the greater part of the medical community declared themselves against such law [11].

Euthanasia is forbidden in **Poland**, however, it is treated as a kind of a murder punishable in a milder way. In the legal language it is one of the privileged homicides, whereas the privilege is expressed in lowering the statutory minimum punishment in relation to the murder of basic type [2]. However, it is not an offense under Polish law to withdraw persistent life supporting therapy, that is the use of measures which could expose the patient to additional pain and persistent procedures that worsens patient's daily condition.

Active euthanasia is not legal in **Switzerland**, however, assisted suicide is permitted by the law, provided that the person assisting performs the procedure with no personal benefit. A presence of a doctor is not required. Assisted suicide is also not "reserved" only for the terminally ill patients or citizens of Switzerland. Four out of six organizations involved in assisted suicide allows representatives of other nationalities to use their services. Drugs usually used are medicines containing barbiturates administered orally [12].

Every state in the **United States** has a different legal situation, however, passive euthanasia is legal throughout the country. Liberal law concerning assisted suicide was also

passed in several states such as: Vermont, New Mexico, Oregon, Washington and Montana which legalized such a form of patient's life termination. In 1997 Oregon enacted the Death with Dignity Act as one of the first countries in the world, but the person applying for the procedure must be diagnosed with a terminal illness that will lead to death within six months.

Some historical facts

To understand present-day law and people's attitude towards euthanasia it's very important to look back to the history.

The word *euthanasia* itself is derived from the Greek words *eu* - good and *thanatos* - death and means "good death" [13]. It was in the fifth century BC in the Cratinus Comedy of undetermined title. The term was not then explained thoroughly but it was used in the context "of a person having a good death" [14].

The theme of euthanasia in contemporary view appeared already in the Old Testament. It was included in the story of Saul fighting in the Battle of Mount Gilboa, where Saul was severely wounded. Willing to die with dignity he asked his armourbearer to pierce him with the sword, however, he refused. So Saul took his sword and fell on it. However, he saw a look of pity from the young man who helped Saul and killed him.

Quite a different attitude towards the use of euthanasia had Sparta where it was the act of extermination. At that time children were not considered as belonging to the family, but as the property of the state. If the child was born feeble or crippled, the decision was taken to abandon them in the mountains or drop them into the abyss. Such procedures also took place in other parts of Ancient Greece, nevertheless they were carried out only when there were too many children born and it was the father of the child whose decision was always taken into account.

The Middle Ages brought the notion of a suicidal euthanasia or mercy killing. One of the most popular ways to take away one's life was a stroke with a misericorde (derived from the Latin *misericordia*, 'the act of mercy', since the act ended the suffering of the dying). It was a long thin dagger, often ornamented, which shortened the life of fatally wounded knights, enemies, or allies.

In the eighteenth century in an increasing productivity became a common goal of the economy and as a consequence of this fact the handicapped and the sick could not be taken into account while creating the image of a good and effective employee. Therefore, there had to be not only created but also financed organizations for the weaker such as homes for the

elderly, hospitals (also psychiatric wards), orphanages, prisons, workhouses, and shelters for the homeless. With time and further development of science, these people were defined as ill and regarded as useless from the point of view of procreation. The weak and disabled began to be called degenerates, psychopaths, subhuman, whereas across Europe, harassment and social degradation grew to a level which later was the basis for the acceptance of euthanasia not only in Nazi Germany [10].

Euthanasia and religion

Talking about euthanasia and its history, it's necessary to mention a bit about the religious aspects.

In <u>Christianity</u> in the Decalogue the fifth commandment says: "Thou shalt not kill!" The Catechism of the Catholic Church explains this law in the following way: "Human life is sacred because from its beginning it involves the creative action of God and it remains forever in a special relationship with the Creator, who is its sole end. God alone is the Lord of life from the conception until the end. No one, in any circumstance, can claim to have the right to destroy directly an innocent human being" and "direct euthanasia, no matter what its motives and means are, consists in putting an end to life of handicapped, sick, or dying. It is morally unacceptable. "It is therefore a procedure completely prohibited and rejected by the Church [15].

In 1995, Pope John Paul II wrote an encyclical "Evangelium Vitae" in which he expressed his views on euthanasia. Active Euthanasia was again rejected, however, a decision to abandon the "aggressive therapy" was treated separately [16].

When it comes to Protestantism and Orthodox Church they express the same values. Community Evangelical Churches proclaim the right of terminally ill people to live until natural death caused by illness, but they separate and recognize the right to withdraw from persistent therapy. However, euthanasia or assisted suicide are not allowed under any circumstances [17].

In <u>Judaism</u> there is no clear interpretation on euthanasia. All measures in civil law aimed at shortening life are denied. Nevertheless, it is sometimes allowed to relieve the pain of patients with the use of means, which cause a significant reduction of life, but only as a side effect. Unlike in previously mentioned religions, all the artificial ways to prolong life in cases when it could end naturally are also rejected [18].

In <u>Islam</u> discussions on euthanasia have began relatively recently. Not only did it condemn suicide and euthanasia, but also shed negative light on any method artificially prolonging life [19].

<u>Buddhism</u> rejects euthanasia for reasons connected with the concept of karma. Suffering has great importance in this religion since it should last until the bad karma that determines it finishes.

<u>Hinduism</u> did not develop its official position on euthanasia, however the procedure is seen by Hinduism adherents as an escape from one's own "self".

Conclusions

As time goes by world seems to be more and more liberal for the euthanasia. But there is always some ethical problem standing behind this. Even when the decision is up to the patient, it should be restricted by the law to prevent overusing.

References

- 1. Glaser S.: Zabójstwo na żądanie. PWN, Warszawa, 1936.
- 2. Krajewski R.: Przestępstwo eutanazji w kodeksie karnym z 1997 r. Prokuratura i Prawo, 2005, 2, 65.
- Szkotnicki W., Kaczor A. : Eutanazja aspekty społecznoprawne. Prokuratura i Prawo, 1997, 2, 54.
- 4. Marcinkowski T.: Medycyna sądowa dla prawników. Wyższa Szkoła Policji w Szczytnie, Szczytno, 2010.
- 5. Huziuk Z.: Kilka uwag o przestępstwie eutanazji. Prawo i Życie, 1973, 9, 6.
- Tarnawski M.: Zabójstwa uprzywilejowane w ujęciu polskiego prawa karnego. Wydawn. Nauk. Uniwersytetu im. Adama Mickiewicza, Poznań, 1981.
- 7. Fenigsen R.: Eutanazja. Śmierć z wyboru? Wyd. W drodze, Poznań, 1997.
- 8. Filar M.: Lekarskie prawo karne. Zakamycze, Kraków, 2000.
- Institut Européen de Bioéthique : Rapport de la Commission d'Évaluation Euthanasie 2014, www.ieb-eib.org/fr/document/rapport-de-la-commission-devaluation-euthanasie - 2014-380.html, edited 7.03.2016.
- 10. Kośmicki M.: Co wiemy o eutanazji? Warszawa, 4. 11. 2010 r., http://www. ostatniaszuflada.pl/prezentacje/eutanazja.pdf, edited 13.11.2015.

- Ministère de la Santé, Ministère de la Sécurité Sociale: Euthanasia and assisted suicide: 25 questions, 25 answers,czerwiec 2010, http://www.sante.public.lu/fr/ publications/e/euthanasie-assistance-suicide-questions-reponses-fr-de-pt-en/index.html edited 7.03.2016.
- Suicide tourism: a pilot study on the Swiss phenomenon, J. Med. Ethics., http://www.jacquelinejencquel.com/wp-content/uploads/2014/08/J-Med-Ethics-2014-Gauthier-medethics-2014-102091.pdf, edited 7.03.2016.
- Tokarczyk R.: Prawa narodzin, życia i śmierci. Wyd. Wolters Kluwer S.A., Kraków, 2000.
- 14. Citowicz R.: Prawnokarne aspekty ochrony życia człowieka a prawo do godnej śmierci. Wyd. Kodeks, Warszawa, 2006.
- Przykazanie V Eutanazja [in:] Katechizm Kościoła Katolickiego, tł. Pol., Pallotinum, 1994.
- 16. "Ja zabijam i ja sam ożywiam" (Pwt 32, 39): dramat eutanazji [in:] Encyklika Evangelium Jana Pawła II do biskupów, do kapłanów i diakonów, do zakonników i zakonnic, do katolików świeckich oraz do wszystkich ludzi dobrej woli o wartości i nienaruszalności życia ludzkiego, Kraków, 1995.
- Bruncz D.: Czas życia i umierania Kościoły ewangelickie o eutanazji. Ekumeniczna Agencja Informacyjna, http://www.ekumenizm.pl/religia/spoleczenstwo/czas-zycia-iumierania-koscioly-ewangelickie-o-eutanazji/, edited 7.03.2016.
- 18. Klöcker M., Twooruschka M., Twooruschka U.: Etyka wielkich religii. Wyd. Verbinum, Warszawa, 2009.
- 19. Ciućka A.: Eutanazja według islamu. Ekumeniczna Agencja Informacyjna, http://www.ekumenizm.pl/religia/islam/eutanazja-wedlug-islamu/, edited 7.03.2016.

Genetic diagnosis of cancer burden as illustrated by interviews with cancer patients and people from families belonging to cancer risk group

Jewdokimow Marcin, Chmielewska-Ignatowicz Tomira

Faculty of Humanities, Cardinal Stefan Wyszynski University in Warsaw

Introduction

According to widely available WHO data, malignant tumors will become the dominant cause of death worldwide in the XXI century. In Poland, the number of cancer diagnoses increased more than twofold [1] over the course of the last three decades, reaching over 140,5 thousand in 2010 [1]. Forecasts prepared by the Polish Oncological Society predict considerable increase (over 25%) in morbidity by the year 2025 [1]. Because of that, existence of a well targeted, timely and large-scale cancer diagnosis system seems to be essential. One in every five cases of cancer is a result of being born with a disease-causing gene mutation that greatly increases the risk of developing a tumor [1]. That is why advantages of preventive genetic testing are increasingly often discussed in the medical community in the context of prevention, diagnosis and treatment of cancer patients. Specific examples of tumors, for which mutations in certain genes can increase the risk of morbidity as much as thirteen times are breast cancer, colorectal cancer and prostate cancer.

According to professor Krystian Jażdżewski, "patients born with mutated genes should above all else be quicker and more persistent in monitoring their health. Despite that, common preventive recommendations do not apply to this group. For example, recommendations regarding mammography tests at the age of 40 refer to general population and do not take into account personal risk of a particular patient. For a woman with BRCA1 mutation, this kind of examination should be conducted at least 15 years earlier. Colonoscopy, on the other hand, is recommended to 50 year olds, when for carriers of dangerous mutations it should be conducted 20 years earlier. As a side effect of this procedure patients have their polyps removed, which ensures that colon cancer will never materialize" [2].

This all leads to conclusion that the ability to examine patients' genetic predispositions, particularly mutations associated with the risk of a disease allows for stratification of patients. In other words, this means diving them into subgroups depending on

the presence of previously defined characteristics. Subsequent targeting of those subgroups with specially selected, personalized therapy strategies leads to increased treatment efficiency [1].

In Western Europe, as well as U.S., genetic testing is increasingly often included into early cancer diagnostic procedures (in the U.S., NIH recommends genetic testing for people with multiple cancer cases, cases of breast cancer or cases of colon cancer in their families). This kind of early diagnostics are something unheard of, not only among Polish patients and their families, but doctors as well.

Considering the still common fear of cancer in Poland, and the fact that a single genetic test would allow a patient to acquire valuable information on their individual genetic burden and consequently undertake early preventive action (possibly leading to full recovery), it seems beneficial to explore the opinions of those affected with cancer and people close to them (potentially at risk of the disease themselves) on this kind of preventive diagnostics. People suffering from cancer as well as people from families affected by the disease seem to constitute a specific target group for this kind of diagnostic offering. They have previous or ongoing experience in dealing with oncologists and are actively seeking information on cancer, preventive practices and diagnostic and treatment options for their loved ones or themselves.

Assumptions and goal of this paper

The main goal of this paper is to present an analysis of in-depth interviews conducted with people suffering from cancer as well as people belonging to "cancer risk groups", defined as people who encountered a case of cancer in their immediate environment (mainly families). This definition, however, excludes people who are at risk of developing tumors because of their genetic or environmental predispositions. The reason for conducting the indepth interviews was to check the level of respondents' familiarity with genetic cancer diagnostics and their comprehension of how socially significant genetic diagnostics are in the case of cancer.

The analysis and interpretation of statements from the two mentioned groups in terms of knowledge and attitude towards medical diagnostic procedures will allow for juxtaposition of the conclusions with the medicalization and geneticization processes. Relying on Peter Conrad's work, the authors of this publication assumed the definition of medicalization as a "process by which non-medical problems are identified and treated as a medical problem, usually in terms of a disease or disorder" [3]. As pointed out by Conrad, medicalization is regarded in the literature negatively, as a process aiming to introduce oversight, social control or risk of subjugation. On the other hand, Hubert Wierciński [4] claims that the medical discourse and practice give individuals undergoing boundary experiences (which are stigmatized by the culture, thus causing the lack of tools necessary to deal with them) a chance to derive personal meaning and adapt medical discourse and practices to their local and family situations, often defined by fear of cancer.

Source material and methodology

10 in-depth interviews with people from cancer risk group and 5 with people suffering from cancer were conducted for the purposes of this paper. The first group is defined as consisting of individuals who encountered a case of cancer in their immediate environment (mainly in their families). The interviews were serving a support role for the quantitative study, conducted during telephone conversations on a random sample of 349 adult residents of Poland between March 23rd and April 2nd 2015 as part of the Bastion project, funded by the European Commission under the 7th Framework Programme and from the funds of the Ministry of Science and Higher Education (FP7-REG PO T-2012-CT2012-316254-BASTION). The small number of interviews conducted thus far indicates that the conclusions of the analysis should be considered exploratory.

What follows is the description for the enrollment process for the interviews. Two of the people suffering from cancer are participants of earlier studies conducted for the purposes of dr Tomira Chmielewska-Ignatowicz's doctorate study in 2014. The remaining 3 were recommended by the first two (utilizing the "snowball" method). The interviews were conducted by the researcher, dr Tomira Chmielewska-Ignatowicz, who collaborates with numerous oncological facilities. According to her assessment, based on professional practice and experience in working with people affected by cancer, the fact that the interviews were being recorded influenced the way in which those surveyed answered the questions, and, above all else, the length of the interviews. The interviewees strived for shorter replies and tried to provide the most precise answer possible, as opposed to driving a loose narrative on their own or someone else's disease. This fact was particularly evident after the recording stopped – interviewees then asked if their answers were acceptable. Only 2 individuals from this group have participated in social studies before; the others have not, which explains their anxiety concerning the precision and conciseness of the replies. The place of interview

seemed to have no apparent effect on the way the questions were answered. Whether in the clinic or in the flat the surveyed focused on providing precise responses to questions. Their anxiety due to the fact the interview was being recorded was palpable.

Individual in-depth interviews were intended to provide answers to select research questions, defining issues of public perception of genetic testing for cancer risk.

Research questions included:

- Knowledge of the existence and characteristics of genetic testing
- Factors of motivation (or lack thereof) to undergo genetic testing
- Sources of knowledge on cancer and its prevention acquired by the surveyed
- General opinions and ideas about genetic cancer prevention (process of being referred for the test, testing circumstances, proper communication of the test results to the patient, test results expectations and personalized medical approach)

Characteristics of interviewees

Individuals from the group consisting of people suffering from cancer (5 in total) are all women born respectively in 1988, 1970, 1973, 1967 and 1945, all of them of higher education. Three of them live in cities with between 50 and 100 thousand inhabitants, one in a city of over 250 thousand inhabitants, and one in a city of between 20 and 50 thousand inhabitants. The interviewed individuals suffer from thyroid cancer, breast cancer (2), renal cancer and laryngeal cancer.

There is a total of ten people in the cancer risk group: 8 women and 2 men, aged between 18 and 25 (two), between 26 and 35 (three) and between 36 and 45 (five). Five of these are of higher education, four – of secondary education and one – of basic vocational education. Three individuals from this group live in cities with between 20 and 50 thousand inhabitants, one in a city with less than 20 thousand inhabitants, one in a city with between 50 and 100 thousand inhabitants, four in cities with more than 250 thousand inhabitants and one in the countryside.

The table presented below contains information on surveyed individuals who are not suffering from cancer themselves but have a relative affected by the disease. In the case when there were multiple cases of cancer in the surveyed individual's family, they were supposed to state their relatives affected by the disease (e.g. parent, grandfather/grandmother from the father's side of the family, grandmother/grandfather from the mother's side of the family,

siblings, etc.). Because of that, the numbers in the table are higher than the number of the survey participants would suggest.

Suffering from cancer	Number	Kind of cancer	Number
mother	2	pancreatic	1
father	1	stomach	2
siblings	1	colon	1
grandfather	6	thyroid	1
grandmother	3	lung	6
mother in law	2	lymph nodes	1
parent's siblings	2	melanoma	1
		brain	1
		ovary	1
		kidney	1
		larynx	1

Tab. 1. Relatives who were affected by cancer; kinds of cancer observed.

Discussion of the survey's results

Limited knowledge on genetic testing

Despite the fact that the surveyed individuals seem to be quite firmly embedded in the broader medical discourse (including the experience of the disease, frequent doctor consultations, hospital stays, knowledge of the medical system and its limits for doctors and patients etc.) their knowledge regarding genetic testing for the cancer diagnostics purposes is very limited. Four out of five people suffering from cancer who took part in the survey had heard about genetic testing, however none of them has been subjected to such testing before the diagnosis. One of the surveyed has been subjected to such testing after completion of her cancer treatment at the Oncology Centre in Warsaw.

"Frankly speaking, I have never heard about it, but if there is a chance [of taking the test] this is one of the most profound medical achievements that exist in our times" (IDI, patient suffering from cancer No. 5)

The majority of individuals from the cancer risk group possess limited knowledge regarding genetic testing, their answers being most often random guesses based only on rudimentary knowledge, hearsay or their own ideas on the subject. Despite the fact that almost all (apart from one) surveyed declare having heard of such tests previously, half of them could not provide any details on the subject. The rest described genetic tests as being designed for checking individual predispositions towards genetic diseases, cancer, obesity, for paternity tests or specific infections (e.g. boreliosis). One of them found out about the tests through the news of Angelina Jolie's condition, another one – through her relative who had the tests done herself.

"[The tests allow to assess] the genetic burden, which causes various health problems such as obesity or other disorders" (IDI, family No. 9).

"In Poland, for example, if you have some genetic diseases, for example metabolic, suppose in the family. Then if you are pregnant you can be tested whether it's actually true. If there is something in your genes. Can your child be at risk "(IDI, family No. 1).

"In addition to these genes, ... in the case of you being a carrier of such a gene you may be suffering from cancer. Additionally, I think it allows for detecting many disorders. For children, perhaps especially for children, detecting many disorders "(IDI, family of 4).

Similarly, among those of surveyed who themselves suffered from cancer and declare having heard of genetic testing knowledge on this subject is limited. One of the surveyed had heard of genetic testing for possible future risk of getting cancer, another of test for celiac disease, third one for various diseases for which her friend tested her children a few years earlier, and the fourth one knew only that this kind of test is indeed practiced. According to two surveyed individuals, these tests are available in Poland, another two think that they are not. This seems worth considering, as the latter two are undergoing an oncological treatment at the moment.

"If they existed, I think they could be performed in Poland, but as of now I can't associate them with Poland" (IDI, patient suffering from cancer No. 5)

"I think they aren't performed, I think that I as a patient have heard nothing about them and have not heard anyone suggesting otherwise" (IDI, patient suffering from cancer No. 1)

On the other hand, one of the surveyed maintains that these tests are not widely available and that it is not possible to perform tests on all genes, only select few:

"If this was a diagnostic tool that was widely available in Poland, that could determine if I was going to get cancer or not, I would apply for it without any hesitation. However, because it is not widely available and accessible to anyone, a criterion for testing myself would not be that I saw someone on TV getting tested, but rather that I had cases of cancer in my family, and now another criterion for further testing is that I have cancer myself. I would like for the tests to be more widely accessible. Right now it's not easy to performs genetic tests, it's not as simple as getting a referral from a doctor and waiting for a visit" (IDI, patient suffering from cancer No. 4)

According to the surveyed, this kind of tests allows for determining the existence of "latent" diseases (IDI, patient suffering from cancer No. 1), as well as undertaking preventive actions:

Question: "What, in your opinion, can be generally tested with such genetic tests?"

"Perhaps the existence of any predispositions towards diseases, predispositions for early detection of some diseases, some kind of tendencies that can be discovered earlier, treated earlier, because many diseases are diagnosed after the fact. These tests could improve preventive medicine" (IDI, patient suffering from cancer No. 5)

Another individual believes that testing one person is enough for the whole family to learn about their health:

"In this case, as I overheard or learned, it's enough for one family member to perform these tests. The genes are the same, so it's not necessary for all family members to be tested. Anyway, from what I heard one of the patients at the oncology center had their request for tests denied because her mother had already done them, but it's just something I heard so I can't be sure." (IDI, patient suffering from cancer No. 4)

The surveyed individuals were not sure where the test material for genetic testing comes from. Three of them guessed that it might be bone marrow, blood or tissue samples. Two others decisively pointed to saliva and blood swabs. Despite the fact that the individuals from cancer risk group had their opinions on how the test process looks like, these were their conjectures rather than factual knowledge. The majority were of the opinion that the test material comes from blood, but some of them pointed to bone marrow and tissue samples.

The knowledge of individuals suffering from cancer and belonging to cancer risk group on the subject of genetic testing is limited and partly based on conjecture as opposed to facts. The surveyed were not sure, where the material for genetic testing comes from.

Genetic testing as an opportunity and fear of knowledge

All of surveyed individuals, apart from one person from the cancer risk group, were eager to submit themselves to genetic testing for cancer. They see it as an opportunity for preventing the development of the disease and preparing for it psychically (argument cited only by those suffering from cancer). One of the surveyed would prefer not to take the test, despite being aware of elevated risk of getting cancer (based on previous cases in the family). There was however no reason provided for that preference. As for the ones willing to participate in testing, their specific reasons for that were as follows.

First, because of greater opportunity for preventive treatment:

"Well, I would like to know what is the matter, which genes are broken and which gene in particular, if that is realistic of course because I don't know anything about that. That's how I imagine it, that I would be able to test my genes and that would tell me if I'm at risk of developing cancer of this or that internal organ. This would definitely give me a sense of empowerment, that I can act on that knowledge before the disease develops. In my case it was too late for that." (IDI, patient suffering from cancer No. 4)

Secondly, because of the possibility of preparing themselves psychically for the possible future disease:

"Because it facilitates the whole psychological process of going through cancer and helps in its diagnostics. If this kind of disease had already happened in my family, I would have known that I am at risk of developing it myself. Apart from that, I think the treatment would have *been much less intrusive as opposed to the situation of not knowing until after the fact.* " (IDI, patient suffering from cancer No. 5)

According to one of the surveyed, part of her acquaintances would prefer not gaining such knowledge:

"Although I know, that not everybody would like that. Based on some talks with people, I know they would rather not know. If it happens, it happens, and if it doesn't they would rather not think about the probability of that". (IDI, patient suffering from cancer No. 5)

Genetic testing is therefore treated as an opportunity to prevent the development of the disease. It is however worth highlighting that there were some among those surveyed who would prefer to remain ignorant about their potential genetic burden and the resulting risk of getting cancer. The interviews do not present an opportunity to explore this issue further, it can however be surmised that this approach results not only from the reluctance to learn about one's future but also to change their individual lifestyle, introduce preventive treatment, etc. This refusal can be seen as a refusal to participate in the genetic discourse. As observed by Jan Domaradzki [5] – "Fueling anxiety and fear of disease, genetics also becomes a source of hope for the patients. They believe that further progress of medicine will result in increase of knowledge about the disease and effective treatment methods. As a result, a culture of risk complements the culture of control and hope". Genetic testing – here Domaradzki agrees with Thomas Lemke [6] - generates new forms of risk, "which would not exist without genetic knowledge has an impact on the individual because it demands an actionable response to the obtained information, which appears to be a major psychological burden.

Although for some of the surveyed the mere possibility of obtaining the knowledge on their genetic burden in terms of a specific kind of cancer seems to be an important guide and motivational force pushing them to take actions mitigating the risk of cancer ever developing, for others it resembles more of a recipe for spending their life in fear. Based on the conducted research, it is hard to point to reasons for this kind of anxiety. Nevertheless, refraining from obtaining knowledge of a possible genetic burden may result from:

 perception of tumor or cancer as a disease on development of which we have no impact: "[Diagnosis] kind of means looking actively for what can happen to me, and not everyone wants to know the future" (IDI, patient suffering from cancer No. 1)

 postponing the moment of receiving the information on the probability of getting cancer is synonymous to postponing the moment of hearing the cancer diagnosis and beginning the treatment:

"Because I think there is a group of patients who would prefer not to know, who will not test themselves in case they hear they are sick. It's clear that people don't want to know about it at that stage" (IDI, patient suffering from cancer No. 1)

One of the interviewed stated he would prefer not to test himself in fear of the possible negative results, which would cause him to live in distress.

"Another question is, what's next. What good will come of the fact, that I give up and live in fear that could happen to me" (IDI, family No. 2).

Although the fear of cancer is often a deciding factor in postponing the doctor's appointment or undergoing the diagnostic tests, this same fear can also influence patient's decision to get tested. The surveyed individuals mentioned various factors which in their opinion can influence the decision on undergoing testing for genetic burden and probability of developing a tumor. These consisted mainly of: recommendation from their doctor (the doctor as one of the most important parts of the institutional diagnosis system), suggestions from their relatives (peace of mind for their friends and family), previous cases of cancer in the family (knowledge of the specifics of the disease, its long treatment time, restrictions associated with it), media (influence of information obtained from media on the observed significance of cancer prevention), and finally, the positive aspect of fear: "Fear of... I think until you reach a certain age, you don't give it any thought. As for me, I can say I didn't. Until you reach a certain age, let's say thirty-something, if you feel well and don't get sick often you don't see the point in doing any tests to check if you have a genetic burden. You are too caught up in this young life. I think we maybe need to raise awareness of this issue". (IDI, patient suffering from cancer No. 1)

Sources of knowledge about cancer and genetic testing

Among the surveyed from the cancer risk group who demonstrated awareness of cancer being a risk for the whole family, some (6 out of 10) looked for information on kinds of cancer and prevention methods. It can lead to the conclusion that experiencing a relative suffering from it not always results in the need to engage in such search or seek preventive care.

Only one surveyed person thought of looking for information on genetic testing allowing to determine the genetic burden. Her search, however, was limited to looking for information on studies of tumor markers (the whole search happened online):

Interview fragment:

"What inspired you to look for this kind of information on the marker?"

"Mainly the fact that my father developed this particular disease. I was looking into it in the context of possible genetic burdens which can result from the family's medical history." (IDI, family No. 10).

"Have you ever researched the diagnostic possibilities?"

"No".

"Why is that?"

"I wasn't aware that such things exist". (IDI, patient suffering from cancer No. 1)

When asked what influences the search for information on any given kind of cancer and its preventive treatment, the surveyed pointed to the occurrence of such disease in the family or developing it themselves as the most important factors. However, contrary to those statements, the disease of a loved one did not become an incentive to engage in this kind of search:

"When? Too late. Too late, no point arguing about that. Right now, the situation seems to be better, because the awareness of this issue is greater than a few years ago, but still for the majority of people they look for this information too late, when the cancer is in its late stages. Only radio- or chemotherapy is able to help these people then, and often not even that" (IDI, family No. 3). Three from the five individuals suffering from cancer stated that their search for information on the disease started after they received their diagnosis:

"I think you don't usually [look for information] when this kind of risk exists or is mentioned in a conversation. I think not until something starts happening. You often think something is wrong and panic when you get a simple cold and the whole discourse going on in the media isn't helping either" (IDI, patient suffering from cancer No. 5).

One surveyed individual (No. 4) sought information before getting cancer, and stopped after being diagnosed:

"Nothing mattered to me [...]. I stopped using the computer, I wasn't able to absorb any information, read anything online or any newspapers. My brain was totally shut itself on any stimuli. Perhaps others look for information after such diagnosis. I needed to rely on my friends, who helped me with that task and relied information to me. Frankly speaking, I even had trouble with processing that. You could say they led me by my hand and helped me" (IDI, patient suffering from cancer No. 4).

Another interviewee (No. 2) stated that interest in seeking out this kind of knowledge depends on age:

" [We look for this information] generally in the second half of our lives, when we are more mature and realize how our lifestyle, and, I don't know, genetic burdens influence us" (IDI, patient suffering from cancer No. 2).

Based on conversations with the surveyed it becomes clear that when it comes to looking for knowledge on the disease and appropriate preventive therapy, there are three main strategies. First, there is looking it up online; second – utilizing multiple sources (Internet, medical literature, doctors, etc.); third – exclusively speaking to doctors. At this point it is necessary to stress the skepticism which some of the interviewed expressed towards online sources:

"[Online knowledge] has satisfied [my need for knowledge] but at the same time caused even more anxiety, because they were consistent, yes, but the more I found, the more anxious I felt, because, well... [later this information was verified during doctor's visit]" (IDI, family nr 5). The surveyed individuals also stressed that their lack of deeper medical knowledge causes the information found online to be incomprehensible, which leads to additional unnecessary anxiety:

"I only looked for information online, but because it was hard to understand, I wasn't familiar with the subject, I didn't understand much of it. I got an overview of what I looked for. It was more frightening than beneficial. And that was the only information I got out of it." (IDI, patient suffering from cancer No.1).

"Later I started to look for information online, but not on these so-called forums, where all manners of things happen and you can read unbelievable stories, which often causes you to lose your grip" (IDI, patient suffering from cancer No. 5).

Another individual added that she prefers to rely on her doctor's knowledge rather than spend too much time online looking for similar information. This could mean that a doctor's authority still prevails when the patient is in need of reliable factual knowledge:

"I reckon that people, doctors, who specialize in a given field can provide me with the most information, so I try not to abuse Google looking for that information" (IDI, patient suffering from cancer No. 2).

The surveyed confirmed that the information about a public figure getting cancer is actually a valuable source of knowledge to them and that they do not dismiss it. However only after the disease reaches someone among their friends or family do they feel motivated to engage more intensively in search for information on a given kind of tumor or its prevention and therapy:

"Sure, media, of course, but I kind of know now what is happening around the world. I know of Angelina of course, and others, who struggle because of that, but it's one thing to know and a whole another story when it happens in your family" (IDI, family No. 8).

Notions about genetic testing

None of the individuals from the cancer risk group has been subjected to genetic testing, therefore their statements on the testing methods, places and other related issues can only be called interviewees' notions of genetic testing (more so as it was demonstrated earlier that they possess limited knowledge of genetic testing itself).

According to the surveyed, genetic testing should be performed in specialized institutions (hospitals and specialized clinics). This opinion may stem from the need of those interviewed for the test and its results to be credible. What is interesting is that one of the interviewed sees the credibility of the test as a purely psychological mechanism, without any significance for the actual quality of the tests.

"That's the first thing that comes to mind, this kind of testing should be performed by a doctor. Obviously, nurses are also diligent and thorough, but a doctor is what comes to my mind first. This seems more credible, if a doctor performs the test, then it should be great, you know? However, as I said, nurses are also qualified in that regard, so everything should be ok as well" (IDI, family No. 3).

The need for adding credibility to genetic testing through a selection of a specialized, trustworthy location and a competent person in charge of collecting the test samples seems to have two main aspects: pragmatic, because those being tested want to make sure the procedure is performed correctly, and psychological, because it allows the patients to feel good about being tested properly.

The factors affecting the trustworthiness of a test are location and staff. One of the surveyed (No. 5) would like for the test to be performed at a hospital, and not "some kind of a clinic":

"Surely in some kind of a more specialized facility, I mean... more of a hospital, not some kind of a clinic, more of a hospital I think" (IDI, family No. 5).

Conclusions

Despite the fact that the individuals participating in the survey possessed extensive knowledge (as well as experience) of the specifics of cancer, their awareness of the existence and specifics of genetic testing was extremely limited. It was based mainly on speculation, partially overheard information and conjecture. The main conclusion that can be drawn from that is that the information regarding possibility of genetic testing for cancer burden in Poland is not yet widespread and easily accessible. One possible explanation for this is that it is not generated by the medical facilities and doctors themselves... In the meantime, fear of cancer among Poles remains high, which is confirmed by small number of patients registering for preventive testing.

Fighting the widespread fear of cancer should become Poland's priority. Whereas only 20% of Poles begin cancer treatment in the early stages of their disease, in the Western Europe this ratio reaches as high as 80% [1]. The so-called "oncology package", which has launched in 2015 and aims to guarantee fast cancer diagnostics and treatment for patients afflicted with malignant tumors, does not include screening tests [1]. These give the patients the highest possibility of early cancer detection and ability to properly assess the risk of it happening in the future, as well as possibility to learn about any changes needed in their lifestyles or nutritional habits to minimize this risk.

Raising awareness of this kind of diagnostics and personal medical treatment is of particular importance in the context of cancer discourse "de-tabooization" as well as decreasing the fear of cancer in the Polish society. The individuals participating in the study often pointed to their emotion of fear/anxiety, which on one hand functioned as a motivator for getting tested for possible genetic cancer burden, and on the other acted as an incredibly strong barrier preventing them from learning about their health.

Fear is an emotion experienced in the face of uncertainty [7]. While it remains, besides pain, one of the most important warning systems informing the patient about a possible health risk and pushes him or her to take preventive action, it can also become a psychopathological problem, contradicting its primal and evolutionary task of risk mitigation. With that in mind, fear is "*a phenomenon that is inscribed in the body, but modified in interpersonal interactions and in culture*" [7] from the perspective of various scientific medical and non-medical discourses. This inextricable tangle of the biological nature of fear and its cultural and social determinants is very clearly exemplified by the fear of cancer, a disease which is considered to be incurable by the society. There are great possibilities for promoting the discourse on genetic testing for mutated genes (responsible for the development of particular kinds of tumors) among the medical community (including primary care family doctors). This is important not only because doctors remain very influential in Poland, but also because medical knowledge referring to cancer is something that is sought out in particular moments

in life (after being diagnosed with cancer or learning about the risk of developing the disease) rather than something that is constantly present in peoples' lives.

References

- Chmielewska-Ignatowicz T., Jażdżewski K., Jewdokimow M., Massalski M., Sztolcman J., Walczak A., Walczak B., Wójcicka A.: Policy Paper dla nowej polityki państwa w zakresie spersonalizowanej profilaktyki onkologicznej w Polsce. Projekt BASTION From Basic to Translational Research in Oncology. Wydawnictwo Warszawskiego Uniwersytetu Medycznego, Warszawa 2015.
- Sygut M.: Na tropie nosicielstwa wadliwych genów. To też profilaktyka raka, http://www.rynekzdrowia.pl/Serwis-Onkologia/Na-tropie-nosicielstwa-wadliwychgenow-To-tez-profilaktyka-raka,156672,1013.html, edited 01.02.2016.
- Conrad P.: Medicalization and Social Control. Annual Review of Sociology, 2003, 18, 209-232.
- 4. Wierciński H.: Rak. Antropologiczne stadium praktyk i narracji. WUW, Warszawa, 2015.
- Domaradzki J.: Genetyzacja społeczeństwa. Społeczne konsekwencje nowej genetyki. Studia Socjologiczne, 2012, 2, 205, 7-26.
- Lemke T.: Disposition and Determinism Genetic Diagnostics in Risk Society. The Sociological Review, 2004, 52, 4, 550-566.
- Widelska K.: Krajobrazy lęku [in:] Lęk. Kępiński A. (red.). Wydawnictwo Literackie, Kraków, 2001, 353-354.

The role of the support groups in the process of mourning a child's death - research conclusions. Support groups – mourning a child's death

Konczelska Katarzyna

University of Social Sciences and Humanities, Wrocław

Introduction

Child's death is a painful and relatively frequent loss. In 2011, 7900 families experienced the loss of a child [1], additional thousands of parents lost their children due to miscarriage. Child loss is extremely difficult to accept as the children, regardless of their age, should not die before their parents. Therefore, a child's death is considered to be untimely and critically disruptive to the parents' lives [2]. Describing the pain of the family members touched by the tragedy, especially the parents, Brown presents it as the biggest life tragedy [3]. The death of a child is considered to be more traumatic than the death of a spouse [4]. Data show that the parents' sorrow is more lasting [5], and that the process of mourning a child's death might be the most complicated form of mourning [6]. Bereaved parents may experience mental and physical health issues. They may suffer from deep depression [6], physical exhaustion [6], different forms of insomnia [7]; they may also feel anger and guilt induced by the loss [8]. Some of the parents are unable to go back to the state prior to the loss [9]. Despite that, it is said that the support received by the family after a child's death has a positive influence on the process of mourning [10]. It has been proven that losing a child is unequivocally one of the most difficult experiences in the life of an adult. It begets defiance and discord among the parents and people close to them. Considering the theoretical knowledge on the subject of processing mourning, the difficulties caused by the mourning process and factors influencing or impeding experiencing mourning, we know that coping with the death of a child is exhausting not only for the mother but for the entire family. It may cause health problems, and when the experienced trauma turns mourning into a chronic state it may permanently change one's personality. Every year thousands of families are affected by this problem. Therefore, this research has been conducted to analyze the correlation between parents' participation in the professional support groups and the process of mourning a child's death.

Research goal and objectives

The hardship of losing a child and consequent mourning is a subject that deserves more substantial analysis. It is a problem that is hard to examine. The leading researchers in the field of mourning, Kübler – Ross and Sanders, have noted a significant role of social support as a factor making the process of mourning more manageable [11,12]. The most popular hypothesis on the subject of support is the buffering hypothesis, which stipulates that social support (existing, observed and received) is like a buffer that protects us from social impairment, allows us to concur our fears and minimizes stress [13]. It has been also stated that the best source of social support in crisis situations, where one needs to work out a realistic image of the situation and oneself, one's feelings and thoughts, are people in a similar situation that experience the same problem [13]. Therefore, it is assumed that the support received in the support groups should have a positive impact on the process of mourning a child. Both Kübler – Ross and Sanders give specific attention to the support groups. According to the authors, this form of help is beneficial to the bereaved parents [11,12].

Personality is an important factor that influences the process of coping with a child's death. Analysis of factors influencing the process of mourning led Krzyżanowski et al to distinguish circumstances of death, availability of support, relationship between the mourner and the deceased and personality of the mourner [14]. According to the theoretical basis of this paper, personality may influence how easy or hard it is to initiate social interactions and participate in them [13]. In noetic personality "problem with noticing life's purpose is a sign of anomaly within functioning of the existence and relations carried out by it, and is directly connected to dysfunctional activity of the noetic personality model" [15]. Therefore, parents who are marked with high scores on the scale will face more difficulties in processing the loss of a child. They may be more prone to experiencing an impaired mourning process through intensification of the symptoms resembling depression, reduced sense of a life purpose, and to solidifying it into a fixed way of processing mourning, when faced with the death of a child. Noetic approach to coping with loss will make it more difficult to process and conclude mourning.

One of the goals of this study is to verify and outline the relationship between participation in the support groups and the process of coping with mourning a child's death. Additionally, it is essential to verify whether participation in the support groups helps to process mourning with more awareness. It is also crucial to specify whether the support groups participants are able to use social support in a more effective way; whether participation in the support groups improves relationship between the parents during mourning and once it is finished.

This paper also verifies whether personality of a bereaved parent influences their mourning process. According to research [13], it is plausible that extroversion and neuroticism have impact on social support (size of the support network and inclination to look for support).

Additional goal of this study is to verify whether the support group participants exhibit lower level of depression than the non-participants. The study also examines whether the support group participants feel greater sense of purpose in life.

Materials and methods

Between July 2013 and January 2014, a group of 66 bereaved parents, between the age of 27 and 63, participated in this research. 33 of the respondents had participated in a professional support group (the participants) for bereaved parents, the remaining respondents were the control group (the non-participants). The qualitative analysis shows that among the participants were people who had experienced the most critical types of a child's death-according to Sanders [12] and Kübler – Ross [11] : child's death by suicide, child's death by murder, death of more than one child, death of an only child.

The Revised NEO personality inventory by Costa and McCrea [16], Beck Depression Inventory, Purpose in Life Questionnaire by J. Crumbaugh and L. Maholik, Social Support Questionnaire, Berlin Social Support Scales and a questionnaire created by the research author were used to conduct the research.

Results

The research objective was to analyze whether participation in the support groups influenced the ability to cope with the loss of a child and what was its role in processing mourning.

The participants and the non-participants were similar in many aspects. Figure 1 presents main differences between them.

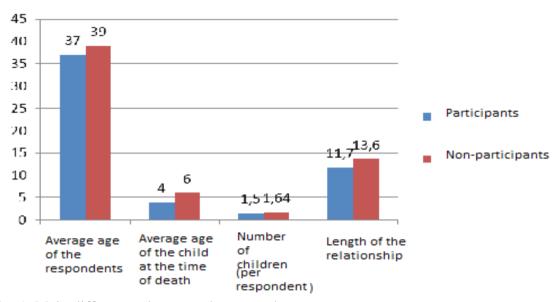


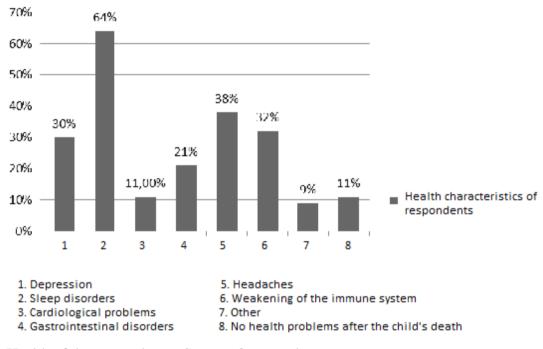
Fig. 1. Main differences between the research groups. Source: Own work.

The average age of the participants was 37 and the average age of the non-participants was 39. The relationships of the non-participants were slightly longer at almost 14 years (approx. 12 years among the participants). The number of children was very close – on average "a child and a half" per every bereaved respondent. Child's age at the time of death was also very similar in both groups, 4 and 6 years respectively among the participants and the non-participants.

Figure 2 presents health characteristics of respondents. According to Figure 2, in most cases (64%) the respondents suffered from sleeping disorders, including insomnia, excessive drowsiness, light sleep or nightmares. 38% of the respondents experienced headaches, 30% had depression. Only 11% of the respondents did not experience any psychosomatic symptoms after their child's death.

The respondents were asked about their opinion regarding the support groups. The majority (78% of all respondents, including 97% of the participants and 61% of the non-participants) stated that they were very helpful. They mentioned that *"only a parent who has experienced loss is able to understand this situation"*, *"in the group it is possible to be understood"*, *"conversations with people who also have experienced their child's death give allow for emotional relief"*, *"it is possible to receive specialist help free of charge, to be*

understood and to understand that we are not alone", "[support groups] help by allowing to process the stages of grief with other parents who have experienced loss".



Healths characteristics of respondents

Fig. 2. Health of the respondents . Source: Own work.

It seems interesting that the support groups are seen in a similar way by the participants and the non-participants.

Analysis of the available literature leads to a conclusion that a child's death very often causes difficulties in a relationship or may even end it [12]. Parents were asked to asses their relationship after a child's death (Figure 3).

67% of the participants noted that their relationship improved after the loss of a child, 18% did not register any changes in their relationship, decline in the quality of the relationship was mentioned by 12%, and crisis was mentioned by 3%. 33% of the nonparticipants mentioned that their relationship improved, 30% did not register any changes, decline in the quality of the relationship and crisis were mentioned by 18% each. The results show that among the participants, the majority of parents had a positive attitude towards their relationship, and only a small number of people experienced lowering of the quality of the relationship (closeness and connection with the partner) and crisis in or end of the relationship.

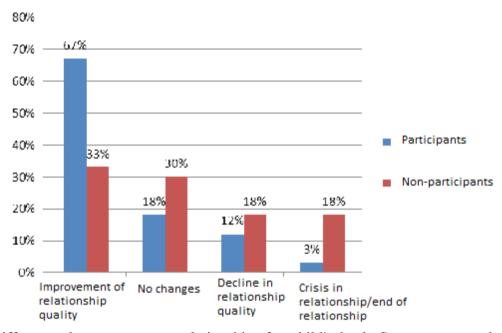


Fig. 3. Differences between groups: relationship after child's death. Source: own work.

Comparison of the participants and the non-participants established that:

- among the non-participants more time had passed since their child's death than among the participants. Mann-Whitney Test for Median Comparison was used to check for differences between the groups. The participants (n=33; M=2,20; SD=1,24) and the non-participants (n=33; M=3,72; SD=2,55) were compared. The result was statistically significant., U= 334,00; p<0,006.
- there are no differences between the groups within the subjective assessment of the current stage of mourning. Independent two-sampe Student's t-test (mean comparison) with Levene's test (homogenity of variance) were used. The participants (n=33; M=6,94; SD=1,93) and the non-participants (n=33; M=5,97; SD=3,14) were compared. The result was statistically insignificant, t(53,277)=-1,511; p<0,137).

It is important to note that among the participants the time that had passed since the time of child's passing was noticebly shorter (less time has passed since the time of child's death than in the control group) It was plausible to assume that the participants thought (subjectively) that they were in an earlier stage of mourning than the non-participants. Although the results show that there are no differences between the groups in this aspect;

• there are no differences between the groups when it comes to symptoms similar to depression. Independent two-sampe Student's t-test (mean comparison) with Levene's

test (homogenity of variance) were used. The participants (n = 33; M=10,24; SD = 7,47) and the non-participants (n = 33; M =12,76; SD =11,84) were compared. The result was statistically insignificant, t (53,994) = 1,032; p < 0,307). Although among the participants the time that had passed since their child's death was noticebaly shorter and the group presented more symptoms resembling depression after their child's passing and before participation in the support group;

there are no differences between the groups when it comes to having a sense of purpose in life. Independent two-sampe Student's t-test (mean comparison) with Levene's test (homogenity of variance) were used. The participants (n=33; M=104,18; SD=17,02) and the non-participants (n=33; M=99,09; SD=22,71) were compared. The result was statistically insignificant, t(59,330)=-0,865; p<0,391).

According to Frankl's concept [17], experiences connected to identifying life's purpose present themselves in a "tragic triad" of suffering, guilt and death [18], lack of differences between the groups means that the experiences connected with the death of a child have a similar impact on all parents, participation in the support groups is not a differentiating variable in this aspect;

there is no difference between the groups when it comes to susceptiblity to various illnesses. Independent two-sampe Student's t-test (mean comparison) with Levene's test (homogenity of variance) were used. The participants (n = 33; M = 2,15; SD = 1,22) and the non-participants (n = 33; M = 2,21; SD = 1,19) were compared. The result was statistically insignificant, t (64) = 2,03; p < 0,839).

Considering the differences between the groups (i.e. the fact that in the support groups participated the parents who had experienced objectively more damaging kind of child's death, presented higher number of symptoms resembling depression after their child's death and the amount of time that had passed since the child's passing was significantly shorter), it could have been concluded that higher number of people who had participated in the support groups would display more psychosomatic disfunctions. The lack of differences in this aspect may be interpreted as a positive effect of participation in the support groups;

there are no differences between the groups when it comes to the number of people in their support networks, although the received results are within the statistical trend. Independent two-sampe Student's t-test (mean comparison) with Levene's test (homogenity of variance) were used. The participants (n = 33; M = 6,21; SD = 1,67)

and the non-participants (n = 33; M = 5,36; SD = 1,81) were compared. The result was statistically insignificant, t (64) = -1,974; p < 0,053).

It is assumed that the participants gain ability to look for social support more effectively. Although the research shows differences on the level of statistical trend. The results above may be interpreted according to the social support activation model [13]. The model assumes that the more intense is the stress that we experience the more we look for and expect support. As the loss of a child is undoubtedly a very stressful factor and is considered to be the hardest life experience [2], the non-participants were looking for support in the same way as the participants did, the non-participants had a well-established network of social support and were able to look for help suited to their needs (priest, psychologist, psychiatrist, message boards, other bereaved parents etc.) People whose natural support network was ineffective, disappointed them or increased their pain and also parents who had experienced traumatic loss of a child participated in the support groups more frequently.

The conducted research established that personality traits are connected to the way of processing mourning (level of symptoms resembling depression, sense of purpose in life) and the ability to look for support. Pearson product-moment correlation coefficient was calculated, among others. The result was statistically significant, there was a positive correlation between variables: depression level and neuroticism, r(64)=0,639; p<0,000. The direction of correlation is consistent with the assumption. Therefore, the higher the level of neuroticism, the higher the level of depression. Strength of the correlation: strong. Details are presented in Table I.

BDI	ne1 (fear)	hostility)	ne3 (depressive ness)	control)	ne5 (impulsi veness)	ne6 (oversensitivi ty)
r	,568**	,614**	,657**	,480**	,225	,467**
р	,000	,000	,000	,000	,070	,000
N	66	66	66	66	66	66

Tab. I. Correlation between depression and subscales of neuroticism

To verify whether there is a correlation between the level of neuroticism and having a sensee of purpose in life, Pearson product-moment correlation coefficient was calculated. The result was statistically significant, variables has a positive correlation, r(64) = -, 786; p < 0,000. The direction of correlation is consistent with the assumption. Therefore, the higher is

the level of neuroticism the lower is sense of purpose in life. Strength of the correlation: strong (Table II).

PIL	ne1	ne2	ne3	ne4	ne5	ne6
R	-,725***	-,681**	-,765**	-,586**	-,372**	-,584**
Р	,000	,000	,000	,000	,002	,000
Ν	66	66	66	66	66	66

Tab. II. Correlation between life purpose and subscales of neuroticism.

The assumed correlation was confirmed in case of all scales of neuroticism. Correlation was moderate on scale 5 (Impulsiveness) and strong on the remaining scales.

To determine whether there is a correlation between extroversion and the size of the support network and level of depression Pearson product-moment correlation coefficient was calculated. The results are presented in Tables III and IV.

SIZE OF SUPPORT NETWORK	EXT.	e1	e2	e3	e4	e5	еб
r	,403**	,397**	,328**	,162	,265 [*]	,166	,306*
р	,001	,001	,007	,194	,032	,183	,012
N	66	66	66	66	66	66	66

Tab. III. Correlation between the size of the support network and extraversion

Source: own work.

The result is statistically significant in reference to the general score of extraversion and scales 1(Cordiality), 2 (Socialibility), 4 (Activeness) and 6 (Positive Emotions). Direction of the correlation is positive, which means that with the increase of extraversion, which mainly measures engagement in interpersonal relationships and energy levels [16], the support network expands.

The result is statistically significant in reference to general extraversion result and scales 2 (Sociability) and 6 (Positive Emotions). Direction of the correlation is consistent with the assumption. The higher is the level of extraversion the lower is the level of depression. It means that people who get high score in extraversion and low in neuroticism cope with the

mourning process after a child's death better as they experience less negative emotions and have a bigger social support network, among others.

BDI	EXT.	e1	e2	e3	e4	e5	еб
R	-,355**	-,143	-,261*	-,193	-,129	-,148	-,573***
Р	,003	,254	,034	,120	,304	,235	,000
N	66	66	66	66	66	66	66

Tab. IV. Correlation between level of depression and extraversion.

Participation in the support groups has a positive impact on parents' relationship after their child's death. Mann–Whitney *U* test was used. The participants (n = 33; M = 2,12; SD =1,26) and the non-participants (n = 33; M =3,09; SD =1,46) were compared. The result was statistically significant, U = 334,00; p < 0,01. The participants had a significantly better opinion about their relationship that the non-participants.

Child's death endangers relationship's durability [12], therefore the influence of participation in the support groups on lowerinng the risk of a relationship crisis was measured. During the time of mourning each parent displays their emotions in a different way, each of them also has different needs. Parents go through mourning stages at different time, which in many cases leads to conflict, feeling of being misuderstood, loneliness. Additionally their social roles give them other responsibilities which, in many instances, impede the process of coping with the loss together [12, experience of working with bereaved parents]. Therefore, relationships of the participants and the non-participants were assessed. The result was statistically significant – the participants stated that their relationship improved after a child's death (67% of parents). Almost half of the participants declared that they would like to have another child, 30% of the non-participants had significantly more positive attitude towards their relationship than the non-participant fathers.

Child's age at the moment of death influences the length of the mourning process – parents who have experienced a miscarriage or death of a young child go through the stages of mourning quicker than the parents who have lost an adult child or whose child commited sucide (Student's t-test of mean comparison was used with two independent samples. Levene's test of homogeneity of variance proved that the variances were equal. People who experienced a miscarriage or death of a young child (n=56; M=6,83; SD=2,33) and people

who experienced death of an adult child or child's sucide (n=10; M=4,3; SD=3,26) were compared .The result was statistically significant, t(64)=-2,975; p<0,004.

Discussion

It has been established then that the lack of differences between the groups of the support group participants and the non-participants in reference to: 1) current stage of mourning, 2) level of symptoms resembling depression, 3) sense of purpose in life, 4) number of people in the support network, is a positive result of participation in the support groups. The qualitative analysis shows that it was a group of parents who were in danger of more severe psychopathology due to a shorter amount of time that had passed since their child's death and the more damaging type of child's death that they experienced (death of an adult only child, murder of a child, loss of more than one child, suicide, among others). It is then plausible that **participation in the support groups is helpful in processing the loss of a child**.

Additionally, it has been established that the control group of non-participants was not devoided of support: some people used other forms of professional help (psychologist/ psychiatrist), had their own response group on a internet message board, others used the help of a priest, family member, partner or other bereaved parents. This fact was certainly significant in the examination. That is why it has been established that **participation in the support groups is not necessary in the process of coping with the loss of a child.**

Parents who exhibited high extroversion had a significantly bigger network of social support. The research added to extroversion two additional indices: Agreeability and Opennes to New Experience. All three of them were statistically significant. Taking into account Rogers and Maslow's theory of personality[17], it can be concluded that the personality traits above have a positive impact on willigness of parents to socialize with other people, which allows them to receive outside help in a situation which is undoubtedly difficult for a bereaved parent. The probability of finding help (in a form of social support) adequate to the needs and particular stage of mourning increases.

It has been also established that participation in the support groups has a positive impact on the relationship after a child loss. The lack of understanding of the partner, their way of processing loss [12] often intensifies the crisis, feeling of loneliness and may cause the relationship to end or suffer a severe crisis [12]. Therefore, it is useful to suggest couples

joined participation in the meetings of the support groups, especially if they notice difficulties in their relationship after a child's death.

The parents who had experienced a miscarriage or death of a young child assessed their stage of mourning as significantly more advanced than the parents whose child had committed suicide or died as an adult. It is consistent with the theoretical assumptions. The conducted research showed that there were slightly different difficulties in processing loss in case of the parents who had experienced a miscarriage or death of a young child. The possible reason for that may be: the relatively young age of the parents, the possibility of having another child, lack of long relationship with the child (that exists in case of teenage or adult children), and therefore lack of memories connected with conflicts, parenting failures and pain of a sick child [11]. Death of an adult child is more often connected to a more difficult case of loss (murder, accident, missing child, AIDS or suicide), which leads to more intense feeling of negative emotions: anger, guilt and, often leads to necessary participation in police investigation or criminal cases, that may impede processing the mourning [12].

Additionally, the answers given by the respondents have allowed to formulate following statements(pertaining to the research group):

- personal determinants are connected to the size of the support network;
- participation in the support groups is helpful in coping with mourning after a child's death;
- participation in the support groups is not necessary to cope with mourning after a child's death;
- participation in the support groups may lower the level of depression in bereaved parents;
- participation in the support groups does not heighten sense of purpose in life;
- participation in the support groups should be suggested to parents who:

a) have experienced the most damaging types of death,

b) have a specific character traits,

- c) do not have a satisfactory social support network;
 - age of a child at the time of their death does not impact the durability of the relationship, relatioships of parents who have lost an adult child do not end more frequently than relationships of parents who have experienced a miscarriage or death of a small child;
 - sex of a parent influences the process of mourning;

- women present higher level of depression after a child's death than men;
- women feel less of a sense of purpose in life after a child's death than men;
- women have more people in their support network than men;
- women need more support than men;
- death of a child has an impact on parents' health (regardless of their sex);
- belief in god does not change after a child's death;
- child's death changes life priorities of the bereaved parents;
- child's death changes a sense of purpose in life;
- the higher the neuroticism index the higher depression level, i.e. coping with a child's death is more problematic;
- the higher the neuroticism index, the lower sense of purpose in life;
- the higher extroversion, agreeability and openness to new experiences, the lower the depression level;
- the higher the extroversion, agreeability, openness indices the higher sense of purpose in life;
- the higher the extroversion, agreeability, openness indices the bigger support network of a respondent;
- people who display higher openness to new experiences index participated in the support groups more frequently.

Conclusions

The conducted research certainly deserves to be expanded. It brings up many interesting issues on the subject of understanding the loss of a child, and at the same time presents that coping with bereavement after a child's death (and by extension with loss and trauma in general) may be determined by personal determinants more significantly than it was initially assumed. The research shows that participation in the support groups is helpful to bereaved parents and has positive impact on their relationships, but is not necessary to cope with the loss of a child.

Familiarity with the factors that influence coping with the loss of a child and better understanding of the mourning process itself are crucial in working with bereaved parents. Additionally, information pertaining to potential effects of participation in the professional support groups may allow to determine new problem areas and allow to implement actions that will prevent impairment of the mourning process or perpetuation of behavior that impedes parents' healing process. The results may be treated as an introduction to further, more advance research within the field.

References

- 1. Główny Urząd Statystyczny: Rocznik Demograficzny 2012. Zakład Wydawnictw Statystycznych Warszawa, 2012.
- 2. Moore A.: Older poor parents who lost an adult child to AIDS in Togo, West Africa: a qualitative study. Baywood Publishing Co., Inc. Omega, 2007-2008, 56, 3, 289-302.
- Brown, F. H.: The impact of death and serious illness on the family life cycle. In The changing family life cycle: A framework for the family therapy (2nd ed.). Carter E. & McGoldrick M. (Eds.). Allen & Bacon, Boston, MA, 1989, 457-482.
- Dyregrov A.: Parental reactions to the loss of an infant child: A review. Scandinavian Journal of Psychology, 1990, 31, 266-280.
- Lehman R., Wortman C. B., Williams A. F.: Long-term effects of losing a spouse or a child in a motor vehicle crash. Journal of Personality and Social Psychology, 1987, 52, 1, 218-231.
- Rando T. A.: Parental bereavement: An exception to the general conceptualizations of mourning. In Parental loss of a child, Rando T. A. (Ed.). Research Press, Champaign, IL, 1986, 45-58.
- 7. Bowlby J.: Attachment and loss (Vol. III). Basic Books Inc., New York, 1980.
- Johnson S.: After a child dies—Counseling bereaved families. Springer Publishing Company, New York, 1987.
- 9. Girasek D. C.: Advice from bereaved parents: On forming partnerships for injury prevention. Health Promotion Practice, 2005, 6, 207-213.
- Davies, B.: Shadows in the sun: The experience of sibling bereavement in childhood. Brunner/MazelPhiladelphia, PA,1990.
- 11. Kübler Ross E.: Dzieci i śmierć. Media Rodzina, Poznań, 2007.
- 12. Sanders C.: Jak przeżyć stratę dziecka. Powrót nadziei. GWP, Gdańsk, 2001.
- 13. Sęk H, Cieślak R.: Wsparcie społeczne, stres i zdrowie. PWN, Warszawa, 2011.
- Krzyżanowski D., Różańska O., Chybicka A., Mess E.: Osierocenie osób dorosłych po stracie bliskiej osoby. Onkol. Pol., 2005, 8, 3.

- 15. Popielski K.: Noetyczny wymiar osobowości. Psychologiczna analiza poczucia sensu życia. Wyd. KUL, Lublin, 1994.
- Siuta J.: Inwentarz Osobowości NEO-PI-R Paula Costy Jr i Roberta R. McCrae. PTP, Warszawa, 2006.
- 17. Frankl V.: Nieuświadomiony Bóg. Wydawnictwo IW PAX, Warszawa, 1978.
- 18. Popielski K.: Człowiek pytanie otwarte. Wyd. KUL, Lublin, 1987.
- Konczelska K.: Żałoba ojca w perspektywie społecznych i kulturowych stereotypów ról płciowych [in:] Z szerszej perspektywy – Gender. Wycisk A., Krawczyk – Antońska Ż. (red.). ARW Omnidus, Katowice, 2013.

The quality of life of oncological patients and the social support

The quality of life of oncological patients and the social support

Rębiałkowska-Stankiewicz Małgorzata

Kazimierz Wielki University in Bydgoszcz, Faculty of Pedagogy and Psychology, The Institute of Pedagogy

The Department of the Care and Nurture Pedagogy with Social Prevention

Introduction

Cancer is often perceived to be a turning point in human life. Because of its colossal impact on human well-being, it's considered to negatively impact the entire species.

A cancer patient must assume a subordinate position to pursue health care. This significantly restricts their ability to perform other important social roles. It is not uncommon for people suffering from cancer to limit the extent to which they partake in work and social life. Cancer also alters family situations and often impoverishes families both socially and economically.

Anxiety is a reaction to a perceived threat and it remains one of the most important emotional reactions to cancer. Most people who have been diagnosed with cancer experience emotional stress in the form of anxiety, anger, and depression, particularly when it comes to being afraid of dying. Cancer also causes physical symptoms and changes in behaviour [1,2].

Everyone suffering from cancer faces problems. These individuals must commonly accept being treated and the side effects that come with it. They must also verify and accept the current possibilities of an ill person. Importantly, they must also accepting the bodily changes that will take place as the disease and treatment progress. Cancer and its treatment may also affect physiological functioning [3]. All of these things put together change how cancer patients assess their quality of life. In cases of chronic disease, an important question arises: To what extent can social support help patients improve their experience of their quality of life?

Assumptions

In highly industrialised countries, cancer is the second most common cause of death

among people (above 20% of all deaths) right after cardiovascular diseases. Due to the fact that the frequency its prevalence exceeds the threshold of 1% of the public at large and the factors that constitute modern civilization and determine the high standard of living increase the risk of its prevalence – cancer is a social and civilisational disease [4]. The typical outcomes of cancer as well as the invasive methods used to treat it cause cancer to be classified as a serious chronic disease [5].

While talking about the quality of life associated with a disease it is worth noting that the term quality of life itself is rather complex and its definition can vary depending on the empirical and theoretical context where it is used. The fields of science that focus on broadly understood health issues, such as medicine, sociology, psychology and also pedagogy, use the term commonly. The term can be used in clinical (no disease symptoms), social (fulfilling a given role), or individual settings (achieving personal aims) [6,7].

Although philosopher Karl Popper urged people not to "try to define the quality of life", there have been many attempts to do exactly that. The World Health Organisation defines quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [8]. Quality of life in medicine is defined as the well-being described by the patient him- or herself and their ability to fulfil life roles and execute their daily tasks with satisfaction [9].

S. Kowalik suggested that quality of life can be understood in two ways. Firstly, as "feeling your own life through exploring it" and secondly, as "feeling your own life through living it" [10].

When talking about quality of life in relation to chronic disease, one should remember that as the disease progresses, patients must deal with many new and difficult experiences and feelings, they must face their own mortality, and even evaluate the achievements of his/her life. The emotional background of disease is composed of sadness, helplessness, hopelessness, and despair. M. Wirsching believed that the way a disease is experienced changes as the disease runs its course. So the perception of the quality of life can be understood as the sum of the effect of experiencing and the effect of exploring [11].

Discussions about defining quality of life often consider quality of life to be a multidimensional phenomenon that consists of the following subjective components: physical, mental, social, and mobility dimensions [12]. Out of these dimensions, the mobility dimension was approached first and has received the most precise focus. For quite some time, mobility was regarded as an indicator of a person's ability to adapt to the symptoms of a

disease. The vast differences between the various attempts at defining quality of life have led to the creation of a term applicable in medicine: "health-related quality of life", or HRQL. HRQL is defined as a state of well-being consisting of two components: the ability to deal with everyday tasks (which reflect human well-being in physical, mental, and social areas) and a patient's satisfaction in his or her functioning in all areas as well as controlling the disease and/or its symptoms [6,13].

K. de Welden-Gałuszko differentiates four basic dimensions of analysing HRQL that concern [6]:

- The physical condition and mobility proper activity of the basic physiological functions and the activity level described by the ability to self-handle, perform manual duties, exert mental effort, leisure etc.,
- The mental condition the level of adapting to the disease and existence of (or lack of) negative feelings (anxiety, despondency, anger) and positive feelings (happiness, satisfaction, hope),
- The social situation type and quality of interpersonal relations, abilities and willingness to take part in social activities,
- And Somatic experiences symptoms present in everyday life of a patient and their influence on his/her life.

Those areas do not cover all dimensions that ill people are capable of functioning in. Areas such as sexuality, participation in culture and spirituality can couple with values like individual autonomy, personal strength, and positive concept of life to give a more holistic definition of the concept [12].

One of the most often considered factors that shapes quality of life is social support [9].

The present study assumes that social support is a type of social interaction that has been undertaken by one or more participants in a complicated, difficult, stressful, or critical situation;

- in the course of this interaction, information, emotions, actions, and tangible goods are exchanged;
- this exchange can be unilateral or bilateral (the "giver recipient" relation can be stable or can change in different temporary spaces);
- in the dynamic system of supportive interaction, there can be a distinguished person who supports (helps) and a person who receives the support;

- the compliance between the type of support and the needs of the recipient is required in order to make this social exchange effective;
- the aim of the interaction is to reduce stress through social interactions and emotional exchanges to create a sense of belonging, fostering security and hope, get closer to solutions to existing problems, and overcoming difficulties [14].

The support understood in such a way can occur in a system, between an individual and group, and between a group and other groups. Among different forms of support, the following can be distinguished:

- emotional support based on giving verbal and non-verbal messages such as: "we love you", "we like you", "you have strong personal characteristics", and "don't give up";
- 2. esteem support based on giving the patient messages such as: "you are someone important to us", "your opinion and decisions are important to us", and "keep going";
- 3. tangible support that provides the patient certain services (i.e. lending money, finding an apartment, researching treatment options, providing care);
- 4. informational support that provides medical and legal advice or information that can help solve problems [15].

In the case of cancer, support can be conceptualized as a "buffer" model where support acts as a "protective shield". It neutralises or reduces the eventual harmful effects of the negative life events associated with cancer and addresses the stress and the coping mechanism associated with cancer to improve how quality of life is perceived [16].

The subject of the study

The subject of the present study was the quality of life among female oncological patients in relation to the support they received from their societal network. The aim of the present study was to assess the how female cancer patients perceived their health-related quality of life as well as to analyse the support provided to these individuals by their societal network as a factor likely to differentiate those views. The study sought to answer the following questions:

The main problem

How do female cancer patients assess their health-related quality of life in relation to the support they received from their societal network?

Specific problems

- 1. How do the participants assess their quality of life in terms of physical, mental and social dimensions?
- 2. Does the social support received by the participants affect their assessment of their quality of life and if so, how?
- 3. Does the social support received by the participants affect their assessment of their levels of perceived anxiety and depression and if so, how?

The survey was conducted among oncological patients who took part in the activities organised by the Academy of Fight Against Cancer in Toruń [Akademia Walki z Rakiem] and in the meetings of the Amazon Club [Klub Amazonek – Polish association that provides women with breast cancer with mental support and practical help]. The present study was conducted between May 2014 and December 2015. The participants composed of 147 individuals diagnosed with cancer. Due to the fact that only 9 men participated in the survey, the study chose to consider the remaining 138 women. The present study is a part of a wider analysis that concerns functioning with cancer.

Material and methods

The present study employed a diagnostic survey carried out via a questionnaire. In order to measure the level of social support received by the participants, the Social Support Scale developed by K. Kmiecik-Baran was used. This scale consists of 24 statements that relate to four types of social support. There are a total of six statements for each type of support (three positive and three negative statements). The statements can be classified as follows: questions 1 to 6 relate to informational support, 7 to 12 relate to tangible support, 13 to 18 relate to esteem support, and 19 to 24 relate to emotional support [17]. The analysed sources of support are: immediate family, friends, healthcare professionals, self-help groups.

The one-item Scale of the quality of Life by W.O. Spitzer and A. J. Dobson was used in order to measure the overall quality of life assessed by the participants [18].

A self-constructed scale based on the Linear analogue self-assessment (LASA) developed by T. J. Priesman and M. Baum was also employed. This scale measures perceived quality of life in physical, mental, social, and somatic dimension [19]. It is a simple method of self-assessment on a linear analogue scale based on marking the quality of life during the last week on a 10 inch spectrum. The measures of quality of life in the physical dimension were

mood, pain, appetite, mobility, and ability to perform domestic wok. The measures of quality of life in the social dimension were relations with husband (partner), mutual relations with other people, sexual contact, social activity, economic activity, and participation in cultural life. The mental dimension related mainly to self-fulfilment with measures like development of interests, life plans, and the ability to make decisions.

The Hospital Anxiety and Depression Scale – HAD developed by A.S. Zigmond and R.P. Snaith was used as a supplement to the Scale of quality of life Assessment. Anxiety in particular, but also depression are referred to in literature as almost inevitable conditions that accompany cancer, thus being an important part of assessing the quality of life experienced by the participants in their mental dimensions. [.....]

Results

Initially, only one measure was developed in the survey for quality of life: the LASA– Scale. This measure was the arithmetic mean of all other measures. However, the submeasures of quality of life in the three selected dimensions, physical, social (interpersonal relations), and mental (concerning self-fulfilment), proved to be more useful for a better insight in the studied problem. Each of the above mentioned measures was calculated as the arithmetic mean of sub-measures. Their statistical characteristics are presented in Table I.

]	The quality of life i	n:
Statistics		The physical dimension	The social dimension	the mental dimension
Ν	Important	138	138	138
IN	No data	0	0	0
Average		5.29	5.20	5.79
Median		5.37	5.31	5.97
Mode		4.00*	4.37*	6.50
Standard deviation		2.10	2.20	2.45
Skewness		-0.09	0.00	-0.20
Range		9.65	9.68	9.87
Minimum		0.25	0.22	0.13
Maximum		9.9	9.9	10.0

Tab. I. The values of the basic statistics for preparing the measures of the quality of life

^{*} The distribution has many modes

The theoretical range of measures for the quality of life developed in this way ranged from 0 to 10 where the larger the value was, the better the quality of life was assessed to be. The arithmetic mean for almost all of the measures of the quality of life in the distinguished areas was over 5. The maximum value was 5.97 and was found in the mental dimension. The values of the standard deviation showed small dispersion of the quality of life assessments made by women in given dimensions. Basically, the distributions were symmetrical – first of all, it refers to the quality of life in the social dimension (the skewness equals 0.00) and in physical dimension (-0.09). A visible but not strong left asymmetry occurred in the mental dimension.

Tab. II. Correlations	of the	particular	dimensions	of the	quality	of	life	with	the	level	of
support (N=138)											

	The assessment of the life quality in:				
	the physical dimension	the interpersonal dimension	the decision- making dimension		
The quality of life in the physical dimension	-	0.620	0.658		
The quality of life in the interpersonal dimension	0.620	-	0.745		
The quality of life in the decision- making dimension	0.658	0.745	-		
The level of the emotional support	-0.227	-0.331	-0.356		
The level of the informational support	-0.255	-0.290	-0.340		
The level of the esteem support	-0.379	-0.461	-0.497		
The level of the tangible support	-0.234	-0.278	-0.321		
The level of the overall support	-0.321	-0.398	-0.444		

Pearson's correlation coefficients included in Table II proved to be turned negative. Separated measures of quality of life had the higher value, the higher women assess the quality of life in a given dimension. In case of levels of support the scale was reversed higher values of measures concerned lower assessments of levels of received support. Hence, although the order of the scales was reversed, the higher value of negative Pearson's correlation coefficients indicated a stronger relation between the examined variables.

When analysing the data related to the influence of social support on the participants' quality of life, one can notice that the measures of the quality of life were strongly correlated. This means that a strong sense of quality of life in one dimension noticeably influenced strong assessments in other dimensions.

All the measures of quality of life were strongly correlated with the overall assessment of social support. Especially strong correlations concerned the mental dimension. These include, among others, the development of interests, life plans, and the ability to make decisions (Pearson's correlation coefficient =-0.444). At the same time, the physical well-

being of the participants had the weakest correlation to received social support (Pearson's correlation coefficient =-0.321). While analysing particular types of social support, it turns out that the assessment of the quality of life in the social and mental dimension had the strongest correlation to received esteem support. The Pearson's correlation coefficients for quality of life are -0.461 and -0.497 in the social and mental dimensions respectively.

Special attention should be paid to the analysis of the impact of social support on the level of perceived anxiety and depression among the participants. Low values of assessment resulted from the HAD-scale indicated the low level of anxiety and depression (in case of the assessment of support low values indicated the high level of support).

Tab. III. Correlation of the anxiety and depression level with the general level of the received social support.

		The level of the sense of depression	The level of anxiety	The level of the general support
The level of the	Correlation coefficient		0.756*	0.374*
sense of the	Significance (bilateral)		0.000	0.000
depression	Ν	138	138	138
The level of	Correlation coefficient	0.756*		0.331*
anxiety	Significance (bilateral)	0.000		0.000
anxiety	Ν	138	138	138
The level of the	Correlation coefficient	0.374*	0.331*	
overall support	Significance (bilateral)	0.000	0.000	
over an support	Ν	138	138	138

* Correlation is significant on the level 0,01 (bilateral)

The table above shows that both the levels of perceived anxiety (Spearman's Correlation Coefficient 0.331, p<0.01) and depression (0.374, p<0.01) were positively correlated with the overall level of the received social support. A similar correlation occurs between the level of the particular types of received support and the level of anxiety and sense of depression that accompany cancer (Table IV).

It appears from the table above that the correlation between the examined variables showed certain diversification in relation to the particular types of support. Generally speaking, low levels of particular types of received support increased the perceived level of anxiety and depression among the participants. However, this relation is strongest when it comes to esteem support.

		The level of anxiety	The level of the sense of depression	
The level of the	Pearson's correlation coefficient	0.271*	0.298*	
The level of the emotional support	Significance (bilateral)	0.000	0.000	
	N	138	138	
The level of	Pearson's correlation coefficient	0.277*	0.276*	
informational support	Significance (bilateral)	0,000	0.000	
	Ν	138	138	
The level of the	Pearson's correlation coefficient	0.393*	0.409*	
The level of the esteem support	Significance (bilateral)	0.000	0.000	
	Ν	138	138	
The level of the	Pearson's correlation coefficient	0,263*	0,264*	
tangible support	Significance (bilateral)	0,000	0,000	
	Ν	138	138	
	Pearson's correlation coefficient		0,752*	
The level of anxiety	Significance (bilateral)		0,000	
	Ν	138	138	
The level of the sense	Pearson's correlation coefficient	0,752*		
of depression	Significance (bilateral)	0,000		
	Ν	138	138	

Tab. IV. Correlation of the level of anxiety and sense of depression with particular types of received social support.

* Correlation is significant on the level 0,01 (bilateral)

Results

The findings of the present study can be used to conclude that:

• Experiencing a quality of life in one of the dimensions significantly influences the quality of life in other dimensions. This confirms the need to analyse the human health condition from a biopsychosocial perspective which was underlined in the holistic model of health.

- The assessment of the quality of life made by the participants in the physical dimension had the weakest relation to received social support. It seems obvious that physical well-being is mostly influenced by the course of the disease and its intensity. On the other hand, it could be expected that women who received social support better coped with the symptoms of the disease. However, the results of the analysis do not indicate such a relation.
- The esteem support based on showing appreciation, acceptance, value of personal suffering, and emotional support, received by the participants significantly improved their assessment of their quality of life related to interpersonal relations and mental functioning (planning for the future and willingness to develop or continue interests). The way the participants assessed their quality of life in all three areas has the weakest correlation with informational support and tangible support.
- The greater support a woman receives from members of her network, the lower her perceived anxiety and depression are. In other words, a low level of a particular type of received support raised the levels of perceived anxiety and depression among the participants. However, this correlation is strongest in case of the esteem support that, one might risk the statement, has the most tremendous impact on the analysed emotions.

Discussion

Humans are social beings (*homo socialis*). From birth, they are placed in societies among others of their kinds whom they use for services. Humans in collectives provide each other safety, a sense of self, a strengthened identity, and the fulfilment of biopsychic needs. An individual in a collective naturally creates a social network with others that secures him or her with social support in difficult situations.

When affected by cancer, most patients experience emotional stress in the form of anxiety, anger, and depression. They also experience physical symptoms that result from the disease and its treatment. All these things create changes in patterns of behaviour connected to everyday activities. These individuals also frequently confront their own mortality. The stress related to cancer can be characterised by threats to life and health, helplessness, insecurity, the inability to meet life goals, negative changes to oneself, anxiety, and depression [20].

A societal network is a specific structure that enables people to formulate their needs and expectations for others and to respond to those needs. It provides them with a kind of "matrix" that enables them to experience culture as well as social support. Social support received while dealing with cancer from both professional and non-professional sources differentiates the assessment of health-related quality of life. In addition, it also reduces perceived anxiety that patients experience which in turn influences the activity-based management of the effects of the disease. The problem of effective support, organising support groups for patients, and training professionals should not be omitted in oncological patient care.

References

- Juczyński Z.: Radzenie sobie ze stresem spowodowanym chorobą nowotworową [in:] Psychoonkologia. de Walden-Gałuszko K. (ed). Biblioteka Psychiatrii Polskiej, Kraków, 2000, 23-45.
- Dolińska-Zygmunt G.: Podmiotowe uwarunkowania zachowania się pacjenta wobec własnej choroby [in:] Podstawy psychologii zdrowia. Dolińska-Zygmunt G. (ed.). Uniwersytet Wrocławski, Wrocław, 2001, 243–259.
- Miniszewska J.: Ująć miecz Demoklesa [in:] Siły, które pokonają raka. Psychologiczne terapie wspomagające w chorobie nowotworowej. Pająk P. (ed.). Wyd. Charaktery, Kielce, 2013, 31-36.
- Simon E., Ramlau C.: Podstawowe wiadomości o nowotworach i ich leczeniu [in:] Podręcznik chirurgii. Góral R. (ed.). Wyd. Medyczne, Poznań, 1985, 64-67.
- Skrzypek M. : Perspektywa chorego w socjologii choroby przewlekłej. Wyd. KUL, Lublin, 2011, 107.
- de Walden-Gałuszko K.: Jakość życia rozważania ogólne [in:] Jakość życia w chorobie nowotworowej. de Walden-Gałuszko K., Majkowicz M. (ed.). Wyd. Uniwersytetu Gdańskiego, Gdańsk, 1994, 13.
- Tobiasz-Adamczyk B.: Wybrane elementy socjologii zdrowia i choroby. Wyd. UJ, Kraków, 2000, 233.
- Dietzfelbinger H., Heubner P.: Kryteria jakości życia [in:] Psychoonkologia. Diagnostyka- metody terapeutyczne. Dorfmuller M., Dietzfelbinger H. (ed.). Elsevier, Wrocław, 2011, 58
- Bumeder I.: Jakość życia -definicja i metody pomiaru [in:] Psychoonkologia. Diagnostyka- metody terapeutyczne. Dorfmuller M., Dietzfelbinger H. (ed.). Elsevier, Wrocław, 2011, 65.

- Kowalik S.: Jakość życia pacjentów w procesie leczenia [in:] Elementy psychologii klinicznej, Volume IV. Waligóra B. (ed.). Wyd. Naukowe WAM, Poznań, 1995, 27-45.
- 11. Wirsching M.: Wokół raka. GWP, Gdańsk, 1994.
- Dziurowicz-Kozłowska A.: Wokół pojęcia jakości życia. Psychologia Jakości Życia, 2002, 1, 2, 80.
- Kiebert G.: Jakość życia jako rezultat badań klinicznych w onkologii [in:] Jakość życia w chorobie nowotworowej. Meyza J. (ed.). Centrum Onkologii IMSC, Warszawa 1997, pp. 43.
- Sęk H.: Psychologia kliniczna a interwencja w kryzysie, sytuacjach traumatycznych i katastroficznych [in:] Wprowadzenie do psychologii klinicznej. Sęk H. (ed.). Wydawnictwo Naukowe Scholar, Warszawa, 2001, 268.
- Kawula S.: Wsparcie społeczne kluczowy wymiar pedagogiki społecznej. Problemy Opiekuńczo – Wychowawcze, 1996, 1, 54.
- 16. Kaniasty K.: Pomocne dłonie. Charaktery, 2004, 6, 62.
- 17. Kmiecik-Baran K.: HIV/AIDS alienacja oraz wsparcie i odrzucenie społeczne. Wyd. UG, Gdańsk, 1995.
- Juczyński Z.: Narzędzia pomiaru w promocji i psychologii zdrowia. Pracownia Testów Psychologicznych, Warszawa, 2009.
- 19. Majkowicz M., Chojnacka-Szawłowska G.: Metodologiczne problemy badania jakości życia, 1994, Wyd. UG, Gdańsk, 1994, 65-84.
- Łosiak W.: Proces zmagania się ze stresem choroby przez pacjentów [in:] Zmagając się z chorobą nowotworową. Kubacka-Jasiecka D., Łosiak W. (ed.). Wydawnictwo UJ, Kraków, 1999, 184-185.

Medical and social risk factors for abortion as the reproductive choice in 19-24 years old Belarusian men

Medical and social risk factors for abortion as the reproductive choice in 19-24 years old Belarusian men

Surmach Marina

Grodno State Medical University, Belarus

Introduction

Abortion is a form of adverse reproductive behavior, and the subject of numerous studies. Reproductive choice to terminate a pregnancy is one of the most important ethical issues, problems of humanity. Despite this, measures of effective prevention of unplanned pregnancies and subsequent abortions are not developed yet. Around 28 million pregnancies are expiring each year in developed countries. Of these, 49% are estimated as unplanned and 36% are terminated by abortion [1]. So far, no universal attitude toward the legalization of abortion in different countries. In Belarus a woman has the right to decide the question of motherhood and to make an abortion under certain conditions [2].

Russo and Denious analyzed data from 2525 women who participated in the Commonwealth Fund's Women's Health Survey (phone surveys) [3]. It was found that women who had an abortion, often revealed the positive symptoms of depression and lower levels of life satisfaction, but also more often indicated the presence of physical and sexual abuse in childhood and by an intimate partner. Analysis of factors associated with the possible unplanned pregnancy in adolescence, conducted by American authors, showed that among them there are four groups: personal factors (self-esteem, the availability of knowledge and experience, the age of first sexual contact); family factors (incomplete family, violation of communication); community factors (cultural norms, religious, media influence, the permissibility of violence); socio-economic factors (poverty, employment, housing availability). The absence of trust relationships in the family of teenager on issues related to sexual life, particularly the first information about an intimate relationship, the nature of family relationships are the leading risk factors of abortion for girl-teenagers in Russia [4]. The lower the age of the women at first sexual intercourse, the greater the probability that this contact was not desirable [5]. The more dysfunctional the relationship between partners, the greater the probability of unsafe abortions [6]. According N. Mufel, about 18% of women who decided to have an abortion, did it under the pressure of the partners or relatives, 38% of responsibility for the decision has been fully passed on to a woman. About 14% stated that would not do an abortion, if their decision received the psychological support [7].

So, solidarity relations between partners in the family (gender partnership) is of great importance at the stage of preparation for the birth of a child.

Materials and methods

In order to identify medical and social risk factors for adverse reproductive behavior (abortion) among young people, 19-24 years old men (2011 survey, n=746) were questionnaired with questions: "What should be the participation of men in the process of fetal development and birth of the child?", "What do you think, is marriage registration required if the child is conceived extramarital?", "Are you blame yourself because of abortion?" (respondents with positive answers about the termination of pregnancy in their anamnesis), questions about relationships in families in which respondents were brought up, their own families, and also about their attitudes towards domestic violence. The sample of 19-24 years old young men was representative to republic one. The survey was carried out by medical workers in health care organizations.

Results and discussion

Analysis of responses to the question "What should be the participation of men in the process of fetal development and birth of the child?" shows that the majority of respondents (59,2%) consider it necessary to provide psychological support to women (63,2%), physical assistance and financial aid (54,4%). Less than half (43,7%) of the respondents consider it necessary to get rid of bad habits, about a third (37,8%) of men think right joint visit to the doctors, the survey, as well as communication with the baby not yet born (28,3%), a smaller part interviewed young men consider it necessary to such forms of participation of men in the process of fetal development and birth of the child, as "reading, watching videos about pregnancy and child bearing" (17,2%), "presence at birth" (16,9%). Only 11,3% of respondents stated that their participation in pregnancy development is not required.

Approximately 55,9% of boys indicate the need for compulsory registration of marriage in the case of pregnancy, but 38,5% do not consider the marriage registration required. A small number of respondents (2,3%) could not answer the question or (0,5% of boys) have expressed their own individual opinion ("everything depends on the

circumstances", "if they love each other, - yes", "not always", "on the agreement", "by agreement of parents").

To the question "Do you have experience of your girl-friend's abortion in the case where you were alleged father?" 8,4% men responded positively, 14,7% did not respond; abortion was carried out once at 61,9% cases, twice – 14,3%, three times or more – 6,4%; part of respondents did not answer the question about the number of interruptions. The most common cause of abortion as the reproduction choice was "young age" (30,2%), next one – "your girl did not want a child" (17,4%), "cash circumstances" (14,3%), "you as a possible father of the child had been against his birth" (12,7%), "the child was conceived out marriage" (11,1%),"housing conditions" (9,5%) and "the previous child was too young" (9,5%). Less common causes were "uncertainty about the ability to provide the future to the child" (6,3%), "poor health" (6,3%), "the availability of a sufficient number of children" (4,8%). To the question "Are you blame yourself because of abortion?" the answer was as follows: "no" – 1,6%, "yes, if I could, all would be changed"- 38,1%; "yes, there is a sense of a guilt, but abortion was a necessary measure" – 19,0%; "other" – 36,5%; about 5% gave no answer.

Analysis of relationships in families in which 19-24 years youths were brought up, and in their own families (future and existing), showed that about two-thirds of young men believe that the relations in their own homes will be warm close.

19-24 years old men represent relationships in their own existing or future families like the same as in the families of their parents (Table I). About 61,5% of respondent's parents families show warm, intimate relationships; 67,7% of young men prefer to see warm, close relationships in their own families, respectively. Approximately 14,5% of boys could not determine the answer to the question, what are the relationships in their own families. Around 17,8% of 19-24 year young men note that relations in their families they are seen as indifferent, hostile, and even with quarrels and scandals.

Respondents recognize as the most important in their parent's families such factors: "children's health" (62,5%); "mutual trust" (48,4%), "material well-being" (50,5%), "love" (37,9%), "to give to children all not worsen than others" (33,1%), "the possibility of assistance in old age, illness" (32,4%) (Table II). The more highly evaluated by young man as important for their own family, compared with the family of his parents, such factors as sexual compatibility and love. At the same time, for parent's families considered as more important the health of children, "to give for children everything, no worse than others", and "the availability of assistance in old age, illness".

Nature of relationships	19-24 years old men,% (n = 746 pers.)			
	Family in which the respondent was brought up	The respondent's own family (existing or future)		
Warm, close	61.5	67.7		
Restrained and	24.8	13.7		
warm				
Indifferent	7.0	2.5		
Hostile	0.5	0.4		
With quarrels and scandals	4.0	1.2		
No answer	2.2	14.5		
Total	100.0	100.0		

Tab. I. - The nature of relationships in families in which the respondents were brought up, and in their own families

Tab. II. - Evaluation by 19-24 years old men of factors important in their parent's families and in their own (existing or future) ones

Factor		19-24 years old men,% (n = 746 pers.)
	Family in which the respondent was brought up	The respondent's own family (existing or future)
«Material well-being»	50.5	49.1
«To achieve higher status in the society with the help of a partner»	5.1	6.2
«Children's health»	62.5	52.5
«To give for children everything, no worse than others»	33.1	24.4
«To does not interfere between family and career»	3.6	5.0
«To does not interfere between family and the personal freedom of the partners»	3.5	4.7
«To trust each other»	48.4	48.5
«Spiritual unity, moral support»	25.6	25.3
«Sexual compatibility»	13.4	25.6
«Love»	37.9	43.8
«The availability of assistance in old age, illness»	32.4	21.2

Note – respondent can select multiple options.

A little more than 3,0% of respondents allow the possibility of violence in their own families as a whole, violence to partner -3,0%, violence against the child from the father or brother -3,8%.

Conclusions

Young men in 19-24 years old reveal positive attitude for gender partnership in general. The majority of respondents consider the factor "children's health" as the most important in parent's families and in their own ones. The proportion of young men who have chosen the answer "This is the case for women, male should not participate in them" to the question "What should be the participation of men in the process of fetal development and birth of the child?" is no more than 11,3%. The possibility of violence in their own families is allowed by no more than 3,0% of boys. So, our results indicate favorable settings among young people in relation to gender partnership.

At the same time, approximately 17,8% of 19-24 years old men point out that relationships in their own (including future) families will be indifferent, hostile, and even with quarrels and scandals. Almost half of respondents do not consider it mandatory to register the marriage if the child was conceived during an extramarital relations, almost every fifth is not considered it mandatory even acknowledgment of paternity. Approximately 57,1% of young men from their who notes the existence of an abortion in their girl-partner are experiencing a guilt.

While demonstrating motivation readiness to participate in the planning of pregnancy, respondents show interest in the birth of a healthy child, the responsibility for his birth as a whole. But the responsibility for the upbringing of the child is passed on to a woman: by the refuse of registration of marriage, and even of the recognition of paternity.

References

- Russo N.F., David H.P.: When Pregnancies are Unwanted [Electronic source]. Transnational Family Research Institute, 2004, http://www.prochoiceforum.org. uk/psy_ocr2.asp., Edited: 17.09.2010.
- О здравоохранении: Закон Республики Беларусь 16.06.2014 №164-3. Национальный правовой Интернет-портал Республики Беларусь, 26.06.2014,

2/2162. http://www. pravo.by/ main.aspx?guid=3871&p0=H11400164&p1=1, Edited: 04.01.2016.

- Russo N., Denious J.: Violence in the lives of Women Having Abortions: Implications for practice and public policy. Professional Psychology, Research and Practice, 2001, 32, 142–150.
- Закоркина Н.А., Банушевич И.А.: Причины абортов у подростков, проживающих в сельской местности. Проблемы социальной гигиены, здравоохранения и истории медицины, 2009, 5, 20–22.
- 5. Гурко Т.А.: Опыты сексуальных отношений, материнства и супружества несовершеннолетних женщин. СоцИс, 2002, 11, 83–91.
- Цхай В.Б.: Особенности репродуктивного поведения женщин в зависимости от социально-гигиенической характеристики их семей: Проблемы социальной гигиены, здравоохранения и истории медицины, 2007, 6, 11–14.
- Муфель Н.: Гендерные проблемы репродуктивного здоровья: психологические аспекты [в:] Женщина. Образование. Демократия. И.Р. Чикалова (ред.). Минск, 2001, 201–204.

Saturation of needs of people with disabilities in the context of the quality of life

Saturation of needs of people with disabilities in the context of the quality of life

Cintulová Lucia Ludvigh

St. Elizabeth University of Health and Social Sciences, Malacky, Slovakia

Introduction

People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others and these people are the object of research study below.

The research is focused on saturation of needs of people with disabilities in daily life activities and providing them environment that encourages and enables them to fulfil their own unique potential (self-actualization) are today more relevant than ever. It is based on the Hierarchy of Needs model developed by Abraham Maslow in 1940-50s USA, and the Hierarchy of Needs theory remains valid today for understanding human motivation, management training, and personal development.

Behind everything thing we do is a need that wants to be satisfied. We have instincts that keep us alive and continue our species. But there are other needs that go beyond our body's instincts. Maslow's Hierarchy of Needs starts at the basic physiological needs we need just to stay alive. Once these are made we have a need for safety, then we want love and affection. Within the group of needs having self esteem is important for impaired people as well as a need of satisfying full potential that Maslow calls Self Actualization. The five needs in Maslow's Hierarchy include:

1. **Self Actualization-Fulfillment Needs** (full potential) This is the rare level where people have need of purpose, personal growth and realization of their potentials. People on this level are fully functional, acting purely on their own volition and have a healthy personality.

The most of people with disabilities do not have enough possibilities to personal growth and miss the purpose of life because they feel no to be useful due to pushing them dependent on help of others, providing social services or attending special schools.

2. **Ego-Self Esteem Needs** (self respect, personal worth, autonomy) On this level, people act from their ego needs. They value the options of others, in order to believe in themselves. It is a matter of self-respect through respect from others.

The people with disabilities suffer from feelings of anxiety, low self-esteem and low belief in own abilities. They meet with psychical barriers such as

- 3. **Social Love and Belongingness Needs** (love, friendship, comradeship) On this level, people need to feel loved. Here loving one's self has not been fully discovered. Some families are tightly bond. If this need is very strong, there can be a rush to fulfill this need resulting in less than ideal partner selection.
- 4. Security Safety Needs (security; protection from harm) Here we might include living in a safe area away from threats. This level is more likely to be found in children as they have a greater need to feel safe. Those who worry about small things, such as drinking out of plastic glasses have strong security needs.
- 5. **Body-Physiological Needs** (air, food, sleep, stimulation, activity) People on this level tend to be sick or in emergency type situations. They have biological needs for physical equilibrium (homeostasis). People with lack of shelter, clothing, food focus on these needs. People often neglect some of these basic needs in normal life when they eat junk food, go without sleep, don't exercise, or do not simulate their minds.

Maslow recognized that not all personalities followed his proposed hierarchy. While a variety of personality dimensions might be considered as related to motivational needs, one of the most often cited is that of introversion and extroversion. Reorganizing Maslow's hierarchy based on the work of Alderfer and considering the introversion/extraversion dimension of personality results in three levels, each with an introverted and extroverted component. This organization suggests there may be two aspects of each level that differentiate how people relate to each set of needs with different personalities relating more to one dimension than the other. For example, an introvert at the level of Other/Relatedness might be more concerned with his or her own perceptions of being included in a group, whereas an extrovert at that same level would pay more attention to how others value that membership [1,2].

At this point there is little agreement about the identification of basic human needs and how they are ordered. For example, Ryan & Deci [3] also suggest three needs, although they are not necessarily arranged hierarchically: the need for autonomy, the need for competence, and the need for relatedness. Thompson, Grace and Cohen [4] state the most important needs for children are connection, recognition, and power.

Level	Introversion	Extroversion
Growth	Self-Actualization (development of competencies-knowledge, attitudes, and skills and character)	Transcendence (assisting in the development of others' competencies and character; relationships to the unknown, unknowable)
Other (Relatedness)	Personal identification with group, significant others (Belongingness)	Value of person by group (Esteem)
Self (Existence)	Physiological, biological (including basic emotional needs)	Connectedness, security

Tab. I. A Reorganization of Maslow's and Alderfer's Hierarchies

Nohria, Lawrence, and Wilson [2] provide evidence from a sociobiology theory of motivation that humans have four basic needs:

- acquire objects and experiences
- bond with others in long-term relationships of mutual care and commitment
- learn and make sense of the world and of ourselves
- defend ourselves, our loved ones, beliefs and resources from harm.

The Institute for Management Excellence (2001) suggests there are nine basic human needs [1]:

- security
- adventure
- freedom
- exchange
- power
- expansion
- acceptance
- community
- expression.

Baková highlights the needs of mutual help in difficult life situations if we are vulnerable and we need to be in close social and interpersonal interaction with others who can offer us helpful hand. If the person is in crisis or difficulties the need of social support is the most important to overcome problems [5].

Aim

The research is aimed at understanding around individual needs of people with disabilities and their subjective feelings of level of their quality of life. The disabled people said that lack of possibilities to fulfil their needs affects every area of their lives – household, working placement, education integration and social inclusion or personal growth. Research question:

- 1. How encouraging and meeting the needs of persons with disabilities is done in reality?
- 2. What is the quality of life of people with disabilities in the 6 scale dimension?
- **3.** How are disabled people satisfied with the fulfilment of their needs according to Maslow's Hierarchy of Needs?

The research sample is consisted of 35 people with disabilities attending the social rehabilitation centre in Malacky in Slovakia. Studies have shown that negative attitudes and discrimination are worse towards people with disabilities than to the others and influence the level of quality of their lives. This may be due to a generally poor level of understanding about these disabilities and how they affect people's social participation or it may be an indication of the prevalence of negative stereotypes concerning the disabilities.

Disabled people involved in the research are age range 25-35 years old, including 54,5% female and 45,5% male; they are clients of social rehabilitation programme as a part of sheltered centre opened from 2012.

Materials and methods

We used quantitative methods emphasize objective measurements and the statistical, mathematical, or numerical analysis of data collected through questionnaire focuses on gathering numerical data and generalizing it across groups of people with disabilities to explain a particular phenomenon of saturation of needs of people who meet with barriers in daily life.

We used a standardized questionnaire as the survey instrument based on Theory of Hierarchy of Needs to collect data from individuals with disabilities about themselves, or about their feelings linked to saturation of the needs and the quality of life. Each respondent with the disability was exposed to the same questions and the same system of coding responses. The aim here is to try to ensure that differences in responses to questions can be interpreted as reflecting differences among respondents, rather than differences in the processes that produced the answers. It was focused on these indicators of the quality of life:

- 1. health
- 2. psychical health and feelings
- 3. social contacts and relationships
- 4. society and self-realisation
- 5. spirituality
- 6. independence.

Results and discussion

The research answers questions about Hierarchy of Needs of people with disabilities and their subjective feelings of level of their fulfilment in daily lives and working activities.

There are specific forms of self-actualization, therefore, vary greatly from person to person. Self-actualization need not to be limited to disability but it is applied to different kinds of individuals in all steps of life due to strong individual motivation. Every individual has an opportunity to fulfil his or her potential by doing well what each does best on behalf of disability degree. The most of disabled people feel poor change for self-realisation due to the fact that the handicapped person is broadly defined through physical or mental impairment that substantially limits one or more major life activities. Disabled people are strongly unsatisfied with self-actualization (43%) and more satisfied with opportunities for self-development by working placement (31%) and less satisfied with ways of solving problems of disabled people in society facing discrimination, unemployment and exclusion (22%).

Self Actualization and Fulfillment Needs	1-2	3-4
Self-realization in daily life	0,518	0,0358
Finding the purpose of life	0,416	0,523
Personal growth	1,357	1,115
Problem solving	1,249	0,752

Tab. II. Saturation of Self Actualization and Fulfillment Needs

scale: 1 strongly satisfied – 4 totally unsatisfied

It is known that disabled people suffer from low self-esteem and self-confidence and the most of them declare these as a strong barrier to have social status in society and fulfil daily life tasks. At the heart of persons self-esteem are his/her core beliefs about the kind of person you are. The disabled people face different labelling that affects their self-esteem in many negative ways and they lose belief in themselves.

If people with disabilities have low self-esteem these beliefs will be mainly negative, because the society and providing social services focus on their weaknesses rather than positive qualities to be empowered. 44% of disabled believe that they do not have enough abilities to succeed. 15% of them have lack of motivation for self-development and achievement and they are passive receivers of services due to used to it or comfort providing by their families, institutions or social environment. 18% of them miss respect of others and making them equal and 11% of them feel respect by others that help them to be successful in daily life activities.

Ego -Self Esteem Needs	1-2	3-4
self-esteem, confidence	1,236	0,058
Achievement and self-development	1,0487	1,0496
Respect of others	1,0261	1,0341
Respect by others	1,0358	1,0673

Tab. III. Ego-Self Esteem Needs

scale: 1 strongly satisfied – 4 totally unsatisfied

63% of disabled find family as the most important which provides them support, safety and care. They cannot image their life without family and friends, but on the other hand, the most of friend are people with the same pity and they are not in close touch with healthy population as they wish (39%).

The building relationship is the way how disabled people stay in touch with community they live in and giving them positive feelings. 65% of the disabled people have low social status and lost working skills due to long-term unemployment.

There is point in increasing conditions to support working integration of people with disabilities, not only within sheltered workshops, but preferring placements in open labour market.

The most of disable people wish to work not in sheltered workplaces, but to be integrated in company in open labour market. More than 30% of them feel socially excluded and not to be involved in sources and services comparing to the other people without handicap.

Saturation of needs of people with disabilities in the context of the quality of life

Social - Love and Belongingness Needs	1-2	3-4
Family	0,018	1,804
Relationship and friendship	1,261	0,023
Work group and social status	1,537	0,014
Sense of social inclusion	1,412	0,002

Tab. IV.	Social -	Love	and	Belongingne	ss Needs
----------	----------	------	-----	-------------	----------

scale: 1 strongly satisfied - 4 totally unsatisfied

Fulfilment needs of security and harm reduction is more important for the disable people than to others due being attack verbally or physically. People with disabilities are often victims of violence, bullying or economically abused (17%). 28% of people with disabilities think that their health conditions are poor and costs of rehabilitation programmes are very high, they cannot avoid to pay for it and so to increase quality of health. More than half of people with disabilities feel no social stability and they are afraid of their future. If disabled people get a job, he does not feel secured because he or she can easily lose his job due worst health or lower work efficiency. 21% of them think that they are not accepted by surroundings and their abilities are underrated, the most people look at them as people who need help or who cannot work or live independently.

Tab.	V.	Security	- Safety	Needs
------	----	----------	----------	-------

Security - Safety Needs	1-2	3-4
Security and protection	1,042	1,033
Health	1,324	1,274
Social stability	1,018	0,026
Sense of social acceptance	1,349	0,025

scale: 1 strongly satisfied – 4 totally unsatisfied

Body-Physiological Needs are needs necessary to stay alive, but we asked disable people how they are satisfied with the quality of food they can order or buy in the shop in context with the quality of life. 53% of them they cannot avoid to buy healthy or better food in shop, but they usually buy cheapest one event they know they are not good quality. 57% of them meet with accommodation problems, they miss wheelchair access to bathroom or toilet at their household or they face stairs to the public buildings and have problems to move from one place to another. 61% of people with disabilities answered they have no sexual life or miss the relationship with the partner. They have lack of information about sexual life and sexuality is taboo for them. They are ashamed to speak about it and the most of them do not confess they have no experience in it (19%). Only 14% of them do free time activities,

especially they are involved in sport clubs or spend time by doing sport games such as table tennis, boccia or wheelchair dancing, 46% of them are passive consumer of free time - watching television, surfing on the internet or chatting. 20% of them spend time outsides with friends a 20% of them going shopping and spend time in shopping centres having walk. They like to spend time in these centres because they are easily accessible for them and do not have problems to move there.

Tab. VI. I	Body-Physiol	ogical Needs
------------	--------------	--------------

Body-Physiological Needs	1-2	3-4
Food	1,324	1,243
Accommodation	1,056	0,487
Sexuality	1,852	0,0101
Free time activity	1,745	0,0147

scale: 1 strongly satisfied - 4 totally unsatisfied

The research studies have shown these indicators of quality of life of people with disabilities:

- 1. **Physical health** disabled people find their health conditions poor, they miss rehabilitation programmes to be accessible for them due to high costs and short-term treatment. They do not have enough energy and have to struggle with many problems affecting their health, the harm-reduction of the disability is a long term process and requires a lot of money, time, energy, personal motivation and social sources.
- 2. **Psychical health and feelings** the negative feelings are often in the mind of the disabled people due to low self-esteem, low confidence, frustration and stress. The most of them have negative picture about themselves and no good believes in their abilities that make barriers to fulfil their needs and increase the quality of life.

Positive thinking helps them to be able to cope with this pain even better or with barriers and prejudices linked to their handicap.

 Independence – more and more disabled people wish to be independent and find place in the community they live in. The problem is that this community is often no prepared to empowered them and make them dependent on help of others or social services.

Many disabled people are experiencing negative attitudes and discrimination tendency making them dependent on special care and social support. There is lack of tools aimed at empowering abilities of the disabled people, not only focusing on the treatment.

4. Social networks and relationship - Social relationships are a ubiquitous part of life, serving important social, psychological, and behavioural functions across the lifespan.

More important, both the quantity and quality of social relationships have been reliably related to successful integration of the disabled people and fulfilment of their needs through daily life activities and action in society. Disabled people need to have great support to achieve well-being and having good relationships link to long-term psychical health.

- 5. Society disabled people often have to face discrimination tendency, social exclusion and negative labelling affected by attitudes of society to the disability and people who are impaired. The society should be opened to inclusion of vulnerable people and open the possibilities to them to achieve self-development, increase working skills and qualification and find their place in social environment to obtain self-esteem.
- 6. Spirituality it is know that the most of people with disabilities find sense of life in belief in God and they attend church ceremony. They do not blame God with disability but the disability is a tool that makes them more stronger to overcome daily barriers and prejudices.



Fig. 1. Indicators of quality of life of people with disabilities

Moreover, programmes, awareness-raising and social support are necessary to change the way society operates and to dismantle the barriers that prevent persons with disabilities from participating fully in society. Furthermore, persons with disabilities need to be provided with the opportunities to participate fully in society and with the adequate means to claim their rights and to fulfil their needs.

Conclusion

The research was focused on measurement of fulfilment of needs of people with disabilities by subjective point of view. The study have shown correlation between fulfilment of needs and level of quality of life and between well-being and saturation of needs.

The social, legal, economic, political and environmental conditions may built barriers to the fulfil needs of people with disabilities and they required a lot of effort to be identified and overcome. For example, their marginalization and their exclusion from education are not the result of their inability to learn but of insufficient training or inaccessible classrooms; their exclusion from the labour market might be due to a lack of transport to the workplace or negative attitudes among employers and colleagues that a person with disabilities is unable to work; and their inability to participate in public affairs might result from the lack of information or no wheelchair access to public places.

References

- Huitt W.: Maslow's hierarchy of needs. Educational Psychology Interactive. Valdosta, GA: Valdosta State University. Retrieved, 2007, from, http://www.edpsycinteractive. org/topics/regsys/maslow.html, edited february 2016.
- Nohria N., Lawrence P., Wilson E.: Driven: How human nature shapes our choices. Jossey-Bass, San Francisco, 2001.
- Ryan, R., Deci, E.: Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. American Psychologist, 2000, 55, 1, 68-78.
- 4. Thompson M., Grace C., Cohen L.: Best friends, worst enemies: Understanding the social lives of children. Ballantine Books, New York, 2001.
- Baková D., Haburajová Ilavská L., Vaňo I., Neszméry Š.: Vnímanie Staroby A Starnutia Optikou Súčasnej Spoločnosti. Hnutí R, Vydavateľstvo s medzinárodnou vedeckou, Radou, 2015.

Naumau Ihar, Lisok Alena, Sivakova Sviatlana

Grodno State Medical University, Grodno, Republic of Belarus

Introduction

About 40,000 doctors work for health care in the Republic of Belarus and the vast majority of them are women in active reproductive age. One of the risk groups for deterioration of health due to multifactorial influence of harmful production factors are women obstetricians-gynecologists. Therefore, the protection of the health of women-doctors, provision of safe working environment for them, reducing the levels of occupational and production related diseases is an important task of modern society.

Medical workers occupy special place in the structure of professional groups among employable population. Firstly, the work of the majority of doctors is characterized by considerable intellectual load and neuro-emotional tension, in some cases it is also accompanied by large physical effort, it always requires a lot of operational and long-term memory, attention, endurance, long-term preservation of working capacity, as well as to a set of personal qualities which allow doctors to work in contact with the patient during the entire of work experience while maintaining the required level of professionalism and compassion [1,2,3]. Secondly, the professionalism of medical staff largely determines the success and efficiency of health care delivery to the population [4,5,6].

One of the risk groups among all doctors on deterioration of health due to multifactorial influence of harmful production factors are women obstetricians-gynecologists. Moreover, it is obvious that the conditions of life and professional activity of women doctors which have formed by now in the Republic of Belarus can be the cause of occupational and production related diseases and also can play an important role in the formation of the pathogenetic mechanisms of development and progression of other diseases, including chronic fatigue syndrome and emotional burnout syndrome which most of the authors regard as clinical signs of chronic stress at work [7,8,9].

In modern researches safety of workers is defined as the lack and reduction of levels or concentrations below the limit values of hazardous and harmful production factors which can cause deterioration in health status and reduce working capacity [10,11,12].

Ensuring safe working conditions is carried by the periodic certification of working places of doctors, which is the main tool for objective assessment and improvement of working conditions among workers who have contact with dangerous and harmful production factors.

Objective of research: to assess the state of morbidity with temporary loss of ability to work among women obstetricians-gynecologists in reproductive age taking into account the analysis of the results of certification of workplaces on working conditions.

Material and methods

Working conditions were evaluated according to the results of certification of workplaces. State of morbidity with temporary loss of ability to work among 46 women obstetricians-gynecologists of the Grodno Regional Clinical Perinatal Center at the age of 23-49 years was evaluated according to data of the official state statistical reporting in 2010-2014. Women aged from 23 to 29 years old in this group accounted for 15.2%, from 30 to 39 years – 65.2%, from 40 to 49 years – 19.6%. Patients with work experience up to 10 years accounted for 34.7%, from 11 to 20 years – 43.5%, more than 20 years – 21.8%.

Control group consisted of 40 women aged from 18 to 49 years who resided in the city of Grodno, but by the nature of the professional activities were not medical staff, but also were examined during periodic medical check-ups (workers of public catering and trade). Patients aged from 18 to 29 years accounted 15.0%, from 30 to 39 years – 65.0%, from 40 to 49 years – 20.0%. Work experience was as follows: up to 10 years – 37%, from 11 to 20 years – 39.1%, more than 20 years – 23.9%.

The normality of the distribution of data was checked by constructing histograms, calculating the excess and asymmetry of the sample. In some cases, Kolmogorov-Smirnov test for normality and Shapiro-Wilk's test were used.

The working conditions of women obstetricians-gynecologists have been studied in accordance with the recommendations of the instruction 2.2.9.11-11-202-2003 «Organization of control of working conditions and health status of working women», approved by the Chief Sanitary Doctor of the Republic of Belarus of 15.12.2003 № 168. The impact of industrial

environmental factors on the health of workers was evaluated by analysis of hygienic parameters, which were obtained through the copy of data from the primary documentation on the results of measurements of the departmental industrial-sanitary laboratory and laboratory of Grodno Regional Center of Hygiene and Epidemiology during certification of workplaces, as well as from the information card on the state of contamination of the working area air by harmful chemicals in the perinatal center, which were compared with the state industry standard 12.1.005-88 «General sanitary-hygienic requirements to the air of the working area», sanitary rules and norms $N_{\rm P}$ 11- 19-94 «The list of regulated air pollutants of the working area», sanitary rules and norms $N_{\rm P}$ 9-80-98 «Hygienic requirements for the microclimate of industrial premises», sanitary rules and regulations $N_{\rm P}$ 13.2.2007 «Hygienic classification of working conditions», sanitary rules and norms $N_{\rm P}$ 9-72-98 «Hygienic requirements for working conditions).

Processing of data on morbidity with temporary loss of ability to work among workers was performed by methods of variation statistics in the application program Statistica 6.0. We identified: Mean (M), Standard error of mean (m) and Standard deviation (δ). Visualization of distribution of parameters in groups was carried out with the help of the frequency histograms, pie charts and line graphs. Estimation of the difference between the general proportions (frequencies) was performed by the parametric Student's t-test. The null hypothesis was rejected at p <0.05.

Results and discussion

It was found that women obstetricians-gynecologists performed work which included the organization and implementation of health care to patients in the delivery room and in different types of obstetric departments. They did bypass of patients together with the head of the department and the head nurse every day and determined the necessary measures for the treatment and care depending on patient's health status, performed planned and emergency operations and dressings, took birth, checked the correctness and timeliness fulfillment of medical prescriptions by nurses according to appointments and guidance on treatment and care, took part in identification of temporary loss of ability to work, wrote history of diseases, and were on duty in perinatal center according to schedule.

The severity of the labor process of women doctors was associated with compelled uncomfortable working posture in which they were up to 60% of the time. They were in fixed posture up to 25% of the time (during delivery and performing operations) and in standing posture – up to 35% of the time during work. Furthermore, as follows from the certification, doctors obstetricians-gynecologists committed around 1000 regional labor movements during work.

The greatest influence on the intensity of the labor process of women doctors was rendered by the following intelligent loads: the content of the work, the perception of the information and its assessment, the distribution of functions according to the degree of complexity of the tasks, the nature of the work, emotional overload (high degree of responsibility for the results of professional work and for safety of patients) as well as the two-shift operation with short time for rest.

Thus, from the data presented in Table I, follows that the working conditions in terms of labor tension of the process of women obstetricians-gynecologists comply with class 3.2 - harmful working conditions (Table I).

The next stage of our work was to analyze the working conditions of women doctors according to the degree of harmfulness and (or) hazard of production factors and factors of labor process, summarized results of which are shown in Table II.

Thus, work places of women obstetricians-gynecologists according to the results of the certification have been classified as harmful working conditions (Class 3.3), which were characterized by the presence of harmful factors of biological nature and the high tension of the labor process and which had an adverse effect on the body of women and were expressed in high morbidity with temporary loss of ability to work.

Thus, during the analysis of morbidity with temporary loss of ability to work we found that in the period from 2010 to 2014 among women obstetricians-gynecologists in the structure of morbidity were prevailed diseases of the musculoskeletal system, which accounted for 33.1%, complications of pregnancy and childbirth – 25.5% and respiratory diseases – 22.8% (Figure 1), which are typical for long-term occupational contact with of biological factors and the high tension of the work process [13], which we have identified during assessment of the working conditions.

During the analysis of morbidity with temporary loss of ability to work (in cases) it was found that among women obstetricians-gynecologists in the review period the values of the indicator had insignificant changes, but they were significantly higher than those in the control group (Figure 2).

Indicators of labor tension		Classes of working conditions		
			3.1	3.2
1. Intellectual loads		1		
1.1. The content of the work				+
1.2. Perception of signals (information) and their evaluation				+
1.3. The distribution of functions according to the degree of complexity				+
of the task				
1.4. The character of the work				+
2. Sensory loads				
2.1. Duration of concentrated surveillance (in % of all operating time)		+		
2.2. Density of signals (light, sound) and messages for 1 hour of work	+			
2.3. The number of production objects for surveillance at one moment	+			
of time	H			
2.4. Size of object for distinguishing (the distance from the worker's eye				
to object for distinguishing shouldn't be more than 0.5 m) in mm at		+		
duration of concentrated surveillance (in % of all operating time)				
2.5. Work with optical devices at duration of concentrated surveillance	+			
(in % of all operating time)	H			
2.6. Surveillance for screens of video terminals (amount hours during	1			
operating time)	+			
2.7. The load on the organ of hearing (if necessary to perceive a speech	1			
or differential signals)	+			
2.8. The load on the vocal apparatus (the total number of hours of				
conversations per week)	+			
3. Emotional loads				
3.1. The degree of responsibility for the results of their own activities.				+
The significance of the error				т
3.2. The degree of risk to their own life		+		
3.3. The degree of responsibility for the safety of others persons				+
3.4. The number of conflicts arising during professional activity		+		
4. Monotonicity of loads				
4.1. The number of elements (methods), which are necessary for the				
implementation of simple tasks or multiply repetitive operations	+			
4.2. The duration (in seconds) of performance of simple production				
tasks or repetitive operations	+			
4.3. The time of active operations (in % of all operating time)		+		
4.4. Monotonicity of the production conditions (time of passive				
surveillance for the production process in % of all operating time)	+			
5. Regime of operation				
5.1. The actual duration of the working day		+		
5.2. The shift system			+	
5.3. The presence of regulated breaks and their duration			+	
The overall grade of labor tension (class)		3	3.2	

Tab. I. Assessment of intensity of labor tension among women doctors

Tab. II. Evaluation of working conditions of women doctors according to the degree of harmfulness and (or) hazard of production factors and factors of labor process

Name of production factors and factors of labor process	Class of working conditions
Chemical	2
Biological	3.2
Aerosols which predominantly have fibrogenic action	1
Noise	2
Infrasound	1
Ultrasound in the air	1
General vibration	1
Local vibration	1
Non-ionizing radiation	1
Ionizing radiation	1
Microclimate	2
Illumination	2
The severity of labor	2
The tension of labor	3.2
The final grade of working conditions according to the degree of harmfulness and (or) hazard of production factors and factors of labor process	3.3

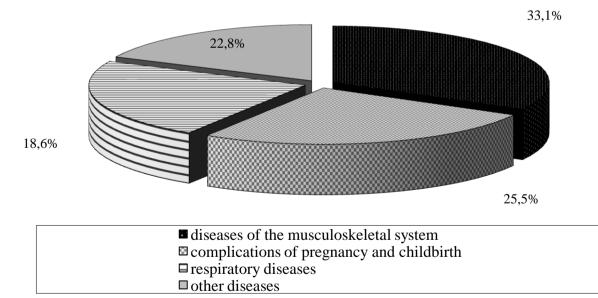


Fig. 1. The structure of morbidity with temporary loss of ability to work among women obstetricians-gynecologists in the 2010-2014

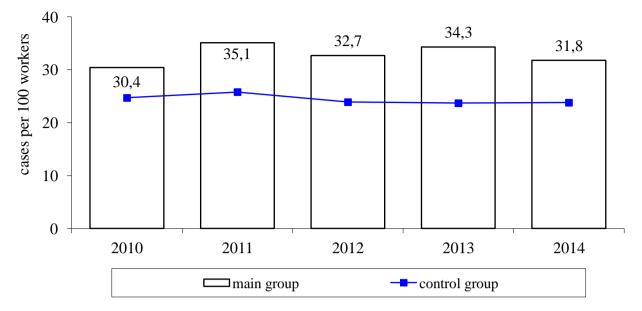


Fig. 2. Dynamics of morbidity with temporary loss of ability to work (in cases) in 2010-2014

Thus, the average value of the indicator for the five years among women obstetriciansgynecologists was $32,6\pm2,49$ per 100 workers, that was significantly higher in comparison to the control group of patients (t = 6,06; p <0.01).

In the period from 2010 to 2014 the most significant diseases which resulted to high levels of morbidity with temporary loss of ability to work among women doctors (in cases) were diseases of the musculoskeletal system, which are quite typical for the increased severity of the labor process which was identified during certification of working conditions (Figure 3).

In addition, among obstetricians-gynecologists was recorded some increase of cases of morbidity with temporary loss of ability to work due to complications of pregnancy and childbirth: the level of the indicator reached 33.7 per 100 workers at the end of the period under review (Figure 4).

This fact can be considered as the realization of a professional risk for the reproductive health of women workers which authors in references defined as the likelihood of damage to the reproductive function, fetal development and infant health in connection with work [14]. Moreover, it is known that the nature and degree of clinical manifestations and their medical and social significance depend on the class of working conditions and risk categories: than more harmful class of working conditions the more significant medical-social damage of health, including reproductive health (Table III).

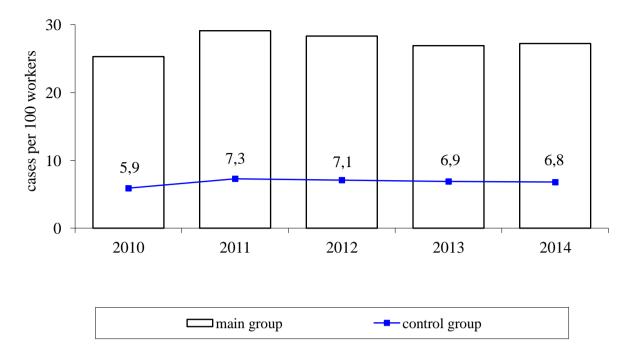


Fig. 3. Dynamics of morbidity with temporary loss of ability to work (in cases) due to diseases of the musculoskeletal system in 2010-2014

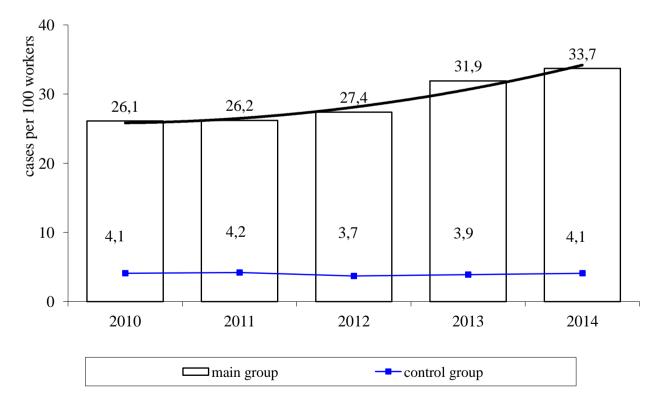


Fig. 4. Dynamics of morbidity with temporary loss of ability to work (in cases) due to complications of pregnancy and childbirth in the 2010-2014

Class of working conditions	The deterioration of health indicators according to the results of periodic medical examinations	The deterioration of indicators of morbidity with temporary loss of ability to work	The deterioration of indicators of biological age in comparison with passport age	The deterioration of indicators of reproductive health and health of generation
3.1	+	-	-	+
3.2	++	+	+	+
3.3	++	++	+	+

Tab. III. Assessment of occupational risk, depending on the degree of class of working conditions [15]

Conclusion

Thus, work of women obstetricians-gynecologists regarded as harmful working conditions (Class 3.3) and it is characterized by a high degree of tension of the work process, and it defines the character of morbidity with temporary loss of ability to work that requires the development of new and effective preventive measures.

References

- Howard M.: The incidence of burnout or compassion fatigue in medical dosimetrists as a function of various stress and psychologic factors. Med. Dosim., 2013, 38, 1, 88–94.
- Jasperse M., Herst P., Dungey G.: Evaluating stress, burnout and job satisfaction in New

Zealand radiation oncology departments. Eur.J. Cancer Care., 2013, 12, 1209–1212.

- Ramírez-Gil J., Toledo-Alfocea D., Tosal-Herrero B.: When the doctor becomes a patient: physician health in university hospitals in Alicante. Arch. Prev. Riesgos. Labor., 2013, 6, 4, 171–181.
- 4. Chism M.: Mastering energy to avoid drama in your healthcare practice. J. Med. Pract. Manage, 2012, 28, 2, 106–108.
- 5. Jackson E.J.. Moreton A.: Safety during night shifts: a cross-sectional survey of junior doctors' preparation and practice. BMJ Open, 2013, 20, 9, 657–663.

- Kirwan M., Matthews A., Scott P.A.: The impact of the work environment of nurses on patient safety outcomes: a multi-level modelling approach. Int. J. Nurs. Stud., 2013, 50, 2, 253–263.
- Johnson J.V., Hall E.M., Ford D.E., et al.: The psychosocial work environment of physicians: the impact of demands and resources on job dissatisfaction and psychiatric distress in a longitudinal study. J. Orthop. Res., 2008, 102, 2, 234–237.
- Reusch A., Schug M., Küffner R.: Medical rehabilitation group-programmes concerning health promotion, patient education and psychoeducation - a 2010 national. Rehabilitation (Stuttg), 2013, 52, 4. 226–233.
- Rovik J.O., Tyssen R', Hem E., et al.: Exploring the interplay between personality dimensions: a comparison of the typological and the dimensional approach in stress research. Perspect. Individ. Dif., 2007, 42, 1255–1266.
- Lamontagne F., Abiteboul D., Lolom I.: Role of safety-engineered devices in preventing needlestick injuries in 32 French hospitals. Infect. Control. Hosp. Epidemiol., 2007, 28, 18–23.
- Dianat I., Sedghi A., Bagherzade J., et al.: Objective and subjective assessments of lighting in a hospital setting: implications for health, safety and performance. Ergonomics., 2013, 23, 245–253.
- Ro K.E., Gude T., Aasland O.G.: Does a self-referral counselling program reach doctors in need of help? A comparison with the general Norwegian doctor workforce. BMC Public Health., 2007, 7, 36–41.
- 13. Chen K.Y., Yang C.M., Lien C.H., et al.: Burnout, job satisfaction, and medical malpractice among physicians. Int. J. Med. Sci., 2013, 10, 11, 1471–1478.
- 14. Селищева И. Н.: Комплексная социально-гигиеническая оценка трудового процесса и условий труда врачей акушеров-гинекологов, Вест. всерос. общ. спец. мед.-социал. эксперт., реабилит. и реабилит. Индустрии, 2011, 4, 39–45.
- Карамова Л. М., Каримова Л. К., Башарова Г. Р.: Профессиональный риск для здоровья работников химических и нефтехимических производств: монография, Уфа, 2006, 306.

Contens

Piątkowski Włodzimierz, Majchrowska Anita: Social worlds of the dying person – selected sociological threads	10-24
Gnus Jan, Antczykowski Maurycy, Maślanka Paulina, Kasperczak Michał, Dawidczyk Piotr, Pfanhauser Monika, Winter Paweł, Dorna Krzysztof, Blok Katarzyna, Paprocka-Borowicz Malgorzata: Live vs. cadaveric donation - two approaches to kidney and liver transplantation. Analysis and evaluation of methods.	25-32
Sivakova Svetlana, Naumov Igar, Shpakau Andrej, Smirnova Galina, Lisok Alena: Deontological problems of euthanasia	33-42
Gnus Jan, Maślanka Paulina, Antczykowski Maurycy, Kasperczak Michał, Gnus Emilia, Ferenc Stanisław, Gonet Martyna, Sebzda Tadeusz, Uruska Paulina, Paprocka-Borowicz Małgorzata: Euthanasia as legal considerations in the world over the years.	43-50
Jewdokimow Marcin, Chmielewska-Ignatowicz Tomira: Genetic diagnosis of cancer burden as illustrated by interviews with cancer patients and people from families belonging to cancer risk group	51-66
Konczelska Katarzyna: The role of the support groups in the process of mourning a child's death - research conclusions. Support groups – mourning a child's death	67-81
Rębiałkowska-Stankiewicz Małgorzata : The quality of life of oncological patients and the social support	82-93
Surmach Marina: Medical and social risk factors for abortion as the reproductive choice in 19-24 years old Belarusian men	94-99
Cintulová Lucia Ludvigh: Saturation of needs of people with disabilities in the context of the quality of life	100-109
Naumau Ihar, Lisok Alena, Sivakova Sviatlana: The analysis of morbidity with temporary loss of ability to work among women obstetricians-gynecologists	110-119

ISBN-978-83-940670-2-1