



Original research article

Psychological support of hospitalised children and their parents in Hungary

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Abstract

Introduction: When children are undergoing hospital care, psychological support is important. This includes providing a child-friendly environment and care, information and preparation for the examinations appropriate to the child's age, stress reducing methods applied according to the child's intellectual level, and the presence of parents.

Objectives: In the course of the study, we examined the psychological preparation and support provided during hospital care in Hungary on the basis of parental opinions. Our goal was to get to know the activities of children's nurses in connection with the psychological preparation and support of children. In light of the results, another goal of the research was to prove the need to adapt a support system, already widespread internationally and with proven positive effects, in Hungary.

Methods: A descriptive and multivariate analysis of the results of the online, quantitative questionnaires filled in by the parents of children between the ages of 0 to 14 who spent at least three days in hospital.

Results: Based on the opinions of the 566 parents who filled in the questionnaires, the psychological preparation of children was carried out in a minimal number of cases in Hungarian hospital care. During the hospital treatment, parents evaluated their own anxiety level as higher than that of their children and stated that they would have liked psychological support themselves.

Conclusions: In Hungarian paediatric care, psychological support given to children and parents is inadequate. The work of Child Life Specialists is essential within the childcare system, and it is essential to work out how to introduce and involve such specialists in caring for children

Keywords: Child; Child life specialist; Childcare; Parents; Psychological support

Abbreviations:

ACLP – Association of child life professionals; ANOVA – analysis of variance; BSc – Bachelor of Science; CLS – child life specialist; IES-R – Impact of Event Scale-Revised; KEB – Committee of Research Ethics; MSc – Master of Science; *p* – probability; PFCC – Patient-centered and family-centered care; SD – Standard deviation; PTSD – Posttraumatic stress disorder; SPSS – Statistical Package for the Social Sciences; Ss – Subjects; STS – Secondary traumatic stress; STSS – Secondary Traumatic Stress Scale; TUKEB – Council of Sanitary Science, Committee of Science and Research Ethics

Introduction

Hospital care can evoke negative feelings for children since they generally see the doctor if they are ill, have pain or when getting compulsory vaccinations; therefore these events may have negative impacts on them. A sick child is more susceptible to harmful impacts since the physical and psychological strain makes the child more sensitive than his or her healthy companions (Slifer, 2014). A change in the environment that they are used to can, in itself, be a source of stress for children – and in particular for babies. This is compounded by the fact that infants possess a lower coping strategy level (Hárdi, 1995; Ler-

wick, 2013). During children's hospital treatment psychological support is essential. This includes providing a child-friendly environment and treatment, information and communication appropriate to the child's age, stress relief methods applied according to the child's intellectual level, and ensuring parental presence, all of which are ever more prevalent worldwide in paediatric care (Brown et al., 2016). Nowadays, patient-centered and family-centered care (PFCC) is already a natural phenomenon in every paediatric department – as the family plays a prominent role in the process of restoring children's health. Children's nurses accept this family-centered care as an ideal philosophy within the care of children and their families (Boztepe and Kerimoğlu Yıldız, 2017; Mendess, 2016). An advan-

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tage is that it supports the retention of parental roles; parents may take part in therapeutic decisions which in turn increases parental trust in healthcare workers (Bairda and Kracen, 2006; Eichner and Johnson, 2012). The relationship between a mother and her child is reciprocal and dynamic, so they are able to influence each other's behaviour (Mérei and Binét, 2016; Novick and Novick, 2014). Thus, parents' anxiety may affect their children's emotions during hospital treatment, so it is also essential to deal with a child's family members (Pannella, 2016).

Olsson et al. (2018) investigated parental anxiety with the help of Impact of Event Scale-Revised (IES-R) questionnaires in 48 parents whose children were treated in hospital. Moderately high levels of anxiety were observed in parents, with the memory intrusion scale showing the highest values.

Franck et al. (2015) carried out a survey of 108 parents with the help of the same questionnaire in the third month after the hospital care of children and found nearly the same values.

Possibilities for providing support to children and parents

Abroad, child life specialists (CLS) are highly qualified healthcare professionals working in the field of paediatrics (e.g. at in-patient wards, intensive care units, departments of oncology or primary care). The CLS form an integral part of the healthcare team and provide assistance to children and their parents during the hospital treatment process as well as spiritual support, including bereavement support, if needed. They prepare children for interventions as appropriate to their age, for which they use toys or stories, or mobile apps and anatomy books for adolescents. During interventions, they apply distractions, such as blowing bubbles, telling stories, performing puppetry or rocking and caressing babies. They also get involved with the family, siblings and classmates of the sick child. The child's emotional state is assessed and they may request the involvement of additional specialists (e.g. a psychologist), where necessary. They create a child-friendly atmosphere (e.g. by developing a playroom) and organise paediatric voluntary programmes as well (Boles et al., 2020; da Silva et al., 2017; Zhang et al., 2015). The importance and efficiency of their work have been proved in numerous fields with the help of studies.

The CLS are present even before the child's birth. At the Le Bonheur Fetal Center in Memphis they support families where prenatal congenital disorders have been diagnosed (Tucker and McCann, 2013). Then, at the NICU the main tasks of the CLS include bereavement support, training of families, and emotional support (Smith et al., 2014). In cases of chronic and tumorous diseases their aim is to provide emotional support for the child and the family during long hospital stays or palliative therapies, as well as providing bereavement support (Basak et al., 2019).

The CLS also plays an important role in the peri- and post-operative support of children and their families. They prepare children for surgery with the help of toys and books and apply play therapy after the intervention. Meletti et al. (2018) conducted a study involving 118 children between the ages of 2 and 8 and their parents, half of whom took part in preoperative preparation, while the other half did not. It was demonstrated that the anxiety of both the children and parents who had taken part in preparation was reduced in comparison to the control group.

By applying different methods, the CLS can reduce the necessity of anaesthesia during some interventions (Grissom et

al., 2015). Scott et al. (2016) found that in children between the ages of 3 and 12 treated with radiotherapy (425 subjects), the work of the CLS could reduce the need for daily anaesthesia. For instance, during the preparation for MRI examinations they show audio and video recordings so that these do not cause anxiety for them during the examination (Durand et al., 2015; White, 2017).

Materials and methods

Objectives

Our overall goal was to conduct a survey of parents of children aged 0–14 who were hospitalised for at least 3 days in order to examine the psychological preparation of and support provided to children and parents. Using the results, we can make recommendations on how to develop and adapt the CLS care system in Hungary with its proven positive effects, including its placement in the care structure and the levels and fields of education to obtain the related competences.

Sampling procedure

The TUKEB examined the research plan that we submitted and granted the professional ethical licence under number ETT TUKEB 31352-3/2019/EKU.

The electronic questionnaire used in our survey was created with the help of the Google application specifically designed for the programming of online questionnaires. We had the parents of children aged 0 to 14 who were hospitalised for a minimum of 3 days fill in the parental questionnaire. This questionnaire was sent to parents on the basis of individual contacts by the registered instructors of a Hungarian teacher training company. It was also published at schools and on the Facebook page called "Gyógyhír" ("Medical News") of a Budapest children's hospital. Data collection started on 1st July 2019 and ended on 31st January 2020 – during which time 566 parents filled in the online version. All questionnaires received during the survey period were assessable.

Research instruments

The instruments consist of two parts. The first part is made up of our own questions and the second part consists of the instrument: Impact of Events Scale.

Parental questionnaire

The questionnaire consisted of 40 questions: I. agreement to participate in the study (3 questions), II. sociodemographic questions regarding the parents (5 questions) and the children (8 questions), III. questions related to the psychological strain related to hospital care for both children and parents (24 questions). The questionnaire contained 21 closed-ended questions, 6 open-ended questions, and a five-point Likert scale for 12 of the questions. Besides the sociodemographic questions, the children's gender, age, the time and length of the treatment, previous diseases, the number and reasons of previous hospital stays were assessed. In the following questions the fear and psychological strain of the parent and the child, satisfaction with the hospital stay and with the preparation during this period, as well as the evaluation of the child-friendly atmosphere of the hospital were assessed with the help of a 5-point Likert scale.

Impact of Events Scale (IES-R)

In our study, we used the improved Hungarian version (Perczel-Forintos et al., 2018) of the Impact of Events Scale deve-

loped by Horowitz et al. (1979). This measures the frequency of phenomena describing subjective stress caused by a traumatic event on a 5-point Likert scale rated between 0–4 end-points (where 0 means not typical at all and 4 means typical each time). Its sub-scales included memory intrusion (re-living of events), avoidance (active avoidance of stimuli reminding them of the trauma) and hyperarousal (sensitivity to the stimuli of the outside world). Parents had to define – in relation to the period that their children were sick – to what extent each statement was characteristic of them. A higher score signified a higher level of subjective distress in connection with a negative life event.

The processing and analysis of data

The processing and analysis of data was carried out with the help of the SPSS 25.0 statistic software package (IBM Corporation, Armonk, NY, the United States of America). During the analysis of data we examined the relative frequency distribution of responses to each question and, in case of derived indexes, also their descriptive statistics.

Before the analysis, each sub-scale of the IES-R had been transformed per sub-scale log ($x + 1$) in order to normalise their distribution. Analysis of variance (ANOVA) was applied in order to be able to examine how the sub-scales of the IES-R affected the given values of some questions. The variables of the ordinal scale were analysed with the application of ordinal regression. Questions for which more than one answer could be marked were tested by analysing contingency tables using the χ^2 (Chi-squared) test. The significance level was set at $p < 0.05$ in every case.

Results

Sociodemographic results

The demographic indicators related to parents is shown in Table 1.

46.1% (261 subjects) of the children treated at the hospital were girls and 53.9% (305 subjects) were boys; their average age is 4.40 years (Std: 3.846, Min.: 0, Max.: 14). The hospital treatment happened within one year in the case of 216 subjects, and more than a year ago in the case of 350 subjects. On average, the children spent 7.28 (SD: 10.763, Min.: 3, Max.: 100) days in hospital for the treatment of respiratory, kidney- and urinary tract diseases – as well as due to accidents and congenital disorders. Before this occasion, the observed children

had been treated in hospital 1.70 times (SD: 3.268, Min.: 0, Max.: 35) on average. In the case of 111 subjects, the children had a permanent disease for which they receive treatment regularly; this is usually a congenital developmental and genetic disorder, prematurity or diabetes type 1.

Data regarding children's care

57.2% of the parents (324 subjects) were next to their children each time an intervention took place, 40.8% (231 subjects) could be there only partially, and 1.9% (11 subjects) could not stay with their children. On a 5-point scale the parents evaluated with an average of 4.93 (SD: 0.34) how important they considered having pre-intervention psychological preparation appropriate to the children's level of intellect. The child-friendly care experienced during hospitalisation was assessed with an average of 3.41 (SD: 1.354). In those cases when the psychological preparation of children was carried out, the parents gave a higher score to child-friendly care ($p = 0.000$). We used the same scale to assess how characteristic it was to explain or present the intervention process to the children playfully. Based on the parents' judgement, the most appropriate answer here is "no such thing happened" (Mean: 2.03, SD: 1.362). According to parents' opinions, the preparation of the children before the operation did not occur.

If the children were prepared psychologically, this was carried out mainly by a nurse or parent, mostly before algesic interventions (e.g. blood sampling, peripheral venous cannula insertion, injections). According to 9 parents, tools were used for each intervention. 47 parents considered that the children received an explanation of only some interventions, mostly with the help of toys (22 cases), books (6 cases) or presenting the equipment related to the intervention (9 cases). The child's age affected the frequency of preparation: the older the child, the more often they were given preparation ($p = 0.000$). According to parents' views, the preparation had a positive effect on the child; it helped reduce the children's fear so that they allowed the intervention to be completed, they understood why it was necessary and thus did not consider it as a punishment.

192 parents (33.9%) felt that their children were provided with the proper information about the interventions appropriate to their age and level of intellect. In those cases when the children's preparation was carried out, parents rated the child's psychological support higher ($p = 0.000$). A 5-point scale was applied in order to evaluate the parental experience of the preparation and care, the results of which are included in Table 2.

Table 1. Sociodemographic indicators regarding parents (n = 566 subjects)

Gender: female: 547 subjects (96.6%), male: 19 subjects (3.4%)		
Age: Mean: 38.23, SD: 6.827, Min.: 21, Max.: 82		
<i>Highest educational qualification</i>		
Primary school	2 Ss	0.4%
Vocational high school	140 Ss	24.7%
Nursing training	97 Ss	17.1%
College/BSc	183 Ss	32.3%
University/MSc	142 Ss	25.0%
Other: (PhD., Doctorate)	2 Ss	0.4%
<i>Marital status</i>		
Married	509 Ss	89.93%
Single	57 Ss	10.07%
Number of children: Mean: 1.98, SD: 0.897, Min.: 1, Max.: 7		

Table 2. Further questions of the parental experience related to preparation and care

	Mean	SD
How adequate did you consider your child's preparation and orientation to be?	2.69	1.494
Were your child's anxiety and fear handled in a way appropriate to his/her age during interventions?	3.00	1.504
Were all the staff on the ward very friendly and patient and did they spend adequate time with you and your child?	3.19	1.397
Did your child find the nurses kind?	3.21	1.368
All in all, how would you assess your child's psychological preparation during the hospital stay?	2.58	1.419

Data related to psychological support for the child and parent

A 5-point scale was used to assess how scared the parent and, in the parent's view, the child was of hospitalisation when entering the hospital. On this scale, the higher the value the higher the level of anxiety. Parents evaluated their own fear on average at 3.85 (SD: 1.288) and their children's fear at 3.48 (SD: 1.419). On the same scale, parents replied to the question of how psychologically demanding the hospital stay was for them with an average of 4.15 (SD: 1.124) and for their children with an average of 3.33 (SD: 1.318), which showed a significant correlation ($p = 0.000$). Parents' own anxiety showed correlation with the number of children, meaning parents with more children assessed their own psychological strain to be of higher value ($p = 0.040$).

When children received psychological preparation, parents estimated their own and their child's psychological strain to be lower ($p = 0.000$). In cases where parents evaluated the children's psychological support positively, their own anxiety seemed to be at a lower level too ($p = 0.000$).

Parental anxiety showed strong correlation with the child's age: the younger the child during the hospital care, the higher the values of the parents' psychological strain ($p = 0.000$). In addition, the more time parents spent at the hospital with their children, the higher they estimated their psychological strain ($p = 0.015$). 68.9% of the parents did not receive any psychological support during the hospital treatment, even though a large section of them required it. Parents who did not receive any psychological support rated their own anxiety higher during the hospital treatment ($p = 0.001$).

Results of the IES-R questionnaires

The sub-scales of the questionnaires of the Impact of Events Scale were examined on the basis of parents' assessment, the results of which are shown in Table 3. Within our study it was also observed that the length of time between the hospital stay and the completion of the questionnaire did not have any effect on the results.

Table 3. IES-R sub-scale values

	Mean	SD
Memory intrusion	1.604	1.101
Avoidance	1.181	0.808
Hyperarousal	1.268	1.021

Analysis of variance (ANOVA) was applied in order to analyse how much the IES-R sub-scales influenced the values given to each question of the independently created questionnaire. (Table 4.)

The memory intrusion sub-scale showed correlation with the educational qualification ($p = 0.01$): parents with university qualification had higher values. The avoidance sub-scale seemed to have significantly higher rates in the case of parents who were at their children's side continuously ($p = 0.03$). Correlation was also found, in cases of those parents whose children had already received in-patient hospital treatment: the rate of the sub-scale of arousal was lower ($p = 0.36$). The value of the previous sub-scale also showed correlation with the extent of the psychological support of parents ($p = 0.003$): parents who received emotional support had a reduced arousal level.

In relation to the length of the hospital treatment, it was observed that a lengthier treatment period increased the val-

ues of the sub-scales of memory intrusions ($p = 0.012$) and arousal ($p = 0.01$). In the cases when children received preparation, the values of the sub-scales of memory intrusions ($p = 0.046$) and of avoidance ($p = 0.03$) were lower. For all three sub-scales a correlation was found: parents who evaluated their fear of the hospital treatment and their psychological strain during the hospital care to be higher, showed higher values of the IES-R sub-scales.

Discussion

In our study, we examined the experience and opinions of the parents of children treated in Hungarian hospitals in connection with psychological preparation and support. We chose the method of an electronic, self-administered questionnaire. The advantage of this is that we obtained data on a widespread scale from different parts of the country.

The average age of the hospital-treated children who took part in this study was 4.4 years and, on average, they had previously received in-patient care 1.70 times. In contrast to international studies, previous hospital experience did not have any effect on the results of our survey.

Following our basic hypothesis, it is also clear from parents' opinions that children rarely receive psychological preparation before examinations and interventions during hospital care, and tools appropriate to the child's age, such as toys or tablets are only used in low numbers.

In Hungary, parents were of the opinion that the preoperative preparation of children did not occur. For their part, Melletti et al. (2018) stated that the anxiety of those children and parents who had taken part in preparation was also reduced in comparison.

According to the answers from the open questions, parents whose infants required hospital care did not consider it important and did not understand what kind of preparation and psychological support their children could be provided with by the hospital staff. The CLS apply distraction during interventions for infants, including rocking and stroking (Boles et al., 2020), which is unknown to parents at present. Our study showed that the younger a child was, the higher the values of parents' anxiety seemed to be. However, bigger children are given preparation and distraction more often during interventions, which in turn reduces parental anxiety. Therefore the younger a child is, the higher the danger of parental anxiety.

If the child was provided preparation, this was carried out by nurses or parents in most of the cases. In Hungary, due to the large shortage of professionals and the resulting number of patients per nurse, nurses are often unable to carry out the psychological preparation of and give support to children.

In other countries CLS experiments showed great support, not only for parents but also for the healthcare team, since a prepared child is calmer and interventions can be carried out much more easily and quickly. As children are less scared, the nursing staff also experienced fewer negative situations. In a study, Drayton et al. (2019) investigated the opinions of children's nurses on the work of the CLS at an Australian hospital. The results showed that the work of the CLS had a positive effect on the nurses' work as well. Nurses found the preparation for the interventions and the distracting techniques to be the most useful – and they might not be able to provide them to children in every case without the presence of the CLS due to lack of time. Besides, children's nurses felt that they were able to focus on the interventions much better.

Table 4. Comparison of the IES-R sub-scales with the questions of the questionnaire

	IES-R sub-scales	Mean square	F	Sig.	Partial eta squared
Educational qualification	Intrusion	0.429	3.022	0.011*	0.029
	Avoidance	0.063	0.577	0.718	0.006
	Arousal	0.069	0.453	0.811	0.004
The time of the child's treatment	Intrusion	0.224	1.579	0.164	0.015
	Avoidance	0.184	1.675	0.139	0.016
	Arousal	0.232	1.517	0.183	0.015
Parental presence during child's hospitalisation	Intrusion	0.427	3.002	0.084	0.006
	Avoidance	0.471	4.283	0.039*	0.008
	Arousal	0.083	0.542	0.462	0.001
Frequency of parents' psychological support during children's hospital stay	Intrusion	0.251	1.768	0.184	0.003
	Avoidance	0.001	0.010	0.919	0.000
	Arousal	0.679	4.434	0.036*	0.009
Length of hospital care	Intrusion	0.905	6.366	0.012*	0.012
	Avoidance	0.003	0.024	0.877	0.000
	Arousal	1.591	10.394	0.001*	0.020
Number of previous hospital treatments before this one	Intrusion	0.067	0.469	0.494	0.001
	Avoidance	0.155	1.412	0.235	0.003
	Arousal	0.675	4.409	0.036*	0.009
The level of parental fear at the time of entering the hospital	Intrusion	2.966	20.871	0.000*	0.039
	Avoidance	0.745	6.776	0.010*	0.013
	Arousal	2.242	14.651	0.000*	0.028
The level of parents' psychological strain during hospital attendance	Intrusion	11.326	79.705	0.000*	0.134
	Avoidance	6.702	60.987	0.000*	0.106
	Arousal	12.002	78.434	0.000*	0.132
Frequency of children's preparation for the examinations	Intrusion	0.568	3.996	0.046*	0.008
	Avoidance	0.479	4.362	0.037*	0.008
	Arousal	0.367	2.397	0.122	0.005

* $p < 0.05$.

Due to the shortage of time for nurses, which is also clearly shown in our study, preparation is often carried out by parents, which has the disadvantage that the rate of parental anxiety is mostly the same as that of the child's, and the parents are not familiar with the process of the intervention in detail.

The emotional state of the parent and the child affect each other, so psychological support should be provided to the parent as well as the child. Parents estimated their own anxiety to be higher than that of their children, the reason for which might be that they could see the possible outcome more realistically or they were worried about complications. Besides, a significant correlation was found showing that parents with multiple children assessed their own psychological strain to be higher.

The work of the CLS is also helpful for parents. On the basis of a study completed by LeBlanc et al. (2014) using questionnaires filled in by 49 parents of children between the ages of 1 to 7, it was found that parents evaluated the work of the CLS positively. In their opinion, the CLS helped them a great deal during the hospital stay.

On the other hand, in our research, more than half of the parents did not receive any emotional support during the hospital stay – even though they believed it to be essential. The results of the Impact of Events Scale also show that parental anxiety was greatly influenced by the rate of children's preparation and of parents' psychological support. The parents who had received emotional support represented a level of reduced arousal, and in those cases when children received preparation, the values of the subscales of memory intrusions and of avoidance were decreased. The data of our research corresponded to the results of the survey by Olsson et al. (2018): the value of the IES-R sub-scale was highest for memory intrusion.

Conclusions

We can deduce from the research results that the preparation of and psychological support given to children and parents reduce the stress related to hospital treatment. At present, due to the shortage of specialised staff, the Hungarian hospital care system is not able to provide psychological preparation

and support appropriate to the child's age for each intervention.

The results of our study show that it is essential to develop the Hungarian adaptation of the CLS care system with its proven positive effects. This includes CLS training and involvement in the care structure. The Hungarian training of district nurses would make CLS training possible in Hungary, as nearly half of their training programmes are identical.

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Division of labour among authors

NP: Planning of the study, creation of the measuring instrument, obtaining permissions, research of literature, database management, statistical analysis, wording of the manuscript. EG: The management of the database and statistical analyses. IB: The professional appraisal of the manuscript. The final version of the article was read and approved by all the authors.

Conflict of interests

The authors have no conflict of interests to declare.

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Psychologická podpora hospitalizovaných dětí a jejich rodičů v Maďarsku

Souhrn

Úvod: Během pobytu dětí v nemocniční péči je důležitá psychologická podpora. Ta zahrnuje poskytování prostředí a péče vhodné pro děti, informace a přípravu na vyšetření přiměřené věku dítěte, metody pro snížení stresu odpovídající intelektuální úrovni dítěte a přítomnost rodičů.

Cíle výzkumu: V průběhu studie jsme zkoumali prostřednictvím názorů rodičů psychologickou přípravu a podporu poskytovanou dětem během nemocniční péče v Maďarsku. Naším cílem bylo poznat aktivity dětských sester v souvislosti s psychologickou přípravou a podporou dětí. Na základě výsledků bylo dalším cílem výzkumu ukázat na potřebu vytvořit v Maďarsku systém psychologické podpory dětí, který je již v zahraničí rozšířený a má prokazatelné pozitivní účinky.

Metodika: Deskriptivní a multivariátní analýza výstupů získaných z kvantitativních online dotazníků vyplněných rodiči dětí ve věku od 0 do 14 let, které strávily alespoň tři dny v nemocnici.

Výsledky: Dle názoru 566 rodičů, kteří vyplnili dotazníky, byla v maďarské nemocniční péči psychologická příprava dětí poskytována v minimálním počtu případů. Během léčby v nemocnici rodiče hodnotili svou vlastní úroveň úzkosti jako vyšší než u svých dětí a uvedli, že by si sami přáli psychologickou podporu.

Závěr: V maďarské pediatričské péči je psychologická podpora poskytovaná dětem a rodičům nedostatečná. Práce odborníků na dětský život (Child life specialists) je v systému péče o děti zásadní a je nezbytné najít cestu, jak tuto profesi zavést a zapojit do péče o děti v Maďarsku.

Klíčová slova: dítě; péče o děti; psychologická podpora; rodiče; specialisté na dětský život

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