

Challenges of the current medicine

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***Challenges of the current
medicine***

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Medical University of Białystok
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***Challenges of the
current medicine
Vol. 6***

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*Fortunately analysis is not the only way to resolve inner conflicts.
Life itself still remains a very effective therapist.
Karen Horney*

Dear Colleagues

The monograph periodical “*Challenges of the Current Medicine - 6 Edition*” is a collection of works written by authors from many different medical centers.

Teilhardem de Chardin once wrote: *'We are aging and we will die. That is, at this or that moment - no matter how strong our opposition is - we find that the pressure of the destructive forces against us is slowly overwhelmed by our vital forces and defeats us physically'*

The leading theme of the monograph applies patient, mainly the dying patient.

The patient should be paramount to health care workers, and ideally describe the words that are the message of St. Christopher's Hospice. - *'You matter because you are you, and you matter until the last moment of your life'*.

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 *'We have to ask ourselves whether medicine is to remain a humanitarian and respected profession or a new but depersonalized science in the service of prolonging life rather than diminishing human suffering'*.

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Death and Dying in Film

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Introduction

Although there is increasingly recognition that future health care providers should be educated in the care of dying patients [1-3], this is very difficult to achieve through traditional methods of teaching which have a primarily cognitive focus. Developing appropriate levels of competency in the provision of end of life care demands the acquisition of skills which need to be cognitively informed, but requires a great deal more than instruction by means of lectures and seminars. Reliance on these traditional methods to achieve this is comparable to trying to learn to swim or ride a bike by reading an instruction manual alone – never venturing into the water or attempting to mount a bicycle. Scientific competence *per se* is insufficient in preparing future health care professionals to travel alongside those patients embarking upon their final journey in life. It is often difficult for students not only to recognize that they will be accompanying patients on this journey, but to know how to offer appropriate care to those forced to take these inevitable, final steps. One of the tasks of medical education must be to raise awareness in this area and to provide students with appropriate ways of gaining the required skills from their earliest days of university training.

This however, provides educators with a singular challenge. It is difficult to provide direct learning experiences with dying patients in the early stages of medical and nursing training. Students are unlikely to be equipped with sufficient knowledge - which is yet to be acquired through the formal curriculum - or skills at this pre-clinical level of training, to engage appropriately with terminally ill patients. Furthermore, in wishing to ensure high levels of quality care for their patients, clinicians understandably may wish to spare them the additional burden of contributing to the teaching of students about their needs and experiences. Students may have acquired some preparatory skills in end of life care through voluntary occupations or internships and whilst such experiences are invaluable and have been shown to bring about positive changes in their attitudes to the care of dying patients [4],

it cannot be guaranteed that all students have indeed had such opportunities prior to their clinical training.

The purpose of this paper is to describe an innovative form of teaching about end of life care using film, in order to provide experiential learning opportunities for pre-clinical medical students and stimulate learning in the affective domain. The programme of learning was, in part, inspired by the *Wit* Film Program [5] which was developed to “*enhance trainee education in the humanistic elements of end-of-life care*”. In general, studies have demonstrated that students have reported that their experience of learning through viewing dramatic performances of “*Wit*” was greatly enhanced and enabled them to access their feelings more easily than through more traditional educational methods [6-10], thereby providing encouragement for the use of the film as means of teaching about death and dying.

The need for education in palliative care early in medical training

Palliative care has come a long way in understanding that the role of the health professional is to help the patient come to terms with loss of health and the suffering that comes in its wake. This task remains and will largely remain unaltered by the technological advances made in the field of medicine. It requires a grasp and understanding of the patient’s experience, in order to act appropriately on their behalf, something that has been referred to as the patient’s narrative [11]. This narrative competence has been defined as: “*the competence that human beings use to absorb, interpret and respond to stories... and suggests that it enables the physician to practice medicine with empathy, reflection, professionalism, and trustworthiness*” [12]. Film is one way of making these narratives available to students in the early years of their medical education and providing them with opportunities for reflection on the issues involved.

Acquiring the skills necessary to be able to provide high quality palliative care, however, requires practice, which has traditionally been left to exposure, much later in medical training, to terminally ill patients. This somewhat haphazard approach is often inadequate, as the majority of medical students may complete their undergraduate studies never having had the opportunity to observe a senior physician delivering bad news to a patient [10]. Moreover, whilst the observation of role models is, from a psychological point of view, extremely powerful, learning within this hidden curriculum does not always encourage reflection and may serve to reinforce inadequate patterns of behaviour, thereby potentiating

less competent approaches to the care of dying patients. This is especially so in situations with high levels of ambient anxiety and it is difficult to imagine more anxiety provoking situations than those in which the patient under our care is facing a terminal diagnosis and illness. The most natural response to anxiety is avoidance of the anxiety-provoking situation. Clearly, it is impossible for the healthcare professional to avoid dying patients, but it is possible to avoid some of the more difficult aspects of their situation, by focusing exclusively on the purely medical components of their care, by-passing their needs for emotional and spiritual support. But this serves only to potentiate the problem. Avoidance of these fundamental care needs may bring temporary relief to the practitioner, but apart from the immediate negative consequences for the patient whose needs remain unmet, undermines the practitioner's own feelings of competency and ultimately challenges their own sense of adequacy in being able to provide appropriate care for the patients with whom they work – admittedly in so far as they have sufficient insight into their own defence and coping strategies. The fact that newly qualified doctors feel inadequately prepared for addressing patients' end of life care needs and recognised difficulties with managing their own feelings in connection with the death of patients is verified by a considerable body of research [13-17].

New pedagogical approaches

Providing appropriate forms of education to meet the needs of pre-clinical medical students requires a departure from the standard pedagogy of medical training to one that is able to accommodate the limitations identified in the more traditional approaches and at the same time provide appropriate learning experiences. In order to be effective, these “new pedagogies” need to fulfil a number of conditions. Firstly, students should be helped to become aware of their need to acquire specific skills and to recognise that this requires learning, albeit in a different form from that, to which they have become accustomed. It requires a shift from content to process learning and as such, will span all the years of medical education and beyond. This kind of learning is encapsulated in Miller's [18] pyramid of clinical competence and includes not only *what* students need to know (basic facts) and *how* to apply this knowledge in theory, but being able to *show how* to use this knowledge in a simulated environment and finally demonstrating their ability *to do*, that is, to implement their knowledge. The first two stages, constituting the lower levels of the pyramid, those of knowing “what” and knowing “how”, represent the cognitive stages of knowledge

acquisition, and it is at this level that the majority of students at the pre-clinical are to be found. The upper two levels, of “showing how” and “doing”, represent behavioural knowledge that is applied, first in the safe setting of a simulated environment and finally in terms of actual performance in the clinical setting. This is the difference between showing that one “knows how” to do something and actually doing it in practice.

Secondly, students should be helped to understand the value of such learning. This is not easy to achieve at a pre-clinical level, against a background of major theoretical subjects, where there is a strong emphasis almost exclusively on mastering content.

Finally, new forms of learning should help students achieve “deep” forms of learning that go beyond mastery of the existing content knowledge and develop their capacity to learn, create and implement their learning [19]. This is in marked contrast to what is often claimed to be a major limitation of traditional teaching methods, namely in “teaching to the test”, whereby teachers’ teaching and students’ learning is constrained by a focus on the standardised tests used for evaluation. Moreover, the outcomes of such teaching methods frequently result in the failure to demonstrate sufficiently strong long-term learning benefits [20] as content is retained only for long enough to pass the assessment and longer-term learning objectives are never achieved.

Finally, the means by which the new pedagogies are to achieve their aims, in stimulating deeper learning, require that students’ interests should be captured and held in order to convince them that this is an acceptable and valid way of learning to be an effective medical practitioner. An important condition for ensuring both acceptability and validity is that the learning process should be perceived as forming connections with real life [21].

One of the most important objectives of learning conceptualised in this way, is that it should bring about a change in attitudes. Moreover, effecting these changes should be registered in behavioural terms, apparent to observers. Thus in learning about end of life care, medical students have to be helped not only to understand the needs of dying patients, and to recognise when they are not being met. Their behaviour should also change in line with this new understanding. However, research has shown that the transition from cognitive knowledge (attitudes) to behavioural application is by no means automatic [22]. Nonetheless, students should be encouraged to practise what they know in order to confirm the validity of their learning for everyday life. This requires a form of experiential learning that attempts to combine high academic standards with real-life situations. Since, as already noted, exposure to such situations may be limited, especially during the early years of medical education, we

propose the use of cinematic film productions as an interim step, prior to full-scale clinical confrontation with terminally-ill patients as providing a controlled environment for discussion of complex issues such as death and dying. This might be seen as providing a way of bridging the transition between the cognitive and behavioural elements of developing clinical competence in end of life care. Appropriate follow-up activities aimed at stimulating personal reflection would create opportunities for Miller's [18] "showing how" stage in a simulated environment. Film, if carefully selected, offers a ready and engaging medium, that is strongly connected to real life, for educating future health care providers about the magnitude of emotions that arise during the many difficult situations encountered in caring for dying patients. As a form of experiential learning it provides a way of encouraging students to reflect on their own experiences while watching and is thus a useful tool f

Experiential learning

Although experiential learning is often defined as the process of learning through experience or "learning by doing" a crucial condition for the full facilitation of the learning process is that reflection on the experience should also take place [23]. David A. Kolb [24] is frequently considered to have laid down the fundamental principles which are now recognised as defining the experiential pedagogies:

"Learners, if they are to be effective, need four different kinds of abilities – concrete experience abilities, reflective observation abilities, abstract conceptualization abilities and active experimentation abilities. That is, they must be able to involve themselves fully, openly, and without bias in new experiences. They must be able to reflect on and observe their experiences from many perspectives. They must be able to create concepts that integrate their observations into logically sound theories, and they must be able to use these theories to make decisions and solve problems" (Kolb, 1984).

Experiential learning then, is more than the acquisition and digestion of factual information. It is what leads to the development of new skills and abilities, acquiring and changing attitudes, fostering innovative and original ideas and challenging established patterns of thinking by providing alternative perspectives.

Numerous possibilities for experiential learning are available to medical students and include role playing, simulated classroom situations, ward rounds, brief immersive

experiences, voluntary activities and internships. These learning opportunities have three essential characteristics in common:

1. They provide a mixture of both content and process and if organised effectively, allow an appropriate balance to be struck between the experiential learning activities and the underlying content and theory.
2. They allow engagement in purposeful, meaningful activities that focus on the more humanitarian aspects of medical care. These activities must have a personal and emotional relevance to the student, and allow them to make connections between their learning and the real world.
3. They provide opportunities for reflection, enabling students to critically reflect on their own learning, connecting their experience to theory and gaining insight into themselves and their interactions with the world. With appropriate guidance and encouragement students may be facilitated in using this learning for their own personal development: they may be able to employ their new skills, knowledge and experiences in other situations or environments, including those presenting outside their academic life. (Adapted from: Teaching and Learning Services [25]).

Many of these forms of active learning are routinely used in medical classrooms, though because of their very nature, they cannot always be implemented until the clinical part of training. The use of film as a means of providing meaningful experiences, generating emotional reactions and strongly connected to real life made it possible to introduce them at the pre-clinical level of training in a controlled manner.

The film selected for the purposes of teaching students about aspects of end of life care was “*Wit*” (2001) directed by Mike Nichols [26].

Brief summary of the film “*Wit*”

The film “*Wit*” is an adaptation of Margaret Edson’s [27] Pulitzer Prize-winning play about death and dying, based on her experience as a clerk in an oncology unit at a research hospital in Washington. There she observed seriously ill patients struggling with aggressive treatment for cancer and was impressed by their fortitude and dignity in the face of death. These observations and her reflections upon what she had seen prompted her to write the play. The film’s main character, Vivian Bearing (played by Emma Thompson) is an accomplished professor of English literature who, since her undergraduate studies has devoted herself to the

interpretation of the metaphysical poetry of the seventeenth century poet, John Donne. The film opens with Vivian Bearing receiving a diagnosis of ovarian cancer from the oncologist, Dr Kelekian. In a manner of direct and brutal objectivity he tells her: “*You have cancer. Miss Bearing you have advanced, metastatic ovarian cancer.*” Setting the scene for the entire tone of the ensuing discussion he goes on to say: “*You are a professor Miss Bearing*”, to which she replies “*Like yourself Dr Kelekian*”. It is thus acknowledged that this interview between doctor and patient is no ordinary interview, in which the delivery of bad news and how it is presented is of paramount concern, but one that can safely dispense with the usual concerns for the patient’s feelings, because the patient herself is no ordinary patient. This is a meeting of minds: like the doctor, she too is an intellectual. There is no need to consider other lesser important factors such as emotional reactions. It is assumed (by them both) that her intellect is sufficient to help her cope with the intensive, experimental chemotherapy treatment that Dr Kelekian proposes over the forthcoming eight months, which he emphasizes must be at full dose. He says, almost rhetorically, “*Dr Bearing, you must be very tough. Do you think you can be very tough?*” and she answers: “*You needn’t worry*”. The intellectual understanding which she brings to this situation are taken for granted by them both as the undisputed guarantee of her reserves of willpower to follow through with the demands of treatment. It is not clear that Vivian Bearing fully understands that her treatment is to be experimental and that her doctors will be merciless in observing the treatment protocol.

The film explores the pathway through terminal illness to its conclusion primarily from the point of view of the patient, but the role of the medical and nursing staff form an inextricable part of this process. A strength of the representation of the hospital staff is that they are not demonised or caricatured in any way and Vivian Bearing is not mistreated or abused by wilfully malignant practitioners. What we do see however, is the way in which routine activities and the day to day functioning of a busy teaching hospital make its staff inured to patients’ sensitivities, for example, by routinely posing standard questions irrespective of the patient’s circumstances: “*Hi, how are you today?*”, and then not waiting for or showing any interest in the answer or articulating their disdain for hospital rules designed to protect the patient’s welfare: “*some crazy clinical rule.*”

More disturbing however, is the emerging realisation as the film progresses, that the doctors’ main concern is not the welfare of the patient under their care, but the research opportunities that her treatment offers. Dr Jason Posner, the ambitious clinical fellow working under Dr. Kelekian who is responsible for Vivian Bearing’s day to day care repeatedly

demonstrates that, in his opinion, clinical work is a mere distraction, an unavoidable necessity, preventing him from focusing exclusively on his main interest in research. Disappointingly, even the senior doctor, Dr Kelekian, despite his greater clinical experience appears to share this preoccupation.

The portrayal of the two doctors, shows that an insufficient understanding of medical professionalism as the need to demonstrate compassion, renders their activities meaningless to those under their care. They might even justifiably be accused of neglecting the patient in terms of their psychological needs. This emphasizes the necessity for preparing medical students to recognise, appreciate and attempt to resolve the emotional needs of dying patients, helping them not to view these aspect of care as irritating obstacles and to cope by ignoring these needs altogether.

Vivian Bearing is the epitome of the “ivory tower academic”, totally immersed in her arcane and somewhat esoteric deliberations upon Donne at the expense of matters of everyday human existence. In her scholarly strivings she is a personification of the intellect as a pre-eminent force in giving direction and finding a resolution for life’s challenges. Intellectually uncompromising herself, she is equally unyielding in relation to her students, both in terms of the standards she demands and her unsympathetic disregard of their pleas for accommodation of their wishes. Her striving for the highest standards leads to her being perceived as haughty, uncompromising and unapproachable by those around her.

There is something of an irony in the fact, that her doctors are shown as espousing an analogous approach in their field of medicine to the treatment of patients, of whom Bearing is one. Focused on the scientific aspects of their work and its outcomes, they are unseeing in relation to her suffering, both physical and mental, and to the obligation that they have to respond to it.

As Vivian Bearing embarks on her treatment, we observe a series of encounters with medical providers which generate the material for analysing her experience and our own reactions to it. The possibilities for eliciting this personal response are strengthened by the dramatic device of having Vivian Bearing address her audience directly, allowing us a glimpse into her thoughts and revealing the subtle changes in her attitudes as the disease progresses. The audience is her only confidante and this serves to accentuate in our minds the loneliness of her journey.

She sets out on her travels through the medical world, very much the participant-observer-academic, commenting on the use of language by medical staff and quoting from

Donne, even using high-brow sarcasm to comment on the impersonal treatment she receives, as when she gives her name to a hospital technician as “*Lucy, Countess of Bedford*” and is taken seriously with the response “*I don’t see it here*”. But gradually, as her physical condition worsens she attempts to reach out to her doctors and we see the first signs of her need for contact with others. She asks Dr Posner: “*Are you going to be sorry when..... Do you ever miss people?..... What do you say when a patient is apprehensive, frightened?*” To which he replies: “*Of who?*” There follows a long silence after which Dr Bearing says: “*I just..... never mind.*” Finally, she finds solace in the warmth and compassion shown to her by the chief nurse, Susie Monahan. Though intellectually far from being her equal, and prior to her illness, unlikely to have been a conversational match for the uncompromising Dr Bearing, Susie alone demonstrates genuine interest and understanding for her patient. Indeed, she shows courage in tackling the issue of resuscitation and Vivian Bearing’s decisions with regard to end of life treatment, something which is normally the responsibility of doctors. But she is aware of their failure to have considered Bearing’s end of life treatment wishes and faces this difficult task, seeing it as part of her care obligation. Later she is also the only member of the medical staff to ensure that it is enforced.

For Vivian, with the realization that there will be no cure, escape into intellectualization becomes increasingly futile, since the purpose that it served has become irrelevant:

“ We are discussing life and death, and not in the abstract either. We are discussing my life and my death and I can’t conceive of any other tone. Now is not the time for verbal swordplay. Nothing would be worse than a detailed, scholarly analysis of erudition, interpretation, complication. No, now is the time for simplicity. Now is the time for – dare I say it – kindness. I thought being extremely smart would take care of it. But I see that I have been found out. Oh..... I’m scared. Oh God, I want..... I want..... No, no, I want to hide, I just want to curl up in a little ball.”

Vivian Bearing in the Film “*Wit*” (2001).

And so in such extreme circumstances, the ivory tower of the intellect is shown to crumble and what remains is a simple truth: that only kindness matters. Vivian herself, earlier in the scene, calls this “*corny*”, but admits that there is nothing more to be said.

The film ends with John Donne’s poem about death, which Vivian recited on several occasions in the film, but refused to hear from her friend and professor just before her death,

despite the solace that one might have expected it to offer. Instead Professor Ashford comforted her with a children's story and a simple gesture of affection. Against a final picture of Vivian's dead body we hear:

*Death be not proud, though some have called thee
Mighty and dreadful, for, thou art not so;
For those whom thou think'st thou dost overthrow,
Die not, poor Death, nor yet canst thou kill me.
From rest and sleep, which but thy pictures be,
Much pleasure; then from thee much more must flow,
And soonest our best men with thee do go,
Rest of their bones, and soul's delivery.
Thou art slave to fate, chance, kings, and desperate men,
And dost with poison, war, and sickness dwell;
And poppy or charms can make us sleep as well
And better than thy stroke; why swell'st thou then?
One short sleep past, we wake eternally,
And death shall be no more, Death thou shalt die.*

(From *John Donne: The Divine Poems*)[28]

“*Wit*” is a film about the personal meaning of terminal illness. It is not intended to be a documentary film about medical care. Its purpose is to encourage reflection about the personal meaning of death and dying, both from the point of view of the patient and the doctor and to this end, its use of drama is intentional [5]. It raises several themes, all of which are relevant to medical students, not only in terms of their professional training, but also in terms of how they will respond to patients at the end of life, both as formal caregivers who must learn to accept adverse outcomes in relation to their professional efforts and in a more personal sense, in reflecting upon the emotional impact that the death of a patient has for them.

Strategies for using the film “*Wit*” as an educational tool

The programme described in this paper was used with second year pre-clinical medical students from the English Division at the Medical University of Białystok, Poland, as part of the course in Psychology for Medicine. In the steps outlined below, an example is given of the

type of immersive learning exercise used to stimulate reflection among the students and promote awareness of the need for self-development in acquiring skills for the delivery of satisfying end of life care. A vital element in facilitating experiential learning is a precise formulation of what it is hoped to achieve through the learning process i.e. a statement of the goals of learning. The goals are set out in Table 1, together with a description of the learning activities designed to facilitate their achievement. These are organised according to topic.

Table 1. Themes raised in the film “*Wit*” identified as topics for discussion with learning objectives operationalised in the form of goals and proposals for learning activities designed to achieve them.

Topic	Goals	Learning activities
<p>I. Communication skills in medicine:</p> <ul style="list-style-type: none"> • Delivering bad news • Obscuring communication through the use of medical jargon • Discussing treatment preferences at the end of life • Medical examinations: ways of maintaining the patient’s dignity in different situations • Showing compassion and empathy 	<p>During the learning process students will have the opportunity to:</p> <ul style="list-style-type: none"> • observe examples of how bad news is delivered by medical personnel and to respond to these examples; • watch the experience of film characters going through meaningful and intimate life events in the presence of other students; • overcome embarrassment and gain confidence in discussing end of life issues; • listen to the views of other students concerning meaningful and intimate life events and learn to express their own; • have the opportunity to practise their ability to break bad news in a “safe” environment and to receive constructive feedback. 	<ol style="list-style-type: none"> 1. Watch the film “<i>Wit</i>” with other students as part of a group. 2. Immersive learning and skills practice through role play and workshop activities for breaking bad news to patients. 3. Small discussion groups to consider reactions to the main characters in the film (patient, doctors, nurse) in relation to specific scenes. Students receive worksheets with questions for guiding the discussion, prepared by the teacher. 4. Create and enact small group presentations based on what they have learned.
<p>II. Psychological aspects of serious illness:</p> <ul style="list-style-type: none"> • Cognitive and affective responses to terminal illness • Defence mechanisms and coping • Symptom management 	<ul style="list-style-type: none"> • understand the psychological needs of patients at the end of life; • consider their own role as future doctors in meeting these needs and build their confidence in their ability to do so 	<ol style="list-style-type: none"> 1. Read about and create a presentation for the whole class on different topics related to the psychological aspects of serious illness. 2. Small group discussion of different aspects of

<p>and patient wellbeing</p>	<ul style="list-style-type: none"> • reflect on their own motivation to become doctors and the extent to which this facilitates a psychological understanding of patients' needs; • reflect on how they are likely to respond to the death of a patient they have cared for. 	<p>death and dying raised in the film.</p> <ol style="list-style-type: none"> 3. Personal reflection task, guided by questions prepared by the teacher.
<p>III. The patient's experience of terminal illness:</p> <ul style="list-style-type: none"> • Suffering in terms of its physical, emotional, behavioural, cognitive and social components • Factors affecting the patient's experience of dying: 	<ul style="list-style-type: none"> • identify Kübler-Ross' stages in the preparation for dying; • understand the use of Vivian Bearing as the narrator in the film and the purpose that this serves in reminding the audience that it is a drama; • gain emotional insight into the patient's experience of illness • explore relevant palliative care topics identified in the film 	<ol style="list-style-type: none"> 1. Read about and create a presentation for the whole class on different aspects of the patient's experience of terminal illness, hospital/hospice care and dying 2. Relate specific episodes in the film to the Kübler-Ross stages 3. Small group discussion of different aspects of death and dying raised in the film.
<p>IV. Professional care issues:</p> <ul style="list-style-type: none"> • Looking after yourself as a medical student: • Defence mechanisms and coping 	<ul style="list-style-type: none"> • identify the problems and difficulties the medical personnel in the film complained about in the course of their work; • identify ways in which the medical personnel dealt with these problems in the film; • facilitate self-reflection on their own roles as future providers for patients who are near the end of life • understand their own ways of coping with adversity and stress; • develop self-care behaviours and understand their importance in helping to sustain a balanced professional and personal life. 	<ol style="list-style-type: none"> 1. Read about and create a presentation for the whole class on professional burnout 2. Evaluate and respond to samples of writing by junior doctors describing their first reactions to the deaths of patients. 3. Examine their own values surrounding death. 4. Write a reflective essay concerning the emotions that surround death and dying. 5. Collect and synthesize information from the internet and other sources concerning the experiences of junior doctors with death and dying. Create their own website for similar purposes.

Steps in the *Wit* film programme

1. **Pre-work:** before viewing the film, students were asked to read about a range of topics specified in the syllabus for the course in Psychology for Medicine, and to prepare multi-media presentations on them, lasting about 20 minutes. The student presentations were dove-tailed into the timetable in order to augment learning of the subjects studied. The selection of topics was intended to demonstrate the vital role that psychological factors play in all aspects of healthcare and to raise students' awareness of the need for a holistic approach to medicine. The topics included:

- I. Communication skills in medicine
 - the SPIKES protocol for delivering bad news - a six-step technique which focuses on appropriate communication, attending to, and managing the patient's distress (other aspects of communication skills are taught in a separate course)
- II. Psychological aspects of serious illness
 - stress and its relationship to physical and mental health
 - psychological aspects of pain
 - psychological adaptation to illness
- III. The patient's experience of illness
 - defence mechanisms and coping in relation to illness
 - psycho-social aspects of hospitalization
 - hospitalization: specific problems associated with children and patients awaiting invasive procedures
 - hospice care
 - the stage model of adaptation to terminal illness Kübler-Ross [29]
- IV. Professional care issues
 - burnout among medical healthcare professionals.

The presentations on these topics were didactic in nature and were delivered by groups of two/three students to the whole class over a period of about four weeks. Any discussion that ensued from the presentations was essentially information based. The teacher was present and available for clarification of any misunderstandings. She also highlighted the important features of the presentation and where appropriate, drew links with related subjects.

2. **Viewing the film:** on completion of the didactic part of the course and three weeks before its end, students watched the film “*Wit*” in one sitting (90 minutes) as a group. This was immediately followed by their participation in discussions which were designed to immerse the students in experiential forms of learning. This session required a doubling up of the normal time allocated to classes.
3. **Preparation for discussion:** after viewing the film, students were prepared for the small discussion groups to follow. It was explained that the goal of the discussion groups was to gain a better understanding of the experience that dying patients go through by reflecting on the four main characters in the film:
 - The patient: Dr Vivian Bearing
 - The medical doctors: Dr Harvey Kelekian and Dr Jason Posner
 - The nurse: Susie Monahan

In exploring their ideas about these characters, it was expected that students would clarify for themselves specific attributes that they considered to be of value in providing care for dying patients. The presumption was that having a clear conception of these attributes would help them to strive to develop specific attitudes and skills in their later clinical work.

Reaction to the film: in small groups students were asked to focus on specific characters in the film. They were provided with worksheets which contained an outline of the main questions they should consider in relation to each character. In relation to the patient, Vivian Bearing, the focus was on her experience of becoming ill, especially around hearing the diagnosis and the early stages of her illness when she is undergoing investigations for diagnosis. Students were asked to:

- note specific events or interactions that they found particularly striking, to say why this was the case and to record how these events made them feel;
- consider how Vivian Bearing reacts to the diagnosis and how her reaction might be interpreted in terms of defence and/or coping mechanisms;
- describe Vivian Bearing and the kind of person that she was;
- explain how Vivian Bearing’s personality affected the kind of care that she received;
- describe how she changed during the course of her illness and to identify the ways in which the film showed this;

- think of a person that they knew reasonably well, who had died. Did Vivian Bearing remind them of this person in any way? What were the similarities and differences? Was facing death easier for either of these people? What made it so?
- think about what or who had helped Vivian Bearing in the course of her illness and to describe some of the events in the film that showed this.

Similarly, the students were asked to evaluate the characters of the doctors and the nurse. They were provided with appropriate questions for the guidance of their discussion in small groups.

4. **Confronting their own reality:** students were provided with excerpts from the reactions of medical students reflecting upon their first experiences with the care of dying patients. In their small discussion groups, they were asked to consider these reactions and to relate to them from their own perspective.
5. **Feedback to the whole class:** students summarized the results of their small group discussions with regard to how the film:
 - helped them to understand how patients experience dying
 - helped to make them aware of ways in which the care of dying patients can be approached
 - affected their personal views and attitudes to caring for dying patients
 - affected their interest in learning more about end of life care.
6. **Reflective writing exercise:** students were asked to reflect on any of the issues raised in the film which had had a strong impact on them or to consider a person whom they knew well, who had died. They were encouraged to write a short essay or a diary entry setting out their thoughts and feelings about the situation and its circumstances. The class was asked to decide as a whole how they might wish to share these reflective essays; they were reassured that the wishes of students who do not want to share their writing with others, would be respected. This exercise was deemed necessary, not only as a way of consolidating the learning process and encouraging reflection, but because viewing the film had been upsetting for some students and the teacher wished to be available to offer support to students in need.
7. **Personal reflection tasks:** it was suggested that students might wish to consider the following questions privately, but were not asked to discuss them with the group unless they felt comfortable about doing so:
 - what do you understand by “suffering”?

- getting support and comfort: what kind of things are a comfort to you when you are stressed or anxious. Write them down.
 - how often do you reach for the things that comfort you? Do you need permission to be kind yourself? Do you drive yourself on, despite any difficulties that you face?
 - how do you think Vivian Bearing might be rated on this score?
 - what did Vivian Bearing have to comfort her as she went through treatment?
 - how successful were the strategies that she used to comfort herself? Why/why not?
 - what does this tell you about what most people find comforting?
8. **Extension Activity:** students were asked to identify a website resource that deals with death and dying from the point of view of medical students or junior doctors. Their task was to identify the purpose of the website, the type of resources it has offer, and They were then to meet again as a small group and to share the resources they had identified and to discuss what they had learned from them. They presented their findings to the whole class and compiled all the information gathered to create their own webpage which was made available to the other years of medical students at the university.
9. **Final evaluation:** students completed an evaluation of the film immediately following the performance, as well as reporting on their experience of participating in the class.

Some of the exercises in this section were adapted from: [5, 30].

Discussion and conclusions

Medical students in their second year of medical training participated in an extended session on end of life care as part of their course in Psychology for Medicine in the second semester of the 2016-2017 academic year. Prior to the module in which they watched the film “Wit” and participated in experiential workshop learning activities, they received formal instruction and made their own presentations on aspects of the course, which included healthcare issues related to stress, psychological aspects of serious illness, the patient’s experience of, and adaptation to, long-term illness, doctor-patient communication, as well as professional care issues such as fatigue and burnout. These classes were seen as providing the cognitive content of the course.

In order to provide a meaningful learning experience in the area of communicating bad news and raising students’ awareness of the issues surrounding the care of dying patients an

experiential learning class was developed. Film was chosen as a useful pedagogical tool to provide students with a meaningful immersive experience of end of life care, which generated emotional reactions and led them to reflect on situations depicted in the screenplay strongly connected to real life. Thus, in so far as it was possible, the exercise was intended to generate a form of experiential learning at the pre-clinical level of medical training. The variety of exercises outlined above were intended to give additional depth to this learning.

The main purpose of this paper was to describe the development of an active learning programme on end of life care for pre-clinical medical students. It has not yet been possible to analyse the students' reports of the learning experience in any detail and the results will be reported in a future publication. However, the majority of the class (60%) rated the film as "excellent or very good" and 45% as "good"; further, 55% reported that the experience of watching the film had been "extremely or very emotional", while 36% said that it had been "somewhat emotional". These findings suggest that in providing a form of immersive learning experience the film may be evaluated overall as a success, though interestingly, the evaluation reports are not as positive as those from medical students in the USA [6]. The results of the present study should be considered pilot data and further studies are needed to confirm these findings and determine the reasons, if any, for the less favourable reception among our students. It may be that different learning experiences pertain and that students used to more traditional forms of teaching are reluctant to engage in more active processes because of the personal risks involved. These include having to examine their own attitudes and values and immerse themselves in an affective learning experience for which they are unprepared. Teachers may also need to reflect on their own attitudes and ways of preparing students for these difficult tasks in medical practice. In the words of Vivian Bearing, teachers might well ask themselves: "*Did I say (to a student) 'You are nineteen years old. You are so young. You don't know a sonnet from a steak sandwich'. By no means.*" Students may also see psychology as a whole, as a "soft subject" of little benefit to their pre-clinical learning [31]. This resistance and avoidance of the non-cognitive aspects of medical education must be tackled so that engagement in more experiential forms of learning can be facilitated and attain its goals. Whilst direct clinical experience may be corrective with regard to these attitudes, it is important for teachers to know that in the early years of training students may be over-confident and/or unwilling to undertake learning in these aspects of the hidden curriculum.

Experiential learning is a cycle which allows students to explore and reflect on their personal views and reactions to stressful situations such as the care of dying patients [6]. This

strengthens their emotional resources and provides the foundation for confidence in the ability to provide compassion care in difficult circumstances. But the learning cycle takes time in order to allow for attitudes to change and for skills to evolve. We therefore recommend that experiential learning methods should be introduced at the pre-clinical level of medical training to sensitise students to concerns surrounding end of life care. The learning process should be extended throughout the whole of medical training building on previous experiences and adapting to newly encountered situations. The effect use of appropriately selected dramatic material in the form of film, as used in this study, can provide opportunities for students to master higher levels of thinking abilities leading to clinical competence.

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Death as a personal myth: deepening self-narratives and reducing death anxiety

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Unavoidable death anxiety

Psychological studies show that people are afraid of death regardless of such psychological variables as calendar age, biological sex, gender, education, place of residence, occupation and the related social and material status. The terror management theory [1] highlights death anxiety and analyses automatic behaviours that are strategies for reducing the terror of annihilation. In the development process throughout their lives, individuals learn that being a decent and moral person protects them from difficult circumstances. In childhood we are protected by our parents; at later stages of our lives – by members of the social groups to which we belong and which give us emotional and instrumental support. A high self-esteem developed through ethical actions constitutes a buffer against death anxiety and helps individuals deny their own mortality [2].

Empirical studies designed to test the terror management theory demonstrated that people try to distance themselves from everything that reminds them of their own mortality. To achieve this, they emphasise the lack of resemblance between themselves and elderly people, whose presence evokes thoughts of death [1]. Research derived the terror management theory proved that, when induced with death-related content, young people perceived the behaviour of an average elderly person as entirely different from their own [3]. Descriptions of the old people and self-descriptions differed widely, and correlation analysis showed that, when thoughts of death were induced in the subjects, their perception of old people was quite unfavourable. Meanwhile, elderly people responded positively if an old person seemed competent and did not show signs of ageing. The reaction was less positive if the old person behaved in an incompetent manner and appeared helpless or touchy.

Aged people are associated with death permanently and strongly. The strength of this permanent association is due to the Western culture, repressive towards death. However, not all cultures repress death, death-related experiences and mourning. Religions and philosophies

of the East – Buddhism, yoga and Confucianism, present in China to this day, represent different attitudes towards death. The Judeo-Christian tradition recognises angels who look after people. Those radiant creatures are sent by God to support people passing to the next world through the gate of death.

For those who were born there is nothing more certain than death. Similarly, the fear of death is the most common kind of fear. While the post-modern world offers numerous personal development and skills improvement courses, but apart from the Japanese not many people wish to take part in dying workshops. Also, no one but the Koreans makes sure to have the last photo taken as a subtle message for the bereaved: *This is the way I want to be remembered*. Preparations, if any, are limited to the making of the will, sometimes issuing instructions as to the burial and funeral arrangements. However, the most frequent style of passing away, not determined by the suddenness of death, includes leaving a mess in properties, a financial chaos and piles of useless documents. Instead of experiencing the process of mourning, which is essential to go through, the bereaved have to get down to hard, often physical work.

We believe that people do not have to experience panic and terror. We are inspired by the life story theory of personality, which emphasises the fact that people can tell stories of their difficult experiences, gaining insight into the meanings of their own lives. They can also think and talk about their own mortality, accepting the fact that their lives will inevitably come to an end. To include one's own mortality in the story of one's life is to capture or formulate its meanings. Thinking and storytelling deepens the individual's self-narrative. It decreases the person's sense of helplessness and death anxiety. Someone who usually wants more of what is here and now gradually turns into someone considering what is beyond the directly accessible sphere. This might not be the path for everyone to take, because a self-narrative poses a challenge. It is taken up by those who disregard the opinions of others and walk a lonely path to acquire one's own kingdom.

What is a personal myth?

Below we present three definitions of a myth as a certain cognitive and interpretative category. The first two approaches remain beyond the scope of our reflection, whereas the third precisely expresses the essence of the personal myth.

Jacques Lacan [4] used the term “personal myth” to denote the reconstruction of a past trauma embedded in one's memory. The individual does not remember the details of the traumatic event but reconstructs it, mixing facts with fiction to fill the gap in their memory and form the foundation of identity. Lacan's personal myth referred to neurotics by describing psychopathological features, but it can also initiate the narrative of a group or nation. A personal myth is neither false nor true – it describes reality from the point of view of the individual (or the group or nation) developing it through the desires and the cognitive-interpretative categories. Lacan emphasised that the content of a myth is individual and unique even if it is composed of phantasms referring to commonly known stories and characters. Personal myths differentiate the individual entities. We do not use this meaning of personal myth because our considerations do not include the issues of psychopathology. However, in our opinion it is worth emphasising Lacan's intuition of the identity-building meaning of personal myth. Without it, the identity and its characteristic depth cannot develop.

The second approach to the myth categories present in discovering and understanding comes from the philosophers of science who emphasised critical thinking. A myth acts against the truth acquired by rational and critical discovery. It substitutes the truth. It cannot be classified or verified. The content of a myth does not explain the reality, as do the questions leading to the truth, but reveal it. The beauty and charm of a myth cloud the mind and thinking.

According to Joseph Campbell [5], a myth enables self-understanding and setting the individual's life events in the context of culture and of other people's fates, which Jung considered to be the spiritual space. A myth as a cognitive category reinterprets the events in an individual's life, transforming it into an identity. Two decades later psychology of personality followed the inspiration that led Dan Mc Adams to formulate the concept of the life story theory of identity [6]. The individuals' narratives of their own lives are their identities, which can be described by means of the dimensions of *agency vs communality* and *decline/deterioration vs redemption/liberation*.

What is the self-narrative?

Theodore Sarbin introduced a differentiation between *I* and *Me*, extending the context of the *I* to include a narrative structure [7]. That differentiation was inspired by William James' deliberations of the psychological functioning of *I* [8].

The subjective *I* tells the story and, as its author, influences the course and form of the story. It tells the story of the objective *Me*. The objective *Me* is the main character of the narrative, acting and setting the story in a certain time. The *Me* develops the plot towards the future, sometimes spreads it on both sides, dips into the past or invokes ghosts of the days gone by, allowing them to hover above the current events like mist that floats low above a meadow only to disperse among the tree branches. The objective *Me* also plays the role of the persona, expressing his or her thoughts, feelings and moods. It is the voice of speaking consciousness.

The Dutch psychologist Hubert Hermans is the author of the influential concept of self-narrative [9]. The narrative, which is the individual's story, combines facts and elements of his or her imagination. Each narrative includes dialogues, and the events are organised by the time, space and characters. The individual talks about his or her identity through two main themes: heroism and love. The first is an expression of concern about the individual's development, whereas the second relates to the formation and strengthening of ties with others and nature or the environment. The narrative encompasses the *I*, arranges the individual experiences and reveals their meanings, which expose the individual's evaluation processes and emotional attitudes towards the things of importance to him or her. Hermans believes that everyone has many *selves*, and their voices resound from different positions [10]. At a particular time, one of the voices dominates over others. The complex dialogical *self* reflects the multiplicity of people of significance that the individual has met.

Paul Ricoeur considered the poles of identity, calling them *idem* and *ipse* [11]. *Idem* means permanence, whereas *ipse* refers to the content that varies over time. An individual has a name and an administrative identity number assigned by the authorities of his or her state of origin. He or she was born to specific parents and attended particular schools, developing specific skills and competences. However, the numerous permanent qualities describing the individual do not reflect his or her development and changes over time, as a result of which the individual is not identical at various stages of development. According to Ricoeur, the self-narrative ties the things that are permanent and those that vary over time.

The self-narrative has a temporal character. It includes the changes and stores fixed qualities. The self-narrative has no final conclusion because continues emerging throughout his or her life, telling his or her story or, to be exact, many stories. The narrative links the life's events and reveals their meanings. The more relationships it establishes and the deeper meanings it formulates or discovers, the better the particular person knows himself or herself. Identity crises revise the narrative often modifying it or creating anew.

The flexibility of the narrative is its strength, but in some situations the story falls silent. The experience of suffering breaks the narrative. Suffering intensifies the individual's sense of existence. Ricoeur aptly referred to the experience of suffering as the sense of existence to “to the quick”. The suffering person is an open wound – focused on the present, he or she does not include the past or future in the narrative. Suffering destroys the subject's intentionality directed towards the outside world and things other than the subject. It modifies the individual's activity, as enduring becomes more important than acting. Although suffering intensifies emotional expression, it takes away the words. The experienced blows are incomprehensible, which means that the person suffering them cannot tell a story that others could understand. Also, no one can share the story of someone else's suffering and therefore the story cannot be accepted by others. An individual discovers utter loneliness in the experience of suffering.

Ricoeur's bold theories met with resistance. It was pointed out that the intensification of experiences would force an entity to search for the meaning of suffering, as the only way to withstand prolonged suffering [12].

We believe that the resistance to Ricoeur's theories was due to the incomprehension of the foundations of his concept. Ricoeur did not conceal (or emphasise) the Protestant roots of his thinking and sad belief that evil cannot be eliminated from the world. The blows of fate undeserved by an individual cause suffering and constitute indelible evil. After many years, the philosophical discovery of narrative interruption inspired new trends in research into the self-narrative. Now we know that one's life story contains not only the motives, values, goals, turning points and actions, but also elements that the individual cannot fully understand or set in time and space. They have something of a mystery about them. They cast a shadow on clear narration, but as every shadow, they reveal the depth of characters and events. Lawrence A. Pervin points to their poignant character and specific emotional atmosphere [13].

Although the concepts of self-narrative differ as to their content and highlighted points, their common feature is the belief in the story that shape the person's identity. Through that story, an individual tries to understand himself or herself and the outside reality. The story is the path to self-knowledge and self-awareness as well as their expression. According to McAdams, only personal narratives express the entirety of human personality in an integral way [6]. The explanation of personality by qualities, dispositions, cognitive structures or motives – less complex, such as needs, or intricately organised such as a system of personal

plans or projects – is not sufficient to describe, understand and explain the personalities of individuals.

Two narratives: Jung and Kübler-Ross about death

Personal narratives tell the story of people's lives and actions. Most stories lack the reference to death and dying, which are features beyond the scope of the story. Only few narratives contain death-related themes, although the cultural myths through which an individual interprets himself or herself and his or her own life contained an account of the death of the protagonist. Death used to be as important as one's life and deeds. By living, acting and suffering beyond measure, heroes were always close to death. Karl Kerényi believes that the cult of heroes was a cult of the dead [14]. Ancient Greeks made the same sacrifice called *enagisma* to the gods of the underworld and the heroes. Death appeared under three names: *Moros*, *Ker* and *Thanatos*, only the last sounding familiar to the modern ear. *Moros* was the male form of *Moirai* (destiny). *Ker* is an individual death, always present by the person's side, the way the individual's daemon is directed towards life.

By forgetting the individual death, people lost the elementary knowledge of the fact that the more they fulfil their lives, the closer they are to death. By restoring the forgotten contents and including the individual death in self-narratives, it would be possible not only to reduce individual anxiety, but also free people's narratives of the cultural oppressiveness against death. All the more so since there are two outstanding narratives known to psychology – different, but focused on experiencing death and dying. One of them was told by Jung, and the other by Kübler-Ross. They both created these narratives through theoretical concepts, the practice of psychology and understanding of the personal life experiences.

Carl Gustaw Jung is interested in death as a personal myth of the self in its actualisation (development) and the reflection of this myth in other cultures and religions, which, in his opinion, are generated by the spirit the way civilisation is generated by the intellect.

Setting specific development task to an individual, Jung mentions the touch of death and dying alive. The task involves building a superego and actualising the self. The self is the individual's fullness of personality and fate/life. Whoever experiences the self, experiences the *psyche* to the full – its unconscious and conscious parts, by directing one's energy to the internal world, the way it was directed to the outside world in the first half of his or her life. Experiencing one's personality to the full changes the attitude towards death. Death ceases to

horrify to become a part of one's life process. An individual fulfilled in his or her own self returns to the collective psyche. This is the only meaning of death.

In his essay titled “Rebirth” Jung [15] lists and describes the changes of personality: its impoverishment, a change meaning an enrichment of personality, identification with the cult hero, the use of magic, changes achieved by appropriate techniques, a change in the internal structure and a natural change. The last two are related to the Jungian concept of the process of individuation. The change in the internal structure points to threats to the individuation process caused by the individual's identification with certain mental elements – persona, shadow, anima/animus, mana personality or an ancestor's spirit, to which Jung devotes the least attention.

The natural change is the basis for the idea of rebirth. We are reborn when the part of us that is old or belongs to the past vanishes or somehow dies. We turn into a different person. That new person in us is not a stranger – we have been together for a long time. The stranger predicted a larger and broader future personality. He or she is the soul mate – twin brother or sister. Jung clearly describes the internal friend as an immortal character. In the process of change, the immortal other in us becomes closer to the mortal individual. He or she only becomes closer because unification is impossible. The ego – the conscious part of the personality may treat him or her as an enemy, because the other, as an immortal being, appears strange and mysterious. If the ego sees an enemy instead of a friend, the inherently quiet voice of the self becomes hardly audible. The fear of death will scream so loudly that the individual will have no alternative but to switch from one extreme method to another to appease anxiety.

Jung appreciates the religions and cultures that do not repress thoughts of death and even look after the dead [16]. Christianity ceased to provide for the dead long ago. Masses for the dead, celebrated only in the Roman Catholic Church, are the only form of fulfilling the need to do something for the departed. Jung contrasts the Western world, which dissociated itself from death and cut the ties to the dead, with Tibetan Buddhism and Lamaism in his enthusiastic comment to *Bar-do T'os-grol* (Tibetan Book of the Dead), containing the essence of his concepts – the archetypes. His comments relate to death and the functioning of souls after death. The archetypal ghosts seen by the living in every culture are the spirits of the dead. The Tibetan text is in line with Jung–psychotherapist's conviction of the timelessness of the soul. Meanwhile, Jung–scientist recognises consciousness as an invisible manifestation of

the soul. Its voice can be heard when the soul formulates metaphysical statements present in ontology as well as theological reflection.

The Tibetan Book of the Dead is a record of the instructions recited by a lama over a dead person. It is impossible to instruct someone who does not exist. The deceased exists because his eternal soul is alive. For forty-nine days after death, the spirit of the deceased travels across *Bar-do*, which is a space of the mind. At the time of death, the deceased enters '*Chi kha'i Bar-do*. If the deceased recognises the radiant, empty being and pure, gleaming, clear and vibrant luminosity and realises what they are, he or she will remain in the state of perfect enlightenment. The first radiance is the deceased's own mind, whereas the second vibrant luminosity appearing simultaneously is the mind called *Budda Samantabhadra*. There is no ontological difference between the two minds, but they are seen and experienced as two entities. The realisation and understanding of the luminosities perceived means the state of *Dharmakaja* – the state of freedom and enlightenment.

If the deceased is unable to realise the meaning of the luminosities perceived, he or she will not break free from the world of given objects and will pass to *Chos n'id[kji] Bar-do*. This sphere, which of course is another state of the mind, is referred to as Bar-do of Experiencing Reality. The experienced reality is the reality of thoughts. Thoughts are forms, which take real shapes of the god of death, wreaking havoc and torturing the subtle body of the deceased. He is accompanied by evil goddesses and bloodthirsty deities. According to the Book, there are 28 goddesses and 58 deities. Even in the midst of horrible torture, the deceased can overcome the karmic illusions (thought-forms). When the deceased understands that he or she is the source of all these thought-forms, he or she will return to the original and atemporal state of '*Chi kha'i* appearing at the time of death. In *Srid-pa'i Bar-do* the deceased feels a strong desire to be alive and to be born, but he or she can also refuse to be reborn here. This state of mind (or another space) is referred to as the Bard-do of Looking for Rebirth. This is where the Judgement of the Dead is held. If the desire to be reborn prevails, the deceased will be drawn to the couple who will become his or her future parents.

The initiation routines recommended by *Bar-do T'os-grol* are intended to return the divine nature to the soul of the dead person. This means the discovery of the ontic identity of the human soul and the Deity. By experiencing itself and perceiving this experience, the mind returns to the original ontic unity (or identity) with the mind called Buddha of Eternal Light. It is described as a uniform radiance and emptiness continuing in a great beam of light, not knowing birth or death.

The vision of death offered by the Tibetan Book of the Dead brings the hope of salvation, although different from the Christian one. To be saved means to separate and break free from darkness and unconsciousness and to transcend everything that the individual considers the external and internal world, thinking that these worlds were “given” to him or her at birth. An individual can step on the path of salvation by changing the ordinary functioning of the mind directed to both these worlds by symbolic death. People have known and practised the rites enabling them to experience symbolic death for thousands of years. The symbolic death takes place during initiation in mystery cults. Its purpose is not to experience the “other world” but to change one's perception to reflect the reality. The mind reverses the perspective, and the initiate becomes free of the sin restricting the growth of his or her soul. Initiation of the living through mystery rites imprints a strong conviction in their consciousness that the soul brings everything into being. In *Bar-do* death is an initiation of the deceased to remind his or her spirit the being identical with the Deity.

We are struck by the noble character of Tibetan Book of the Dead and its respectful consent for the deceased to exercise the freedom of choice. The deceased are not being threatened or thrown onto their knees. They are taught how to recognise different mind states. If the deceased chooses to listen to the instruction, they will understand that they are the authors of the events in their lives – things did not just happen to them. The soul will break free from its animal nature, returning to the divine unity in radiant emptiness.

Elisabeth Kübler-Ross meditates about death [17]. The rhythmic sentences about passing and simultaneous continuing in memory hypnotise the reader. The description of the things here and now, and of the past evoked by imagination are strikingly sensuous. The eternity is reflected in a hummingbird, blue flowers, snowy mountain peaks and a curious salamander. In plants, animals and landscapes. It is the paradise of tranquillity which protects us all, unlike the paradise of abundance and innocence from the Genesis. There is a place for the Indians fighting for their lives and the greedy settlers destroying the world, although they all followed an illusion. The picture of temporal transcendence accepts all beings and dissipates the pains of the human life. The motionless, radiant continuance becomes close to the Christian paradise. To get here, people have to die.

The life-giving nature of death is expressed in the gift of change whereby an individual opens to everything that is new. The presence of death inspires thinking. Intuitively, Kübler-Ross might have reached for the idea mentioned by Platon, Heidegger and Arendt, of the thinking process not only in the cognitivist sense, which is against life, and excludes the

thinker from the world of people. Thinking is the most solitary act, as is death. However, the author's subsequent statements point to a different direction of considerations. Death can lead to the understanding of human nature better than any other existential event. According to Kübler-Ross, there is something permanent and relatively unchangeable, which the aforementioned philosophers would deny; alternatively, they would say: there is only one permanent quality in people. It is the thinking process, continuing as long as life continues.

Unlike the thought philosophers, Kübler-Ross can see an existential and practical dimension in death and dying. The sense of death is to understand the life given to the individual. Death is part of one's life. Jung's personal myth was the self. Its important element is death. For Kübler-Ross the personal myth was death. It formed a personal narrative. It was present during her difficult birth with an uncertain perspective of survival. But for her mother's efforts, the little Elizabeth would not have stayed alive [18]. She guided the young Elizabeth in her hitch-hiking journey across Europe destroyed [18]. It invoked intuitions, whispering instructions to the author, trying to save her small children after a plane crash [18]. It sent her dreams, anticipating the mystic sense of completeness, which Kübler-Ross experienced several years later, during a trip across South-Western America [18]. With such a self-narrative, can one choose an occupation other than work with the dying? The personal tales of death and dying supplement the self-narrative with a feature that is usually omitted and feared. The data collected by Kübler-Ross and other psychologists investigating the issues of thanatology open new possibilities for the narrative psychology.

The butterfly metaphor

A keen eye can see an adult dog in a sweet puppy, or a woman in a little girl, but it is difficult to see large trees in May bloom in the shiny conkers. It is even difficult to deduce the fact of life concealed in the brown shell. Who could guess without prior observation that a voracious, fat and sluggish caterpillar will turn into a charming, winged butterfly?

Psyche used to have a double meaning. According to Kerényi, the Greek word originally denoted the soul, and then a butterfly [20]. It may well have been the other way around, as colloquial words were given philosophical meanings over time, but what is more important, the double meaning cannot be expressed in another language. The semantic intuition of ancient Greeks captured the essence of transformation. An ugly or revolting thing conceals the beauty worshipped by Greeks. It also conceals a form so unlike the original one that it can

be considered something completely new – a new identity. However, the new identity would not be possible without the former entity. The butterfly was brought to life in light, air and motion once the caterpillar had ceased to exist. Death always evokes at least uneasiness. By including it in one's personal narrative, it is possible to appreciate the world, understand it, admire, experience and transform, which is a unique privilege. The completeness of identity and fate opens individuals to something completely new, which they cannot perceive or deduce from the forms and beings to which they are accustomed. This is what Gustaw Jung and Elisabeth Kübler-Ross tell us about. The fragile butterfly turns out to be indestructible.

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Obstetrician in the face of lethal genetic defects - palliative care in perinatology

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Introduction

Medical studies and residency training in gynecology and obstetrics still cannot find out about fetal diseases that are impossible to cure. Knowledge of proper maternity care in the perinatal period is particularly important in countries, that in some cases are forcing women to give birth to children who would die outside the uterus or if their first and last days of life would be fully dependent on medical devices. This paper will discuss the situation of mutual cooperation between obstetricians and primatologists in hospice care at the turn of the century and the legal situation of women concerning this case in Poland.

Historical view

The approach to the problem of caring for a woman during pregnancy, especially the complication that does not lead to its successful termination. First and foremost, it is important to know how early women learned about their own pregnancy and about possible complications. The first mention of a method that allows a woman to detect if she is pregnant appeared in ancient Egypt. Egyptians gave their urine to wheat and barley seeds for several days. If it sprouted wheat, it meant that a girl would be born if the barley was that the boy is coming to the world. As it turns out, in the 1960s scientists confirmed the reliability of these methods up to 70% [1]. Only external symptoms such as bleeding, pain or observation of inadequate gestational age of abdominal circumference may have suspected that pregnancy is not progressing properly. Only with the development of ultrasound diagnostics and laboratory tests of the patient's blood, the physician was able to anticipate future parents with a very high risk for postnatal survival. Unfortunately, most ancient societies did not have mercy on

children who were born with serious flaws that would not give them the opportunity to function independently. In ancient Greece and Rome, the killing and abandonment of handicapped and sick neonates was common and accepted practice. In these societies physical strength has been affirmed, so children were judged on their "fitness" to play the role they played in a healthy "athletic" state. Therefore, there was no place for people with disabilities and disabilities [2]. The killing of sick newborns was accepted, for example, by Aristotle, Plato or Seneca. In the oldest known gynecology treatise, Roman physician Soranus, who lived at the turn of the 1st and 2nd centuries, in the chapter for midwives, gives clues as to how to distinguish a healthy newborn from a sick person who must be prevented from furthering life [3].

A different approach exists in the Judeo-Christian tradition, in which the pregnant woman is particularly worshiped as well as perinatal and postnatal period. Numerous evidence for this thesis is found in the Old and New Testament. This philosophy is based on the premise that every human life was created by God, and as such must be protected [4]. In the New Testament, the role of children in society, whether they are healthy or disabled children, is often emphasized. The best example of this is the passage from the Gospel of Sts. Matthew [5]: "At that time, the disciples joined Jesus and asked," Who is the greatest in the kingdom of heaven? "He called the child, set them before them, and said," Truly I say to you, If you do not change and become like children, You will not enter the kingdom of heaven. So whoever humbles himself like this child, he is the greatest in the kingdom of heaven. And whoever receives one such child in my name, accepts me. »" Christians from the beginning gave this expression in practice, creating orphanages for orphans and hospitals, believing that caring for the weak is one of the principal duties of the Christian. Modern hospice movement is a continuation of this tradition.

Modern eugenic philosophers such as Peter Singer [6] justify the killing of neonatal and infant infants, citing historical data from the ancient pre-Christian world [7]. Singer emphasizes that quality of life has more value than life itself. Such views, influencing public opinion, justify the legalization of abortion in cases of fetal defects and also infanticide in some countries [8].

Nowadays

In the 21st century, in many countries, the law allows pregnancy to be terminated in case of fetal disability or disease. In most cases, it is not clear exactly how severe these

conditions should be [9]. Both legal regulations and the recommendations of medical societies defining the period of doing fetal ultrasonography, and in what cases and in which period of pregnancy is abortion acceptable, are different in different countries of the world. Renowned scientific journals publish articles promoting "euthanasia" of severely ill newborns and infants, but there are no reliable scientific studies on palliative care for the same patient population. This care is offered by physicians specializing in maternal and fetal medicine and neonatologists and they are responsible for preparing parents for the incubation of an incurable newborn baby. Most of the issues discussed in articles about neonatal palliative care involve non-qualification or cancellation of treatment in intensive neonatal intensive care units.

The impression is that modern medicine offers to terminally ill abortions, and to newborns "euthanize". This is not the case, because children who do not die immediately after delivery are often resuscitated and then persistent, ineffective, and costly treated in specialized hospitals. This attitude seems to prevail in Poland today, but some neonatal units have introduced procedures called Basic [minimum] therapy and refrain from resuscitation, protecting terminally ill infants from iatrogenic effects. There is no next stage, like to take a child home and to provide the family with palliative care in their place, although there is already a nationwide network of hospices for children in Poland.

The misunderstanding is that perinatal medicine, according to the general opinion, aims at early detection of a defect and to not allow to birth of an impaired or sick child. This is a very young, dynamically developing branch of medicine. Good quality ultrasound equipment and fetal knowledge are essential for development. The proof that the USG part of perinatal medicine is the most interesting, there are several thousands of publications about fetal ultrasonography on the Internet.

Ultrasound examinations of pregnant women are performed by obstetricians who are unaware of the potential for treatment of malformations [e.g. the results of surgical treatment]. Because of this, their most common suggestion after diagnosis of fetal pathology is abortion. Many of those malformation can be treated successfully in several Clinics in Poland or European countries, but parents usually are afraid to participate in therapy that seems to be high-risked and hard to bear.

Reality

In the prenatal period, much more often than after birth, pathologies that cannot be cured are recognized. That are mostly central nervous system defects [e.g., holoprocencephalia] or incurable chromosomal aberrations, such as trisomy 18 [Edwards syndrome] or rarely trisomy 13 [Patau syndrome]. Most prenatal consultants do not know that palliative care is available outside of pregnancy. Many times, women who, because of their worldview, do not want to stop pregnancy, despite the incurable disease of the child, are not understood by obstetricians. Many of doctors do not acknowledge that the birth of a child and saying goodbye to him/her is a desirable and best solution to these families. Such attitude of parents is treated as an expression of their backwardness and lack of modernity in decision-making. It is often the case that a lethal defect is recognized only in the late period of a normal pregnancy, when the abortion is not permitted under Polish law [abortion is legally permitted until the fetus is able to live independently outside the body of a pregnant woman].

That issue the palliative care should be in perinatology is worth to consider. Of course, the initial condition is to diagnose a fetus disease that cannot be cured, and to tell about this information carefully to parents. Parents should then be provided with the opportunity to act in accordance with applicable law. One of them is the proposal of home palliative care as a form of treatment where the child survives the perinatal period. If parents choose this procedure, it should be agreed with the neonatologists that the child will not be resuscitated and under intensive therapy, but if survived, will be discharged home. Only then there is possible to start home hospice activities. The principles of care are similar to those of older children and rely on the symptomatic treatment of respiratory, neurological, gastrological, craniological and other disorders in this group of patients as well as care and physiotherapy. The methods used are intended to provide relief rather than additional suffering [this means that painful surgeries that are routinely used in hospitals in neonates in life-threatening situations are dropped.] A physician, nurse, psychologist, chaplain, social worker and rehabilitator - members of the hospice team - develop and then implement an individual care program for the sick child and his family, solving all problems, not just medical ones. Children whose health is stabilized and whose family becomes independent in care are, after some time, discharged from the hospice under the care of a GP and possibly a team of nursing long-term care. On the other hand, families of deceased children are offered a mourning support program implemented by the hospice.

Based on many conversations with parents, we know that their first reaction to prenatal diagnosis is to deny the fact that a child is ill. They hope we are wrong, putting such an unfavorable diagnosis. By giving them information about your child's illness, you should

do it in such a way that they understand why you will not be able to cure it. Most children with lethal chromosome aberrations are also diagnosed with defects of various organs [such as the heart]. In other children, such defects can be effectively treated. However, in cases of chromosomal aberrations it is important to understand that, irrespective of the surgical correction of congenital malformations, cells with abnormal chromosomes can not be corrected. For this reason, even a successful operation will not change the bad prognosis of the child. Therefore, the exposure of the child to unnecessary suffering and stress related to surgery is medically unjustified. This would be an action motivated by the wishes of parents and doctors who prefer persistent therapy rather than the good of the patient. It is important that all doctors who give feedback to their parents take this argument into account and try to use a coherent language [10].

Summary

Under the Law on the Support of Pregnant Women and Families, „Za życiem" there is plan to publish three regulations that change the existing laws in the case. They relate to palliative and hospice care benefits, guaranteed hospital services and a list of medical devices ordered. The first of them introduces into the so-called „guaranteed benefit package” with perinatal palliative care. The benefit is to ensure the continuity and coordination of care for a pregnant woman who has had a fetal malformation. To benefit from perinatal palliative care, a woman will need to provide a medical referral to confirm a fetal malady. Due to the current legal situation in Poland and the tendency to tighten the rules on abortion, it seems very important for the hospital staff to increase awareness of palliative perinatal care.

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Stimulation fetus with sounds

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Introduction

Honestly, who does not love music? Music can make us smile, relax, fall asleep, or even remind us of something or someone special. Probably there are some of us who cannot stand music in some ways, but for most, music is a big part of our lives. Whether it's the music that we listen to on the way to work, while we workout, or the music we hear in a symphony or films, it can bring up our moods, tell us a story or even bring us down. Music has touched cultures all over the world since very early times in human history. However, how music can affect our health?

Many studies, in both physiological and psychological fields, have demonstrated the dual psycho-therapeutic effect of music: music evokes feelings and moods, can trigger subconscious mechanisms, helps to strengthen 'me' and serves as a bridge between the conscious and subconscious [1,2]. It can help to unlock repression and resistance, allowing for impulses and complexes which cause conflicts and neuro-psychical problems to surface on a conscious level, as well as through a cathartic process (tension-liberation). Music sends signals to the brain and to the limbic system, the part of the brain which holds mankind's most difficult feelings and instincts regarding an evolutionary phylogenesis of the entire cerebral nervous system [3].

Music has several health benefits including lowering stress levels, raising states of consciousness, changing moods, accessing different states of mind, developing the brain and is useful in meditation. Recent research shows that music can meaningfully reduce the perceived intensity of pain, improve workout motivation and endurance, enhance blood vessel function, relieve stress by triggering biochemical stress reducer or even help people perform better in high-pressure situations [1,2,3].

However, how music can affect the fetus? Now we know that unborn infant hears the sounds and even it can remember them after birth. For an unborn infant, music prepares the ear and brain to listen, integrate and produce language sounds later in life. Music helps create a wonderful bonding experience for mom and baby, reduce stress levels during pregnancy, enhance the stimulation of the unborn baby's growing brain, and improve sleeping patterns for a newborn baby. It is important to realize that exposing a baby to music in the womb means not only sharing your musical preferences but also allows the baby to use music as a way of connecting with his/her new mom [4].

The beginning of music therapy

The idea of music as a healing influence which could affect health and behaviour is at least as old as the writings of Aristotle and Plato. The 20th-century profession formally began after World War I and World War II when community musicians of all types, both amateur and professional, went to Veterans hospitals around the country to play for the thousands of veterans suffering both physical and emotional trauma from the wars. The patients' notable physical and emotional responses to music led the doctors and nurses to request the hiring of musicians by the hospitals [1].

Music therapy is a relatively young technique which was defined during the 1950s in the United States of America. It is a part of the behavioral sciences and is based on a scientific approach. Its main aim is to help clients use the emotional experiences of music to improve or enhance their level of physical, psychological and socio-emotional functioning. Increasingly, a music therapist works within an interdisciplinary team [4].

Nowadays, the area of the music therapy in medicine is unusually wide. It involves such medical disciplines like rheumatology, orthopedics, cardiological and neurological rehabilitation, oncology or even palliative care. The music therapy is also applied in the resocialization, to work with residents of institutions of the social welfare as well as in work with children and teenagers which school problems [2,5].

The therapeutic influence of the music on the psychological and somatic sphere of the human body is confirmed by numerous research. The examinations concerning the influence of the music on physiological reactions of the organism, most often concern changes in muscle tone, respiration system, cardiovascular digestive system and in many vegetative activities. Also, a positive influence of music therapy on the psychological sphere was

confirmed. Relaxation, reassurance, excitement or improvement of the mood are the exemplary effects of music stimulation [3]. Music therapy can reduce increasing psychopathological manifestations as fear and depression, improves the quality of sleep and eliminates a sleeping disorder. Appropriately selected music can affect an emotional state, lead to the psychophysical relaxation, and in consequences reduce pain. The influence of music on an emotional state is excusing by the stimulation of secretions of endorphins - hormones which are provoking the feeling of pleasure, satisfaction, and contain the feeling of pain [6].

It is said that music assists people through their lives. Contemporary research shows that this statement is not entirely obvious and true. The unborn infant can also hear the music. In the prenatal period, it is possible to investigate the meaning of the music both regarding the person of the expectant mother, and the unborn child. These two perspectives will be mutually overlapping each other because the period of pregnancy is a time of the biological symbiosis between the mother and the child. The prenatal period is a first phase in the psychophysical development of the unborn infant which is very important for the future well-being of the child [7].

Prenatal music therapy

Listening to music during pregnancy has a positive influence for both mom and baby. Also, the influence on the child is held indirectly - through the psychophysical condition of the mother. It means that mother's psychological well-being positively influences the fetus. During pregnancy, the woman's psychophysical state constantly undergoes through the significant transformation. It can cause the intensification of stress. It is important to provide the opportunity for pregnant women to relax and take care of their psyche [7].

The significance of the proper music selection during pregnancy relates to changes in the musical sensitivity of pregnant women. During the prenatal period a greater sensitivity to very low or very high, and to inharmonic sounds of the rapid and great volume. Sounds above 70 decibels and music performed too long (above 4 hours) are contraindicated in pregnant women [8].

It is important to notice that music can lower stress levels, and because of it muscle tones are reduced. It causes the relaxation and the improvement of the pregnant woman's state of mind. This phenomenon appears not only during listening to music, but also during singing, or playing on musical instruments [7].

Prenatal psychology

In the first half of the twentieth century, there was a conviction that prenatal stimulation of the baby through the verbal communication was not needed [9]. Recently, the prenatal period is said to be a crucial period of the psychophysical development as well as the first stage of communication between people [10].

The development of prenatal psychology and pedagogy and medical science has allowed being defined as a period filled with a variety of stimuli. There was also a child activity linked to the parental activity. Contact with the unborn baby in the prenatal period is critical because it lays the foundation for a future – the direct relationship between the parent and the child. The prenatal psychology emphasizes all aspects of the unborn infant, his parents and any connection between them [11].

What is very important to notice is the fact that, during the prenatal period, there is a rapid and intense development of the hearing organ. At about fifth month of fetal life, the fetus starts to hear, which allows us to say that at this stage the central part of the hearing organ begins to function properly. It is conditioned by the ability to respond to sounds coming from the inner and outer environment such as body movement, selected muscles, or heart rhythm. It should be noted that the fetal development involves the reception of sounds as well as the development of auditory memory [12]. The correct development of verbal communication between the mother and the baby is possible due to the child's perceptual abilities. The child through the fetal water hears the voice and through the already formed structures of the central nervous system remembers the vocal qualities of the voice: for example, the intonation and the accent [12]. The child in the prenatal period is focused on receiving all the stimuli: physical - food, sounds - auditory stimuli. The literature mentions that the child is more likely to learn the language spoken by the pregnant mother, as it recognizes the specific characteristics of a given language. Also, the unborn infant prefers high (feminine) to low (male) voices as they are more likely to pass through fetal waters. This does not indicate, however, a situation that only the mother should speak to the child. Both parents should be involved in the child's prenatal development [7].

Fetus's auditory system

In the moment of birth, the baby has a fully formed sense of hearing. Prenatal development of the child can be transposed into the embryonic stage that occurs up to the

eighth week of age and the fetal period from the 9th week of age to termination of pregnancy. At the fourth week of fetal life, you will notice the anlage of the labyrinth, which at the fifth week have already changed morphologically to form future parts of the membranous labyrinth. From about 37th day of pregnancy, semicircular canals begin to develop and are fully formed at the 22nd week of fetal life. Approximately in the 6th month of fetal life, the twisting of the cochlea worm starts to form and is fully formed about the half of the course of pregnancy. At the end of the 6th week, there are semicircular canals, scala media, auditory ossicles (their ultimate shape at the end of pregnancy) and the anlage of auricle with shapes individually. The development of the peripheral hearing organ - Corti's organ begins about 12th week of fetal life and lasts until the 21st week. At the 23rd week of fetal life, the membranous labyrinth is formed. The auricle is formed by breaking the nodi surrounding the ostium of the first branchial cleft. Up to the 3rd month of fetal life, the ear canal is formed, and in a 5th month, its light is formed. The tympanic membrane is already formed in about third month of pregnancy from the primary tympanic membrane. The tympanic cavity and the Eustachian tube develop with the passage of the Eustachian tube-tympanic membrane. The ossicles are derived from the skeleton elements of visceral. Their associations can be seen already around 2-4 week of fetal life [13].

Music for the mother

A large number of musical experiences employed around the world confirm how useful musical activities are in anti-natal courses: music can help the expectant mother to relax, contain her anxiety and reach a state of overall psycho-physical well-being [14].

Most women experience a variety of stress when confronting the emotional, physical and social changes that occur during pregnancy [15]. Pregnancy brings a series of changes with it which are not only physical but also psychological. The changes happen over the nine months and are sometimes accompanied by moments of anxiety, stress, fear and fatigue which can prevent the mother from experiencing this extraordinary moment in life in complete serenity [16]. Moreover, pregnant women experience concern over their baby's health and pending lifestyle change. It is not uncommon to experience a sudden change of mood due to the lack of comfort caused by excess weight, back pain, and limited mobility. That adds up to the fear of childbirth and the anxiety to see the baby's face and to check that he or she is healthy and everything went as expected [4].

Music can be a useful way to help an expectant mother to improve her emotional health. Because, during pre-natal music therapy sessions, the mother prepares herself for the birth of her child by getting used to listening to motor actions and reactions in response to her voice and music by listening to herself, her internal rhythms and the changes that are happening to her during the pregnancy. With specifically studied musical activities, future mothers can live in complete tranquility during the nine months, as well as learn some techniques which could help them during childbirth. This also allows them to go through childbirth in a state of complete serenity and awareness, ready and waiting to comply with the signs coming from their bodies and children [17].

Music for the baby

Prenatal music therapy also includes a series of activities which stimulate the baby and promote communication between the mother and the baby. During the long wait, music is a channel of communication, and numerous rhythmic and sound activities let mothers prepare for a balanced and serene emotional relationship with their children, as well as adequately stimulate the structural and functional development of the fetus's nervous system [18]. In fact, all stimuli present during the fetus's growth (internal and external sounds) contribute to the development of the sensory and acoustic pathways, as well as encouraging the structural and functional development of the nervous system. The music which babies like the most, however, is produced by the mother herself. Her voice: the tone and melody of the maternal mother's voice is a vehicle of emotions and feelings, a caress and a 'cuddle of sound', but it is also a way to tell the child that the mother is anxiously waiting for him/her, or perhaps that she is coldly refusing the baby [19].

Research on the developing fetus has proved the ability to receive different stimuli from the environment, which can be differentiating and responding adequately. The fetus recognizes and remembers sounds: acquires reactions based on the sound material. Although the ability to learn in the prenatal period is limited, the baby's body might produce simple conditional reactions already in the third trimester of pregnancy. In this phase, the unborn infant can learn the meaning of sounds and adapt to them [7].

Evidence for the existence of so-called prenatal memory is provided by numerous research during which children listen to the recording tape with human's heart beating. It turns out that these children develop better, cry less, gain weight faster, sleep better, breathe quietly, and get less ill. The sound of a beating heart, already known in fetal life, gives the child a

sense of continuity with prenatal life and increases the sense of security after birth [20]. The practical result of research conducts in the creation of the so-called prenatal lullabies. This is a collection of sounds heard by the baby during the fetal period, enriched with specially prepared relaxation music. The combination of heart beating, fetal noise, prenatal sounds, and soothing musical harmonies, calms down the baby and falls asleep easier [7,18,20].

However, what about listening to different types of music? It has been found that music affects the behaviour of the fetus [7]. Every type of music listens to by pregnant women increases the frequency of the fetal movements, during the intensification of the music pace. There is several research which shows that the best for the fetus is classical music [21]. This type of music usually includes a range of notes creating lullaby sounds which are desirable during fetal life. What is also important is the fact that when the pregnant woman wants to calm down and relax the fetus, she should listen to very low sounds between 1200 and 1500 Hz. The bassoon's sounds are strongly recommended by a specialist, especially those composed by Prokofiev. Chopin's, Debussy's and Schumann's compositions are also recommended [22].

At this stage, it is important to notice that the baby after birth remembers sounds that he/she listened to during the fetal life. There is a specific "imprinting," or encoding melodies listen to during pregnancy. If mother presents the same tunes after birth, which have been already known to the baby, it is possible to bring him/her peace and relaxation. For example, if the child has previously listened to Prokofiev's music, he or she will have problems to set up his/her interest in Bach or Beethoven music. However, hearing Prokofiev's songs with bassoon sounds, the child probably turns his/her head, stops moving, and starts to smile. It turns out that if some music pieces are listened to by the pregnant woman more often, the child will remember them and react to them after birth. Because the child remembers the prenatal impressions, there is a better chance of communicating with him/her through the same forms after birth, for example, calming the baby by adjusting to the same relaxing melody known to him/her from the prenatal period [7,23].

What's more, the songs listen to by a woman, according to her own preferences, may cause the reaction of the unborn baby – its quick or slow movements. The child's reaction depends on the type of music listen to by the mother. It might influence on the baby's future overall personality. For example, if a pregnant woman listens to soothing sounds and soft music, her baby could develop a calm personality. On the other hand, if she listens to music

that is loud and jarring, it could lead to an aggressive and anxious personality of her baby [18,19].

Singing during pregnancy

Music affects muscle relaxation through mental relaxation. During pregnancy, there are various forms of verbal activity that are directed to the child and during which women do not consider their state. One of such forms is singing. It is worth to notice that singing alone in pregnancy is very beneficial and valuable activity not only for the child but also for the mother and the relationship between her and the child [7]. It is indicated that mothers who sing are happier, calmer, relaxed, better coping with stress, and the changes that are during pregnancy are milder and easier for them to survive. Significantly, singing relaxes the muscles associated with speech production but also those associated with breathing - the diaphragm and abdominal muscles. The work of these muscles affects the increased oxygen flow in the mother's limb, which also translates into the fetus [7]. Remember that your voice changes during pregnancy. Hormonal changes are affected by this. The vocal folds may become thicker, and the voice may be down, and it is shameful that every woman should individually observe and monitor the possibilities during pregnancy and not force the discomfort.

Singing is also very beneficial for the baby. The unborn infant might calm down, get used to the contact with the voice they like, which is related to the functioning of prenatal memory. When an unborn infant listens to a mother's voice, songs are singing by her remembers them. At birth, they may also remember their traits that can affect a child's behavior. It is also a form of stimulation of the development of the central nervous system of the fetus because the condition for the reception of sounds is the working neural connections [12]. It is also a natural way to bond with the baby from the beginning of its life. This is another way of child's contact with a language spoken by its mother, and all those characteristics contain in this language. Singing can affect the baby's activity - lullabies can asleep and calming the baby [24].

Emotional bounding experience for future parents

During the prenatal period, the mother and the child are connected by simple and inimitable emotional bond. This relationship does not occur only on biological or hormonal pathways but also on psychological one. It should be emphasized that the forms of the contact

with the child be closely related. The emotional state of the mother causes the formation of chemical compounds in her body that are passed on to the baby. For this reason, stress is undesirable for pregnant women. The long-term cortisol levels, which is the side effect of the stressful situation, have a negative effect on the fetus. It is important to notice that the joy of the mother, as well as her expectation for the child, cause the baby's positive attitude towards the world later in life [25].

It is worth to emphasize that the positive attitude of the mother affects the development of the child's nervous system - the correct and complete formation of synaptic connections [20]. It is important that the prenatal period affects the child's personality. All mother activities about the child support its development [25] and affect the building of emotional bonds. It is suggested that the elements of emotional bonds during pregnancy are: the thoughts about the fetus as a separate being, the attempts to define its traits, and the contact with the unborn baby [26].

This third element, that is, establishing the contact is very extensive. It contains every activity of the mother and the father directed to the child: all conversations, singing songs, stroking of the belly, paying attention when he/she moves or trying to calm down [20].

The role of the father in creating a holistic parenting is also extremely important. Although the woman feels all the changes and is experiencing pregnancy while being physically involved, the future father should also attend this period, and be involved in it. In the literature, a term has been set up as the Participating Father, who has the attitude of helping a woman to prevail pregnancy in many aspects. Symptoms of this attitude should be a strong relationship between the father and the unborn child. The expectant father should contact his future descendant by talking to the pregnant belly, stroking and touching it, to intensify his bond with the unborn infant [23].

Summary

Exposing a baby to music in the womb means not only sharing your musical preferences but also allows the baby to use music as a way of connecting with his/her new mom.

Music and singing has a soothing effect on the pregnant mother and the unborn baby alike and contributes to a healthy and happy baby later in life. The positive vibes that you get from listening to music will create a prenatal stimulation that will help you to bond with your

unborn baby. It will enable to lower stress and anxiety levels and reduce any stress that unborn baby may feel in the womb.

Listening to music during pregnancy is said to increase the hearing capabilities and concentration skills of the baby. After a certain development, babies can perceive sound and react to it as well. The type of music you listen to while you are pregnant can influence the baby's overall personality. If you listen to soothing sounds and soft music, your baby could develop a calm personality. On the other hand, if you listen to music that is loud and jarring, it could lead to an aggressive and anxious personality of your baby.

Overall, there are many benefits for both mom and baby associated with listening to music during pregnancy — from early bonding and stress reduction to the encouragement of early brain development and improvement of a baby's sleeping habits. Listening to or even playing music during pregnancy is one of many proactive steps an expecting mother can take to ensure the well-being of an unborn baby.

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Sexuality in patients with terminal diagnosis

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Introduction

The process of dying is often associated with reducing your physiological needs to the minimum, the most important. Sexual needs are often overlooked as inadequate to the present state. No one is aware of how this sphere can affect the last days of a man by reducing pain and mental build-up. Sexuality is an integral part of the lives of most people. It is curious, how palliative care professionals, the physicians, nurses, social workers, chaplains and home health care, who comprise the interdisciplinary hospice team, could be so reticent, or absent, when it came to the subject of human sexuality [1].

The Scale of the Problem

Even if there is not so much data about patients who are undergoing palliative care, there appears to be a high spread of sexual dysfunction in this population [2,3,4,5]. Depends on disease, types, and frequency of sexual dysfunction in palliative care patients seems to be different [6,7,8,9,10,11].

More and more often terminal diagnoses are heard by young people who are still active but also have partners and sexual needs. Especially in that population sexuality in the last days of life exists and is undoubtedly an indispensable element of the process of dying.

Sex Life in Oncology Patients

Because patients with a diagnosed cancer are the best example of patients with incurable and soon-to-die illness, and it is common for patients who are still in the age of

sexual activity it is essential to look at this problem from this perspective. Cancer and its treatment affect sexuality in many dimensions. The body of patients is changing. From a well-known it becomes strangely - it looks, functions, and feels differently. Lack of the breast, stoma, scar, other traces of surgical intervention, alopecia is awkward in intimate contact. Patients notice less sexual performance, nausea, and vomiting, fatigue, depression or irritability, as well as doubts about their femininity or masculinity. The patient withdraws from his or her current sexual intercourse. It is possible that he will also experience changes in his relationship.

Illness is a challenge for couples, meaning that both partners are in strong stress. Most often, the strengths of the relationship are revealed when mutual care and support deepen the bond between partners. However, it may then happen that earlier unresolved conflicts will explode with increased force, increasing distances and mutual misunderstanding. The typical conversation may not be enough. It is worth to use the help of a psychologist, psychologist, to cope with this crisis. There is natural that both partners have different fears. The patient may feel uncertain whether he or she is still attractive. His/her partner may worry about his or her health, can be afraid that the touch is painful for the partner. A partner can feel that sex is not adequate when someone is struggling for a living and may be tired because of additional responsibilities such as caring for children, taking care of the household, providing a supportive partner and appropriate medical care alongside professional work and the tasks they have done so far. Return to active cohabitation is a gradual process. It can be different for both partners. Talking about their feelings, needs, and expectations in the new situation is a major step in this process that will reveal other ways of expressing and enjoying sex in two. In addition to the sincere and open conversation, the emotional and physical proximity of the partner/partner communicated by touch, hugging, stroking, embracing, kissing is of particular importance [12].

Sexual Dysfunction and Leukemia Treatment

Leukemia treatments, including chemotherapy and radiation, can cause physical and psychological problems that lead to sexual dysfunction in men and women. Chemotherapy side effects, like nausea and fatigue, can make patients too weak or disinterested to have sex. In the beginning, a person with leukemia will use all her energy to work on survival. Usually, when chemotherapy treatment ends, people feel better, and the desire for sex returns to normal. In men, chemotherapy or complications after a bone marrow transplant [graft-versus-

host disease] can cause low testosterone levels that result in a loss of desire and perhaps erectile dysfunction. In women, vaginal dryness is a common chemotherapy side effect and can cause painful sex. Radiation to the pelvic area or chemo can bring on early menopause. Graft-versus- host disease, a disease where transplanted cells can attack healthy patient cells, can cause a narrowing of the vagina. And it could not be surprising if in the patient more frequent yeast infections are developed; they are common during chemotherapy and can cause burning during intercourse. Chemotherapy can also bring on a flare-up of genital herpes or warts in people who have had them before. Chemotherapy side effects like changes in weight or hair loss may leave you feeling unattractive [13].

Communication about Sexuality

Attitudes of health care professionals may act as a barrier to the discussion and assessment of sexuality at the end of life. There is still a huge problem to medical staff to face their attitudes, beliefs, and knowledge with patients questions. I can also be uncomfortable with talking about sexuality with patients or with the idea that very ill patients and their partners may have sexual needs at this time. The experience of doctors during training and practice may lead them to believe that patients at the end of life are not interested in sexual life.

How often do we see a patient and their partner in bed together or in an intimate embrace? I can never have seen because the circumstances of hospitals and even hospice may be such that privacy for the couple can never be assured and so couples do not attempt to lie together. For the patient who remains at home during the final stages of illness, the scenario is not that different. Often the patient is moved to a central location, such as a family or living room in the house and no longer has privacy.

While this may be more convenient for providing care, it precludes the expression of sexuality, as the patient is always in view. Professional and volunteer helpers are frequently in the house, and there may never be a time when the patient is alone or alone with his/her partner, and so is not allowed for sexual expression. Health care providers may not ever talk about sexual functioning at the end of life, assuming that this does not matter at this stage of the illness trajectory.

This sends a very clear message to the patient and his/her partner that this is something that is either taboo or of no importance. This, in turn, makes it more difficult for

the patient and partner to ask questions or bring up the topic if they think that the subject is not to be talked about [14,15,16,17].

Summary

Although talking to a patient about his illness is not easy, it is essential to allow patients in the terminal state to be informed about the possibility of continuing or initiating sexual activity. Staff dealing with dying patients should bear in mind the difficulties that a palliative patient may face. In hospices, the provision of patient intimacy should be part of the core responsibilities of the staff. Patient continuing professional life, hobbies, physical activity, including sexual activity as much as possible can help to make the process of leaving the world easier. In all of this, doctors should not forget about the least cumbersome fight of the ailment and the pain of pain until the last days.

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Effectiveness of care for patients with bedsores in the Hospital of J. K. Łukowicz in Chojnice from 2005 to 2016

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Introduction

"Any idea - good or evil - starts only when we try to put it into practice."

Paulo Coelho "Veronica decides to die"

Bedsores have always been a problem when it comes to the care of the sick and the disabled. According to the European Pressure Ulcer Advisory Panel and National Pressure Ulcer Advisory Panel, a bedsore is a localised lesion of the skin and deeper tissue that usually appears on the proximal bone as a result of compression or a combination of compression and tear. A bedsore is also associated with some favourable or unclear factors, which importance has to be still clarified [1]. When the patients with bedsores or with patients endangered with bedsores are hospitalised, the special team for education, prevention, treatment of sores and bedsores has a great role to play - its task is monitoring, prevention, treatment and in-depth analysis of their occurrence. The team consists of nurses, a doctor, a nutritionist, psychologist and rehabilitator.

The importance of monitoring and reporting bedsores by nurses as well as taking appropriate actions are of utmost importance for the quality of a patient's care and the safety of nursing staff. Healthcare institutions subjected to external certification (CMJ Accreditation in Cracow and the ISO standard) monitor patients with bedsores. An in-depth analysis of the causes of bedsores and taking correct and preventive actions are indicated here. Such actions are more conducive to the introduction of modern solutions in the field of nursing management, the increase of competitiveness between individual health care institutions and above all a high level of a patient's awareness of the quality of nursing care. To assess patient's satisfaction if a service has

been carried out as intended, the following areas are distinguished:

- material dimension (appearance of the medical establishment - internal and external)
- reliability (performance is fair and according to the current rules and standards)
- speed and readiness to respond to patient's / client's expectations
- professionalism (care based on current knowledge and experience of nursing staff and based on postgraduate education)
- empathy (ability to feel the patient's needs) [2].

In health care units, where the patient's health and wellbeing are important, the quality of service provided must always be sought. A high quality should be a feature of the provided health services. Improving the quality affects the patient's satisfaction and also the employees' satisfaction. To gain the trust of patients and provide services at a high level, healthcare institutions should meet patients' expectations regarding quality regarding safety, competence, sensitivity, reliability [3].

Adapting care to the level which a patient expects depends on the standards at an individual medical institution. The essence of meeting expectations according to the standard is to focus on the desired level which strives for perfection with respectability and realism. According to the data from the United States, bedsores occur to bedridden patients ranging from 0 to 17%, to patients with a long-term treatment ranging from 0 to 17%, and in the case of emergencies ranging from 0.4 to 38% [4].

In Poland, there are data concerning the occurrence of bedsores to about 5-25% of hospitalised patients. Decubitus wounds are most commonly found in intensive care units, long-term care units and patients with post-traumas [5].

Based on the recommendations of the National Consultant in nursing for good nursing practice Safe Hospital - Safe Patient from 2011, it has been implemented to monitor adverse events in the Specialist Hospital of J. K. Łukowicz in Chojnice since 2011. Within the framework of the Good Nursing Practices Report, the following adverse events are monitored and analysed: Incorrect patient, Vascular infections, Patient's falls, Falling out of bed, a couch, a wheelchair, Pharmacotherapy, Remoteness, Bedsores, Other.

For this study, the study concerned the presentation of monitoring bedsores, and this problem has been dealt by the team for prevention, education, sores and bedsores care since 2004. Since 2005, prevention and treatment of bedsores have been monitored by the hospital.

From 2005 to the end of 2016, 12 conferences on chronic wounds, stoma, using a correct diet and prevention of infections were organised. There is a register of patients with bedsores and patients undergoing a preventive treatment against bedsores. There is a cooperation with external entities to which the patient is sent (care and treatment plants, hospices, Primary Health Care). Each patient is given a nursing handbook. Members of the team for education, prevention, treatment of bedsores take an active part in the preparation of tender specifications for specialised dressings. Once a month, they participate in the meetings of the Commission for hard-to-heal wounds and bedsores at the District Chamber of Nurses and Midwives in Gdańsk.

Cooperation with CMJ in Cracow established in the area of reporting bedsores for a program „Decubitus”.

To minimise the occurrence of bedsores and proper monitoring of them in the Specialist Hospital of J. K. Łukowicz in Chojnice the following action were implemented:

- forms of prevention, care and supply of bedsores wounds have been implemented
- exposing a patient to the occurrence of bedsores was originally assessed according to Norton's scale, but currently according to the Waterlow 's scale, which allows for a more thorough assessment and consideration of more risk factors.
- levels of bedsores are evaluated according to the Torrance's scale
- the standard of prevention against bedsores has been developed
- photographic documentation of bedsores has been implemented
- a bedsores registration card has been implemented (reporting once a month)
- nursing guidelines for prevention against bedsores have been developed
- a consultation card has been implemented, and it is conducted by the members of the team for education, prevention, care of bedsores wounds

In the hospital, information about bedsores is reported in a daily electronic report to the Deputy Director of Nursing. Every month linking nurses provide the team with data concerning the patients endangered with the occurrence of bedsores and patients with bedsores.

Every six months, a thorough analysis, preparation of conclusions and possible improvement area are made. Semi-annual analyses are presented directly to the interested people and also during the management meetings.

A semi-annual report is sent to the Director of the hospital.

The aim of study

The aim of the study is to present the effectiveness of care for hospitalised patients with bedsores in the aspect of work of the team for the education, prevention, treatment of wounds and bedsores, and nursing care in the Specialist Hospital of J. K. Łukowicz in 2005-2016.

Material and methods

The study material was the documentation at the Specialist Hospital of J.K. Łukowicz in Chojnice concerning: reports of bedsores monitored; Waterlow's scale sheets; Torrance's scale sheets. The research method was analysis of documentation.

Results

By fulfilling the objectives of the Good Nursing Practice project, the hospital implements the solutions in terms of equipment, eliminating technical barriers and organization to eliminate adverse events [6]. Apart from lifts, rollers for moving the patients and other facilities in the hospital, there are also special mattresses with a variable pressure which are used against bedsores, and their amount is shown in Table I.

Tab. I. Number of mattresses in individual ward (for the date 31.12.2016)

Ward	2010	2012	2013	2015/2016
General surgery	3	7	7	8
Cardiological	2	4	4	4
Neurological	8	9	10	10
Pulmonological	3	4	4	4
Internal diseases	2	7	10	10
Anaesthesiology and intensive care	7	8	8	8
Traumatic / orthopedic surgery	2	2	3	4
Otolaryngological	0	1	1	1
Ophthalmic	0	0	1	1
Urological	0	0	0	2
TOGETHER	27	42	48	52

Diagram 2. shows the number of patients taken to the hospital: endangered with bedsores when taken to the hospital, taken to the hospital with bedsores, patients whose bedsores began during the stay at the hospital, discharged with bedsores.

Figure 1 presents an analysis of the number of patients with varying levels of bedsores according to Torrance’s scale at the hospital in Chojnice over the years 2005 - 2016.

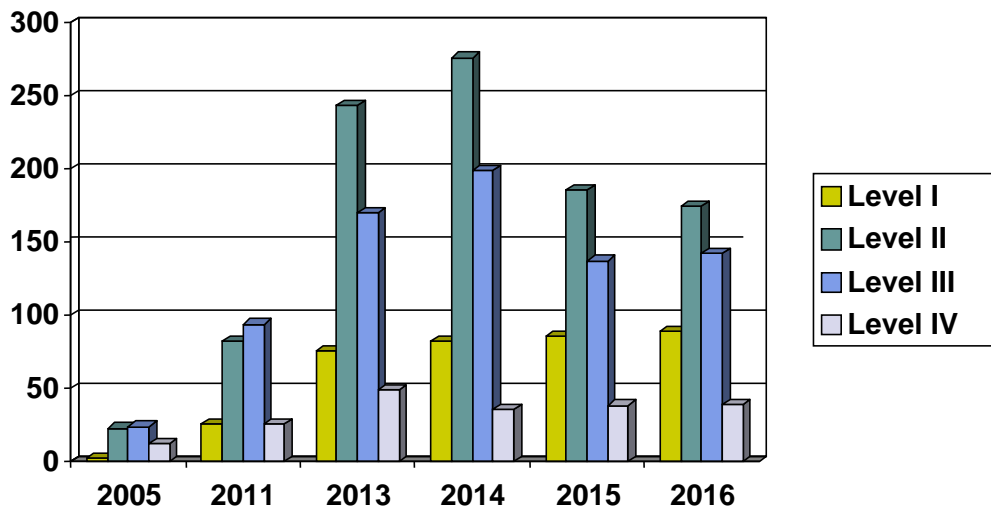


Fig. 1. The level of patients’ bedsores acc. Torrance’s scale at the hospital in Chojnice from 2005 to 2016

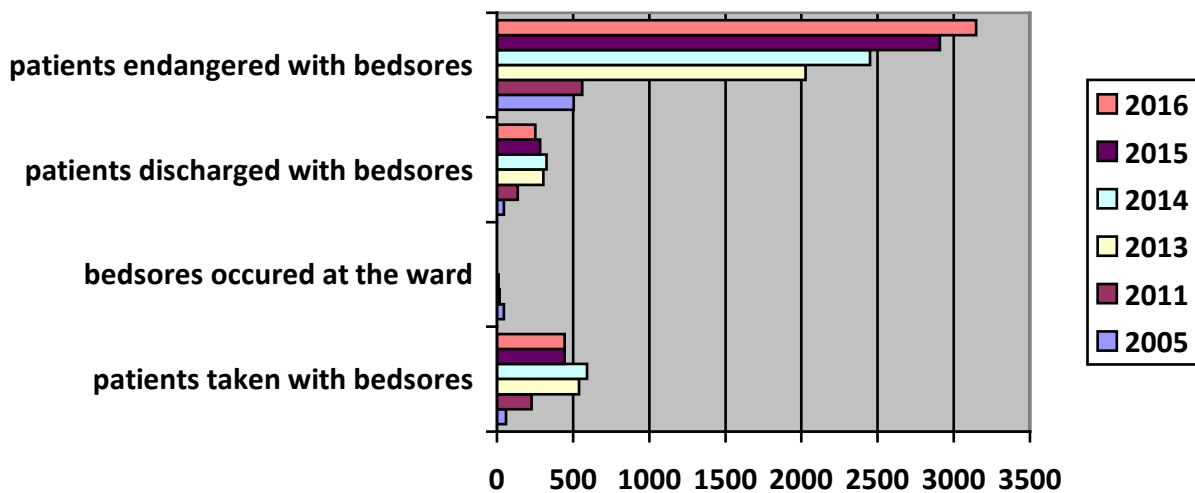


Fig. 2. Patients’ bedsores at the hospital in Chojnice from 2005-2016, divided into groups

The number of patients taken to the hospital with bedsores has remained at a similar level for 2 years (in 2015 - 445 patients and in 2016 - 444 patients). The number of patients discharged with bedsores is lower in relation to the patients taken to the hospital with bedsores. In 2005, 47 out of 61 patients taken to the hospital with bedsores were discharged with still existing bedsores, in 2013 538 patients were taken to the hospital and 304 people were discharged. The situation looked similarly in 2016 when 444 patients with bedsores came to hospital and 253 were discharged. Unfortunately, the number of patients at risk of bedsores is growing steadily. The indices of bedsores occurring at the hospital are shown in Table II.

Tab. II. Bedsores indices appearing in the hospital in 2011 - 2016

Year	Indicator for all the patients taken	Indicator for the patients at risk of bedsores
2011	0.13%	2.85%
2012	0.12%	0.98%
2013	0.10%	0.54%
2014	0.04%	0.16%
2015	0.03%	0.13%
2016	0.04%	0.16%

Figure 3 illustrates the level of bedsores acc. Torrance's scale which appeared during the stay at the hospital.

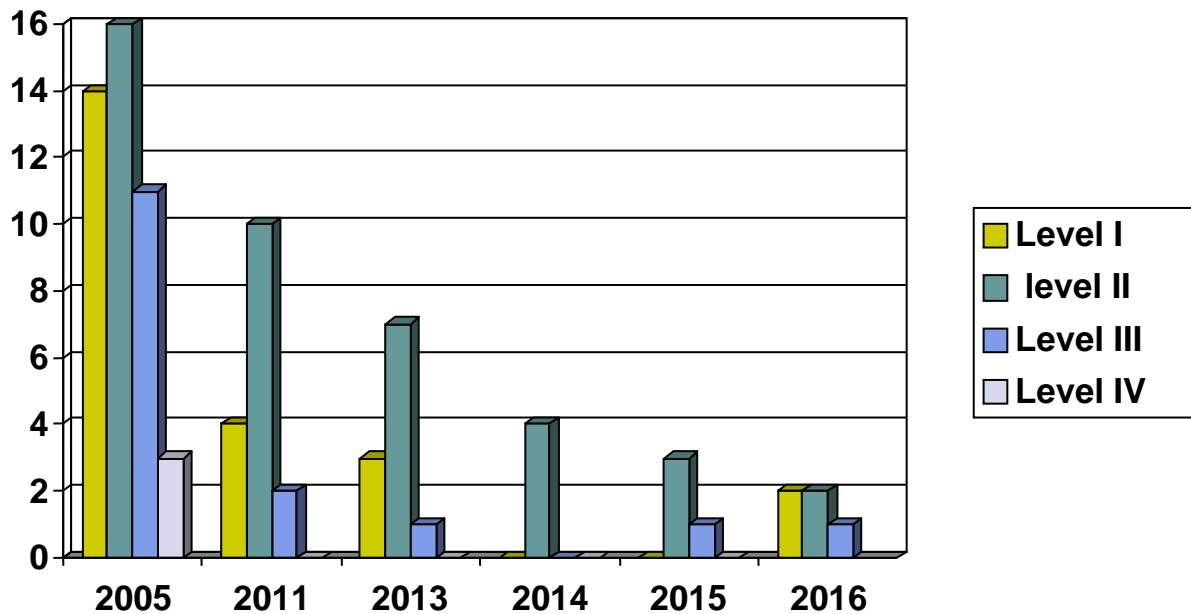


Fig. 3. Bedsores appeared in a hospital, grouped by the levels of Torrance's scale

Discussion

Analysing the reasons for appearing of bedsores and monitoring them in nursing is essential at every stage of patient's care starting from the admission room through a stay at the ward, participating in research and treatment, and preparing for self-care after leaving the hospital. Nurses/midwives in the interdisciplinary hospital team play a major role in the prevention, care and treatment of bedsores wounds. The role of the team dealing with these issues in every healthcare facility is extremely important. The benefits include continuous improvements in the quality of provided hospital care, patients' safety and staff safety, and above all meeting patients' expectations related to the problem of prevention, appearing and treatment of bedsores. The declining incidence of reporting the adverse events happening to patients and nurses, the patient's sense of safety in the hospital's management policy and the staff trust to their supervisors determine, according to Kózka et al. [7], a high quality of work by staff.

The results of the research show that the hospital in Chojnice annually receives an increasing number of patients exposed to bedsores. This fact is indeed related to the adaptation of assessment tools and the implementation of the program of good nursing practice. It may also be related to the increasing average age of patients admitted to hospital wards. This hypothesis about the hospital in Chojnice requires confirmation in the research. According to the Department of Social Research and Living Conditions, Central Statistical Office (GUS) [8], the number of people aged 65 and over treated at the wards in general hospitals is growing from 2074.4 thousand in 2010 to 2269.3 thousand people in 2013. The number of elderly patients who were given a health service by emergency medical services has increased by 15.8%. The number of patients taken with bedsores to the hospital in Chojnice has remained at a similar level for two years (445 people in 2015 and 444 people in 2016). The number of cured patients is increasing. In 2005, 47 out of 61 patients taken with bedsores to the hospital were discharged with bedsores, which is 77% of all the patients, while in 2016, 253 patients out of 444 patients taken with bedsores were discharged without improvement, which is 57%. This is still a high indicator that requires continuous, intensive work not only in hospital wards but also in the primary care and home care.

At the hospital in Chojnice, patients and their families receive information about nursing, treatment and prevention against bedsores. Excellent effects of the actions taken are the results of

the number of bedsores that occur to the patients in the hospital wards. In 2005, the number of patients who started to have bedsores when in a hospital was 44 and in 2016 only five patients. Of course, the type of a hospital ward is of great importance for the results. For example, the results of Dzikowska et al. [9] might be mentioned, wherein 2010 the bedsores were found to 76 patients at the ward of Internal Diseases and Geriatrics in a specialist hospital with a conservative profile. In 2011, the rate of bedsores of hospitalised patients in Europe was 17-27%, while to residents of nursing homes from 8.3 to 24.25% [10].

Similarly, as with the case of monitoring the infections, monitoring of bedsores requires monitoring, analysing, comparing the rates of bedsores occurring and the number of patients taken to the hospital with bedsores. It seems necessary to standardise the scales, standards and procedures used by each health care facility.

Conclusions

In the Specialist Hospital of J.K. Łukowicz in Chojnice, we observed an increase in bedsores detection when patients are admitted to the hospital.

The number of patients who have been discharged from the hospital with no bedsores has increased.

The indicator of bedsores which occurred during hospitalisation has decreased.

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Impact of nurses' religious beliefs on their job satisfaction

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Introduction

The process of professional development is an inherent part of overall human development. The implementation of all potential possibilities is a result of a natural drive to develop and reach our full potential.

Employment, in its current form, involves a bond to one's workplace, being dependent on one's employer as well as performing certain functions and services. Striving for professional development, we should take into account professions and specialties that to the lowest degree violate our personality or limit our desire for personal freedom. There is no type of work which has ever been assessed unequivocally by everyone.

Scientific interest in job satisfaction and its consequences dates back to the first half of the 20th century, and according to Bugdol [1] "Der Kampf um die Arbeitsfreude" by De Man published in 1927 was probably the first paper on this subject.

According to Quarstein et al. [2], Roethlisberger and Dickson showed in their studies in 1939 that high job satisfaction significantly enhanced employee productivity. The results inspired other authors to look into the issue more closely. As a result, job satisfaction has been one of the most intensively studied phenomena in management and organizational psychology since the 1940s [2].

According to Staples and Higgins [3], job satisfaction is most often interpreted as positive attitudes and feelings toward work environment and work-related duties. It is dependent on the balance between what we invest in our job (e.g. time, commitment) and what we gain in return (promotion, salary, development opportunities, relations with coworkers).

Schulz and Schulz [4] point out that lack of satisfaction occurs if considerable employee investment meets with low gains. Czajka and Szumski [5] believe that satisfaction

is also dependent on the extent to which the job meets the needs of an individual and how much it is in line with their expectations. Hellriegel et al. [6] consider satisfaction an outcome of the difference between what employees gain at work and what they believe they should gain.

Overall job satisfaction consists of several different factors. Therefore, according to Bugdol [1], the following types of job satisfaction may be distinguished:

- satisfaction with salary, motivation systems,
- satisfaction with relationships with superiors and coworkers,
- satisfaction with the company's market position,
- satisfaction with others' opinions of the company,
- satisfaction with the organization and the nature of the work.

Scientific reports on the role of religious beliefs in nurses' job satisfaction are sparse.

The aim of this paper was to assess the effect of nurses' religious beliefs on their job satisfaction.

Materials and methods

The study was conducted between 2010 and 2011, after approval No R-I-002/244/2009 was obtained from the Bioethics Committee of the Medical University of Białystok. We included 150 professionally active nurses. A total of 160 questionnaires were distributed, but 150 were used in the study. The study was preceded by a pilot study conducted in a group of 50 patients to verify the clarity of the statements included in the questionnaire.

The study used a diagnostic survey method using:

- The original questionnaire consisting of a general part related to, among others, age, sex, place of residence, education, place of work, seniority, post, specialization, self-assessment in terms of religiousness and its role in the respondent's life, as well as 17 questions concerning an assessment of job satisfaction, including: reasons for choosing the nursing profession; job satisfaction; job description; recommending one's workplace to others; pay satisfaction; assessment of relationship with patients, their families and superiors; potential desire to change jobs within Poland or abroad; a declaration of continuing working in the present workplace for another 10 years; an assessment of chances of finding another place of work; about the reasons for a possible desire to

change jobs; identifying emotional reactions related to selected factors associated with the performed work.

- The Quality of Life Enjoyment and Satisfaction Questionnaire /Q-LES-Q SF/- General Activities and Q-LES-Q – work, in accordance with Endicott [7,8]. The questionnaire consisted of two parts: Part I consisting of 16 items – “General Activities,” and Part II consisting of 13 items – “Work” [7].

The questionnaire was independently completed by a nurse by marking answers to each question on a 5-point scale: 1 point – very dissatisfied, 2 points – dissatisfied, 3 points – neither satisfied nor dissatisfied, 4 points – satisfied, 5 points – very satisfied [7]. The first part of the questionnaire assessed the last 7 days prior to questionnaire distribution in relation to a selected aspect of life. Question 15 concerned satisfaction with received medications. Respondents who did not receive any medications could omit this question. The scores on the first 14 items were summed to obtain a total raw score. The last two items were not included in the total score, but assessed separately. The total raw score ranged from 14 to 70. The total score was converted into the maximum percentage using a formula developed by the author: the difference of the sum of raw scores and the minimum score divided by the difference of the maximum possible number of points and the minimum score. The minimum raw score was 14, and the maximum raw score was 70. Thus the formula for a percentage could be formulated as raw score of 4/56 [7].

Part I – the lower the achieved score, the higher the dissatisfaction of the respondent. Part II - the lower the achieved score, the higher the difficulty in performing work, solving problems, making decisions regarding work, etc. [7].

Results

The study group included 33.3% of nurses aged 20-30 years, 32.7% aged 31-40, 32% aged 41-50, and 2% aged 51-60 years. Women and city dwellers dominated among the respondents (94.7% and 77.3%, respectively).

Individuals with an undergraduate education (54%) dominated among the respondents. Others completed medical vocational schools (20.7%), medical high schools (19.3%) or had a higher education, including nursing (4%) and other faculties (2%).

The nurses worked on different hospital wards, usually surgical (30.7%) and treatment (26%). The remaining respondents were employed on other wards (23.3%), outpatient clinics (18%), or did not mention their place of work (2%).

The seniority of the respondents ranged from 1 year up to over 30 years; 1-5 years reported by 36.7% of respondents, 6-10 years by 6%, 11-15 years or 16-20 years by 12.7% each, 21-30 years by 26.7%, and more than 30 years by 3.3%.

The vast majority of respondents (84.7%) declared themselves as believers and practitioners. A different opinion was expressed by 5.3% of nurses, and 10% had difficulty providing a clear answer.

More than half of the respondents (52.7%) reported attending mass once a week, 18.7% a few times a month, 12% a few times a year, 4% every day, 5.3% a few times a week, and 4% only during holidays.

The vast majority of respondents (76.6%) declared that their choice of profession was completely independent and thought out. The reason for 9.3% of respondents was a refused admission to other faculties/universities, and in the case of 6.7% their parents' decision. The remaining 7.3% of nurses were not able to provide an obvious reason for their choice of profession.

A large percentage of nurses (over 80%) were moderately or very satisfied with their work, including 49.3% rather satisfied, 35.3% rather satisfied, 4.7% very dissatisfied, and 4% rather dissatisfied. A total of 6.7% of respondents had difficulty answering the question.

Opinions on satisfaction with received salary were definitely negative. Only one in four respondents (24%) was satisfied with their salary. The opposite opinion was expressed by 77.7% of nurses, and 3.3% of respondents were not decided in this regard.

The opinions of nurses on relationships in the workplace varied significantly, however, positive opinions dominated in each category: Relationships

- with coworkers – assessed by 56% of respondents as rather good, 41.3% as very good, 0.7% as rather bad, and 0.7% of respondents did not provide a clear answer;
- with patients – assessed by 48.7% of respondents as very good, 46.7% as rather good, 0.7% as very bad, and 4% of respondents did not provide any answer;
- with patients' families - assessed by 60.7% of respondents as rather good, 21.3% as very good, 0.7% as rather bad, 17.3% of respondents expressed their doubts on this matter;

- with superiors – assessed by 66.7% of respondents as rather good, 27.3% as very good, 3.3% as rather bad, 0.7% as very bad, and 2% of respondents were unable to provide a clear answer.

The majority of nurses did not want to change their current job (51.3%). A total of 30.7% of respondents would definitely change their job, and one in five respondents (18.5%) was not able to express their opinion on the matter.

Almost every third respondent (30.7%) was not certain whether they would like to continue working in the same place for the next 10 years. This was confirmed by a total of 50% of respondents, whereas 29.3% were not certain.

The most common reasons for changing jobs included: low pay (44.7%), workplace liquidation (42.7%), redundancy (28.7%), poor working conditions (28%), lack of opportunities for professional development or conflict with the employer (20.7% each), family situation or contract expiry (20% each), conflict with coworkers (19.3%), and other unspecified factors (3.3%). Only 3.3% of respondents did not provide any answer.

The highest satisfaction among nurses was associated with good relationships with coworkers, a sense of meaning and importance of one's work, and the opportunity to help others. The highest dissatisfaction, on the other hand, was associated with low pay, social security benefits, difficulty finding a new job, poor or lack of promotion opportunities. Details are provided in Table I.

In the next stage of the study, we measured quality of life using Q-LES-Q. Summary measures were related to such aspects as: general activity, the use of medications, general satisfaction, and work. The first and the last quantity were determined based on several questions from the standardized questionnaire, while the second and third ones were standardized answers to one question. The values were presented on a 0-100% scale, where 0 stands for the worst, and 100% stands for the best quality of life.

As can be seen from the tables below (Table II and III), quality assessment in the category of work was better compared to the 'general activities' category (a mean of 73% and 59%, respectively). Every fourth person assessed their overall activity as at least 70%, and 83% in the case of the work category.

Table I. Influence of selected aspects of work on nurses' emotional reactions

Aspects of work	Emotional reactions			
	dissatisfaction	neutrality	satisfaction	considerable satisfaction
autonomy in making decisions	7.3%	35.3%	46.7%	10.7%
safety at work	11.3%	22.7%	40.7%	25.3%
good organization at work	13.3%	20.0%	38.0%	28.7%
good relationships with superiors	4.7%	15.3%	54.7%	25.3%
good relationships with coworkers	0.7%	10.0%	47.3%	42.0%
organizational culture	8.7%	35.3%	38.0%	18.0%
ease of finding a job within career field	34.0%	26.0%	24.7%	15.3%
promotion prospects	27.3%	29.3%	27.3%	16.0%
reconciliation of family life with work	10.0%	23.3%	40.0%	26.7%
opportunities for contacts with people	1.3%	12.7%	60.7%	25.3%
possibility to help others	1.3%	9.3%	54.7%	34.7%
possibility for shift work	11.3%	25.3%	43.3%	20.0%
opportunities for professional development	15.3%	21.3%	42.0%	21.3%
adequate remuneration	41.3%	12.0%	20.7%	26.0%
sense of job security	22.7%	22.0%	29.3%	26.0%
feeling a sense of meaning and importance of one's work	6.0%	16.7%	38.7%	38.7%
society's respect	16.7%	22.7%	41.3%	19.3%
respect and recognition from superiors	8.0%	32.0%	43.3%	16.7%
interest in work	2.0%	23.3%	47.3%	27.3%
social security benefits	38.7%	24.0%	24.0%	13.3%

Table II. Mean quality and satisfaction with life values assessed on Q-LES-Q

Components of Q-LES-Q	\bar{x}	Me	s	c ₂₅	c ₇₅	min.	max.
General activities	59%	61%	14%	50%	70%	20%	100%
Medications	56%	50%	21%	50%	75%	0%	100%
General satisfaction	63%	75%	23%	50%	75%	0%	100%
Work	73%	73%	12%	67%	83%	33%	100%

Table III. Maximum percent on Q-LES-Q

Maximum percent Q-LES-Q	Self-assessment of	
	General activities of the respondents	Work
10%	1%	
20%	4%	
30%	5%	
40%	19%	2%
50%	21%	2%
60%	29%	7%
70%	20%	21%
80%	2%	37%
90%	1%	25%
100%		6%

A total of 78% of nurses reported that religion has no effect on making new acquaintances. The opposite opinion was expressed by 6% of nurses, and 16% had no opinion on this matter.

A total of 14.7% of nurses were convinced that religious beliefs can affect job choice. The opposite opinion was expressed by 42%, and as many as 43.3% were unable to express their opinion on this matter.

According to 61.1% of nurses, religion has no effect on performing work-related tasks, whereas 24.8% were of the opposite opinion, and 14.1% had difficulty answering this question.

As can be seen from the table below (Table IV), no correlation was found between life and work quality and the opinion on the role of religion in the choice of nursing profession, or regarding religion as an obstacle in performing work-related tasks.

The majority of respondents (69.3%) declared that they never asked their patients about religion. An occasional inquiry about religion was reported by 17.3% of nurses, and

4.7% admitted that they always asked their patients about their religion, while 8.7% did not answer this question.

Table IV. Opinion on the role of religion in choosing profession in relation to Q-LES-Q

Q-LES-Q	Response						<i>p</i>
	yes		no		difficult to say		
	\bar{x}	<i>s</i>	\bar{x}	<i>s</i>	\bar{x}	<i>s</i>	
role of religion in choosing profession							
General activities	59%	16%	58%	15%	60%	13%	0.8879
Work	75%	11%	74%	12%	73%	13%	0.8129
religion as an obstacle in performing work-related tasks							
General activities	60%	12%	59%	15%	55%	15%	0.3598
Work	76%	10%	73%	12%	70%	13%	0.1620

The majority of patients who had contact with the surveyed nurses were Catholics (83.3%), followed by members of the Orthodox Church (40%), Jehovah's Witnesses (11.3%), Muslims (2.7%), and Jews (0.7%). The remaining 16.7% of respondents had difficulty answering this question.

As reported by every fifth nurse (23.5%), the patient's religion could affect decisions regarding treatment. This was denied by one in three respondents (35.3%); and one in four respondents (26.7%) was not able to present their views on the subject. Nurses' religion, on the other hand, had a much smaller impact on therapeutic decisions as it did not seem to affect the treatment of patients, as reported by 50% of respondents. A different opinion was expressed by 13.3% of nurses, whereas as many as 35.5% did not know how to answer this question.

There was no relationship between the numerically described attitudes using the scale and inquiries about patients' religion (Table V), about the role of patients' religiousness in making therapeutic decisions, or about the role of nurse's religiousness in making therapeutic decisions (Table VI).

Two-thirds of the respondents (68%) were not able to provide a list of procedures which would be affected by a nurse's religiousness, and 37.3% of nurses provided examples of such procedures relating to patients' religiousness. According to nurses, the most important procedures affected by a patient's religious beliefs included blood transfusion (58%), transplant (14%), abortion (8.7%), euthanasia (5.3%), and in vitro fertilization (4%). The most important procedures affected by a nurse's religious beliefs included blood transfusion

(18.7%), abortion (12.7%), euthanasia (7.3%), in vitro fertilization (2.7%), and transplant (2.7%).

Table V. Asking patients about their religious beliefs in relation to Q-LES-Q

Q-LES-Q	Patient's religion				<i>p</i>
	yes	no	sometimes	difficult to say	
General activities	54%	58%	59%	67%	0.3047
Medications	54%	56%	56%	63%	0.7949
General satisfaction	64%	61%	67%	73%	0.3319
Work	70%	74%	73%	70%	0.3495

Table VI. Impact of religion on therapeutic decisions in relation to Q-LES-Q

Q-LES-Q	Impact of religion on therapeutic decisions								<i>p</i>
	yes		sometimes		no		difficult to say		
	\bar{x}	<i>s</i>	\bar{x}	<i>s</i>	\bar{x}	<i>s</i>	\bar{x}	<i>s</i>	
patient									
General activities	59%	15%	58%	11%	59%	15%	59%	15%	0.9772
Work	73%	12%	74%	9%	72%	13%	75%	12%	0.8312
nurses									
General activities	59%	15%	60%	13%	58%	15%	58%	15%	0.7664
Work	74%	11%	73%	12%	73%	12%	73%	12%	0.9310

The question regarding procedure performance which may be affected by a patient's religious beliefs was very complex (it involved several different answers, most of which were marked by only a few respondents). The nurses were divided into two different categories: those able to identify procedures potentially affected by a patient's religious beliefs, and others (Table VII) in order to perform the analysis. No statistically significant correlations were found between the answers to these two questions and the level of quality of life. Mann-Whitney *p*-values quite clearly exceed the cutoff level of 0.05. Nurses' answers related to coping with the necessity to perform procedures against a patient's religious convictions were not clear. Most respondents had difficulty providing an unambiguous response (30%) or selected treatment discontinuation (29.3%). Other responses included assigning the patient to another nurse (9.3%), and performing the procedure against the patient's beliefs (2%);

whereas 29.3% of nurses claimed they would take another course of action, but did not provide any details in this regard.

Table VII. Ability to indicate procedures which may be affected by religious beliefs in relation to Q-LES-Q

Q-LES-Q	Ability to indicate procedures which may be affected by religious beliefs		<i>p</i>
	no	yes	
patient			
General activities	60%	58%	0.5414
Medications	56%	57%	0.9492
General satisfaction	65%	62%	0.4039
Work	72%	74%	0.6292
nurses			
General activities	59%	59%	0.7587
Medications	57%	54%	0.2920
General satisfaction	63%	63%	0.9344
Work	73%	74%	0.3522

Table VIII shows data on the relationship between the types of nurses' behaviors in a situation involving a conflict between the procedure and a nurse's religious beliefs or a patient's beliefs and quality of life. No statistically significant relationship was found in this regard.

Table VIII. Nurse's choice if a procedure is in conflict with religious beliefs in relation to Q-LES-Q

Q-LES-Q	Nurse's choice if a procedure is in conflict with religious beliefs										<i>p</i>
	assign the patient to another nurse		perform the procedure		treatment discontinuation		take another course of action		difficult to say		
	\bar{x}	<i>s</i>	\bar{x}	<i>s</i>	\bar{x}	<i>s</i>	\bar{x}	<i>s</i>	\bar{x}	<i>s</i>	
patient											
General activities	58%	14%	60%	17%	60%	15%	59%	12%	57%	16%	0.9458
Work	73%	15%	76%	5%	73%	13%	74%	10%	74%	12%	0.9796
in accordance with their beliefs											
General activities	60%	14%	65%	15%	57%	14%	60%	15%	57%	14%	0.5436
Work	72%	11%	78%	10%	74%	12%	78%	11%	72%	13%	0.3127

In the case of a procedure against a nurse's religious beliefs, patients were usually assigned to another nurse (38%). Other respondents would refuse to participate in a therapeutic procedure that was contrary to their conscience (15.3%), whereas some of the nurses would participate in the procedure (6.7%), and 11.3% would take another course of action, but did not provide any details in this regard. More than ¼ of respondents (28.7%) were unable to take a clear stance on this issue.

Discussion

In the present study, most nurses were moderately satisfied with their work. No correlations were found between work satisfaction and the opinion on the role of religious beliefs in the choice of nursing profession, or regarding religion as an obstacle in performing work-related tasks.

According to Rzewska [9], new challenges faced by nurses combined with low professional prestige, limited promotion opportunities, low pay, and lack of clearly defined competencies lead to frustration and dissatisfaction with work. Therefore, it is not surprising that nurses, more frequently than other Polish women, declare that they are dissatisfied with their lives and convinced that they are unable to achieve success in their professional career [9].

Mickiewicz et al. [10] included 103 palliative care workers in their study. They used their own questionnaire to assess job satisfaction, which covered 16 aspects of work identified by SHRM, as well as Q-LES-Q SF and MBI questionnaires. The study showed that palliative care workers were usually (85.2%) satisfied with their work.

A study by Zajkowska and Marcinowicz [11], conducted among nurses employed in primary health care in Poland and in the United States, showed that all surveyed American nurses were very satisfied with their work, whereas Polish nurses usually chose "I am rather satisfied" – 43 respondents (47.8%). In our study, a total of 59% of nurses assessed their current work as being in line with their education, 49% as responsible, and for most respondents (76.6%) the choice of profession was independent and thought out.

According to Wilczek-Różycka [12], stress in the workplace, work disorganization and specificity, interpersonal contacts associated with both helping patients as well as therapeutic effects on the patient's mental health may all result in a negative outcome in medical personnel. The consequences of close interactions and confronting suffering and

death as well as long-lasting stress can occur especially when physicians and nurses have difficulty coping with their own negative emotions, fatigue, and stress [12].

According to Pines [13], this is of particular importance due to the fact that work plays an increasingly important role in the life of modern man, as now the sense of the meaning of our lives is mostly derived from our work. Such appreciation of work seems a positive phenomenon, however it also has some negative effects when professional success becomes the primary value overshadowing all other values, and when stress caused by work leads to professional burnout [13].

According to Szulz [14], factors affecting the level of satisfaction from work include: pay, promotion, supervision, nature of work, coworkers, achievements, independence, recognition, and working conditions. Employees who negatively assess working conditions are less engaged in performing their tasks, whereas those who fulfill themselves at work and are satisfied perform their tasks more carefully, which further increases their level of satisfaction [14].

A study entitled "Work satisfaction 2009" [15], which was conducted for the fourth time by the Interactive Institute for Marketing Research (Polish name: Interaktywny Instytut Badań Rynkowych, IIBR) and the recruitment portal Pracuj.pl, showed that 63% of Polish respondents declared general satisfaction with their current workplace, although the level of job satisfaction among Poles has changed over the past few years. The percentage of people satisfied with their current workplace decreased by over 10% compared with data from October 2005. Only 14.5% of respondents believed that their position on the labor market would improve this year, and one in three (35%) claimed that their situation would deteriorate [15]. A smaller percentage of respondents assessed their chances of finding new employment positively, compared with 2007. Remuneration (97%) and job stability (96%) were the most important aspects of work for Polish respondents. The atmosphere at work, i.e. good relationships with coworkers (93%) and superiors (91%), was also an important issue. Professional development opportunities (88%) and possibility for promotion (83%) were also significant.

A study by Zielinska-Więczkowska and Buska [16], showed that the atmosphere in the workplace, considered by 92% of nurses as a very important determinant of job satisfaction, differs significantly depending on the type of ward [16].

According to 44% of palliative care workers [10], job satisfaction largely depends on the employer [10].

The fact that job satisfaction depends on the employer was confirmed by 31% of nurses from our study.

The vast majority (98%) of professionally active nurses included in the Zielińska-Więczkowska and Buska study [16] reported that their pay affects their level of work satisfaction. Further analysis showed that the impact of pay on work satisfaction did not vary depending on the type of ward [16].

A study by Czekirda et al. [17] indicate that nurses also show dissatisfaction with their monthly income and signal a deterioration in their financial status. Low remuneration can be a major source of stress in the work environment of nurses, as evidenced by Kimak et al. study [17]. This fact was indicated by 100% of respondents.

The above is also supported by Zajkowska and Marcinowicz [16], who showed that higher income, greater doctors' trust, more funding for educating patients, the possibility to improve qualifications, and generally better working conditions would allow Polish nurses to achieve full job satisfaction. Factors like the ability to communicate, the possibility to improve qualifications, and higher pay were indicated by American nurses [16].

In the study by Mickiewicz et al. [10], only 38.6% of respondents were satisfied with their pay. In the present study, the opinions of nurses on satisfaction with their salary were definitely negative (77.7%).

According to Lipińska-Grobelna and Głowacka [19], the level of job satisfaction depends on compatibility with a given job, which results in higher level of emotional and cognitive satisfaction. The authors [19] believe that those highly compatible with their jobs show high levels of satisfaction with work-related factors such as coworkers, management, type of work and working conditions, organization, opportunities for development, and remuneration, compared with those poorly or moderately compatible with their job.

However, in the present study, the nurses showed satisfaction with their current job, as reflected by the fact that they would not be willing to change their current job (51.3%), definitely would not want to work abroad (73.3%), and 50% declared their willingness to work in the same place in ten year's time.

Conclusions

1. Most nurses were moderately or very satisfied with their jobs and expressed a positive opinion on relationships between personnel, patients and their families.

2. No significant correlations were found between work satisfaction and the opinion on the role of religious beliefs in the choice of nursing profession, or regarding religion as an obstacle in performing work-related tasks.
3. Nurses derived the greatest satisfaction from good relationships with their coworkers, a sense of the meaning and importance of their work, as well as from helping people; whereas the issues of income, social security benefits, and lack of promotion prospects were associated with the greatest dissatisfaction.

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Burnout syndrome in parents of intellectually disabled children

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Introduction

According to Maslach [1-3], the burnout syndrome is “*a prolonged reaction to chronic emotional and interpersonal stressors, related to the performance of specific functions, usually, professional work; as a rule, it is defined as a syndrome of emotional exhaustion, depersonalization and reduced personal accomplishment*”.

The first definition of the “burnout syndrome” was given in 1974 by Herbert Freudenberger [4,5], an American analyst, who described it as “*the decline of a worker’s energy caused by being overwhelmed with problems of other people*”. The author [4,5] admitted that its occurrence was typical for professions based on working with people and he emphasized that it developed especially in people, whose work was socially and ethically responsible.

In the opinion of Aronson [6,7], the burnout syndrome is a state in which “*a person, who experiences it, feels no motivation, ambition and calling to one’s work (...), a state of fatigue, which can be caused by many different things*”. On the basis of the works of Buchk and Hackenberg, the author [6,7] prepared a list of the syndrome’s features - including fatigue, which he recognized as the main feature.

In the reference literature [6-9] the symptoms of professional burnout syndrome are divided into three categories:

- *physical* – lack of energy, chronic fatigue, weakness, susceptibility to accidents, tension and cramps in neck and shoulders, back pain, change of eating habits, change of body weight, increased susceptibility to colds and viral infections, sleep disorders, nightmares, increased intake of medicines or alcohol in order to level physical fatigue
- *emotional* – feeling of cold, helplessness, hopelessness and lack of perspectives, uncontrollable crying, dysfunction of emotion control mechanisms, feeling of

disappointment, sense of emotional emptiness, excitability, feeling of emptiness and despair, loneliness, discouragement

- *mental* – negative attitude towards oneself, one's work, one's life; surfeit, development of a disavowing attitude towards clients (cynicism, disrespect, aggression), loss of self-respect, sense of one's own inability or lower value, breaking relationships with clients and colleagues.

The professional burnout syndrome was distinguished by Maslach [2] in her research conducted among workers practicing social professions, and she recognized it as a specific syndrome occurring in people working for other people, staying in direct interpersonal relationships with them. As the components of this syndrome she recognized [2]:

- **emotional exhaustion** – the central dimension, the most noticeable and experienced in a team, a feeling of extreme exhaustion, being burdened and emotionally exploited, a feeling that one's emotional resources are extremely depleted and there is no more willingness to act. The person becomes irritable and impulsive, he lacks joy and is sad. According to the latest definition, the author distinguishes exhaustion as a sense of loss of emotional and physical strength
- **depersonalization** – a negative, insensitive, heartless, objective and distanced attitude towards other people, remaining in dependent interpersonal relationships (patients, students, wards, etc.). Today, Maslach calls it dimension cynicism, and it is manifested in coldness, distance or indifference, both in interpersonal relationships and in relation to one's tasks
- **reduced personal accomplishment** – understood as lack of professional satisfaction, reduction or loss of sense of one's own professional competences, but also no success at work. Currently, the author defines this element as inefficacy and it is understood as losing confidence in oneself, one's abilities and skills.

Based on Maslach's theory, Golembiewski [10,11] constructed an eight-phase model of the professional burnout syndrome:

- Phase I – initial state – low level of all dimensions (the syndrome does not exist)
- Phase II – high level of depersonalization, low level of emotional exhaustion and personal accomplishment

- Phase III – high level of personal accomplishment, low level of depersonalization and emotional exhaustion
- Phase IV – high level of depersonalization and personal accomplishment, low level of emotional exhaustion
- Phase V – high level of emotional exhaustion, low level of personal accomplishment and depersonalization
- Phase VI – high level of depersonalization and emotional exhaustion, low level of personal accomplishment
- Phase VII – high level of emotional exhaustion and personal accomplishment, low level of depersonalization
- Phase VIII – high level of all dimensions (the most dangerous phase).

Each phase [10,11,12,13] shall be considered in three dimensions and two degrees of severity: L – low, and H – high. Phase I – low level of burnout in all dimensions. Phases II-VII – average level of burnout in all dimensions, and phase VIII – high level of burnout in all dimensions.

Kamrowska [14] describes the source of burnout syndrome in three dimensions:

- **individual:** so-called favourable personality traits – low self-esteem, defensiveness, reliance, passiveness, perfectionism; sense of external control, irrational beliefs, low sense of remedial efficiency, specific type of control consisting in avoiding difficult situations,
- **interpersonal:** between workers and patients – emotional involvement between superiors and co-workers, interpersonal conflicts, competitiveness, lack of mutual trust, disturbed communication, verbal aggression, mobbing, intended or unintended contribution of the employer to lowering the value of employees, e.g. questioning their competences and blocking their professional activity,
- **organizational:** institutional goals in conflict with values and norms recognized by the employee (e.g. no time for family life), stressors related to the physical environment (e.g. noise, stressors related to the way of performing work, e.g. haste, monotony, working in the evening and night), stressors related to the employee's functioning as a member of the organization (e.g. no possibility of expressing one's own opinion on significant questions), stressors related to professional development (dissatisfaction with one's carrier, no possibility of

professional development, lack of job stability), management style maladjusted to facility tasks and employees needs.

According to Kamrowska [14], the American Psychology Association (APA) distinguishes several phases of professional burnout syndrome process:

- *honeymoon* – a period of being excited about work, full satisfaction with professional achievements, energy, optimism and enthusiasm,
- *awakening* – a period in which one realizes that the idealistic assessment of one's work is inadequate, he works more and more and tries to keep that idealistic image undisturbed,
- *roughness* – implementation of professional tasks requires more and more effort, there also occur problems in social contacts,
- *full-blown burnout* – complete physical and mental exhaustion develops, there occur depressive disorders, feeling of emptiness and loneliness, willingness to free oneself, escape from work,
- *rebirth* – time of healing the “wounds” caused by the burnout.

The reference books [15,16] indicate diversity of the burnout syndrome symptoms. In the opinion of Frenkler [16] these are: aversion accompanying going to work, constant complaints about unwillingness to work or about overwork, sense of isolation from the world, seeing life as being hard and dreary, increasing number of negative cross-overs in contacts with clients, irritation, negation, irritability, frequent diseases with unknown causes and thoughts about escaping and committing suicide. According to Barański [15] the symptoms are: physical fatigue, somatic and functional disorders, outbursts of anger and irritation, periods of idleness at work, initiating conflicts at work, escaping from decisions, change of behaviour – abusing alcohol, drugs, lack of a sense of identification with the profession.

Pines [9] emphasizes that the phenomenon of burnout may be the basis for the development of certain disease entities (e.g. depression or addictions) and it has to be differentiated between e.g.:

- *so-called “daily stress”* – the burnout syndrome treated as a specific psychological reaction in response to chronic stress related to the type of work/occupation
- *mobbing* – the differentiation is supported by a lack of psychological profile specific to the burnout syndrome

- *depression* – the differentiation is supported by the fact that people with the burnout syndrome may function very well in situations outside their professional environment, whereas, depressive disorders refer to all spheres of life.
- *chronic fatigue* – the differentiation is supported by the fact that after taking some rest, the person feels better, whereas, in case of the burnout syndrome, each contact with the situation that caused it, release the symptoms. Tired people often have a sense of fulfilment, success, whereas the “burnt-out” feel only defeated.

Numerous researchers dealing with the professional burnout syndrome pay attention to the fact that the same phenomena occur in people taking care of the disabled.

However, most researchers dealing with the burnout syndrome [1, 2, 14, 16-24] mostly focus on the burnout related to the professional work, and only some of them refer it to the family situation.

In the opinion of some authors [25-30], the prolonged need to take care of a family member, who is chronically ill, may result in distress and cause occurrence of the “burnout syndrome”, which is different from the professional burnout syndrome, however, its causes, process and consequences are similar.

According to Dąbrowska [31], Sullivan, who is considered to be a pioneer of the above mentioned researches, as in 1979 she initiated the discussion on the burnout syndrome in the context of families. In her studies, she dealt with parents of autistic children and she stated that taking care of a disabled child for a long time lead to a sense of loneliness, isolation, hopelessness and losing strength [31]. She saw the main cause of the burnout syndrome in no breather and in the need to take care of the child constantly, and in her opinion the symptoms of the burnout syndrome in parents [31] were: loss of family contacts and relationships, no interests, resignation, hyperactivity, dissatisfaction with one’s situation, negative feelings toward the sick child, lower assessment of child’s development, increased fear level related to stress, sleeplessness, headaches, gastrointestinal tract disorders and cardiovascular system disorders.

Pisula [1] presents the view that the cause of occurrence of a sense of “strength burnout” in parents is a lack of progress in child’s development but also the fact of not getting “*support, adequate therapeutic or educational services, etc.*”

Referring to the results of the English scientists’ studies, the author [1] emphasizes that as a result of long-term stress and a sense of “strength burnout” in mothers there took place “*strong deterioration of their health state, intensification of such ailments as: diabetes,*

pulmonary emphysema, hypertension.”, therefore, it is very important to “*provide the disabled child’s mother with mental support in situations of stress, exhaustion and discouragement.*” [1].

Care of a seriously ill, disabled child contributes to the development and strengthening of anxiety and a sense of threat in the child’s parents/guardians, caused e.g. by disease exacerbation and difficulties related to the child’s treatment. The parents get mentally exhausted, they experience numerous breakdowns and their faith in the ability to make effort gets weaker [1].

The strength burnout syndrome also occurs in teachers, who decide to work with the disabled, including e.g. people with autism, which was described e.g. by Sekułowicz [32].

In the opinion of Maciarz [33], the strength burnout syndrome occurs most often in single mothers, who are overburdened with responsibilities and are not supported by their close ones.

Also, Siek [34] agrees with the above, stating that mothers of disabled children “burn out” as a result of severe stresses, which worsen the functioning ability of their mental apparatus: they experience depressed moods, show reduced sense of security, their faith in themselves becomes weak, the activity of self-defence mechanisms intensifies. Long-term load with stress results in increased level of anxiety, sense of guilt and grudge and tendency to aggressive defence, i.e. irritability and indirect or verbal aggressiveness, which is more intensive than in women of healthy children [34].

The comparative studies, conducted by Siemiańska [35] in a group of parents having children with leukaemia, provide the results concerning characteristics ways of dealing with stress, which are different in case of fathers and mothers. The author showed great difficulties for fathers to reshape the meaning of the situation, to redefine it. Despite potentially higher capacity for such actions in an intellectual dimension (manifested in different dimensions), in case of their own child’s, sickness, helplessness of fathers was much greater, as opposed to mothers, who dealt with the situation more actively and efficiently. The author claimed that the difficulties in redefining the situation by fathers were based on several factors, which are: relatively stronger feeling of disease by a father, low level of knowledge of the child’s problems, their causes, prognoses, forms of help, but also greater readiness of mothers to undertake care actions, conditioned biologically but also by cultural division of roles, education, social expectations [35].

The aim of this study was to assess the rate of the burnout syndrome in parents of children suffering from intellectual disability.

Methods

The consent of the Commission on Human Rights in Biomedicine of Medical University of Białystok no. RI-002/432/2010 was obtained for the research. The research was conducted between October 2010 and October 2012.

The research included two groups: group I consisting of 108 mothers and group II consisting of 108 fathers.

The fundamental research was preceded by the pilot study in groups of 30 parents, which allowed to verify the clarity of statements from questionnaires and develop a final version of the author's questionnaire and the Questionnaire on the strength burnout syndrome in parents, based on the standardized Questionnaire on the Burnout Syndrome (MBI – Maslach Burnout Inventory) in the Polish adaptation of Pasikowski [36].

The Questionnaire on the Burnout Syndrome MBI consists of 22 statements related to some situations and accompanying feelings. In the version used for the purpose of the research, professional work was understood as taking care of a child, and in problems 1, 3-11, 14, 15, 17- 21 the fragments about professional work were replaced with the expression – child care:

- My work causes that I feel emotionally exhausted was replaced with child care causes that I feel emotionally exhausted.
- I feel tired when I wake up in the morning and I have to face another day of intense work was replaced with I feel tired when I wake up in the morning and I have to face another day of intense child care.
- I can easily tell what attitude the people with whom I remain in professional relations have was replaced with I can easily tell what attitude the people who help me with child care have.
- I feel that I treat some people, who I work with, impersonally, as if they were “objects” was replaced with I feel that I treat some people, who help me with child care, impersonally, as if they were “objects”.
- Everyday work with people is really stressful for me was replaced with Everyday child care is really stressful for me.
- I deal with professional problems of people, who I work with, very effectively was replaced with I deal with problems of people, who help me with child care, very effectively.

- My work causes that I feel “burnt out” was replaced with child care causes that I feel “burnt out”.
- I feel that my work influences other people positively was replaced with I feel that my child care influences other people positively.
- I have become “rude” in my relations with people, since I took this job was replaced with I have become “rude” in my relations with people, since I decided to take care of my child.
- I am afraid that my work changes me emotionally was replaced with I am afraid that my child care changes me emotionally.
- My work causes that I feel frustrated was replaced with child care causes that I feel frustrated.
- I feel that I work too hard professionally was replaced with I feel that I work too hard.
- I do not care what happens to some people I work with was replaced with I do not care what happens to some people, who help me with child care.
- I can easily create a state of relaxation in people I work with was replaced with I can easily create a state of relaxation in people helping me with child care.
- I feel excited after working with some people was replaced with I feel excited after working with people, who help me with child care.
- In my present job, I have achieved many valuable things was replaced with In child care, I have achieved many valuable things.
- In my job I solve emotional problems very calmly was replaced with I solve emotional problems related to child care very calmly.
- I feel that people I work with blame me for some of their problems was replaced with I feel that people helping me with child care blame me for some of their problems.

The wording of problems 2, 12, 16, 20 was not changed. The examined defined how often the situations, mentioned in particular statements, concerned themselves, using a seven-stage scale: 0 – never, 1 – several times a year, 2 – once a month, 3 – several times a month, 4 – once a week, 5 – several times a week, 6 – every day. The questionnaire allows to assess the stage of burnout in three dimensions: emotional exhaustion (EEX), depersonalization (DEP), and personal accomplishment reduction (PAR). The sub-scale indexes were calculated separately by summing up the results achieved for particular dimensions: I DEP, categories:

high (13 and higher), moderate (7-12), low (0-6). II EEX, categories: high (27 and higher), moderate (17-26), low (0-17). III PAR, categories: high (0-31), moderate (32-38), low (39 and higher).

In the group I, 150 questionnaires were distributed, 108 of which were used for the research, same as in the group II. A condition for qualifying the questionnaires for an analysis was giving answers to all the questions and completing them by both parents. The difference in the number of the questionnaires that were distributed and used results from the fact that some of them were incomplete or filled in by only one parent, despite declaration that both parents filled it in.

The study used methods of analysing descriptive statistics, t test and coefficient of determination R^2 .

Results

The examined group included 108 mothers and 108 fathers. One case of an adoptive parent was noted in both groups. About 3% of men were foster parents.

The vast majority of respondents (166 persons) were 31-50 years old. 42.9% of them were 42-50, 36.2% - 31-40, 18.1% - over 50 and only three of them were under the age of 30.

The majority of respondents lived in large cities, only 16% - small cities, and 1/3 of them – villages.

Most of the examined parents had secondary education (53.3%). 21% had basic vocational education, 17.1% - higher education, and 8.6% - primary education. Almost 2/3 of respondents had professional qualifications related to the physical work (63.8%), 30.5% - intellectual work, and 12 persons (5.7%) did not have any profession.

In case of 85.7% of the parents, the only source of income was professional work of a father, and 34.3% - professional work of a mother. In case of 14.3% of respondents it was a pension, 41% indicated benefits, and 5.7% other sources. The rates do not give 100%, because the respondents could indicate more than one source of income.

37.1% of the respondents indicated only one source of income. 26.7% of them indicated gainful employment of a father, 5.7% - benefits, 4.8% - pension. 49.5% of the respondents declared two sources of income, 22.9% of them indicated gainful employment of a father and benefits, 20% - gainful employment of both parents. 10.5% of the parents indicated three sources of income.

Most of the examined declared that their incomes were enough for everyday expenses – 17% of the parents could allow themselves to build up some savings, 41% was able to cover all expenses without any difficulties, but 36% of them could only pay for basic needs. Only 6% of the respondents were in a bad financial situation and were not able to cover everyday expenses, or even went into debts. Almost half of the respondents (46.7%) were parents of children with severe intellectual disability (98 persons). 42.9% had children with moderate disability (90 persons), and only 10.5% - mild disability (22 persons). The intellectual disability of a child was diagnosed at the age of more than 2. And 81.75% of the cases were diagnosed to the age of about 6. 78.1% of the parents also had healthy children. On the basis of an analysis of descriptive statistics and coefficient R^2 it was assumed that the variables: “depersonalization” and “loss of a sense of personal accomplishment” may significantly differ depending on a parent’s sex (Tab. I).

Tab. I. Descriptive statistics, strength burnout scale and sub-scales

Scale		Minimum	Maximum	Average	Standard deviation	R^2
General burnout	Mothers	11.250	78.750	37.765	15.990	0.001
	Fathers	7.407	71.034	36.685	15.833	
Emotional burnout	Mothers	3.000	45.000	19.358	11.442	0.000
	Fathers	3.000	44.000	18.942	10.230	
Depersonalization	Mothers	0.000	24.000	7.679	6.405	0.029
	Fathers	0.000	24.000	9.885	6.486	
Loss of a sense of personal accomplishment	Mothers	5.000	48.000	24.887	8.763	0.078
	Fathers	0.000	33.000	20.173	7.485	

These results are confirmed with the analysis based on distribution functions (Fig. 1, 2, 3, 4).

On the basis of t tests results (Tab. II) it was stated that H_0 of equal averages in groups shall be rejected only in case of the variable “loss of a sense of personal accomplishment”, which means that this index is 4.7 points lower for fathers (a parent’s sex explains its differentiation in 7.8%).

Most of the parents presented mild depersonalization (45.7%) and emotional burnout (47.6%). The rates were moderate for 30.5% and 28.6% of the respondents, respectively. Both sub-scale rates were low in case of 23.8% of them. Whereas, as much as 83.8% of the parents felt severe loss of a sense of personal accomplishment. Only 15.2% and 1% declared moderate and low level of this unfavourable rate (Fig. 5).

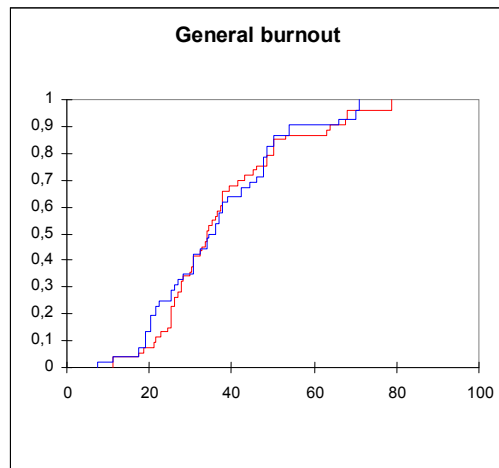


Figure 1. Burnout distribution functions for mothers and fathers (red – mothers, blue – fathers) – general burnout

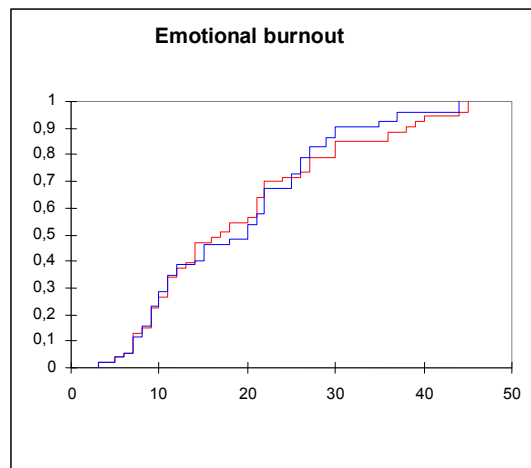


Fig. 2. Burnout distribution functions for mothers and fathers (red – mothers, blue – fathers) – emotional burnout

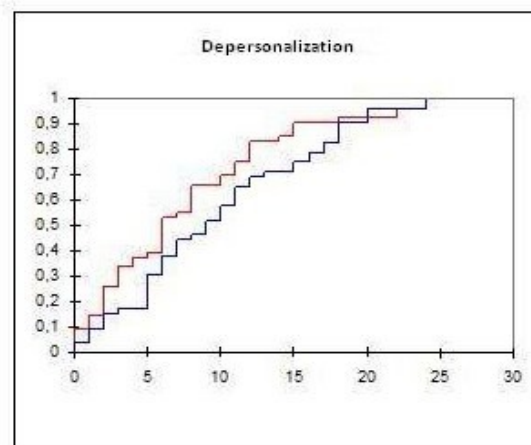


Fig. 3. Burnout distribution functions for mothers and fathers (red – mothers, blue – fathers) – depersonalization

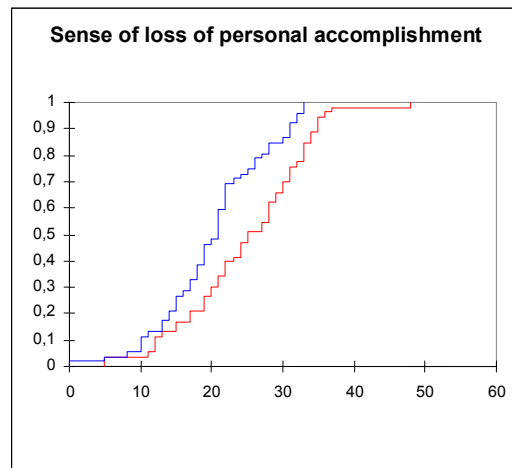


Fig. 4. Burnout distribution functions for mothers and fathers (red – mothers, blue – fathers) – sense of loss of personal accomplishment

Tab. II. Results of t tests for burnout scales

General burnout		Emotional burnout		Depersonalization		Loss of a sense of personal accomplishment	
Difference	1,080	Difference	0,416	Difference	-2,205	Difference	4,714
t (Observed value)	0,348	t (Observed value)	0,196	t (Observed value)	-1,753	t (Observed value)	2,961
t (Critical value)	1,983	t (Critical value)	1,983	t (Critical value)	1,983	t (Critical value)	1,983
DF	103	DF	103	DF	103	DF	103
p-value (Two-tailed)	0,729	p-value (Two-tailed)	0,845	p-value (Two-tailed)	0,083	p-value (Two-tailed)	0,004
alpha	0,05	alpha	0,05	alpha	0,05	alpha	0,05

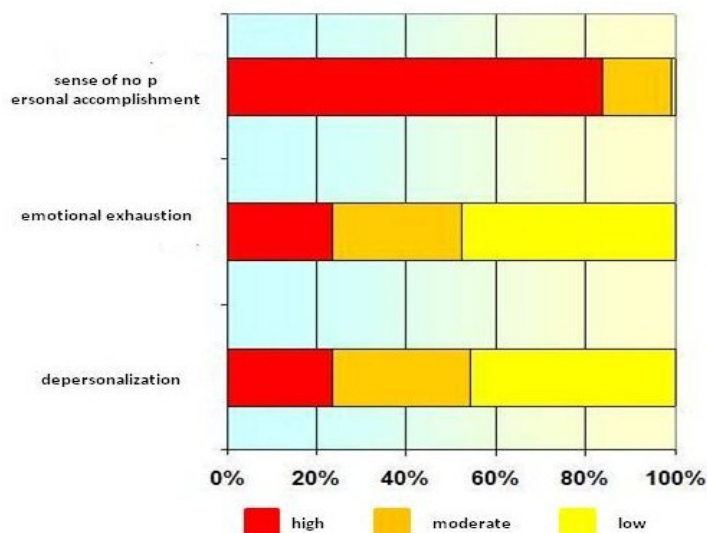


Fig. 5. Level of depersonalization, emotional exhaustion and sense of no personal accomplishment presented by parents

On the basis of standardized sub-scales (EEX, DEP and PAR), an aggregated scale of the strength burnout syndrome in the parents was created. In a standardized 100-degree scale an arithmetic average of strength burnout values was 37.2 with a standard deviation of 15.8 points. The size of one sten was a half of a standard deviation. Sten 1 represented the lowest risk of the strength burnout syndrome in the parents (equivalent to 2% of likelihood function density in a theoretical distribution of scale values in the examined population). Sten 10 stood for the highest risk of the strength burnout syndrome (Tab. III).

Tab. III. The number of particular stens for the scale of the parents burnout

STEN	1	2	3	4	5	6	7	8	9	10
NUMBER	0	8	26	38	50	28	32	16	8	8

The distribution of the risk of the strength burnout syndrome in the examined parents was characterized by right-side asymmetry, which means that in case of the majority of the respondents, the scale values were average or slightly below the average. Only 3.8% of the parents were characterized by a very low risk of strength burnout. In case of 30.5%, the risk was moderate, and 36.2% - average. In 29.5% of the parents the strength burnout was higher than the average, and in case of 11.4% of them it was very high (according to the theoretical distribution of population we might expect the risk of about 7%). The details are not presented.

The examined parents presented a distribution of the risk of the strength burnout syndrome in child care that was similar to the one presented by the entire population of Polish adults, and only a slightly bigger group was characterised by a low level of the risk, as well as lower emotional burnout, depersonalization and extremely strong sense of no personal accomplishment.

Discussion

Maciarz [37] notices that long-lasting mental load in a mother that usually coexist with physical exhaustion, can cause distress syndrome called “strength burnout”. As it develops, functioning of the maternal role is disturbed, which may result in gross negligence of her child, distancing from him emotionally, lack of interest in his health and improvement, losing the ability of empathy, reluctance or even hostility towards the child [37]. The author also thinks [37] that the mother has a strong feeling of helplessness and exhaustion, her own

incompetence for the care and improvement of her child, reduced self-esteem and emotional control. She experiences alternate states of impulsiveness and apathy; losing emotional motivation and a sense of meaninglessness of further efforts causes that she neglects her duties, and her sense of maternal responsibility becomes weaker [37].

Kurpas et al. [38] conducted the research among parents of children with autistic disorders, and stated a high risk of the strength burnout syndrome occurrence in 68.5% of them.

The results of Pisula's study [39] confirmed that long-lasting parental stress, related to raising a disabled child, raises the level of anxiety. Its higher level, resulting from raising a sick child, may reduce the parent's immunity to stress, and in case of persons, whose ways of coping with stress are not sufficient, it may cause strength loss.

Pisula [40], in her other researches, dealt with an assessment of factors causing stress and resulting in the burnout syndrome in parents of autistic children. The level of anxiety as a personality trait was higher in parents of autistic children and children with Down syndrome than in parents of children developing normally. The best assessment of professional situation was given by parents of children developing normally, next, parents of children with Down syndrome, and it was the worse in case of parents of autistic children [40].

Mandal [41] states that the strength burnout syndrome is divided into three basic dimensions: emotional exhaustion (discouragement, sense that one cannot offer anything more to others), depersonalization (treating others as objects) and lack of satisfaction and achievements at work (loss of faith in one's work, one's abilities, combined with decreasing effectiveness despite devoting more time or effort, shirking duties).

Care of a disabled child, constant anxiety and threat caused by exacerbation of the disease, its nuisance or lack of a possibility of treating causes that parents become mentally exhausted and experience numerous breakdowns.

In the research of Karwowska [42], analyzed families with intellectually disabled children, and they were characterized by – fatigue (67.6%), helplessness – apathy (61.3%), loneliness – lack of understanding (47.7%), sense of ineffectiveness (72.3%), sense of lack of competences (29.3%), remorse (81.5%), sense of meaninglessness and irritation (43.9%), tension (79.8%).

In this study, the Questionnaire of Burnout Syndrome *Maslach Burnout Inventory* in the Polish adaptation was used to assess the occurrence of the strength burnout syndrome in the examined parents [36]. It allowed to assess the degree of burnout in three dimensions: emotional exhaustion, depersonalization and loss of a sense of personal accomplishment. In

this study about ¼ parents was characterized by empathic understanding that was lower than the average, 40% - moderate, and 39.5% above-average.

Conclusions

1. Fathers experienced loss of personal accomplishment more often than mothers.
2. In the majority of the respondents, the values of risk of the strength burnout syndrome was average or slightly below the average.
3. A group of the examined parents – slightly bigger than in case of the entire adult population of Poland – was characterized by a lower degree of emotional burnout and depersonalization, and extremely strong sense of lack of personal accomplishment.

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Satisfaction with life and marital relationships in families with intellectually disabled children

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Introduction

A family, as the most important educational element, is responsible for the overall development of a person from one's earliest days until death; however, the perception of a family may differ, e.g. depending on the field of science that is interested in it – it is perceived differently in the sociological, psychological, pedagogical aspect, and differently in the medical aspect. In the opinion of Barbaro [1], the family structure is “*an invisible network of mutual expectations, conditioning the way in which members of a family interact with each other*”. According to Grudniewski [2], functions of a family are equally affected by: interdependence of its members, their interactions and division of roles performed in this social group.

Makarovič [3] distinguishes several typologies of parental attitudes, such as: *monarchic type* (where parental responsibility is in a mother's “hands”, but it is usually the kind authority), *democratic type* (the child has the right to independence, but in difficult situations he/she can count on a mother's help) *tyranic type* (the mother has the authority over the child, thereby, the child cannot fulfil his/her dreams; the mother uses the child as a tool thanks to which she can achieve her own goals) and *anarchic type* (the mother does not care about the situation of her child, therefore, she gives the child considerable independence; the child cannot count on her help in difficult situations).

The reference books [4-6] describe the cases in which tasks associated with a parental role are much more often neglected by fathers than mothers. Fathers do not experience the child's disability to a lesser extent than mothers, however, they do it more reservedly. It is believed that the attitude of fathers in the process of raising a disabled child may be referred to the concept of Erikson's psychosocial development, according to which at every point a person may have a psychosocial crisis related to the occurrence of new needs, new

requirements imposed by the person's environment [4-6]. According to Erikson [7], the crisis has a developmental nature, it is not a catastrophe but a turning-point in one's life, and its successful resolution is conditioned by the following factors: trust, autonomy, initiative, diligence, identity, intimacy, generativity and integrity, as well as becoming familiar with the new function and making it possible to cope with the requirements in the next stages of life.

Synthesizing the literature on families with disabled children, Twardowski [6] takes the interactive and systemic approach, related to putting a problem of a disabled child in the framework of family conditioning (emphasizing a role of interactions), perceiving the influence of the child's disability on family life conditions, both material and psychological (changes in the structure of values, etc.) and seeing the family situation in a long-term perspective, not only as a cause-and-effect relation.

Each type of a child's disability becomes a factor that disturbs the previous relations in a family, and it causes disorganization of its previous lifestyle, as care of a sick child is connected with the need of giving him much more time, energy and strength.

According to Kościelska [8], another important factor affecting the way of accepting a disabled child is a kind of relationship between his parents, and a sense of support from their parents and other close persons. Very often parents have no basic information about the child's disease, they feel lonely and helpless, and *"the awareness that there are no methods of treatment, and the child's development will deteriorate, and probably the child cannot be protected from premature death is a very difficult experience"* [8].

The purpose of this work was to evaluate the satisfaction with life and relationship in marriage of parents with mentally disabled children.

Materials and methods

The study was approved by the bioethics committee of the Medical University of Białystok No. RI-002/432/2010. The study was conducted between October 2010 and October 2012.

The study included two groups: the group I, consisted of 108 mothers and the group II, – 108 fathers of intellectually disabled children.

In the group I, 150 questionnaires were distributed, whereas 108 of them were used; the numbers were the same for group II. A condition for qualifying questionnaires for an analysis was giving answers to all questions and completing them by both parents. The difference in the number of the distributed and used questionnaires results from the fact that some

questionnaires were incomplete or completed by only one parent, despite previous declaration of completing them by both parents.

The study used: the authors questionnaire, the Satisfaction with Life Scale (SWLS) [9] and the standardized Questionnaire of Well-Matched Marriage (QWMM) (Plopa, Rostkowski) [10].

The original questionnaire was completed separately by fathers and mothers. It was the same in both groups. The questions concerned *inter alia*: age, place of residence, degree of relationship with the child, education, profession, sources of income, material conditions, structure of expenses, length of marriage, degree of the child's mental disability, age at which disability was diagnosed, having other children with intellectual disability.

The Satisfaction with Life Scale (SWLS) by Diener, Emmons, Larsen, Griffin, Polish version by Juczyński [9], a version for other professionals that are not psychologists. The scale includes five statements. The examined assessed to what extent they referred to their previous lives, where 1 meant – I do not agree at all, 2 – I do not agree, 3 – I rather do not agree, 4 – I neither agree nor disagree, 5 – I rather agree, 6 – I agree, 7 – I fully agree [9]. The results were summed, and the general result stood for the level of satisfaction with their own life. The range of results could be between 5 and 35 points, where the higher the result, the better the sense of satisfaction with life: 5-9 points – definitely not satisfied with life, 10-14 – very dissatisfied with life, 15-19 – rather not satisfied with life, 20 – neither satisfied nor dissatisfied, 21-25 – rather satisfied with life, 26-30 – very satisfied with life and 31-35 – definitely satisfied with life [9]. In the interpretation of results, properties characterizing sten scale were applied to. The results of 1-4 stens were treated as low, whereas, 7-10 stens as high, which corresponds with the area of 33% of the lowest results, and the same number of the highest results in the scale. The results of 5-6 stens were treated as the average [9]. The index of reliability (Cronbach's *alpha*) of SWLS determined in the examination of 371 adults was 0.81. The index of the scale's constancy, determined in two examinations of 30 persons at an interval of 6 weeks, was 0.86 [9].

Standardized Questionnaire of Well-Matched Marriage QWMM-2 by Plopy [10] allows to describe the quality of marriage in the perception of each spouse and obtain the general measurement of bond and measurements of the following factors (dimensions): *Intimacy* (meaning high level of satisfaction with being close to a partner), *self-actualization* (when a partner is highly satisfied with a marriage, which gives him an opportunity of realization of himself, his system of values and life goals), *agreement* (when there is a high level of agreement between partners on implementation of important marriage and family goals),

disappointment (when a spouse has a sense of life failure resulting from the fact of getting married) [10].

Each person took an attitude towards the statements by choosing one of the five categories of answers and assigning an appropriate numerical value to each answer: 5 – “I fully agree”, 4 – “I agree”, 3 – “I do not have an opinion”, 2 – “I do not agree”, 1 – “I do not agree at all” [10].

The sum of points obtained in the framework of the scales gave a raw result, which next was converted into a sten result. The sten scale consists of 10 different units. Stens 1-2 indicated very low results; 3-4 – low results; 5-6 – average results; 7-8 – high results, and 9-10 – very high results. *The intimacy scale*: a result of 7-10 stens indicates very high level of satisfaction with being in a close relationship with a partner (a description adequate to the one in the paper); a result of 1-4 stens indicates lack of intimacy and lack of satisfaction with a relation with a partner (a description contrary to the one in the paper); a result of 5-6 stens – average relation of intimacy in the opinion of the examined [10].

The disappointment scale: a result of 7-10 indicates high level of disappointment with marriage (according to the description); a result of 1-4 stens indicates lack of disappointment (features contrary to the description); a result of 5-6 – average sense of disappointment with a relationship, autonomy [10].

The self-actualization scale: a result of 7-10 indicates high sense of self-actualization in marriage (according to the description); a result of 1-4 indicates a belief that self-actualization is impossible in one’s marriage (features contrary to the description); a result of 5-6 – average sense of possibility of self-actualization [10].

The agreement scale: a result of 7-10 stens – there is a sense of high level of agreement on implementation of important marriage and family goals (according to the description); a result of 1-4 – lack of agreement (features contrary to the description); a result of 5-6 – average sense of agreement [10]. The results of each scale were considered separately. The moderate results (5-6 stens) were treated as the average, typical for all Polish marriages. For better evaluation of the situation in marriage, the examination of both spouses was conducted [10].

The basic research was preceded by a pilot study in groups of 30 parents, which allowed to verify clarity of the statements formulated in the questionnaires and develop a final version of the questionnaire.

In the research there was used an analysis of descriptive statistics, t test, determination coefficient R^2 .

Results

The examined group consisted of 108 mothers and 108 fathers of children with mental disability, mostly biological parents. Both in a group of women and men, one case of an adoptive parent was noted. 3% of men were foster parents.

The vast majority of the examined (166 persons) were at the age of 31-50. The age of 42.9% of parents was 41-50, 36.2% - 31-40. 18.1% of the respondents were over the age of 50, and only three parents were under the age of 30. The majority of respondents lived in large cities and 16% in small cities, and 30% lived in villages.

Most of the parents had secondary education (53.3%). 21% had vocational education, 17.1% - higher education, and 8.6% - primary education.

Most of the parents declared that their incomes were enough for everyday expenses – 17% of parents could allow themselves to build up some savings, 41% was able to cover all expenses without any difficulties, but 36% of them could only pay for basic needs. Only 6% of the respondents had a bad financial situation.

Almost half of the respondents (46.7%) were parents of children with severe intellectual disability (98 persons). 42.9% had children with moderate disability (90 persons), and only 10.5% - mild disability (22 persons). The intellectual disability of a child was diagnosed at the age of more than 2. Also, 81.75% of the cases were determined to the age of about 6.

The examined population was characterized by the evaluation of satisfaction with life similar to the entire Polish adult population. The respondents assessed the level of their satisfaction with life to be approx. 20.13, i.e. close to the neutral and only slightly lower than the average of the county. The standard deviation in both groups was similar, and the median was 20 (Table I).

Tab. I. The standardized scale of satisfaction with life by Diener – comparison of the descriptive statistics for the examined group and the Polish adult population*.

	Minimum	Maximum	1st Quartile	Median	3rd Quartile	Mean	Standard deviation (n-1)
parents	8.000	35.000	16.000	20.000	23.000	20.13	5.39
Polish adults				20.000		20.37	5.32
*The result of 1-4 stens was recognized as low, 5-6 – average, 7-10 – high.							

The sten norms for the examined population were determined in accordance with the following procedure – the results of the questionnaire for SWLS were put in the rising order. Next, a number of people was assigned to each result. In the next stage, the cumulated relative frequency for the results was calculated and division into stens was carried out on the basis of the available scale (Table II).

Tab. II. The sten norms for the examined population of parents

Points	Sten	Frequency	Points	Sten	Frequency
5-9	1	4	21-22	6	38
10-13	2	10	23-24	7	30
14-15	3	30	25-28	8	22
16-17	4	34	29-32	9	6
18-20	5	34	33-35	10	6

Summing up – 35.25 of the respondents indicated low level of satisfaction with life, 34.3% - average, 30.5% - high. This result is close to the one obtained by the Polish adults. The average was 2% higher than the result of the parents satisfied with their life, and 2% lower in case of the parents not satisfied with their life.

The subgroup of the examined mothers had the higher average satisfaction with life in Diener's scale (by approx. 0.42 point), with a slightly higher difference in the results. The value of determination coefficient R^2 in the auxiliary regression model indicated that a parent's sex explained the difference in the level of satisfaction with life only in 0.1% (Tab. III).

Tab. III. The descriptive statistics, SWLS

	Minimum	Maximum	Average	Standard deviation	R^2
Mothers	8	35	20.208	5.311	0.001
Fathers	9	35	19.885	5.102	

On the basis of the results of Mann-Whitney's test (Tab. IV) it was stated that there are no bases for rejection of H_0 with equal distribution of levels of satisfaction with life in mothers and fathers (value p significantly higher than 0.05). It means that gender did not affect the level of satisfaction with life of parents with intellectually disabled children in a statistically significant way.

Tab. IV. The results of Mann-Whitney's test

U	Z	p	With corr.	p
1371.500	-0.038455	0.969325	-0.038576	0.969229

The minimum length of marriage in the examined population was less than 12 months, the maximum length was 35 years. In case of 25% of the examined parents the length of marriage was shorter or equal to 14 years, 50% - shorter or equal to 20 years. The average length was approx. 19 years and 3 months. Almost 70% of the parents was married for 11.5-27 years, and only 25% - 24 years or more.

Over a half of the respondents declared that they were in a close relation with their spouse, only less than 4% argued all the time and complained about lack of emotional bonds with a husband/wife. A group of spouses, who shared their problems with a husband/wife, was 5 times bigger than a group of those, who did not share (34% to 6.7%). Almost a half declared helping each other at home, 16.2% - clear division of household duties, and almost 2/3 – joint decisions on the most important matters concerning their family. 21% claimed that they took decisions themselves. Almost 7% indicated a spouse as a main decision-maker. These results show taking too much responsibility for decisions related to family functioning by some parents, but also good relations in their marriages.

The most frequent causes of arguments in marriages of the examined parents were related to the organization of everyday life, 45% indicated division of duties, 44% - way of spending money, and 31% - professional work. Relatively insignificant factors generating conflicts was a sense of marriage and parenting (respectively 17% and 15%). Factors that were potentially connected with intellectual disability of the child were indicated by the parents moderately often – arguments about parenting methods were declared by 40% of them, 31% - attitude towards children, and only ¼ - involvement in care (Fig. 7).

For the purpose of assessment of deepened relations in marriage, the Questionnaire of Well-Matched Marriage QWMM-2 was used in the research, allowing to obtain general measurement of bonds and quality of marriage, as well as measurements related to the dimensions of intimacy, self-actualization, agreement and disappointment.

The examined parents had moderately higher index of agreement than of self-actualization (26.333 to 22.886 with the same scale). In case of agreement, higher standard deviation was noted (by approx. 0.46 point). Taking into consideration a spread of scales, there was observed lower level of disappointment than of intimacy, with a much wider relative “results spread” (larger standard deviation). It means that the examined parents

significantly differed in the “level of disappointment”. The level of strength of marriage bond of 25% of the parents was 105 points lower than in QWMM-2, 50% - lower than 119 points, and ¼ - higher than 129 points (Tab. V).

Tab. V. The descriptive statistics for the raw results of scales: general QWMM-2 (well-matched marriage), intimacy, disappointment, self-actualization and agreement

	KDM-2	intimacy	disappointment	self-actualization	agreement
Minimum	86.000	21.000	17.000	13.000	15.000
Maximum	160.000	48.000	49.000	30.000	35.000
1st quartile	105.000	32.000	30.000	20.000	24.000
Median	119.000	35.000	35.000	24.000	27.000
3rd quartile	129.000	39.000	39.000	25.000	29.000
Average	118.686	35.410	34.057	22.886	26.333
Standard deviation	17.189	5.579	8.001	3.791	4.255

In case of the intimacy scale, the results below the average were stated for 11% of the parents, 20% - average, 79% - above-average. These results are significantly better than the average for the Polish adult population.

An analysis of the disappointment scale did not show the results below the average for any parent, 14.3% - average, and 85.7% - above-average. These results are extremely better than the average for the Polish adult population. In case of the self-actualization scale, the results of as much as 76.2% of the parents were below the average, 21.8% - average, and only 2% - above-average. These results are significantly worse than the average for the Polish adult population.

The values of the agreement scale were below the average in case of 39% of the parents, 36.2% - average, 24.8% - above-average. These results are significantly better than the average for the Polish adult population. Summing up, the average level of marriage relations of the examined parents was lower than in case of approx. 70% of Poles.

However, they were positively distinguished by significantly higher level of intimacy in terms of trust, love, motivation, etc. The value of this index was higher than in case of 84% of Poles.

The level of disappointment of the examined parents, caused by the situation in which their relation functioned, was extremely high (probably grief caused by the child’s disability).

The level of self-actualization and realization of their life goals was also extremely low; the level of agreement on their relation, its goals and ways of acting was also low. The level of disappointment was higher than in case of 93% of Poles, self-actualization – lower than in case of 70% of Poles, and agreement – lower than in case of 60% of Polish marriages.

It is impossible to state significant differences in the averages of scales and subscales of the questionnaire of well-matched marriage between mothers and fathers on the basis of an analysis of descriptive statistics (Tab. VI).

Tab. VI. The descriptive statistics – the questionnaire of good marriage and subscales

Styles:		Minimum	Maximum	Average	Standard deviation	R ²
QWMM	Mothers	86	149	119.660	17.171	0.003
	Fathers	89	160	117.692	17.317	
Intimacy	Mothers	23	48	35.943	5.157	0.009
	Fathers	21	46	34.865	5.980	
Disappointment	Mothers	17	47	34.491	8.163	0.003
	Fathers	18	49	33.615	7.887	
Self-actualization	Mothers	13	30	22.887	3.479	0.000
	Fathers	13	30	22.885	4.119	
Agreement	Mothers	15	33	26.340	4.328	0
	Fathers	16	35	26.327	4.223	

The results of t tests (Tab. VII) clearly showed that there were no bases for rejection of H₀ of equal average values in the groups, which means that there were no statistically significant differences between the groups in the way of perceiving marriage.

Tab. VII. The results of t tests – QWMM

Good marriage scale		Intimacy		Disappointment		Self-actualization		Agreement	
Difference	1.968	Difference	1.078	Difference	0.875	Difference	0,002	Difference	0,013
t (Observed value)	0.585	t (Observed value)	0.990	t (Observed value)	0.559	t (Observed value)	0.003	t (Observed value)	0.015
t (Critical value)	1.983	t (Critical value)	1.983	t (Critical value)	1.983	t (Critical value)	1.983	t (Critical value)	1.983
DF	103	DF	103	DF	103	DF	103	DF	103
p-value (Two-tailed)	0.560	p-value (Two-tailed)	0.325	p-value (Two-tailed)	0.578	p-value (Two-tailed)	0.998	p-value (Two-tailed)	0.988
alpha	0.05	alpha	0.05	alpha	0.05	alpha	0.05	alpha	0.05

Discussion

A modern family and agreeable marriage affects personality and functioning of individuals, shaping their lives; thus, if its shape gets worse, the above negatively affects functioning and lives of particular members of a family and the family as a whole.

Obuchowska [11] distinguishes several crises that may concern families of disabled children. In her opinion, the first crisis is the novelty crisis, which causes a change in thinking about oneself as a parent, about one's family and future. The second crisis is the personal values crisis, characterized by emotional ambivalence – sometimes they love their child, for it is their child after all, but some other time they reject the child, because of the disability. It is accompanied by a feeling of being ashamed in front of strangers, thinking that it is their fault and living in constant stress. The third type is the actual crisis, related to the problems in raising the child with more severe disability. The author [11] distinguishes five types of family atmosphere that negatively affect the child: *intense* (characterized by mutual distrust, a sense of danger, where the child constantly feels unsafe and often takes an aggressive or apathetic attitude), *noisy* (characterized by frequent arguments that may be caused by the disabled child, who usually takes a defensive attitude in such atmosphere and chooses a stronger – in the child's opinion - side), *depressing* (where all misfortunes and problems are associated with the child's disease, which causes that the child is constantly unhappy), *indifferent* (leaving the child on his/her own, having no interest in the child) and *overly emotional* (excessive protection, preventing the child from being independent).

Having a disabled child disorganizes not only inter-family relations, but it also affects mood of parents, siblings and the family's relations with the closest environment. In this paper, the use of the standardized Satisfaction with Life Scale [9] allowed us to state that the largest percentage of the parents (35.2%) showed low level of satisfaction with life.

Kościelska and Zalewska [12] notice that being a mother of a disabled child is especially difficult when a man is not good enough partner and does not fulfil a role of a father, at least minimally.

According to Karwowska and Albrech [13], the stability of a family also depends on its functioning before the disabled child was born. If it was cohesive and its members were strongly connected emotionally, then there is great likelihood that the child will consolidate the family and improve mobilization of its members to make effort to cope with difficulties connected with the child's illness [13]. The situation would be different in families, in which the relations between its members before the disabled child was born had not been good, and

the problems had not always been solved, and sometimes only ignored. In such case, the disabled child's birth and accumulation of the problems may result in revealing the true nature of the marriage [13].

Karwowska [14] tried to diagnose the state of emotional and social relations of the examined parents with other people and asked them, whom they raise their children with, including the disabled child. The situation of the respondents was highly diverse, as in case of 69% of them children were raised by a mother and father, who were in a legalized marriage, 12 mothers (10%) raised their children together with their fathers in an informal relationship, and 2% of mothers raised their children together with their step-fathers, who they were legally married to (reconstructed family) [14]. In 22% of the cases, the children was raised in a broken home, where 8.4% of them were raised without a father or step-father, but with their grandparents or mother, 13.6% - raised only by mother without continuous participation of another person. 2% of the mothers raised their children with present partners, in an informal relationship. 7% of the children were raised in an incomplete family. In 3% of the cases, the incompleteness was caused by death of a parent, and in 4% of the cases, the mother was not married and raised the child alone [14].

In this study, the minimum length of marriage was less than 12 months, and the maximum – 35 years. More than half of the respondents declared that they were in a close relationship with their spouse, only less than 4% of them argued all the time and complained about lack of emotional bond with their husband/wife. The most common causes of the arguments concerned the organization of everyday life, including division of household duties, way of spending money or professional work, thus, they did not directly result from the fact of having disabled offspring.

According to Tyszka [15-17], the basis of every family is marriage, which *“is a legal and relatively permanent relation of a woman and man, whose aim is to live together, collaborate for the good of the family, i.e. mostly raise children, run a household and collaborate in any other field for the good of the family”*.

Minczakiewicz [18] diagnosed emotional bonds in families with disabled children, using the Family Relations Test (FRT). Analysing the results she stated that the disabled children noticed that they received more positive feelings from their mothers and sisters than from their fathers and brothers. Their attitude was also more positive towards mothers and sisters than towards fathers and brothers.

The study conducted by Randall and Parker [19] among parents of autistic children showed that the greater their satisfaction with marriage, the better the healthy siblings

assessed their competences. It was shown that the high level of satisfaction with marriage in parents positively influenced not only themselves, but also their children, which may be connected with better adaptation of both the parents and children to the fact of having a disabled child in a family [19].

In the study of Tway et al [20] on a group of people recruited from the Californian support group, the level of adaptation of families with children having autism diagnosed at the age of 12 and earlier was analyzed. They stated that the level of adaptation was similar for all respondents, but men received slightly higher results. No significant differences between gender and time devoted to the organization of help for the child were stated [20].

In the study of Kurpas [21] 26% of parents of children with autism assessed their marriage relations very well.

Conflicts and relation break down were experienced by 34% of the parents in Bodora's study [22]. In the opinion of Konopczyński [23], there are many factors that negatively affect the organization of family life, leading to the disturbance of structure of family role, destructing the child's life, such as: family breakdown by death, divorce or separation, which is a shock for the child and leaves trauma; separation from one parent, lack of sense of safety, or inadequate parental attitudes.

Kozak [24] believes that a child expresses many needs already at the moment of birth, which are satisfied or not, and it has an influence of the development of the child's personality and behaviour. In consequence, lack of a father in a family causes the occurrence of "no father syndrome" in the child's personality, manifesting in states of tension, aggression, poor adaptation to life [24].

Braun-Gałkowska [25] is convinced that a father has an influence on the child's adaptation to life in a community that is larger than the family. Father develops the need of accomplishment in the child, when he wants him/her to do everything as well as possible, when he demands independence. Frequent and positive contacts of father and child positively influence the results at school, develop intellect and creative attitude of the child.

In the study of Karwowska [14], on a group of 63 families of mentally disabled children, it was shown that the atmosphere in the examined families was defined as: agreeable, full of love and understanding (23.3%), good (39.1%), average (13.2%), tense (14.3%), bad (7.1%) or hostile (4%).

In this study, the parents were analyzed also using the standardized Questionnaire of Well-Matched Marriage QWMM-2 [10], and it was found that they showed considerably lower level of marital relationships than the average marriages in Poland, but they were

positively distinguished by feeling much higher level of intimacy with their partners in terms of trust, love, motivation, etc. In comparison to the entire Polish adult population they also showed extremely high level of disappointment caused by the situation in which their relationship functioned, extremely low level of self-actualization and realization of their life goals, as well as lower level of agreement on the nature of their relationship, its goals and ways of acting.

The examined mothers much more often indicated no involvement of their husbands in care of the disabled child as a reason of conflicts in their marriage.

According to Ryś [26,27], in an analysis of determinants of marriage quality the attention is paid to psychological differences between women and men, which is important for creating good interpersonal relations.

According to Argyle [28], women have stronger affiliate needs, they spend more time with other people, they establish more intimate friendships more willingly, they care about social relations and good relationships with others, they prefer kind atmosphere in interpersonal relations. They are also more supportive, they more often provide positive support, smile or reduce the distance, e.g., by touch.

Deaux [29] notices that in social relations men are more confident, or even aggressive. Women talk with each other more often, while men spend more time on participating in different activities together (sports, watching games).

A birth of a disabled child is not only an extremely painful blow for the parents, but also a series of endless worries, and a great challenge. Due to that it is very important that a family, especially spouses, support each other in order not to feel emptiness, loneliness and to know that they can count on each other at any time; to accept their own child and adapt to changes that have to be introduced in their future life and in the functioning of their family. It is also important that they receive support from the closest environment.

Conclusions

1. The examined parents, in comparison with the whole Polish adult population, showed much lower average level of marital relationship, high level of disappointment caused by the situation in which their relationship functioned, extremely low level of self-actualization and realization of their life goals, lower level of similarity of opinions about a relationship's shape, its goals and ways of behaviour, and much higher level of intimacy with a partner in terms of trust, love, motivation, etc.

2. No significant differences between fathers and mothers were found in terms of the ways of perceiving their marriage and in the level of their satisfaction with life.

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