

## **Experiences with a psychosocial screening instrument (S-FIRST) to identify the psychosocial support needs of parents of children suffering from cancer**

Experiences with a psychosocial screening instrument (*running title*)

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## **Abstract**

**Objectives:** A large proportion of families with a child suffering from cancer are heavily burdened, both psychologically and in their social functions, thus requiring treatment. Therefore, a systematic assessment of burden and needs is essential to identify clients with a high psychosocial burden and to allow for accurate decision making regarding indications for treatment. There is a great need for the development and validation of screening instruments in psychosocial counseling.

**Methods:** The receiver operating characteristic curve is a basic method to evaluate the discriminatory power of diagnostic tests. We computed sensitivity/specificity indices based on a sample of parents of pediatric cancer patients; the parents were screened with the S-FIRST and completed another standardized instrument with reliable indicators.

**Results:** We found significant AUC values from 0.671 to 0.882, meaning that the S-FIRST screening instrument has small to medium discriminatory power.

**Conclusion:** Our results support the use of a screening instrument for case history analyses in psychosocial counseling to identify clients with a high psychosocial burden.

## **Keywords**

clinical social work, psychosocial counseling, social diagnosis, screening instrument, case history, ROC curve

# 1 Background

Every year, approximately 200 children in Switzerland, 180 children in Austria, and 1,800 children in Germany are newly diagnosed with cancer,<sup>1</sup> and from one moment to the next, the life conduct system of the family changes. Often, the disease leads to acute psychosocial stress on both children and parents.<sup>2-4</sup> Uncertainty, feelings of guilt, the medical treatment of the child, the effects of childhood cancer on siblings, financial worries, and other factors cause parents to feel overextended and lead to psychosocial distress, primarily immediately after diagnosis.<sup>5,6</sup>

In addition to processing the negative diagnosis and the intensive care necessary for the sick child, parents must quickly reorganize their everyday lives for a long period of time and address the limitations of daily life.<sup>5,7</sup> The social dimension of cancer can lead to problematic forms of integration and life conduct or to social problems in the family that involve other areas of life, such as partnerships, work, and school.<sup>8</sup>

## 1.1 Clinical social work with the families of children with cancer

Especially in the first phase of the diagnosis of cancer, it is important for affected parents to receive professional help as soon as possible.<sup>9</sup> This stage is where clinical social work in pediatric oncology comes in, as this discipline helps to address the social dimension of cancer.<sup>11,12</sup> Access to adequate support and a systematic assessment of psychosocial needs are provided as per the standards for the psychosocial care of children with cancer and their families.<sup>10</sup>

The professional basis of the aid is an adequate social diagnosis, which allows for a resource-oriented view and a case-specific understanding of the problem-causing dynamics.<sup>8</sup> Such a case-focused diagnostic ideally and in accordance with psychosocial care standards precede an empirically-based screening.<sup>10,13</sup> Screening instruments can help to focus on highly impaired parents in a standardized way, establish an indication for social work, and enable a systematic referral.<sup>9</sup> This is especially important in locations where

organizational structures make it impossible for (early) social work practitioners to come into contact with parents.<sup>14</sup>

## **1.2 State of research**

It is widely acknowledged empirically that most families of children with cancer experience distress. Compared to parents with children suffering from diabetes or an unintentional injury, rates of posttraumatic stress disorder are higher for parents of children newly diagnosed with cancer.<sup>15</sup> The results from several studies on parents with children suffering from cancer show the incidence of stress and behavioral changes or symptoms of anxiety or depression.<sup>2 3 16</sup> In a review of pediatric medical traumatic stress, 40% to 83% of parents of children with cancer experience distress within the first month after the diagnosis. This range reduces to 18% to 30% six months after the diagnosis and to 7% to 22% more than 10 months after the diagnosis.<sup>6</sup> Other longitudinal studies confirm that distress generally decreases in the first year after diagnosis, and in the long term, most families are resilient.<sup>17</sup><sup>18</sup> However, a considerable proportion of families develop ongoing psychosocial problems, including feelings of loneliness, uncertainty about the future, and the fear of recurrence; thus, “the end of treatment is not the end.”<sup>19</sup>

The systematic assessment of burden and needs is essential to identify clients with a high psychosocial burden and to allow for accurate decisions to be made regarding indications for treatment. Screening instruments, such as the Distress Thermometer<sup>20</sup>, the (revised) Psychosocial Assessment Tool (PAT)<sup>21</sup> or others,<sup>22</sup> allow for the screening of psychosocial risks (and competencies).<sup>15 21 23</sup> The PAT is a parent-report screener that classifies families into a low-risk, medium-risk or high-risk group.<sup>24</sup> The rate of classification into the high-risk group (clinical risk level) ranges from 4% to 13%.<sup>16 23 24</sup> An assessment with the PAT has been shown to predict the intensity of social work services<sup>25 26</sup> and to correspond with the psychosocial care provided.<sup>13</sup> A research study indicated that the use of the (revised) PAT may help to reduce the psychosocial risks of families six months after diagnosis.<sup>24</sup>

Despite standards for the psychosocial care of children with cancer and their families,<sup>10</sup> the clinical implementation of psychosocial screening in pediatric oncology is rather rare.<sup>9</sup> An international survey of pediatric oncology sites found that only 9% reported using PAT.<sup>27</sup> Challenges for implementing screenings are an increased workload for social workers and trained and skilled staff.<sup>9 28</sup>

### **1.3 Central research questions**

At present, the number of validated instruments for the measurement of psychosocial problems used in hospital social work in Switzerland is extremely limited. Screening instruments such as the PAT<sup>21</sup> or the Distress Thermometer<sup>20</sup> focus primarily on psychological variables and take only the social dimension of cancer in particular into account.

As part of a study funded by the Swiss Cancer Research Foundation, we tested and analyzed such a screening instrument, namely, the S-FIRST. The study relied on pediatric oncology cases in a children's hospital in Switzerland and examined the following:

- (1) With respect to parents of children suffering from cancer, can the S-FIRST screening instrument accurately distinguish between parents with a high psychosocial burden and those with a low psychosocial burden?
- (2) Can we find an optimal threshold to separate the group with a high psychosocial burden from the group with a low psychosocial burden?

## **2 Methods**

### **2.1 Research Design**

Finding answers to our research questions was part of a study that analyzed the effectiveness of social counseling based on different social diagnosis methods. The overall design included an experimental design in the framework of a longitudinal prospective study

with three measurement points.

As part of a social case history, social workers used the S-FIRST to screen parents at the beginning of their contact with the social counseling service. Each questionnaire (first survey wave) had a corresponding completed screening instrument ( $N = 71$ ). The threshold was computed on the statistical part of the S-FIRST (questions 19–25). High psychosocial burden was defined as having at least one value under “very bad” within the 5-point Likert scale in one of the following areas: financial situation, training and working conditions, social support, opportunity to talk about worries, physical condition, mental health, and housing situation. Thus, based on the analysis of a preliminary sample of S-FIRST data ( $N = 50$ ), we set the threshold between 13 and 14 (in a range of 7–35). Therefore, we expected approximately 50% to be in the “high psychosocial burden” arm of the study. Indeed, the screening divided the parents into a group with a high psychosocial burden (56%) and one with a low psychosocial burden (44%).

The quasi-experimental design of the study randomly assigned only the group of parents with a high psychosocial burden into the experimental group (consult with descriptive system modeling) and the control group (consult with the S-FIRST). Of the 40 parents with a high psychosocial burden, 45% ( $N = 18$ ) were randomly assigned to the control group, and 55% ( $N = 22$ ) were randomly assigned to the experimental group (see Appendix, Figure 1).

## **2.2 Screening and counseling with the S-FIRST**

The S-FIRST is an instrument that social workers in a children’s hospital in Switzerland use during the first consultation to take uniform social histories (anamnesis) and to conduct a standardized assessment of the burden situation (screening). The S-FIRST provides an overview of the family situation and aids in the assessment of the need for social work action. It was developed in 2010–2012 in an internal project of social counseling services in a children’s hospital in Switzerland.<sup>29</sup> The S-FIRST was used in this study for both the social anamnesis and the screening of all new cases. In this article, the results refer only to the S-

FIRST as a screening instrument.

### **2.2.1 S-FIRST as a social history instrument**

The first part of the S-FIRST follows a classic classification logic for histories, with questions (1–18) eliciting narrative information in the areas of social support, housing situation, financial situation, work, parents' health, care of other family members, patient integration, mobility, insurance, monitorability of the happenings, and value systems, as well as problems and available resources. All of this information is recorded by social workers and serves as the basis for a social anamnesis.

### **2.2.2 S-FIRST as a screening instrument**

The statistical part of the S-FIRST (questions 19–25) assesses the housing situation, financial situation, working and training conditions, social support, opportunity to talk about worries, physical condition, mental health, and total burden. Each dimension can be rated on a fully verbalized, 5-point response scale ranging from very poor (1) to very good (5); higher values indicate a better life situation.

Parents completed the statistical part of the instrument by themselves at the beginning of the consultation. In the majority of cases ( $N = 68$ ), the mother (71%,  $N = 48$ ) completed the screening assessment, and in 28%, the father ( $N = 19$ ) completed the screening assessment. In addition, the responsible social workers completed the statistical part for each client separately (see Appendix, Figure 2).

Furthermore, both assessments in the dimensions of the housing situation ( $r = .758, p < .05$ ), training and working conditions ( $r = .715, p < .05$ ), physical condition ( $r = .698, p < .05$ ) and financial situation ( $r = .686, p < .05$ ) are in relatively good agreement with each other, as measured by the correlation coefficient. A lower correlation between the assessments was found in the assessment of support ( $r = .495, p < .05$ ) and the opportunity to talk about worries ( $r = .573, p < .05$ ) (see Appendix, Table 1).

Reliability analyses of the S-FIRST dimensions yielded satisfactory values for Cronbach's alpha, both for the self-assessment and for the external assessment, which can be summarized into one overall dimension of burden as a whole (for the self-assessment:  $\alpha = .647$ , item  $N = 7$ ; for the external assessment:  $\alpha = .741$ , item  $N = 7$ ).

Overall, the parents showed little burden; Figure 1 shows that both lines are in the right area of the table, indicating a positive rating. Nevertheless, the two groups of parents differed significantly from one another in many dimensions. In addition, parents with a high psychosocial burden showed a higher burden in most dimensions.

{Insert Figure 1 here}

### **2.3 Characteristics of the sample**

The population of this study represented all parents whose children were diagnosed with cancer and treated in the pediatric oncology unit of a children's hospital in Switzerland.

We provided our research participants with a written informed consent information document that included everything they needed to know about the study to make an "informed" decision about participating. The ethics approval came from the responsible Cantonal Ethics Committee (KEK-StV.-Nr. 07/13). They did not express any concerns about the ethical issues of the study.

All parents ( $N = 109$ ) were invited to participate in the study, which used the social counseling service of the children's hospital from February 2014 to November 2016.

Screening data are available for 71 cases with a high or low psychosocial burden, corresponding to a response rate (adjusted gross sample) of 85% (first survey wave).

Despite the relatively low sample size, an exceptionally high response rate (in all three waves) provided a solid foundation of data.

The children suffering from cancer were, on average, 6 years old, ranging from 1 to 16 years old at the time of the survey. There were 45% boys and 55% girls. The parents were, on average, 38 years old, ranging from 22 to 62 years at the time of survey. Concerning marital



status, 80% of parents were married, and the remaining parents were single (6%), divorced or separated (11%), widowed (1%), or in registered partnerships (1%). A total of 66% of parents had Swiss or dual citizenship, while 34% were of different foreign nationalities. Regarding family size, 54% of families had two children, 21% had one child, 20% had three children, and one family had more than four children (see Appendix, Table 2).

## **2.4 Instruments**

The diagnostic performance of a screening instrument, or whether it will allocate clients to the right psychosocial burden group during the social case history, was assessed with a method called the receiver operating characteristic (ROC).<sup>30</sup> This method requires that, in addition to the values of the screening instrument, an independent measurement is available that divides the population of interest into two groups. Usually, this allocation is achieved through the use of another diagnostic test.<sup>20,22</sup> We used two reliable instruments—the Impact on Family Scale (IFS) and the Munich List of Quality of Life Dimensions (MLDL)—as they assess for comparable dimensions. In addition, we used the social workers' external assessments of the dimensions of the S-FIRST.

### **2.4.1 Impact on Family Scale (IFS)**

The IFS is a self-report instrument that assesses the well-being of families with children with chronic conditions and disabilities. We used the German version of the IFS,<sup>31</sup> which has been translated and tested psychometrically. The IFS contains 33 Likert-scaled items to describe social relationships and assess the general negative impact on parents, concern for siblings, financial impact, and coping problems, as well as provide a total score.<sup>32</sup> The fully verbalized, 4-point response scale runs from “fully correct” (1) to “not correct at all” (4).

### **2.4.2 Munich List of Quality of Life Dimensions (MLDL)**

The MLDL measures satisfaction with several quality of life dimensions. The questionnaire contains 19 items to assess physical (health, physical and mental resilience, health care,

disease management), psychological (well-being, self-esteem, recognition, relaxation), everyday life (job, finances, home, leisure, autonomy), and social life (marriage/partner, sex life, family, friends, social support) dimensions. The items can also be used to assess the importance of desire for change.<sup>33</sup> The 11-point response scale ranges from “dissatisfied” (0) to “satisfied” (10).

## **2.5 Statistical Analysis, ROC curve**

Using a screening instrument to split a population into two groups (in this case, a group with a low psychosocial burden and a group with a high psychosocial burden) rarely leads to a disjunctive separation of the groups. The distributions of the test results overlap in some areas. Any possible threshold that separates the two groups will, in some cases, classify correctly (“true positive”) but will also misclassify some cases (“false negative”). On the other hand, cases that have a low psychosocial burden are correctly classified (“true negative”) or wrongly classified as having a high psychosocial burden (“false positive”). Two central concepts are involved here: sensitivity and specificity.

Sensitivity describes the ability of the screening instrument to recognize parents with a high psychosocial burden (“high-risk cases”), i.e., highly burdened clients are in fact recognized as highly burdened. Specificity describes the ability of the screening instrument to recognize parents with a low psychosocial burden (“low-risk cases”), i.e., clients with a low burden are in fact recognized as having a low burden. This logic is illustrated in the Appendix in Table 3.<sup>30 34</sup>

The ratio of sensitivity and specificity is equally important for the choice of the optimal threshold. The selection of the threshold should be made carefully because it determines whether patients or clients are classified as test-positive or test-negative.

The question about the optimal threshold cannot be answered unequivocally because the answer depends on how important the sensitivity and specificity of a screening instrument are in a given situation.<sup>35</sup> Sensitivity should be emphasized if the situation involves a disease

with bad or even life-threatening consequences for the patient, if a promising therapy is available, and if false positives can be resolved with reasonable effort and without too much burden for the person involved.<sup>36</sup>

Specificity should be emphasized if no therapy is known to treat or cure, if the therapy leads to disproportionately high financial burdens for the patient or the health care system, if the therapy is associated with severe side effects, and if follow-up examinations are associated with significant risks or mental stress for the patient. For various reasons, we decided to optimize the screening in terms of sensitivity and accept wrongly classified parents with a high psychosocial burden.<sup>36</sup>

### **3 Results and conclusions**

#### **3.1 Results**

In the ROC curve, the rate of the correctly classified (true positive, sensitivity) as a function of the rate of the wrongly classified (false positive, 100% specificity) was plotted for different cut-off points of a parameter. Each point on the ROC curve represents a sensitivity/specificity pair that corresponds to a decision threshold. The area under the curve (AUC) shows how well a parameter can distinguish between two groups (low versus high psychosocial burden). A screening instrument that discriminates perfectly (no overlapping of the two distributions) would have a ROC curve running through the upper left corner (100% sensitivity, 100% specificity). The closer the ROC curve is to the upper left corner, the higher the overall accuracy of the screening instrument.<sup>30 34</sup>

The size of the AUC provides information about the instrument's discriminatory power. If the ROC curve follows the bisector, then the AUC = 0.500. In this case, the test cannot distinguish between the two groups. An AUC = 1.00 would indicate a perfect separation of groups.<sup>37</sup> The closer the AUC value is to 1.00, the more reliable the diagnostic method or the screening is; the closer the AUC value is to 0.500, the less reliable the screening is.

{Insert Figure 2 here}

The black dotted diagonal in Figure 2 corresponds to the null hypothesis (no sensitivity, no specificity), i.e., the closer the colored curves are to the black dotted line, the worse the screening instrument divides into the two groups. The area under the colored curves gives an indication of how accurate the screening is.

The following parameters for interpretation are recommended:  $0.500 < \text{AUC} < 0.700$  = small discriminatory power;  $0.700 < \text{AUC} < 0.900$  = medium discriminatory power; and  $0.900 < \text{AUC} < 1.000$  = high discriminatory power.<sup>37</sup> We obtained significant AUC values from 0.671 to 0.882, meaning that the screening instrument has small to medium discriminatory power (see Table 1). Regarding the S-FIRST external assessment dimension, the associated 95% confidence interval (CI) extends from .805 (lower bound) to .959 (upper bound). If the screening were repeated with a random sample of 100 people, the AUC value would have a 95% CI between 0.805 and 0.959, indicating favorable results.

{Insert Table 1 here}

Regarding the value of screening instruments, another significant question arises: How do we calculate the best threshold for ROC curves? This calculation depends on whether the specificity or sensitivity of a screening should be increased. If sensitivity is maximized at the expense of specificity, the test would be maximally sensitive, or it would correctly categorize everyone who is affected but would produce many false-positives. Likewise, if specificity is increased (minimizing the axis of 1-specificity), the test will be more accurate in ruling out the disease. Our goal was to find a threshold that was maximally sensitive, thus recognizing parents with a high psychosocial burden as such.

We followed the recommendation of some authors<sup>20</sup> and used a two-number expression for the threshold, such as 2–3, indicating that the threshold is between these two numbers. This approach avoids any ambiguity that may arise with the use of a single number (e.g., a threshold of 3).

{Insert Table 2 here}

Table 2 shows the AUC value and the associated values of sensitivity and specificity for selected dimensions. The optimal threshold for the IFS total burden is between 2 and 3, which corresponds approximately to a separation of the original answer scale between those who agree with the items and those who disagree. The optimal threshold for MLDL total burden is between 5 and 6, which corresponds approximately to a separation of the original answer scale between those who are satisfied and those who are dissatisfied. It is obvious that if a lower threshold is chosen, the sensitivity is higher. Concerning the 1-specificity values, we obtained a relatively high rate of parents with low psychosocial burden (false positives). The optimal threshold to identify parents with a high psychosocial burden in social workers' external assessments is between 13 and 14. Choosing the optimal threshold depends on several economic and ethical factors. An important factor in the selection is how many falsely classified patients or clients will be accepted.

### **3.2 Conclusions and implications for Psychosocial Practice**

We computed sensitivity/specificity indices based on a sample of parents with children suffering from cancer; the parents were screened with the S-FIRST and completed other standardized instruments with reliable indicators. Our results support the use of a screening instrument for case history analyses in psychosocial counseling to identify clients with a high psychosocial burden. We found significant AUC values from 0.671 to 0.882, meaning that the S-FIRST screening instrument has small to medium discriminatory power.

The best results for the threshold were found with social workers' external assessments of the relevant dimensions. The self-assessments and external assessments of parents' burden with the S-FIRST showed high consistency for several reasons. Social workers' communication skills might help to create a trusting relationship between a social worker and a client, which is necessary for addressing emotional problems and burdens.<sup>38</sup> Furthermore, there existed no class barriers, which are typical for doctor-patient communication.

### **3.2.1 Study limitations**

Despite these results, we must acknowledge some methodological shortcomings of this study. Our analyses were based on a very small sample. We recommend that the screening instrument be verified using a large sample of representative cancer patients' relatives; the verification should consider both sexes, all cancer subtype populations, and cultural minorities. A larger sample will allow for more accurate analysis of thresholds and will aid in future empirically based decisions about the use of thresholds.

A further point relates to the question of whether the use of screening instruments in a social counseling service is not uniquely relevant for cancer patient relatives but rather appears to be pertinent for other chronic disease populations as well.<sup>39 39</sup>

### **3.2.2 Clinical implications**

The results of this study support the feasibility and acceptability of the S-FIRST as a brief screening tool for relatives of cancer patient receiving social counseling services. The structured assessment of relatives' psychosocial burden with the screening instrument can help the social worker arrive at a detailed expert evaluation, which might help improve the psychosocial counseling of cancer relatives. The results are also promising as to whether the S-FIRST can serve as a tool to reliably control the allocation of families to social counseling according to their burden situation. The practical relevance arises in particular in care situations in which, due to the (limited) resources, access to social counseling is only selectively possible. This study has not examined the practice and effects of such an approach. For this purpose, further analyses that also examine the practical application of the calculated threshold values are necessary.

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### **Conflict of interest**

The authors have no conflict of interest to report.

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