UNIWERSYTET HUMANISTYCZNO-PRZYRODNICZY IM. JANA DŁUGOSZA W CZĘSTOCHOWIE

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# The (un)commonness of being ill. The kaleidoscope of colours, smells, and tastes in hospital school

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### **Editorial preface**

The quality of life, self-satisfaction and the feeling of one's worth depend to a large extent on recognition signs which we give and receive from others. The theory of transactional analysis emphasizes the importance of positive and unconditional recognition signs. However, due to the fact that a human being is a transactional individual, every type of recognition shall be better than lack of it. In an ordinary life situation, the needs of "being noticed" are usually met. It is different in case of big changes in the way of functioning, e.g. hospitalization or separation from others. Boredom, nothing to do and helplessness in case of hospitalization limit the exchange of recognition signs, leading to transactional hunger. The situation is particularly difficult for children, who are usually not able to deal with lack of stimuli successfully. From the point of view of transactional analysis, boredom and no possibility to act are not only discomfort but a serious developmental issue. A change in everyday routine, stimulation and encouragement to act is not only amusement but a therapeutic activity. Apart from interaction, the character of medical treatment requires diversified stimulation of senses, which should be clearly rewarding for the Child ego state. A meal can be eaten alone but it can be also an opportunity to maintain interaction and to enjoy the smell and atmosphere.

Zbigniew Wieczorek

### Abstract

The research has been aimed at examining how children and teenagers perceive their everyday life during their hospitalization and to show the ways that allow these patients to leave behind un-

pleasant emotions resulting from both the illness itself and the monotony of being confined to a hospital. The everyday life has been presented here as both commonness and uncommonness. Furthermore, solitude and boredom have been discussed as states experienced by pupils suffering from protracted diseases, followed by a presentation of teacher-therapists' reflections on (un)commonness of their work in hospital conditions. The research has been conducted with the participation of pupils and teachers at Special Needs Elementary School No. 38 and Special Needs Junior High School No. 38, both of which constitute departments of the Independent Public Clinical Hospital No. 1 in Zabrze.

Keywords: everyday life, protracted disease, hospitalization, hospital school.

### Introduction

In the life of a child, every illness is an undesirable phenomenon. It permeates and disrupts the child's development and everyday activities. Cancer particularly penetrates and damages this immature organism, attacking both *some* and *psyche*. Additionally, the experience of being hospitalized in the haematology/oncology ward has a detrimental effect on the patient's state of mind. So do separation from relatives and isolation from basic educational environments, which increase pain, suffering, anxiety and uncertainty of the ill child. The white or grey of the hospital, the monotony of surroundings and social contacts, the smell of canteen food can intensify negative feelings of patients. What may offer hospitalized children a certain substitute for commonness and normality are the activities organised in the hospital school (cf. Antoszewska, 2006; Binnebesel, 2000, 2003; Mickiewicz-Grudzińska, 2011; Moczia, 2010, 2016, 2017; Samardakiewicz, 2011). They often lend colour to the world of illness. Despite the uncertainty, the drips or pumps, the nausea and other unpleasant aspects of this life, *here and now* such activities let one hope for a better tomorrow (cf. Murawska, 2016).

Nowadays, the subject matter of everyday life is no longer "uncommon" in specialist literature published in the fields of sociology, psychology and educational studies. In Poland, the scholars who have devoted their research and publications to this issue were, inter alia, the authors of a monograph titled *Socjologia codzienności (Sociology of everyday life)*, edited by Piotr Sztompka and Małgorzata Bogunia-Borowska (2008), and a volume titled *Barwy codzienności. Analiza codzienności (The colours of everyday life. Analysis of everyday life*; Bogunia-Borowska, 2009).

Among publications in the field of educational studies, which deal with everyday life issues, worth mentioning is *Codzienność w szkole. Szkoła w codzienności (Everyday life at school. School in everyday life*, 2010), edited by Maria Dudzikowa and Maria Czerepaniak-Walczak, as well as a duet: *Codzienność szkoły. Uczeń (Everyday life of a school. Student*; Bochnio, Nowasad, Szymański, 2014) and *Codzienność szkoły. Nauczyciel (Everyday life of a school. Teacher*, Łukasik, Nowasad, Szymański, 2014). In the group of special needs educators, everyday life has been analyzed by Zenon Gajdzica (2009, 2010), Magdalena Bełza (2014), and Dorota Prysak (2014, 2015), but their interests lay mainly in intellectual disabilities.

### **Problem of Research**

### What is everyday life? Theoretical considerations

Zygmunt Bauman was of an opinion that:

In the past the word *everyday*, whenever one chanced upon it, brought first to mind associations with *routine*. Monotony. Today is the same as yesterday; tomorrow is going to be the same as today [...]. Everyday life exuded the sense of safety, the certainly as to what is going to happen [...]. The daily bread and lack of deceptive temptation. Absence of surprises and amazements. Peace and boredom (2009, p. 77).

According to another sociologist, Piotr Sztompka, "the everyday represents the most obvious form of being, present in direct experience, the most real and overwhelmingly imposing on our perception"<sup>1</sup> (2008, p. 25). It is not contrary to the festive and is not of an elite nature. Particular elements of life are equal, although they may occur with varied frequencies. He also believes that everyday life should not be equated with private, "home" life.

Sztompka distinguishes features of everyday events and practices:

- 1. everyday life always denotes life with others, in the presence of others;
- 2. everyday events are repetitive, cyclical, rhythmic, and routine;
- 3. sometimes they take ritual forms, performed according to a certain scenario;
- 4. everyday life involves our carnality, our biological equipment with all its limitations, weaknesses and infirmities, but also with its potential, strength and capabilities;
- 5. everyday life is located in a specific space, in a particular place;
- 6. episodes of everyday life have a certain durability and time range.

Marian Golka's stance is that uncommonness has to a certain extent been annexed to the area of everyday life (2009). He expresses the view that the reasons for distinguishing everyday life from uncommonness are:

- the attitude to time, i.e. the so-called *calendar greying out* (dwindling number of days and even moments experienced as exceptional);
- the attitude to *sacrum* and *profanum* the prevalence of states experienced without the feeling of attentiveness, uniqueness and rapture;
- the attitude to space, understood as the decrease in the number of exceptional or unusual places;
- the attitude to clothing and other accessories of appearance;
- the attitude to aesthetic and artistic values present in art;

<sup>&</sup>lt;sup>1</sup> All transl. – author.

- the domination of well-known, repetitive, almost routine issues;
- the attitude to play which stops being unique and becomes a daily entertainment, filling every free moment (cf. Wojnar, A., Alma Mater http://www2.almamater.uj.edu.pl/104/32.pdf).

Anna Zadrożyńska-Barącz writes about the everyday/uncommonness in a similar manner: "daily life is permeated with the formulas of festivity, and vice-versa – everyday habits penetrate into festivities" (2010, p. 51).

This thought can be applied to eating food, i.e. both daily and unusual activity. With the words of prayer, "give us this day our daily bread", we place it at the forefront of all food. The common term "sharing bread" denotes not only giving a slice of bread to the poor, those in need, but also sitting together at the table. Urszula Jarecka is of an opinion that "meals can still connect people, but they are not necessarily based on bread. Gathering at one table, the family community is a good example of the image of bonds" (2015, p. 232). The authoress continues stating that meals are not celebrated every day, and Sunday dinners may not differ much from everyday ones very much. It also states that the availability of certain products, such as exotic fruit, makes it possible to have a holiday feast on the table every day.

Meals, especially when consumed in the company of others, demand time and often take long to prepare beforehand. While considering time as a pedagogical category, Anna Murawska refers to the opinion expressed by Marek Szulakiewicz: "To have time means to be with someone, in something, for someone. To have time means to experience things, the world, people" (2014, p. 25). Time understood in this way has to be allowed for in the course of a protracted disease during hospitalisation. Referring to Murawska, one can conclude that having time does not mean doing nothing, because such a state can lead to fatigue and monotony.

Fatigue is above all the fatigue of oneself and one's duty to exist. It does not result from the colourlessness and commonness of the environment, or from the repetitiveness and banality of actions, but is a consequence of the obligation towards one's own existence... (Murawska, p. 26).

At this point, the following questions should be asked: is the illness, along with the hospitalization resulting from it, monotonous and boring in itself? Is it possible to bring colour to the child's world in illness and help the young patient discover some taste in it? Who is to be responsible for such an endeavour – the child's parents, teachers, medical staff or volunteers from various foundations?

#### Disease, monotony, boredom, occupation

Aleksandra Maciarz defines a child's protracted illness as: "a long-term impairment of the child's health and wellbeing, which violates their appropriate psychomotor development, hinders their education and causes changes in the family situation" (Maciarz, 2006, p. 9). What does the term "protracted disease" actually mean? This concept has not been given a uniform definition – sometimes it is difficult to distinguish it from such terms as disability, incurable disease or chronic illness. However, some features are common for many types of diseases: long duration, severity (resulting in – to some extent – exclusion from "normal" life), course of disease that is milder than in acute cases, irreversibility of pathological changes, need for continuous treatment, i.e. long-term medical care and physical rehabilitation (Nowakowska, 1983; Maciarz, 2006).

The above characteristics show that the life of a child with protracted disease is far different than the life of a healthy child developing in natural conditions, such as the family home, school environment and peer group. One should recognise that not only contacts with parents and other relatives, but also with teachers and peers constitute a substitute for the sick child's normal life (cf. Moczia, 2016; Samardakiewicz, 2011).

When ill, people are bored. The monotony resulting from daily rituals discourages from taking any actions. Fears and anxieties caused by the disease itself are rarely conducive to intellectual upheaval or mental stimulation. Boredom is an unpleasant state which often cannot be helped (cf. Moczia, 2009). Is it possible to stop "nausea" that "makes one sick"? These concepts seem to be very similar in meaning and difficult to prevent.

How should the sick child's illness, hospitalisation, social isolation be made more attractive? How to substitute for the family table? Is it acceptable to compare the time of illness to the time of "occupation," to war? The next question: do cancer, tumour, neoplasm invade the child's organism, or do patients invade and occupy the hospital together with their parents? This comparison arose after listening to a lecture by Anna Czocher, Ph.D. (Institute of National Remembrance), titled *Occupational boredom in egodokuments. Example of Krakow from 1939–1945* at the 4<sup>th</sup> National Conference on Boredom: Academic Tedium (21.04.2017):

[...] in general, war disease<sup>2</sup> is the time of great waiting, the time of great boredom [...]. Life, although different than before the war disease, quickly turns into a routine. It is permeated with monotony, also with the monotony of repetitive problems and difficulties affecting the foundations of existence, with a sense of no perspective. The great waiting....

Referring daily life during the occupation to existing, persisting or vegetating in illness, one can find several concurrent situations:

- the invader takes over houses, streets, cinemas, cafés...,
- there is a police curfew, because you must not go out and come back when you want,
- it is not possible to turn on the light when you want to,
- one is not allowed to eat what they like,

<sup>&</sup>lt;sup>2</sup> The word "war" has been replaced with the word "disease."

- one is not allowed to work/study where they prefer,

- one is not allowed to visit or meet with others who they want.

### **Methodology of Research**

#### **Research assumptions**

In her book *Teoretyczne i metodologiczne podstawy pedagogiki antropologicznej. Studium sytuacji wychowawczej (Theoretical and methodological basics of anthropological education. A case study of educational situation)* Krystyna Ablewicz, an educator of anthropological and axiological interests, discusses the problem of everyday world and refers to "doxa" as a basis for relevance studies. Doxa (or *sens pratique*) is the "generated" knowledge, showing regularities of the nature of temporary truths – true from the perspective of generally accepted assumptions which are limited to given time and space. In this context, the terms "experiencing life" and "experiencing the world" are also applied (2003, pp. 99–104).

Maria Czerpaniak-Walczak believes that

learning about what is happening in the natural conditions of everyday life, about both what is 'fully visible in the bright sunshine' as well as what is 'unclear behind the glass pane,' is done in two parallel processes: through intentional, professionally undertaken specialized research focused on a selected fragment, or in the process of spontaneous, occasional, fragmentary observation (p. 94).

Further, she describes what measures should be undertaken in order to dispose of subjectivism: "individual events are often interpreted from the perspective of personal experiences and constitute the basis for the formulation of generalised judgments". She also explains the understanding of emancipation in the context of everyday life (pp. 96–97) and emphasizes what psychologists and psychoncologists of the humanistic and existential trend (i.a. A. Maslow, C. Rogers, V. Frankl) pay particular attention to, i.e. the subjective process of "here and now" (F. Perls – Gestalt therapy).

Czerpaniak-Walczak also inquiries about the search for emancipation conditions in everyday life at school: "What to change in the curricula?" After Paulo Freire, she cites: "they must not be boring. The sense of seriousness must not be exaggerated; on the contrary, joy and fun in the teaching-learning process should accompany the daily interaction of teachers and pupils" (p. 110). Referring to the words of Pierre Bourdieu, she writes that the process of school learning "is a selfless ludic activity" (p. 110).

Murawska implies:

More and more often in education we are also dealing with a phenomenon defined as *edutainment*, i.e. a combination of education and entertainment, introduced in order to make the former more attractive and effective (2014, p. 25).

Further on, she states:

If, however, an attempt is made to treat everyday life as an inspiration or opportunity for personal development, to draw joy and satisfaction from it, to confirm the sense of one's own existence, one could learn to turn everyday life into a festive celebration (p. 103).

In the methodology of educational research, cognitive behaviour has nowadays acquired a great significance, which is connected with the humanistic approach. The humanistic model of scientific cognition is grounded in theoretical and methodological trends from the circles of sociology, philosophy, psychology and educational sciences (Palka, 2006).

The present research with the humanistic approach is qualitative and empirical. It examines experiencing (un)commonness as a social phenomenon in a hospital ward. One can assume this research to be classified as educational ethnography, which describes and interprets events in a formal educational context (cf. Juszczyk, 2013, p. 115; Kubinowski, 2010, p. 164).

### **Procedure of Research**

I have been observing everyday life and uncommon events organized in the Paediatric Clinic in Zabrze for many years. During this year's 5<sup>th</sup> All-Polish Conference titled "Only children know what they are looking for"<sup>3</sup>, during the break between lectures I had an opportunity to taste delicious and healthy snacks prepared by the teachers from the hospital school. The meals were served as part of a presentation of the "JedzOnko" ("OncoEats") project carried out in cooperation with the Iskierka and Zdrowolandia Foundations and were very popular with the guests (http://www.szkola38.pl/szkola/konferencja.html). There was also an opportunity to purchase a guidebook titled *JedzOnko (OncoEats*; 2017) by Katarzyna Stanko.

When talking to teachers who run classes at the haematology ward, I made arrangements to conduct interviews on the issues of interest to me.

The research aimed at learning how children and adolescents perceive everyday life during hospitalization and showing how patients can get out of the confines of unpleasant emotions resulting from the illness and hospital monotony.

The following research questions were asked:

 How do the patients of the Paediatric Haematology and Oncology Ward perceive the hospital's everyday reality?

— What classes/activities do teachers of the hospital school offer to students who suffer from protracted diseases to prevent monotony and inactivity?

The techniques applied in the research are adequate for qualitative research: document analysis (website, school chronicle), expert narrative interview (with

<sup>&</sup>lt;sup>3</sup> The conference was organized by Special Needs Primary School No. 38 in Zabrze, 23–24 March 2017.

teachers as facilitators<sup>4</sup>), projection method (creating everyday common and uncommon plate through drawing, writing) (Juszczyk, 2013; Palka, 2006).

An attempt has been made to show everyday life as both a daily routine and a festivity, as well as to depict loneliness and boredom as a condition experienced by students suffering from protracted diseases. The research included selected students and teachers of the Special Needs Elementary School No. 38 and departments of Special Needs Junior High School No. 38 organized by the Independent Public Clinical Hospital No. 1 in Zabrze.

### **Analysis of Collected Material**

## (Un)commonness at the Paediatric Haematology and Oncology Ward in Zabrze

I analysed the events recorded/archived on the internet sites of the school (http://www.szkola38.pl/szpital/strona\_glowna\_2.html) and the hospital (https://www.szpital.zabrze.pl).

When interpreting the collected material, I observed many (un)common activities of child patients and the responses of various communities to their expectations. Among other things, the following can be listed:

- The project "How art is made" meetings with interesting people representing the world of theatre, film, literature. The guests of the hospital school were Grzegorz Kasdepke (writer), Marcin Pałasz (writer), Andrzej Marek Grabowski (song writer and a television programme creator), Waldemar Cichoń (writer), Maciej Patucha (conjurer).
- A mobile hospital library called "Bajkowóz" ("The Tale Wagon") with 100 therapeutic fairy tales for children. Art workshops are often inspired by a selected book (cf. Klinowska, Zimon, 2017).
- Art workshops titled "Sunny Gallery" Urtica for Children the artworks created during workshops are auctioned at charity actions in Wrocław. The profits are given to 17 hospitals in Poland to fund medical equipment and art materials for patients.
- The action of the Rosa Foundation from Wrocław called "A Postcard from hospital" – in cooperation with the Museum of Warsaw Uprising, postcards are made for the heroes of the Warsaw Uprising who are still alive. The action called "BohaterON" ("HeroON") is a patriotic action whose aim is to cultivate Polish nationality, respect for the symbols, and traditions of our homeland among the young generation.

<sup>&</sup>lt;sup>4</sup> Teacher-facilitator does not teach ready-made knowledge to the students, but supports their intellectual effort and exploratory activities connected with self-inquiry and seeking answers on their own (Nowak, 2007).

— "Pictures of the world" – the Nationwide Art Contest organised for hospital and sanatorium schools (in the school year 2016/2017, the fourth edition was held). The contest is very popular, which is reflected by numbers – approximately 200 artworks are evaluated by the jury every year.

My attention was especially drawn to the photographs and accounts of activities of "JedzOnko" ("OncoEats") project and culinary workshops called "Zdrowiaki gotują" ("Healthy Ones Cook"). Extremely colourful, happy and appetizing!

Analysing the answers obtained during the interview, I would like to present selected statements of the examined teachers:

# What is a usual day at the ward like? Is there a regular daily schedule (doctor's visits, medical procedures, meals, school classes)?

A day at the ward is organized according to a regular schedule. Meals, medical examinations, school and pre-school classes. Everything is prearranged, however, there are situations when the routine is broken. As an example, a situation may serve when treatment (e.g. steroids) affect the children's behaviour so much that they must eat all the time, and cannot participate in the activities since they are irritated, whiny. However, this concerns only particular children. The whole daily schedule is routinized.

[...] such daily order, without unnecessary chaos, is strongly needed and offers the feeling of security to us all. However, in the long run, both, routine and mundanity are tiring for everybody and can decrease activity and strength mobilisation to combat the disease. I can see here a huge task for teachers [...] who should organize time and space in such a way as to overcome routine and mundanity.

I believe that meals, medical procedures and tests which are regulated by a schedule offer stabilisation and a feeling of safety to both children and their parents. Also, visits from family and friends. Pupils know when and at what time they can expect a teacher. All additional activities: art, culinary classes, theatrical workshops, etc., projects and meetings organised by the school are earlier reported to the hospital director and a ward sister.

# Which activities, in your opinion, are special, uncommon, unusual for children?

All activities which result from educational projects which are carried out. Generally, I can say that the aim of all these activities is to bring joy to children. They result from observed needs, and are prepared with great ingenuity and teacher passion. They are uncommon, periodic and attractive, and therefore special.

All extraordinary ones, the ones which a child has not dealt with ever before. Activities developing creativity: culinary, musical – playing the instruments, reading – therapeutic fairy tales, meeting interesting people – especially those known from TV, photography and journalism workshops and others.

What ways of freeing themselves from unpleasant emotions can you observe in patients? Internet? Television? Conversations with medical staff? Conversations with a psychologist? Same classes with other patients in kindergarten, at school? All the ways in which patients free themselves from bad emotions listed in the question occur in our ward. Also, I would add the need for isolation (silence and peace), which is so difficult to get in this place, need for sleep and to have a quiet cry-out.

I observe various behaviours in the ward. For some, it is sleep and isolation, for others using the Internet or watching television, some need an ordinary talk and we, teachers, must adapt to this, too. Most frequently, however, the youngest pupils participate willingly in various activities organised in the hospital school. Starting from classes, and ending up with activities in an educational group or specially organised activities as a part of educational projects.

### My question is aimed at ... cooking classes. What did they start with and ... where are they heading?

The main goal of the classes is to increase the awareness of children and parents of highquality nutrition of ontologically treated children. Adjusting the diet to individual needs of a patient. Learning tastes and smells of dishes, desserts, juices, etc., prepared during classes.

Culinary workshops "Zdrowe JedzOnko" ("Healthy OncoEats") resulted from the need to educate parents and children on a healthy diet, and proper diet in the course of an oncological disease. After entering a competition for schools called "Live Tasty and Healthily," we drew a lot of conclusions. During the activities related to the competition, it turned out that children do not have sufficient knowledge on the subject regarding a healthy diet. A huge problem constituted also eating habits which translated into buying chips, coke or other unhealthy snacks and fast food by parents. We decided that the competition was just a beginning, and we should organise periodical culinary workshops whose goal would be to acquaint parents and children with the rules of a healthy diet. We decided that the classes would be practical. We did not want other meetings with illustrations and a text but with a real carrot, spinach and all products which are necessary for the body. A further step to make a dream about real culinary workshops on the Paediatric Haematology and Oncology Ward in Zabrze come true, was to get allies and sponsors – good spirits that would like to help children and parents to survive the period of treatment in fine fettle. Our first thought was the Iskierka Foundation, which has helped Silesian oncological wards for many years. People from the Iskierka Foundation joined our project very willingly, and were funding the products necessary for workshops for some time. Katarzyna Stankow - a dietician, blogger of "Zdrowolandia" ("Healthyland"), and most importantly, the mother of little Agatha, a girl treated in the clinic in Zabrze – helped us offering her knowledge and time. Since then, we had conducted workshops together. After a year we realised that we needed an additional sponsor who would equip workshops with knives, cutting boards, aprons, blenders, mixers and other kitchen essentials. The firm called Marco sp. z o.o. responded to our request. In this way, we obtained professional kitchen equipment, and additionally food products for our every workshop.

The observations of my friend, who also works at the ward, and mine were shocking. Unhealthy snacks, instant Chinese soups, and McDonald food were a common sight. We both joined the competition for schools called "Live Tasty and Healthily" [...] In the course of time, we got an additional sponsor for the school, the firm called Marco from Gliwice. We named the project "JedzOnko" ("OncoEats"). All participants liked the workshops a lot. Their value consists in the fact that children themselves prepare dishes and drinks which we all eat and drink together later. Our flagship product is a spinach cocktail which arouses controversy among children, and consequently everybody likes it

very much. Unfortunately, since the foundation and the dietician failed to keep the terms of cooperation, we had to continue our workshops alone. The firm called Marco gladly helps us financially and in this school year (2017/ 2018) we called the workshops "Zdrowiaki gotują" ("Healthy Ones Cook"). During the classes for an educational group, children and I make posters which invite all patients present on the ward to the workshops, and they and I sew "healthy ones," that is fruits and vegetables which are given various names by children, e.g., Tolek Banana, Raspberry Vitamin, etc.

The respondents were asked to describe uncommon colours, tastes, smells in a few words. Common colours of a hospital were described as grey and white (walls, doors, beds); however, there occurred a statement: "And that is why this whiteness needs to be coloured continuously". Uncommon colours were those "which children create during art classes", "they are colours of rainbow".

To describe common smells, the following were used: sterile, hygienic, smell of dinner brought from a hospital kitchen. Uncommon smells bring to mind citrus fruit, fresh herbs, vegetables and fruit, and baked (unsweetened) biscuits.

Common tastes, in the opinion of the studies, were bland, lousy, but there also occurred a statement "it is favourite food prepared by our mothers". Uncommon tastes were sweet, sour, "surprisingly delicious spinach cocktail".

Surveys among children were conducted in October 2017. Students-patients of the Paediatric Haematology and Oncology Ward in Zabrze received paper plates and the instruction, and were asked to "fill up" the paper plates.

You get a paper plate. It is a "plate of a common day in hospital."

Write on a piece of paper all activities, tasks, duties, medical procedures, classes which accompany You during a typical day at hospital.

Similar activities group together, e.g.

- breakfast, dinner, supper = meals;
- collecting blood, inhalations = procedures;
- visits from a grandmother, brother = visits from family;

Now, transfer your notes on the plate and mark separate groups with colours.

Are there other days in hospital?

Write down rare, unusual events on a piece of paper.

You get another paper plate. It is "a plate of an uncommon day at hospital."

Transfer your thoughts and notes onto the plate. You can write down in detail UN-

COMMON THINGS, emphasizing their festive character, uncommonness.

How children-patients perceive commonness on the ward? The following notes on the plates were as follows:

- Procedures (blood collection, dressings, pumps);
- Meals;
- Visits from family (dad, grandma, aunty, siblings);
- Learning;
- Games;
- Conversations.

There also was a note "[...] it is such a usual day".

How is everyday life perceived by hospitalised patients? Pupils enumerated:

- Classes with a ma'am from the Iskierka Foundation;
- Meetings with authors; special guests' visits;
- Classes with arts Teacher;
- Preparing meals together (cocktails, salads, snacks);
- Visits (relatives, classmates);
- Contests organised by teachers.
   There were also single answers: "Fr. Peter comes" and "renovation of the ward".

### **Results of Research**

On the basis of the collected material, one may conclude that children participating in the studies perceive commonness as an ordinary, normal day full of routine activities typical of a hospital (examinations, meals, visits, learning).

For them, uncommonness means both attractions, such as meeting famous people, extraordinary activities organised by the representatives of foundations (e.g. "OncoEats"), as well as fascinating, attractive lessons conducted by teachers (e.g. "Healthy Ones Cook," artistic competitions, making decorations). Uncommon events also include the spiritual component (priest's visit) and peers' visits.

Based on the information from websites, the school chronicle, interview with the teachers, it should be concluded that the teachers follow the mandatory curriculum with great involvement and awareness, using standard methods of instruction and innovative educational projects (e.g. the mobile hospital library "The Tale Wagon", culinary workshops, artistic competitions). What should be noted is also the involvement of representatives of foundations (such as Iskierka, Serdecznik, Rosa) in the educational activities. The prestige and the patient's joy related to the meetings with famous people (writers, actors, journalists) cannot be overlooked, either.

According to the teachers participating in the study, the hospital ward is associated with white and grey colour, the odour of medicines and disinfectants as well as canteen food. The polysensory stimuli activate a patient and this should be taken advantage of through painting and colouring, decorating the ward, but also preparing colourful, fragrant and tasty foods.

Cooking classes are of special value. They appeal to various senses: smell, taste, sight, but also touch (active and passive). They are of special importance to a child with cancer, with dietary limitations.

### Discussion

Uncommonness in the paediatric haematology and oncology ward should be seen in a multifaceted manner: through intentional, professional, specialised actions initiated by teachers or volunteers, but also in the process of spontaneous, occasional, separate activities (cf. Czerpaniak-Walczak). You can look from the perspective of the illness and its negative defence mechanisms (aggression, regression, escape, projection, resignation), but also from the perspective of hope, which can be aroused on the basis of positive defence mechanisms (rationalisation, compensation, transformation).

Uncommon events stimulate and activate, e.g. interesting school classes and extracurricular activities. It is the teacher that the child associates with the hope for returning to the ordinary everyday life and to the acceptance of what is. One should remember it is one of the basic purposes of the work performed by an educator and therapist in a health care institution (Binnebesel, 2000).

Uncommonness in a hospital is also embodied by meetings with people known from the media, a priest's visit, visits of distant relatives or peers. One cannot forget that peers are often the best predictor of the children's self-esteem, especially among adolescents (cf. Antoszewska, 2006, pp. 214–218; Moczia, 2017).

Shaping proper eating habits among patients with cancer is not only aimed at promoting healthy lifestyle, but it is also designed to speed up the healing process and return to health (cf. Stanko, 2017, p. 5). Preparing meals together is also a substitute for home cooking and shared dining room (Jarecka, 2015). It is a hope for returning to the ordinary, or maybe even for making a celebration of what is ordinary (Murawska, 2014). Shared meals are also consolidated, concentrated efforts of the parents against the common enemy that is the cancer (Stanko, 2017, p. 97).

### Conclusions

A protracted disease and the resulting hospitalisation are difficult, unpleasant and uncomfortable for patients of all ages. Children are especially at risk of not having their development needs met. Their natural activity, contact with the nearest and dearest, eating favourite foods are all limited due to the illness and the hospital rigour. The patient has to give up their habits, everyday duties and pleasures for an unspecified time, unfortunately. The patient experiences pain, suffering, nausea, takes medicines and has prescribed injections and medical procedures. Commonness boils down to routine activities performed at specific times: meals, medical procedures, limited contact with the family and friends and classes at the hospital school as a substitute of everyday life.

The issues related to perceiving (un)commonness by children suffering from protracted diseases and their teachers from the hospital school, as discussed in the article, make it possible to suggest the following actions:

— ensuring education to the patients with cancer while they stay at hospital;

 organising activities that arouse the children's creativity, cognitive and emotional activity by using valorisation methods (impressive and expressive);

- resorting to methods that appeal to multiple senses: sight, hearing, smell, taste and touch (active and passive);
- making it possible for patients to meet special guests (famous people, peers, a priest);
- on the basis of the analysis conducted on the results of the studies, cooking classes should be presented as those with priority value. They are of special importance to a child with cancer, with dietary limitations.

During the patient's stay at hospital, the child cannot be constantly flooded with attractions and singularities. The children need time to sleep, to rest and sometimes to cry. They need some time to be alone, separated, quiet. However, one should prevent alienation and estrangement, as well as the feeling of monotony and boredom. The latter never help patients recover.

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### (Nie)codzienność choroby. Kalejdoskop kolorów, zapachów i smaków w szpitalnej szkole

#### Streszczenie

Celem badań było poznanie postrzegania codzienności w trakcie hospitalizacji przez dzieci i młodzież oraz ukazanie sposobów pozwalających pacjentom na wyjście poza obręb nieprzyjemnych emocji wynikających z samej choroby i monotonii szpitalnej. Ukazano codzienność jako powszedniość i odświętność oraz zobrazowano samotność i nudę jako stan doświadczany przez uczniów chorujących przewlekle. Przedstawiono również refleksje nauczycieli-terapeutów o (nie)zwykłości pracy pedagogicznej w warunkach szpitalnych. Badaniami objęto uczniów i nauczycieli Filii Szkoły Podstawowej Specjalnej nr 38 i oddziałów Gimnazjum Specjalnego nr 38 zorganizowanych przy Samodzielnym Publicznym Szpitalu Klinicznym nr 1 w Zabrzu

Słowa kluczowe: życie codzienne, choroba przewlekła, hospitalizacja, szkoła szpitalna.