

ASSESSING THE COMMUNICATION NEEDS OF PARENTS OF CHILDREN WITH CANCER - SEMANTIC, GRAMMATICAL AND PSYCHOLOGICAL ANALYSES

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Abstract:

The objective of the present study is to evaluate the communication needs of the parents of children with cancer from the perspective of the semantic values of the morphological units used and integrated into sentence structures or sentence segments (with response status to open questions) and from the perspective of the factual analysis of the percentages of closed questions. We believe that the results we have reached, processed with interdisciplinary tools of psycholinguistics, morphology, syntax and semantics of the Romanian language and psychological analysis, can provide data that can contribute to the identification of the best strategies for ensuring emotional well-being and increasing the quality of life of families where there is a child with cancer.

Keywords: parents, cancer, child, communication, psycholinguistics.

Introduction

The results of the 2022 study (Niță et al. 2022) regarding the psychomechanics of the language of adolescents with oncological disease, reveal more precisely, the need for affirmation, the need to belong, the desire for independence and individual expression, self-knowledge, the development of the affective system - emotional, but also the importance of parent-child communication in the context of pediatric cancer (Kenny et al. 2021)

represent the benchmarks from which we started the elaboration of this paper. Using mixed methods, we explored the dimensions in which the psycho-emotional support needed by parents of children with an oncological diagnosis, which the mixed care team, could be located.

Having a child diagnosed with cancer certainly represents a trauma for the family and, for specialists, a conjuncture to observe the psychology of parents, who demonstrate exceptional powers to adapt and therefore, resilience to such a major life stress (Phipps et al. 2015). Understanding family culture is essential to ensure adjustment and care related to the illness, as cultural factors influence treatment experiences and coping strategies for children with cancer in several ways, and a specific approach is important for providing care to child patients and their families (Park et al. 2022).

Research in the field shows that parents of oncological children have a high level of unmet needs, including psychosocial, emotional, physical, informational, communication, financial, educational and spiritual needs. To date, little quantitative research has been conducted in the specialized studies regarding the specific needs of parents of children with cancer, which creates uncertainty around the areas that should be addressed carefully (Lewandowska 2022). That is why we considered that the analysis of this group can provide important data to the multidisciplinary team dealing with the case, targeting the communication needs of the parents and, from here, everything that means the path of the treatment of the disease. Because the disease is for every parent a black swan, a very unlikely one (Taleb 2019: 8), which, once installed in the emotional register of the family, devastates the paradise of the micro-universe, producing mental, behavioral, and somatic disorders. A 2022 study identified parental depression as a risk indicator among family resilience factors, affecting the adjustment of families of children with cancer in addition to the severity of the child's condition, stigma and discrimination, and highlighted family communication skills as protective factors (Park et al. 2022).

Material and method

In August 2022, through a survey, 45 parents with children diagnosed with cancer answered two open questions and seven closed statements, to obtain information about their communication needs.

N.B. About the purpose of questions, in a vision of the philosophy of language and Platonic logic, see Constantin Noica (1996: 22): Indeed, the question "charges" the world with the possible. It brings to life more than the answer can satisfy. In a sense, the question never covers itself with or is not covered by the answer; for, apart from the striking fact that, to the questions of knowledge, any answer raises new questions or enlarges the old question (as happened with modern science), the fact remains that the first question

itself raised a wealth of possibilities, which is preserved as an aura around the answer. The partial question, even as the question of existence - a simple question however immediate, a "who is coming?" - projects, both in the consciousness of the questioner and on the work, a bundle of possibilities: many others could come than the one that comes. By the simple fact of asking, the world increased.

The open questions were *What words do I want to hear?* and *What words don't I want to hear?*, and the closed statements were *I miss what I was doing before I came to the hospital/ I learned new things about myself/ In life, everything happens with a meaning/ The important thing in life is to find your resources to deal with stress/ An effective treatment also requires love for those who are by my side/ An effective treatment also requires faith in my heart/ The treatment is more effective if I don't let the stress get me down.* For closed statements, the psychometric ordinal Likert scale was used, with the following response options: 1. Totally disagree/ 2. Disagree/ 3. Neither agree nor disagree/ 4. Agree/ 5. Totally agree.

Results

The responses of the 45 participating parents to the closed statements (M=40, 2 years +- 1.26 SD, 95% CI) are presented in table 1:

Table 1 - the answers of the parents in percentage

Enunciation	Totally disagree (%)	Disagree (%)	Neither agree nor disagree (%)	Agree (%)	Totally agree (%)
<i>I miss what I was doing before I came to the hospital</i>	4,44	2,22	15,56	51,11	26,67
<i>I learned new things about myself</i>	0	2,22	2,22	55,56	40
<i>In life, everything happens with a meaning</i>	2,22	2,22	8,88	53,34	33,34
<i>The important thing in life is to find your resources to deal with stress</i>	0	0	0	56,56	44,44
<i>An effective treatment also requires love for</i>	0	0	2,22	40	57,78

<i>those who are by my side</i>					
<i>An effective treatment also requires faith in my heart</i>	0	0	2,22	42,22	56,56
<i>The treatment is more effective if I don't let the stress get me down</i>	0	0	0	48,89	51,11

For the fidelity of the statements, the internal consistency (α Cronbach) was calculated in Excel, and the internal consistency has a value of 0.86, a very good result (Popa 2011: 85-89) for the reliability of the internal consistency, which indicates that the elements in the statements are correlated with each other. Principal component analysis (PCA) was also used in the statistical program JASP 0.16.3 to identify factors with greater explanatory power (Sava 2011: 162). In other words, PCA reduces the dimensionality of a multivariate data set to two or three principal components, which can also be visualized graphically with minimal loss of information. (Balog et al. 2019). The components with eigenvalues greater than 1 that explain the data variation in the percentage of 57.8% are the following: An effective treatment also involves love for those who are with me, The treatment is more effective if I don't let the stress get me down. (Table 2)

Table 2- Variation of components

Component Loadings				
	C1	P	C2	Uniqueness
An effective treatment also requires faith in my heart	.841			.277
The treatment is more effective if I don't let the stress get me down	.822			.278
The important thing in life is to find your resources to deal with stress	.764			.367
An effective treatment also requires love for those who are by my side	.617			.610
I learned new things about myself	.577			.658
I miss what I was doing before I came to the hospital			.789	.331
In life, everything happens with a meaning			0.643	.432
<i>Note. Applied rotation method is varimax.</i>				

Component Characteristics								
	Unrotated solution				Rotated solution			
	Eigenvalue	Proportion var.	Cumulative	Variance explained	Proportion var.	Cumulative		
Component 1	.902	.415	.415	.882	.412	.412		
Component 2	.145	.164	.578	.165	.166	.578		

For the open questions, thematic content analysis (Vaismoradi et al. 2016) and grammatical, semantic analysis, in terms of philosophy of language (Noica 1996: 26), psycholinguistics of the meanings included in the notional content of the parts of speech used by parents responding to direct questions.

For open questions, thematic content analysis (Vaismoradi et al., 2016), grammatical and semantic analysis (Lyons 1995: 69, 157, 165, 450 passim), in terms of philosophy of language (Kripke 1963; Tîrneanu&Enescu 1966; Russel 2005; Surdu 1991; Noica 1996), of the psycholinguistics of the meanings included in the notional content of the parts of speech used by parents responding to direct questions (Aitchison 1998; Austin 2005).

Thus, to the question *What words do you want to hear?*, the answers were distributed as follows: there were 2 equal answers (8 respondents for each): *It will be fine* and *Believe in God!* The answer *I love you!* Was given by 4 parents and another 12 used extended combinations of two of the previous 3, including terms of solidarity and declarations of affection and certifications of God's care for their cause. The solidarity response *I am with you/we are together* was given by 3 parents; there were other answers, structured as phrases and including sentences of encouragement (*5- Everything will be fine. Trust in yourself! I know you are strong, wise, and balanced/ I am here and we will overcome this together/ Everything will be fine, stop stressing and don't take everything to heart/ I'm by your side, it'll be fine, strength*), but also nihilistic (*1- I don't want to hear a single word*). The resulting statistics warrant extended comment. Thus, parents who prefer abstract terms, such as adverbs (*well, together, alongside*), give a positive, optimistic meaning to the child's future, at least at the theoretical level of the underlying desires. Adverbs being extensions of verbs, are a kind of positive reserve fund in everyone's mind, they save him from the most unusual circumstances (here, during the course of the disease), precisely through the circumstantial meanings they encode. The idea of solidarity that the parent wants from those around him also originates from adverbs (*alongside, together*), which are also modals of verbs, suggesting the parent's confidence

that, in the fight against the child's illness, he is not alone. C. Noica's interpretation (1996): *Not only does the adverb modulate the verb, just as the adjective removes the rigidity and gives all the nuances to the noun, but only through it, through the adverb, the action or state that the verb expresses manages to emerge from inertia is opportune and the semantics of the contexts investigated by us.*

The Romanian philosopher had made an analysis and labeling of the cultural epochs of Europe, fixing each part of speech which, he believes, characterizes their structure. Taking the interpretation with the same tools, but, mutatis mutandis, substituting European culture with the ages and, hence, with human experiences, we admit that, in childhood, the island is, in order, under the dominance of the noun, which is nominative and descriptive, followed by of the adjective, whose role is to sprout the noun until its dissolution. Adulthood is under the sign of the adverb, which enlivens, specifies, but also extends the action of the verb to its extreme limits. The verb is the sine-qua-non part of speech, characterizing the species in an absolute way: *the verb is present everywhere, in speech, as well as in the manifestations or processes taking place; he is their heart, their living center, in modern terms he is the functionary par excellence, that is, the goal-creating term. Being like that everywhere, the verb no longer characterizes anything, but it demands characterizations, of the order of those that the adverb brings to it.*

The evocation of God, which appears in 8 responses, is established naturally in the context of the disease, the statement that gives its meaning and grounds it in the parents' pre-mental being the well-known saying that the doctor treats, God heals. From our direct experiences, we have found that both the child and the parent form a triptych with God throughout the treatment, and also after. The prayer, the invocation, and tears that accompany their dialogue with God are props with great benefits for recovery, creating a comfort of the idea that they are not alone, that someone else, with the greatest force in the universe, directs their destiny at stake. In a few cases, I also highlighted a mutiny against God who allowed the disease to enter the family, a revolt configured by the question *Why (exactly) me?* Integrating the questioning into the complicated context of the illness, I assessed that this is an attitude practised by those who do not have the exercise of systematic encounter with the sacred or by atheists. Other respondents transcribe to the maximum expected words, words of spirit approved and practiced by generations: *With faith you will move mountains, Nothing without God, With faith in God you can do anything, God does not leave us, Stop putting everything to heart, Everything has a solution in life.* A single respondent from the sample of parents *does not want to hear anything*, he perceives the child's illness as a disaster and, in order to recover, he needs, as M.

Heidegger (2019: 112) says, solitude, isolation from anything worldly. But, we find in C. Noica (1996: 26), any answer comes, in fact, from an inverted question, everything we assert can naturally be questioned. In our study, the answers *Everything will be fine, God is with you, I love you are*, primarily, in the premental of a parent, queries that betray bitter existential doubts: *Everything will be fine? God is with me? Does he love me?*, that is, it suggests those uncertainties that he turns into possible optimistic assertions, because he wants the medically complicated situation to have a positive finality.

As verbal modes, statements formulated by parents to open questions are organized in the core of imperatives, which have the maximum role in positive suggestion: *Be strong!, Believe in God!, Don't give up!, Fight!*. The meaning of the imperative is to stimulate the absolute involvement of the parent in the story of his child's illness. Among the verb tenses, the future is the most frequently used, because it is the time of the projections in everyone's mind. In the present case, it is time to wait for the optimal conditions for the desired, subjective reality, projected as an ideal, to become pure reality, to re-enter the current life of the family. Thus, a hidden desire will be established, which is born smouldering in the parent's mind and which is ready to trigger the isotopes of a future. Fr. Hegel was convinced that, in existential diptychs, the slave models his master, that the defeated models his winner (Hegel 2015: 65); in the present couple, we are convinced that the parent of the one in pain can shape the future of his child, building it according to his wish, by act of will. The conglomeration of data from chaos theory is also at play here, because what is the future reality for a parent whose child has an oncological diagnosis but a sum of positive events, which are expected to come from anywhere, according to an ideal that he has built as a script?

Propositional constructions (Lyons 1995: 362, 451, 470) are organized around the verbal center 'to be', which is best represented in the answers, signifying, through the future or present indicative forms, the de facto state of humans. The Romanian philosopher glosses over the fact that, in the Romanian language, something different happens compared to other languages (Noica 1996: 26): With the verb to be, all kinds of linguistic formations are obtained. For example, in modal logic, the meanings of contingency, impossibility, possibility are built with stable blocks of terms, as it is possible, it happens (Kripke 1963), or with epistemic modal operators which, in some views, are also illocutionary operators [Lyons 1995: 450]. In Romanian, they also derive from the verb to be, compounded with itself, as C. Noica says, as it was to be. From actual reality, parents extract ideas that they materialize in words, the logic of the existing itself giving the logic of the possible and the necessary (Noica 1996: 26; Surdu 1991; Kripke 1963; Bidu-Vrânceanu et al. 2001: 321)]. In the contexts investigated by us, the verb to be is sovereign, in the statements about the being, because the disease is a

circumstance between human and Being (Noica, 1996: 26; [Nietzsche](https://www.libris.ro/librarie-online?fsv_77564=Fr.%20Nietzsche,%20M.%20Heidegger) [HYPERLINK "https://www.libris.ro/librarie-online?fsv_77564=Fr.%20Nietzsche,%20M.%20Heidegger"](https://www.libris.ro/librarie-online?fsv_77564=Fr.%20Nietzsche,%20M.%20Heidegger) & [HYPERLINK "https://www.libris.ro/librarie-online?fsv_77564=Fr.%20Nietzsche,%20M.%20Heidegger"](https://www.libris.ro/librarie-online?fsv_77564=Fr.%20Nietzsche,%20M.%20Heidegger) Heidegger, 2020). On the other hand, the verb 'to love' is used by parents, which suggests a great need to express affection. In the colloquial style, 'I love you' also signifies solidarity, and can, in fact, be read with multiple semantics: as a greeting formula when parting in family or friend groups, as a certainty of feelings; other times, it seems to be used neutrally and slightly de-semanticized from its affective meaning, being contextualized with goodbye! The option for broader syntactic structures revealed to us a category of parents who are in great need of multidimensional support (*I know it's hard for you, I'm here if you need something, if you want to talk to someone, if you want someone to listen, if you want to cry or if you just need a hug, The treatment is working, it's on the right track, I don't want to hear anymore: you are strong, you can, you have nowhere to go, Look at your children's smiles, they are there because you faced difficult situations!* demonstrate that their authors are in a projective relationship with the world they have already constructed (Surdu 1991).

These complex architectures evoke deep feelings and, for the care team, are a sign of an involvement that needs to be much more organized and diversified in supporting parents.

The analysis of the words that the parent of a child with cancer does not want to hear revealed to us the opinion that, certainly, they have been heard before, from diagnosis to the moment of applying the questionnaire, because they can hurt, which explains why he doesn't want them repeated. In this way, he builds a secure area for himself, keeping away contexts that would disturb his peace, and affection and make his subsequent actions difficult. The results are as follows: out of the 45 parents surveyed, 2 do not want to hear compassionate words, because, in the chaos of the disease, they cannot be anchors of strength to support him; 3 parents do not accept the terms of resignation (*Whatever you do, the end is the same, In the context of the disease, everything is possible, Keep calm, that's it!, That's how it was - the last being, in our opinion, the opposite of was to be*), for they induce the state of inaction in the future or of blasphemy against any possible action, the end being the same. Another parent rejects the suggestion of self-isolation, motivated by the fact that the future, which means a long series of treatments and investigations, has its obligatory dynamism. Anticipatory verdicts with a negative meaning, represented by syntactic combinations of the type: the negation no + the copulative verb to be + the adverb good (it won't be good, it's not good) or by the verbs to be able, to be able to in the negative forms (you can't, it's not maybe) were rejected by 6 respondents. Some of the parents

declared themselves against encouraging words, such as *You are strong, you can cope, You must be strong. God is punishing you., It will be fine., And others go through this., Come on, you can!*; the motivation depends on the history of the person, who, in our view, has the exercise of solving family problems alone. In the new context, the parent does not want to be alone anymore, he needs support. It also irritates a parent whose child is diagnosed with cancer to be suggested that they will face, early on, the battle is now unequal, with a treacherous and merciless disease, where weapons freeze and support falls silent (Sontag 1995). Other parents don't want to hear a word about the disease; these are those who deny it or who avoid pronouncing its name, out of protectiveness or superstition.

Most parents reject pessimistic terms; for example, one respondent rejects the sentence 'There is nothing more to be done', because it brings into focus the human finitude, his collapse in the face of incurable disease, his placement as in an antechamber of death. Another remark that is not accepted by parents is to look for guilt for the appearance of cancer in a child in the family, because they know that, in the scenario of the disease, the effectiveness of the treatment is also supported by its acceptance as a datum, without unnecessary questions (Sontag 1995). An analysis of the preferred parts of speech in statements that a parent does not want to hear highlights the presence of the modal operators *could* and *should*, which structure the statements according to their meanings of possibility and necessity. Thus, if it could reveal the inner springs of human, stimulating them for their necessary exercise towards a future with many uncertainties, it should suggest, through its imperative substratum, the need for the execution of some subsequent actions, the realization of which is under the auspices of a nebulous maximum (Bidu-Vrânceanu et al. 2001: 36).

As syntactic structures, the terms that a parent does not want to hear are generally organized into developed sentences, ready-made by them, which proves our assumption that they have been present in the history of their thoughts (*Why it happens so?*). Mono-member sentences, such as *It doesn't matter, Negative, Too bad, We are waiting, Advice, About the patient's condition* highlight a balanced, well-organized person, willing to go through all stages of treatment with the child. Other syntactic structures are larger phrases, launching either multiple themes (*You have to be strong, God is punishing you, It will be okay, Others go through this too, You have to see the glass half full, That's all we can do*), or containing, parallel to the actual communication plan, also a subjective plan, of the comments on it, of the incidence (*Let it go, Don't be upset!, Wow, What a trouble!, Of, but why you can not!*).

Discussions

The recommendations of the pediatric psychosocial preventive health model also assume that family functioning, effective communication, assessment of cancer diagnosis and quality of life are also related to the management of emotions given by the disease (Van Schoors et al. 2019). Pediatric cancer is actually a family disease, leading to emotional instability, uncertainty, stress, and feelings of guilt. As parents are the primary caregivers of the child, the multiple and complex duties arising from the child's illness result in many challenges that need to be addressed (Mojen et al. 2021). A 2022 study used a narrative methodology to examine online accounts written by Canadian parents of children with cancer, which focused on exploring the experiences, events and emotions described in personal narratives, with attention to how and why the stories are told, on their content and the context from which they appear.

The methodology was based on interpretive epistemology and constructivist ontology, in which knowledge is characterized as subjective and contextual, and reality is constructed by individuals and unique to individuals. Thus, three dominant narrative types related to the Idealized Child, Belief, and Failure emerged, and the results obtained can improve understanding of family experiences with childhood cancer and inform psychosocial interventions that help healthcare teams more effectively support families of children with cancer (Burlles&Bally 2022). Awareness of the emotional aspects of cancer, such as threat perception, protection and affection seeking, can help in treatment planning to provide better medical care for both the patient and the family (Arruda-Colli et al. 2015).

A 2020 study highlights key elements that influence family support for the pediatric cancer patient, namely the psychological and spiritual well-being of family caregivers. Psychological well-being involves managing anxiety, depression, helplessness, suffering. And spiritual well-being involves hope, the meaning of life, inner strength and the exercise of faith (Bekui ey al. 2020).

Conclusions

In the present study, we found that, in the open-ended questions, three families of spirits of parents who have a child with cancer are identified: the optimists, the moderates/reservations, and the nihilists. Optimists and moderates stand out from the answers to the question What do you want to hear? and moderates and nihilists to the question What words do you not want to hear? Our conclusion claims that if we know the communication needs of the family type, we can make the standards of care more efficient (Benini et al., 2022), namely the assessments of the specific needs of children and their families and, from

this, the assistance of parents, in maintaining their parental role and effectively dealing with children's troublesome behaviours.

The results of our research highlight the fact that psychological and spiritual well-being complement each other, depending on the type of family, and the communication themes necessary for the emotional prosperity of families in which there is a child with cancer are: initiative, positivity, tranquillity, perseverance, tenacity, compassion, empathy, engagement, social connectedness, wisdom, self-awareness and meaning-making. The communication themes that emerged from the words a parent wants to hear or doesn't want to hear are also found in a 2021 study, which emphasizes that they aid in a individualized assessment of quality care during each stage of treatment and to an intervention adapted to the stage of development (Cho et al. 2021). The themes that emerged from the open questions in our study - the need for communication and the need for acceptance - are also found in the results obtained from the closed questions, and both categories of questions elaborate on the importance of meeting these needs to reduce the elements of distress, such as pain, anger, anxiety, depression, to manage the psycho-emotional impact of pediatric cancer, which is profound and difficult to manage.

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