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Providing information about a child's oncological disease - a challenge for a pediatric oncologist

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Abstract:

Introduction: The diagnosis of a serious illness in a family affects all members. The child is a special subject, as he cannot yet understand many aspects of life at such a high perceptual level as an adult. Communicating difficult information is part of the doctor's task and is one of the most difficult parts of the therapeutic process.

The aim of the study: To analyze the methodology of communicating difficult information to pediatric oncology patients.

Material and method: Polish and English-language scientific literature from 2012 - 2022 from databases such as PubMed, SCOPUS, Google Scholar, Web of Science was reviewed. Searches were conducted according to keywords: communicating difficult information, oncology, pediatrics, physician.

Results and conclusions: One of the most well-known protocols for communicating difficult information is SPIKES. It describes the basic and necessary steps for properly informing parents and the child about the diagnosis, for example. Healthy siblings should also learn about their brother's illness, but this task falls to the parents. Psycho-oncological support for both the child and parents should be holistic, based on best practices, and tailored to the family's needs.

Streszczenie:

Wstęp: Diagnoza ciężkiej choroby w rodzinie oddziałuje na wszystkich członków. Dziecko jest podmiotem szczególnym, ponieważ nie potrafi jeszcze zrozumieć wielu aspektów życia na tak wysokim poziomie percepcyjnym jak osoba dorosła. Przekazywanie informacji trudnej należy do zadań lekarza i jest jednym z najtrudniejszych elementów procesu terapeutycznego.

Cel pracy: Analiza metodyki przekazywania trudnych informacji pediatrycznych pacjentów onkologicznych

Materiał i metoda: Dokonano przeglądu polsko- i anglojęzycznego piśmiennictwa naukowego z lat 2012 – 2022, pochodzącego z baz danych takich jak PubMed, SCOPUS, Google Scholar, Web of Science. Wyszukiwania przeprowadzono według słów kluczowych: przekazywanie trudnych informacji, onkologia, pediatria, lekarz.

Wyniki i wnioski: Jedynym z najbardziej znanych protokołów przekazywania trudnych informacji jest SPIKES. Opisuje on podstawowe i niezbędne kroki dla właściwego poinformowania rodziców i dziecka na przykład o diagnozie. Zdrowe rodzeństwo również powinno dowiedzieć się o chorobie brata, jednak zadanie to należy do rodziców. Wsparcie psychoonkologiczne zarówno dziecka jak i rodziców powinno być holistyczne, oparte na dobrych praktykach, dostosowane do potrzeb rodziny.

Introduction

Communicating unhelpful information is one of the most difficult phases of the oncologist's clinical work. This statement is particularly apt when the subject of the process

becomes the pediatric patient and his caregivers (parents/legal guardians). The population of children and adolescents is a group with specific needs, depending mainly on the stage of psychomotor, emotional, and spiritual development. During any medical procedure (except for emergencies), the overriding principal binding on medical personnel is the communication triad: medical professional - child-parent (Figure 1). It obliges to inform and communicate in parallel with two people, the parent, and the child. It is worth emphasizing the fact that it is the child who is the direct recipient of our actions and should not be overlooked during the consultation, even though the parents are usually the main decision maker [1]-[4].

There are several protocols for communicating unhelpful messages or those that cause major changes in the life of the patient and his family, these are ABCDE, BREAKS, or SPIKES. Standards have also been developed for assessing the quality of the communicated data according to SORT (Strength of Recommendation Taxonomy), as well as mnemonics, for example, to facilitate the expression of empathy during the consultation such as NURSE [5]-[9].

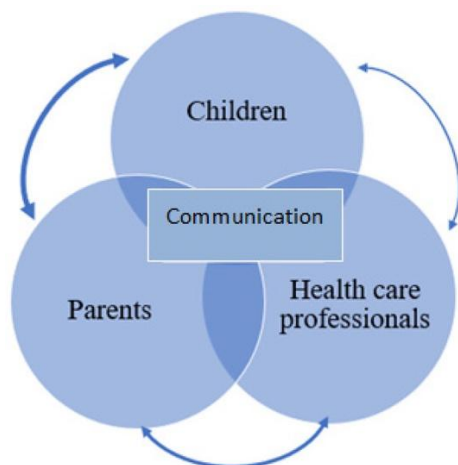


Figure 1. *Communication triad in the doctor-parent-child (patient) relationship* (source: <https://www.mdpi.com/2227-9032/7/1/47/htm>)

The Aim of the work

The aim of the work is to present the methodology of disseminating information about an unfavorable diagnosis of cancer in a child.

Material and methods

Information on the research methodology is presented in Figure 2.

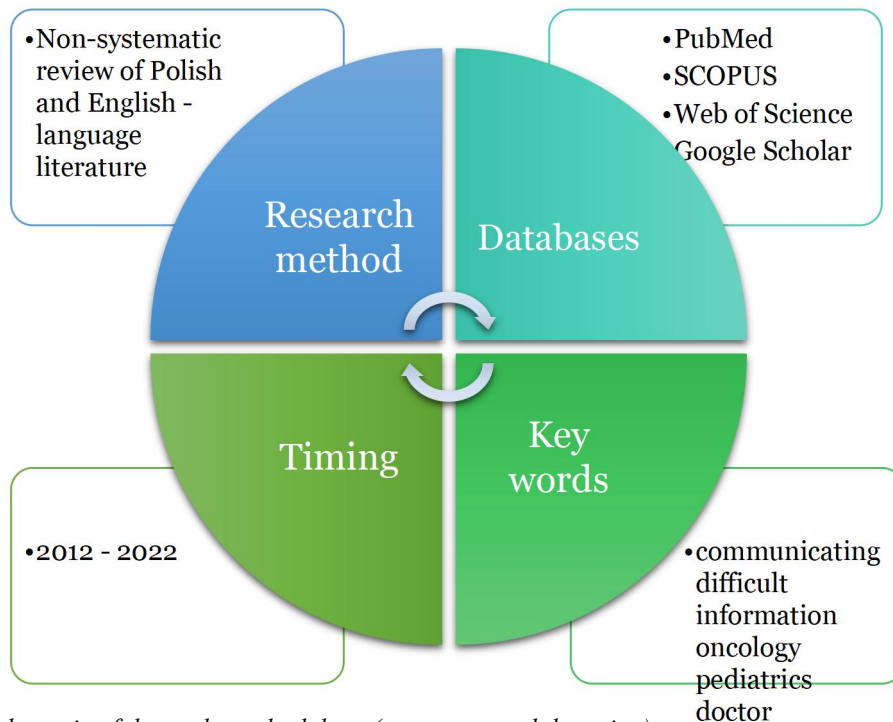


Figure 1. Schematic of the study methodology (source: own elaboration).

Results

For the purposes of the non-discussion study, one of the best-known protocols - SPIKES - was chosen. The expansion of the acronym is: S - Setting, P - Perception, I – Invitation, K – Knowledge, E – Emotions, S - Strategy and summary - Figure No. 3. For each interview, it is necessary to prepare appropriately, ensure a quiet, peaceful place, plan the time to give all your attention to the patient and his parents, remind the basic data about the patient and his disease. In the next phase, the knowledge of the parents and the patient should be examined, and the image and attitude toward the disease should be established. It is necessary to move smoothly from the next phase - to jointly establish expectations, the extent of the detail of information, followed by a summary of the course of the disease, to warn about the need to provide unfavorable information (the so-called "warning shot") and to move to the core of the information. After the unfavorable news resounded, the parents should be given time to receive it, think about it, and experience individual emotions. After a short while, the interviewer is obliged to let the recipient know that his feelings are important and show high-quality empathy. The end of the conversation is to summarize, reassert an understanding of the fullness of the situation, and arrange a plan and purpose for further action [5]-[9].



Figure 3. *SPIKES model* (source: <https://www.islanddocs.com.au/2020/07/20/breaking-bad-news/>)

Dialogue about the diagnosis should initially begin with an individual consultation with the parents, so that they can work through their own emotions on their own, without them erupting uncontrollably in front of the child, which could become a confirmation for the patient of the parent's inability to cope with the fact of their illness and therefore inability to support them. Parents' reactions to their child's illnesses can vary widely. The three basic types of caregivers' perceptions of the disease are harm, threat, and challenge. The most desirable is the last of these, then parents are mobilized to work together for the health of the child, actively participate in the therapeutic process, and are a source of knowledge, hope, and support. It is natural to feel sadness, depression, fear, terror, and anger, but these emotions should not dominate the welfare of the child [10]-[13].

In the next stage, information about the diagnosis should be given to the minor patient in the presence of the parents, using the protocol described above. The child's reaction to the disease depends mainly on age, gender, the severity of the disease, physical condition, and past experiences with the health care system. In the case described here, we are dealing with a 15-year-old boy in whom the onset of cancer has led to a loss of perspective in life. He does not undertake any activities and is passive about the diagnosis and the disease. These behaviors confirm the occurrence of a displacement reaction as an adaptive mechanism. From the case description, it can also be suspected that the boy is strongly emotionally affected by the loss of freedom, and has a sense of incapacitation, generating compensatory aggressive behavior towards his parents. Younger, actively athletic siblings intensify the negative

emotions in the boy, through a comparative reaction. Any objections to the physical exertion associated with the disease reinforce the 15-year-old's belief in the loss of previous activities and the high risk of no return of the pre-disease state (even more so as the cancer is related to the musculoskeletal system). The patient is characterized by depression, and frustration, leading to the dysfunctional behaviors described [14], [15].

Healthy siblings should also learn about their brother's illness, but this task belongs to the parents. It is they, educated, skilled and competent, and ready to pass on the information, who should do so. Brothers and/or sisters of a sick child may feel lonely abandoned, feel anxiety and fearful of abandonment. They also often feel jealousy, lack of parental attention, and feel familial isolation. They usually take over the instrumental household duties of absent parents, which consequently leads to earlier psychological maturation, excessive feelings of duty, and loss of childish happiness, in favor of "adult responsibilities" [16], [17].

Psycho-oncological support for both the child and the parents should be holistic, preceded by an examination of the needs and deficits of the individual therapy links, and during the therapy, the therapist should focus the parents' attention on their own positive resources. Education in coping mechanisms, ways to deal with stress, and styles of conversation with the child are also elements of work with the parent of a child with a disease. A caregiver with knowledge and skills is comfortable in situations of exposure to adverse environmental factors. The psycho-oncologist should also direct the caregiver's attention toward the healthy sibling, pointing out the need to maintain a "golden mean" between the care of the child and one's own development, relationships, and rest. The therapist should systematically carry out the prevention of caregiver burnout syndrome [18]-[20].

Children need support in many aspects related to their own cancer. At the age of fifteen, they usually deny the need for help and place a premium on independence, and high vitality, glorifying their autonomy above all else. A child in this age group is a demanding partner in any conversation, sensing any negative emotions, lies, and falsehoods. Also, the level of language and understanding of the health situation can rank at different levels. Therefore, the specialist providing therapy should adjust to the language, the amount of information, as well as the way it is conveyed to the individual's perceptual level. Children feel, already at the spiritual level, that death is near, and therefore the psychologist should conduct discussions on its understanding, at a pace adapted to the patient's internal resources. Chronic fear of death in the long term can be a source of psychopathology and personality disorders. Therefore, prevention and early perceptual mastery of the concept of death is extremely important. Staying in the hospital also disrupts the child's psychosocial

development, the psycho-oncologist should mobilize the child to interact with peers both in and out of the hospital environment. In the 1980s, van Eys constructed the "truly cured child" theory, confirming relational deficits during cancer. It assumes that full recovery is not only the absence of clinical symptoms, but also proper biopsychosocial functioning appropriate to developmental age [21]-[24].

Conclusions

1. Communicating difficult information is an important competency in the work of a pediatric oncologist.
2. There are many protocols to facilitate the communication of difficult disease information.
3. For pediatric oncologists, the principles of the communication triad in the doctor-parent-child relationship apply.
4. The information provided to the child and parents should be adapted to the child's perceptual abilities, needs, and developmental stage.

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