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**PAT Questionnaire for the Screening of Psychosocial  
Risk Factors in Pediatric Oncology**  
*Reliability, Usability and Relation to Team Judgement Score*

Eindwerk neergelegd tot het behalen van het getuigschrift van de  
opleiding 'psycho-oncologie' door Katrien Verhoeven.

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## Abstract

Pediatric cancer is now seen as a chronic disease with acute and long-term effects, both physical as psychological. The Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) developed evidence-based standards for pediatric psychosocial care. Their guidelines included systematic assessments of the psychosocial health care needs of youths with cancer and their family (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). In 2006, Kazak et al. presented the Pediatric Psychosocial Preventative Health Model (PPPHM), concerning the assessment and treatment of families in pediatric health care. The Psychosocial Assessment Tool is a questionnaire that assigns the patient and its family to the Universal, Targeted or Clinical risk category from this PPPHM model.

In this research, the PAT questionnaire was tested for the first time in Belgium. Together with the PAT, a usability questionnaire was completed by the parents of 55 patients and the multidisciplinary team also made a judgement of the psychosocial risk.

The internal consistency of the total PAT questionnaire was questionable and varied considerably for the subscales (unacceptable to acceptable). The internal consistency was similar to the reliability in the study of Sint Nicolaas et al. (2016), but considerably lower than in the research of Pai et al. (2008) and Kazak et al. (2018). This might be due to limited participants or cultural differences. Furthermore, the numeric PAT and Team scores were significantly related, but the categorical scores were not. Both measurements appeared to have a small overlap but also include supplementary risk factors. Finally, the families rated the usability of the PAT as acceptable.

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## **INTRODUCTION**

### **Pediatric Oncology**

Getting diagnosed with cancer is one of the most devastating events one can imagine. Hearing that your child is diagnosed with cancer is possibly even worse. Unfortunately, 400 children under the age of 15 receive a new diagnosis of cancer every year in Belgium (Alles over kanker, 2018).

Childhood cancers differ from cancer in adulthood on many aspects, both biologically and psychologically. First, the types of cancer that are most common differ. In adulthood the most frequent cancers are prostate cancer, breast cancer, lung cancer and colon cancer (Stichting tegen Kanker, 2019). The most common cancers in childhood are leukemia, lymphoma and brain tumors (Alles over kanker, 2018). Second, when children and adults get the same type of cancer, the subtype often differs. For example children get more acute leukemia, where elderly are more prone to receive chronic leukemia. The treatments and intensity of treatment is also different with childhood cancers. Furthermore, some psychological aspects are also different. Pediatric cancer and the accompanying treatment often puts the child in isolation and therefore interferes with the normal social and emotional development. The children's normal growth in autonomy is impeded, as they are forced to rely on others through their illness.

### **Biopsychosocial Problems in Pediatric Oncology**

As survival rates improved during the last decades, pediatric cancer is now seen as a chronic disease with numerous acute and long-term effects. Physically, many children experience nausea, fatigue and pain during their disease and treatment (Ibitoye & Dawson, 2017). Pediatric cancer survivors are more prone to fatigue, infertility, secondary malignancies, ... during adulthood (Kopp, Puja, Pelayo-Katsanis, Wittman, & Katsanis, 2012). The effects vary according to cancer type, used treatment and individual predisposition.

Childhood cancer also turns the world of the child and their family upside down in a psychological way. Research of Rodriguez et al. (2012) suggests that children are mostly concerned about their functional impairments (e.g., not being able to do the things they used

to do). Most pediatric cancer survivors do not experience increased psychosocial problems later in life, but some survivors do. Age appears to be an important risk factor: survivors diagnosed with cancer as adolescents were significantly more likely to experience elevated global distress than their peers diagnosed earlier in life (Bitsko et al., 2016). Boulmalf and Fitzpatrick (2018) also found that younger age at diagnosis and less social support predicted more severe post-traumatic stress symptoms.

Research of Rodriguez et al. (2012) suggests that parents of a child with cancer find the uncontrollability in the context of caregiving the most stressful aspect, such as not being able to help their child feel better or having concerns about their child's survival. Post-traumatic stress symptoms are common for both mothers and fathers during the treatment of their child. Those symptoms include intrusive thoughts, physiological arousal and avoidance (Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005). While couples are resilient on most domains (emotional closeness, marital support, etc.), an increase in conflict and difficulties with sexual intimacy are reported by some couples (Van Schoors, Caes, Alderfer, Goubert, & Verhofstadt, 2016).

A child with cancer is also part of a broader family system. In their systematic review Van Schoors, Caes, Verhofstadt, Goubert, and Alderfer (2015) found that most families are resilient on many domains of family functioning. For example, many families report stable or increased communication, family support and adaptability. Nonetheless, there is also a small subset of families that sometimes struggles with the challenges of pediatric cancer. Increased conflict during treatment or a sibling who feels like he/she is at the periphery of the family are some of the difficulties some families may experience.

## **Psychosocial Risk Assessment**

### **Psychosocial screening as a standard of care**

Despite the broad consensus about the importance of these psychosocial problems in pediatric oncology, Wiener et al. (2015) found that there were no international, evidence-based standard of care guidelines. To address this critical gap, the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) developed evidence-based standards for pediatric

psychosocial care. Their first guideline states that there need to be systematic assessments of the psychosocial health care needs of youths with cancer and their family members (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). The importance of systematic assessment in order to provide accurate interventions was also underlined by Kazak et al. (2015) and Kearny, Salley and Muriel (2015).

The guidelines of 2015, however, did not specify which screening instrument has to be used for this assessment of psychosocial problems. Shaeffeler et al. (2015) found that researchers use different instruments for distress assessment (Distress thermometer, Patient Health Questionnaire 9, Hospital Anxiety and Depression Scale, etc.). These instruments measure different areas of distress. Shaeffeler et al. (2015) recommend to be careful when implementing a screening instrument and to compare the used instrument's characteristics to other screening instruments.

### **Pediatric Psychosocial Preventative Health Model (PPPHM)**

In 2006, Kazak et al. presented the Pediatric Psychosocial Preventative Health Model (PPPHM), a biopsychosocial theoretical framework for the assessment and treatment of families in pediatric health care. This model consist of a conceptualization of how psychosocial care can be matched with the needs and risks of the families. The first and largest subset are the 'Universal' families, who are expected to be adaptive and resilient when being confronted with health-related stressors. Standard psychosocial support and information is expected to be sufficient for this subset of families. The next and smaller subset are the 'Targeted' families, who are more prone to psychosocial difficulties because of acute distress or pre-existing risk factors. These families should receive psychosocial interventions. The last and smallest subset are the 'Clinical' families, who have multiple factors indicative of high risk for ongoing distress. Intensive, specialized psychosocial care and treatment is needed for them. The PPPHM can be visualized as a pyramid (figure 1).

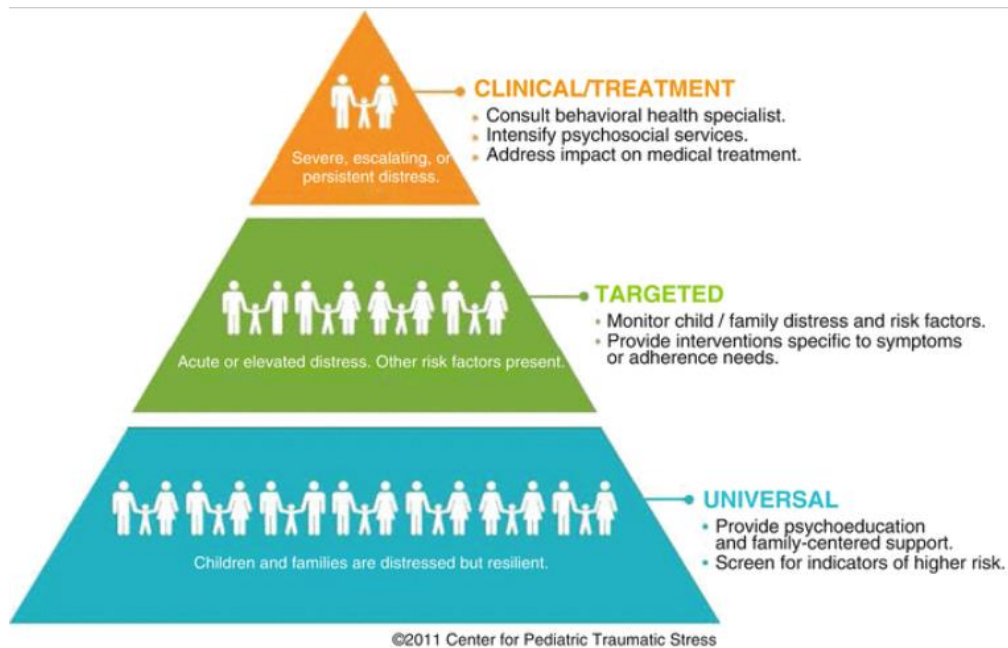


Fig. 1: The Pediatric Psychosocial Preventative Health Model (Kazak, 2006).

## Psychosocial Assessment Tool

**General** - The Psychosocial Assessment Tool (PAT) was developed by Kazak et al. (2001) to assess psychosocial risks in pediatric oncology. The initial version of this parent reported screening instrument contained 20 items, divided over 10 potential risk domains: family structure, family resources, social support, child knowledge, school attendance, child emotional and behavioral concerns, child maturity for age, marital/family problems, family beliefs, and other stressors. Higher PAT scores were associated with higher levels of psychosocial risk (Kazak et al., 2003).

The initial PAT was modified to improve the clarity of the questions, formatted to be more user friendly, and the content of some items was changed (Pai et al., 2008). The result was the PAT 2.0, a two-page parent self-report measure for families of patients across a broad age range (from infants to adolescents). Completion of the PAT2.0 takes approximately 10 to 20 minutes and can be administered through a web-based version or a paper and pencil format. The PAT 2.0 is comprised of 7 subscales: Family Structure and Resources, Family Social Support, Family Problems, Parent Stress Reactions, Family Beliefs, Child Problems and Sibling Problems. Based on the available literature and expert consensus, each item response is classified as indicative of risk or no risk. Subscale scores are created by calculating the



proportion of items on the scale indicated as risk. The total score can be calculated by adding up all the subscale scores. The total score classifies each family into one of the three risk levels of the PPPHM: universal, targeted and clinical. More specific, a total PAT2.0 score of  $<1$  represents the universal category, a score  $1 \leq \text{PAT2.0} \leq 2$  the targeted category and  $\text{PAT2.0} > 2$  the clinical category (Alderfer et al., 2009).

Recently, Kazak et al. (2018) made some additional changes to the PAT 2.0 in order to create the PAT 3. The child and sibling subscales were divided according to age (younger than two years old versus two years and older). Both age categories have six shared items. Four items were added specific to families of infants and preschoolers (younger than two years) to replace the longer set of child items. Risk items about aggression, suicidality and medication for behavioral concerns were added to the pre-existing child and siblings subscales (two years and older). Three risk items were added to the family problems subscale about suicide, crime and abuse, and mental health treatment.

**Validation and implementation** - The PAT has grown into a screening instrument of psychosocial risk that has been used in several treatment centers worldwide and is applicable to a broader range of patient groups. A recent meta-analyses study assembled information about validity and liability across all of these studies (Kerstens, 2019).

For the reliability of the PAT, a strong internal consistency of the total PAT was found. There were also no substantial differences between two measures on different occasions, which indicated a strong test-retest reliability of the total PAT-scores. A good inter-rater reliability between different family members was also found for the total PAT scores. Therefore, results support the good reliability of the total PAT in terms of internal consistency, test-retest, and inter-rater reliability across studies. On subscale level, there was a strong test-retest reliability. However, mixed results were found for the internal consistency and inter-rater reliability of the subscales.

Concerning the concurrent validity the PAT appeared to be a useful instrument in detecting families experiencing psychosocial problems. The convergent validity analysis showed overall significant but rather low or medium correlations between the PAT subscales

and validation instruments. The strongest convergent validity was found for the subscales Child Problems and Stress Reaction, and the lowest for the subscale Family Beliefs. Evidence for discriminant validity was provided by the PAT subscales Family Structure, Stress Reaction, Child and Sibling Problems which were not associated with unrelated measures. There was however some disagreement between studies regarding the discriminant validity of the other subscales. Predictive validity was not included in this systematic review. Stating overall conclusions on the validity of the PAT based on the literature was difficult. The validity analyses do allow us to conclude that the PAT is a sensitive or responsive tool.

One study that deserved particular interest was conducted by Sint Nicolaas et al. (2015). They were the first to study the reliability, validity and usability of the PAT in a Dutch speaking population of children with pediatric oncology. Acceptable reliability was obtained for the PAT total score and majority of subscales, only two subscales showed inadequate internal consistency (Social Support and Family Beliefs). Content and criterion validity were also good. For the total PAT score, mostly medium to large correlations were found. Concerning the subscales, only one subscale did not correlate significantly with its associated validation instrument and the other correlations ranged from small to large. Finally, the parents rated the comprehensibility, length, clarity and appropriateness of the PAT positively. This gave the PAT a good usability score.

### **Other Screening Instruments**

The PAT is a unique screener. There are still no other questionnaires that are equally comprehensive and brief. The findings of Pierce et al. (2017) point to the importance of short screening instruments to reduce the burden on families while still providing the team with an informative assessment. The efficient nature of these brief screening tools would then facilitate the use of psychosocial services towards families who can most benefit, offering an advantage over more time consuming forms of psychosocial screening.

Next to the PAT, the Distress Thermometer (DT) is also a very brief screener (Patel et al., 2011). Wiener, Battles, Zadeh, Widemann and Pao (2017) found that the Distress Thermometer correlated significantly with both caregiver and patient reports of depression,

anxiety, pain, and fatigue (concurrent validity). Parent, child and caregiver report demonstrated moderate inter-rater reliability. The DT is a sensitive instrument for screening of psychosocial distress. However, the DT was not highly specific. For example, the accompanying symptom checklist provided additional information about the child's distress but not whether these symptoms interfere with the child's daily life. The distress thermometer is also focused on the individual, either child or parent, instead of on the family system as a whole (Sint Nicolaas et al., 2015). Another advantage of the PAT is that the content is based on both scientific research and clinical experience (Sint Nicolaas et al., 2015). The PAT is linked to the Preventative Health Model (Kazak, 2006). Due to this risk classification and the additional information on the risk and protective factors, the PAT is able to provide personalized, family-based, and cost-effective psychosocial care based (Kazak, 2006).

### **Clinical Judgement versus Questionnaire**

All of the above screening instruments used (web)questionnaires. The advantages of this data collection technique are its cost and time efficiency, combined with the low training required by the person administering them (Jones, Murphy, Edwards and James, 2008). The questionnaire can also be completed in real life or through the internet. However, there are also some general drawbacks to the use of questionnaires. Hauksdóttir, Steineck, Fürst and Valdimarsdóttir (2006) found that the order of questions could impact the total score of bereavement. Individuals aren't always able to report information about themselves or others accurately (self-awareness). Even the self-reported physical activity correlates only modest with the objective measure of physical activity (Steene-Johannessen et al., 2016). If people cannot even rate their exact level of activity, how can we expect them to rate their more confusing inner feelings accurately?

Shaeffeler et al. (2015) recommended to combine an assessment instrument with an evaluation of the patients' subjective need. The patient's subjective need was evaluated through the question: 'Do you currently need support in coping with the disease or psychooncological counselling?' However, the patients' subjective need evaluation could have some of the same drawbacks as other self-report instruments. If individuals cannot estimate

their own amount of distress, they will neither be able to do this in questionnaires nor in one open question.

Another option would be to add the evaluation of an expert. Bonacchi et al. (2010) combined the use of questionnaires with a clinical interview. The clinical interview made it possible to detect the presence of distress in 39 (13.7%) patients who would not have received a diagnosis only based on the questionnaires. Topics like illness and distress experience, psychopathology and family support were evaluated in the clinical interview. These topics are similar to the ones explored in the PAT questionnaire. Additionally, the members of the multidisciplinary team, and in particular the psychologists, are also sensitive for these topics in their standard of care. We should strive for the best estimation with the least necessary resources (best cost-efficiency). From this point of view a psychosocial expert evaluation (after multidisciplinary consensus) might also be combined with a questionnaire like the PAT questionnaire to assess distress.

### **Current Research Design**

In analogy with the research of Sint Nicolaas et al. (2016) a Dutch translation of the PAT questionnaire will be tested, but now for the first time in a Flemish population. We will again evaluate the reliability and the usability of this questionnaire.

It will also be evaluated whether a clinical expert score, as rated by the multidisciplinary team, and the PAT score are similar or different in the information they provide.

## **METHODS**

### **Procedure**

Two Flemish pediatric oncology centra worked together to make this research possible (UZ Leuven Gasthuisberg and UZ Gent). The psychologists of these centra introduce themselves to every family confronted with a new diagnosis of pediatric oncology. For this research, they also handed over the PAT-questionnaire, a usability form and other questionnaires to be filled in by the parents or guardian soon after the diagnosis. In general,

only one parents was asked to participate, except when the parents were divorced. Afterwards, a clinical judgement was made by the multidisciplinary team. Both the PAT and the team judgement provided a categorical and a numeric score.

## **Questionnaires**

### **PAT**

After consideration with the research department of professor Kazak, it was decided to develop a Flemish version of the PAT 2.0 instead of using an altered version of the Dutch PAT questionnaire (Sint-Nicolaas et al, 2016). In this regard it was possible to use specific Flemish language expressions and to adjust the questionnaire to the Belgium healthcare and school system.

The PAT is comprised of 7 subscales: Family Structure and Resources, Social Support, Caregiver Problems, Caregiver Stress, Family Beliefs, Child Problems and Sibling Problems. Each subscale includes 3–15 items, which were scored dichotomously (risk or no risk). Subscale scores were created by calculating the proportion of items on the scale indicated as risk. The total PAT score could be calculated by adding up all the subscale scores. The PAT total scores can range from 0 until 7 and these numeric scores can be linked to a specific risk category: Universal (0-0.99), Targeted (1-1.95) or Clinical (>2).

The mean time between the diagnosis and the PAT questionnaire was 26.91 days, with a minimum of 0 days and a maximum of 117 days. The scoring of the PAT was conducted by an independent research assistant, to guarantee the independency between PAT score and the team score.

### **Usability questionnaire**

In analogy with the research of Sint Nicolaas et al. (2016) a usability questionnaire was developed. After filling in the PAT questionnaire, parents rated five items on a visual analogue scale (VAS) scale ranging from 0 (not at all) to 100 (very much). This items included the comprehensibility, clarity, unpleasantness, the length of the questionnaire and the

applicability to their own situation. The final question was an open question where the participants could add additional remarks about the PAT.

### **Team judgement**

The clinical judgement of the team was made soon after the diagnosis, at the multidisciplinary team meeting. In this regularly multidisciplinary meeting the psychologist, doctor, physiotherapist, nurse, etc. come together to discuss the patients evolution. The mean time between the diagnosis and the team judgement was 49.15 days, with a minimum of 6 days and a maximum of 172 days. They gave both a numerical as a categorical estimation. The numerical estimation could range from 0 to 10. The categorical estimation included the same categories as the PAT: universal, targeted and clinical.

### **Other questionnaires**

Together with the PAT and the usability questionnaire, the participants were also asked to fill in other questionnaires (Inventory Social Reliance, Strengths and Difficulties Questionnaire, Hospital Anxiety and Depression Scale, Parenting Stress Index-short version and Illness Cognitions Questionnaire, parent version). These questionnaires were all previously validated in other research and could therefore be used to test the construct validity of the PAT. Due to practical considerations, the validity of the PAT will not be evaluated in this study. This data will remain available for follow-up research.

### **Participants**

UZ Leuven and UZ Gent worked together to include 55 families in this study (mean age = 8.76, *SD* = 5.33). There were 33 girls (60%) and 22 boys (20%) with cancer included. The cancer type of each child was categorized according to the classification of the Cancer registry (Belgian Cancer Registry (2013). Leukemia (25.5%), lymphoma (23.6%) and central nervous system tumor (16.4%) were the most common cancer types in this study.

Every family confronted with a new diagnosis of pediatric oncology was invited to participate in this study. With 49%, UZ Gent had a slightly higher response rate than UZ Leuven (42%). There were several reasons for non-inclusion in UZ Leuven: 12% explicit refusal, 29% language and 56% diverse reasons (e.g. agreement but noncompliance with the questionnaires).

### **Analysis**

The Cronbach's alpha was used to examine the reliability (internal consistency) of the PAT questionnaire. Afterwards, correlational statistics were used to explore the relation between the PAT and the team judgement, both on the categorical as the numeric level. Finally, descriptive statistics were used to define the usability questions.

## **RESULTS**

### **Descriptive Statistics: PAT and Team Judgement**

Descriptive statistics were calculated for both the PAT scores and the team judgement scores (Table 1). The mean total PAT-score was .84, with a standard deviation of .57. The total PAT score ranged from .00 to 2.69. The mean scores of the subscales are also depicted above in Table 1, with their according standard deviation and range. The subscale Sibling Problems (under two years old) has the lowest mean value ( $M = .00$ ,  $SD = .00$ ) and Patient Problems (under two) has the highest ( $M = .28$ ,  $SD = .23$ ). These numeric scores were also associated with a categorical classification. Of the 55 participants, 36 participants (65.5%) were in the universal category, 16 participants (29.1%) were in the targeted category and only 3 participants (5.5%) were in the clinical category.

The Team judgement scores ranged from 1 to 9 ( $M = 5.54$ ,  $SD = 2.29$ ). There were no subscales in this measurement. Parallel to the numeric score, the team gave also a categorical score to each participant: 23 participants (43.4%) were assigned to the universal category, 24 participants (45.3%) to the targeted category and 6 participants (11.3%) to the clinical category. In the PAT questionnaire, these categories were entirely determined by the numeric

PAT scores. However, in the Team Judgement these categorical scores were given together with the numerical score, but not based on its value. Nonetheless, a strong correlation between the categorical and numerical Team judgement scores was found ( $r = .83, p = .00$ ).

Table 1. *Descriptive Statistics and Reliability of Total PAT, PAT subscales and Team Judgement*

Variable	Mean (SD)	Min – Max	Chronbach's alpha
PAT Total	0.84 (0.57)	0.00 – 2.69	0.61
1. Family Structure	0.08 (0.15)	0.00 – 0.86	0.65
2. Social Support	0.03 (0.08)	0.00 – 0.25	-0.05
3. Child Problems			
Age < 2 years	0.28 (0.22)	0.00 – 0.63	0.60
Age ≥ 2 years	0.21 (0.15)	0.00 – 0.61	0.67
4. Sibling problems			
Age < 2 years	0.00 (0.00)	0.00 – 0.00	-
Age ≥ 2 years	0.07 (0.12)	0.00 – 0.53	0.74
5. Caregiver Problems	0.19 (0.19)	0.00 – 0.80	0.71
6. Caregiver Stress	0.15 (0.21)	0.00 – 0.60	0.57
7. Family Beliefs	0.11 (0.11)	0.00 – 0.40	0.27
Team Judgement	5.54 (2.89)	1.00 – 9.00	-

### Reliability

Internal consistency for the (numeric) Total PAT score was questionable ( $\alpha = .61$ , table 1). This Cronbach's alpha was calculated based on the internal consistency between subscale cores and not based on all of the item scores. For four of the nine PAT subscales the internal consistency was poor or questionable ( $\alpha = .57 - .67$ ). For two subscales, Sibling Problems (two years and older) and Caregiver Problems, an acceptable score was obtained (respectively:  $\alpha = .74, \alpha = .71$ ). An important remark is that for the subscale Sibling Problems (two and older) the Cronbach's alpha was based on only 18 of the 40 participants, due to many missing values. Internal consistency was unacceptable for the subscales Social Support and Family Beliefs (respectively:  $\alpha = -.05, \alpha = .27$ ). Finally, internal consistency for the subscale Sibling Problems (younger than two) could not be calculated due to a lack of variance. In this analysis, items



were included even in the absence of spread. The internal consistency of the subscale Caregiver Stress was questionable ( $\alpha = .61$ ) instead of poor ( $\alpha = .57$ ) after removing question 12B due to lack of variance. Removing these items without variance did not change the category of the Cronbach's alpha in other subscales.

### Relation PAT Scores and Team Judgement

An important focus of interest in this research was the relation between the PAT scores and the Team judgement scores. A significant correlation between the two numerical scores was found ( $r = .43, p = .001$ ). A higher Team Judgement score is positively related to a higher total PAT score. This relation is depicted in Figure 1.

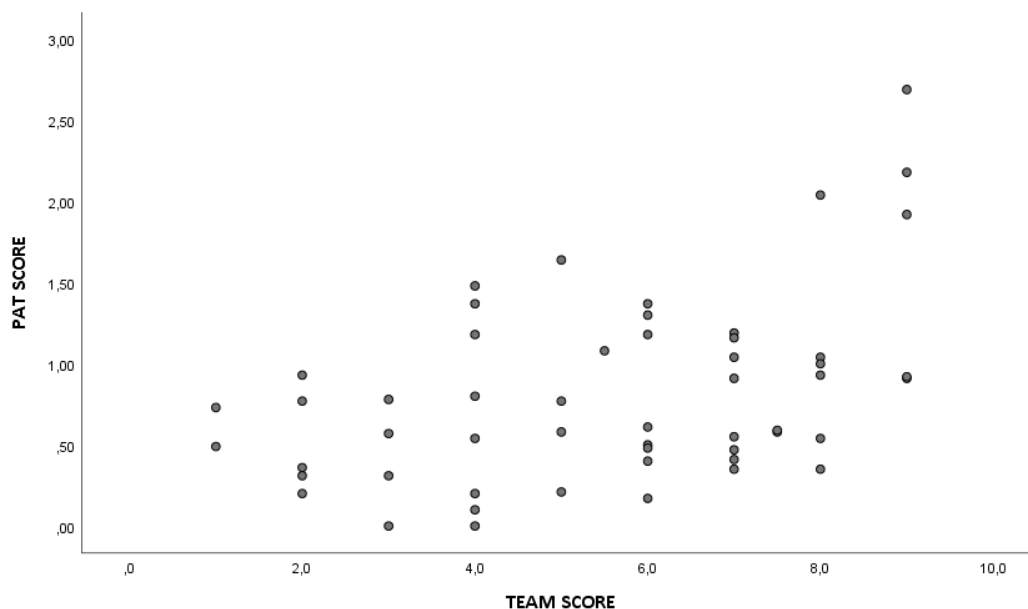


Fig. 2: Relation between the numerical PAT-scores and the numerical Team Judgement scores.

However, the correlation between the categorical Pat scores and the categorical Team judgement scores was not significant ( $r = .26, p = .06$ ). In 26 cases (49 %), the same category was given by the PAT and the team. In 20 cases (37.8 %) the team assigned a higher risk category than the PAT questionnaire. In 7 cases (13.2 %), the Pat risk category was higher than the team category. The relation between the categorical Pat-scores and the categorical team judgement scores is depicted in Figure 3 (number of cases is represented). Despite a large overlap between the PAT and Team judgement categories, there are also many cases where

they did not provide the same category for a specific participant. A remarkable observation is that within the Universal PAT Category, there are almost as many participants with a Team judgement score in the Targeted category as in the Universal category.

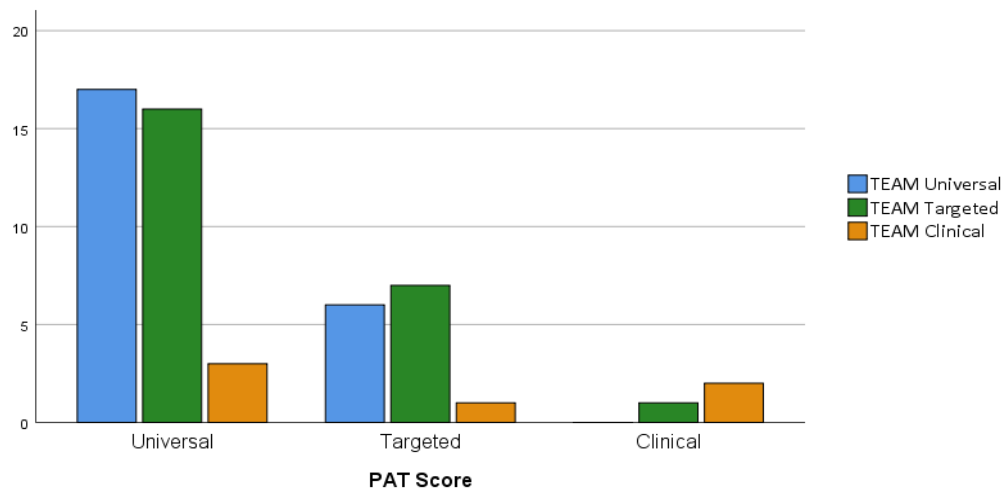


Fig. 3: The relation between the categorical PAT scores and the categorical Team scores.

In order to explore the limited correlation between the two categorical measures, the correlation between the categorical Team judgement score and each of the PAT subscales was calculated. This correlation was only significant for the subscales Family Structure ( $r = .47, p = .00$ ) and Family Beliefs ( $r = .27, p = .04$ ). Additionally, also for the individual items of these two subscale the correlation with the categorical Team judgement score was calculated. Several questions were significantly related to the categorical Team score, for example the level of education, marriage status, financial problems and the belief that cancer is a death sentence. In addition, we also explored how much of the variance in the categorical Team score was related to the variance of these two subscales of the PAT. In a multiple regression model with the categorical Team judgement score as dependent variable and the subscales Family structure and Family beliefs as independent variables, 27.8 % of the variance of the Team score could be explained ( $F(2,50) = 9.65, p = .00$ ). In a regression model with the numerical Total Pat score as independent variable, only 10.3% of the variance of the Team score could be explained ( $F(1,51) = 5.88, p = .02$ ). These analysis were conducted based on the correlation matrix and were not part of the initial hypothesis.

## Usability Questionnaire

Finally, the participants were also asked to rate the PAT questionnaire. The questions about the unpleasantness and length were reverse-scored, which means that a lower score was more positive than a higher score for these items (e.g. Length of Questionnaire: 0 = perfect, 100 = far too long). These reverse-scores were inverted in order to calculate a Total Usability Score ( $M = 76.50$ ,  $SD = 13.16$ ). In general, the participants perceived the PAT questionnaire positive (Table 2). The lowest mean score was given to the Applicability question ( $M = 67.76$ ,  $SD = 29.55$ ), in which participants rated whether they found the questions of the PAT relevant to their own situation.

Table 2. *Descriptive statistics of Usability questionnaire*

Variable	Mean	SD
Comprehensibility	83.85	15.80
Clarity	86.67	13.13
Unpleasantness	24.69*	29.55
Applicability	67.76	23.54
Length	29.75*	26.64
Total Usability	76.50	13.16

\*Reverse-score (higher score = negative)

## DISCUSSION

### Reliability

The internal consistency of our total questionnaire was questionable. For the subscales, the internal consistency varied considerably (from unacceptable to acceptable). The distribution of the Cronbach's alpha over the categories (unacceptable, poor, questionable and acceptable) was somewhat similar to the distribution in the study of Sint Nicolaas et al. (2016; Table 3). Our research even observed a slightly higher amount of subscales in higher categories of internal consistency (2 versus 1 in the acceptable category and 3 versus 2 in the questionable category). However, a slightly higher total Cronbach's alpha was observed in the research of Sint Nicolaas et al. (2016). Nonetheless, in both studies the total Cronbach's alpha

was questionable. However, as depicted in Table 3, the studies of Pai et al. (2008) and Kazak et al. (2018) the Cronbach's alpha was considerably higher for both the total questionnaire as for the subscales than in our research. None of the subscales had an unacceptable internal consistency and respectively only one and two subscales had a poor Cronbach's alpha.

How can these difference be explained? First, it is known that the number of items in a subscale has an impact on the Cronbach's alpha. Due to the limited number of items in several subscales, Sint Nicolaas et al. (2016) used a cut-off of .50 and higher for an acceptable internal consistency. This decision was based on research of Field (2009). With the same cut-off value, the total questionnaire and 6 of the 9 subscales of our research would have an acceptable internal consistency. Second, in our study were only 55 families included, compared with 204 participants in the study of Pai et al. (2008) and 394 in the study of Kazak et al. (2018). This might have had an impact on the observed variance of the items and accordingly the internal consistency. For example, the study of Kazak et al. (2018) reported a higher standard deviation on all both one subscale when compared to our research. Finally, even with a threshold of  $\alpha \geq .50$ , the internal consistency of three subscales remained unacceptable or impossible to calculate due to lack of variance. It is remarkable that the same subscales were also unacceptable in the research of Sint Nicolaas et al. (2016). Their research was conducted in the Netherlands, which is an adjacent country to Belgium (where our research took place). The unexpected pattern of unacceptable internal consistencies might be determined by cultural differences between these two adjacent countries and the United States (study of Pai et al. (2008) and study of Kazak et al. (2018)). A systematic review of Gray, Szulczewski, Regan, Williams and Pai (2014) discussed several cultural differences regarding pediatric oncology worldwide. An important cultural difference was that all parents question why their child has cancer, but the answers to the "why" question differ substantially across cultures. For example, the Latino-Americans strongly belief that "Everything happens for a reason", which is a specific question in the subscale Family beliefs.

Table 3. *Reliability Comparison*

<i>Variable</i>	<i>Our research (2020) Belgium</i>	<i>Sint Nicolaas et al. (2016) Netherlands</i>	<i>Pai et al. (2008) VS</i>	<i>Kazak et al. (2018) VS</i>
PAT Total	0.61	0.69	0.81	0.81
1. Family Structure	0.65	0.31	0.62	0.61
2. Social Support	-0.05	0.19	0.69	0.59
3. Child Problems			0.81	0.80
Age < 2 years	0.60	0.67		
Age ≥2 years	0.67	0.82		
4. Sibling problems			0.73	0.85
Age < 2 years	-	0.36		
Age ≥ 2 years	0.74	0.69		
5. Caregiver Problems	0.71	0.50	0.72	0.64
6. Caregiver Stress	0.57	0.55	0.64	0.84
7. Family Beliefs	0.27	0.20	0.59	0.59

### **Relation PAT and Team Judgement**

A main focus of interest was the relation between the Pat scores and the Team judgement scores. The numerical Pat total score was positively related to the numerical Team score. However, for the categorical scores this relation between the PAT and Team scores was not significant. For 20 families (37.8%), the multidisciplinary team assigned a higher risk category than the PAT questionnaire. In a smaller number of cases (7 families), the PAT assigned a higher risk category than the team. In order to understand this relation, the correlation between the categorical Team judgement score and the seven subscales was calculated. These correlations indicate which information is related to and thus might have influenced the multidisciplinary team judgement. The subscales Family structure and Family beliefs appeared to have a significant correlation with the categories given by the multidisciplinary team. When exploring the individual items who were positively associated with the Team judgement score, items concerning socioeconomic status appeared significantly related (marital status, level of education, financial status,...). Two items

concerning illness beliefs were also positively related to a higher risk category given by the multidisciplinary team ('cancer is a death sentence' and 'everything happens for a reason'). This analysis showed that only a minor subset of the risk items reported by the PAT were related (and thus might have influenced) the risk assessment given by the multidisciplinary team.

Nonetheless, the limited portion of explained variance by the PAT (total and subscales) might indicate that there are also factors that had an impact on the risk assessment given by the multidisciplinary team, but were not included in the PAT questionnaire. Potential other influencing factors can concern the medical situation, like the prognosis of a particular diagnosis and the invasiveness of the treatment. The multidisciplinary team might also had knowledge of some psychological risk factors that were not included in the PAT, for example faulty illness understanding, poor treatment adherence... We can conclude that the PAT and the Team judgement scores were not fully related and both measurements might include risk factors not included in the other.

### **Usability**

The families rated the usability of the PAT as acceptable on several domains. These usability measures were in line with the ones reported in the research of Sint Nicolaas et al. (2016).

### **Clinical Implications**

The PAT and Team score assigned the families to a different risk category in 51% of the cases. We can thus conclude that both measurements do not evaluate the same construct and therefore can not replace each other. We recommend longitudinal (and validation) research to determinate which risk assessment is the most accurate, i.e. to compare the two risk assessments with the needed psychosocial care in the first year after diagnosis (outcome).

Until this further research is conducted, we recommend to start using both measurements (PAT and Team judgement) in the standard of care for each participant. If the

PAT and team do not provide the same risk category, the highest risk category should be used to estimate the needed psychosocial care. Thus, if one or both measurements assigns a family to a high-risk category, the team should be extra careful because extra psychosocial care might be needed.

The families rated the PAT questionnaire as acceptable on all domains of usability. We can thus conclude that the families evaluated the PAT as positive, which strengthens the decision to include it in the standard of care. During the follow up research, we do recommend to further evaluate the reliability of the three unacceptable subscales.

### **Limitations and Recommendations**

There were also some limitations to our study. First, there were many missing values in the subscale Sibling problems. We presume that these missing values were due to the possibly unclear layout of the questionnaire. This could be prevented by using a web based version of the questionnaire, which notifies the user when questions are left incomplete.

Second, there might be an underestimation of the families in the clinical category. For example, insufficient knowledge of the Dutch language and a palliative or relapse diagnosis were excluding criteria. However, we can presume that these are families with a greater chance of many risk factors. To rule out this assumption, it would have been better to make a Team judgement score of these families as well. Thereby these scores could have been compared to the scores included in this study.

Finally, validation of the PAT questionnaire was not included due to practical considerations. We recommend to include this in future research. It is also advised to follow the families of our research longitudinal, so we might conclude whether the PAT or the multidisciplinary team risk assessment was the most accurate. Lastly, it is recommended to further explore the pattern of reliability and possible cultural influences.

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