Validation of the Swedish Acceptance and Action Questionnaire (SAAQ) for parents of children with cancer

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ABSTRACT

Experiential avoidance (EA) has been shown to constitute a generalized vulnerability for psychopathology. It is described as unwillingness to be in contact with aversive private experiences followed by behavioral responses to avoid those experiences. The Acceptance and Action Questionnaire (AAQ-II) is the most frequently used measure of EA and has been shown to correlate with a wide range of measures of mental health and long-term functional behavior. The Swedish version of the scale has previously been evaluated in a non-clinical sample but remains to be evaluated in a clinical one. A subgroup of parents of children with cancer report psychological ill-health long-term. The aim of the study was to investigate factor structure, norm values and psychometric properties of the Swedish Acceptance and Action Questionnaire (SAAQ) for parents of children with cancer. Parents of all children undergoing cancer treatment in Sweden at the time of the study were invited to participate. Factor structure was investigated and norm values, internal consistency, test-retest reliability and convergent validity were calculated. 243 parents participated. The mean of the SAAQ in the sample was 16.69 (SD 8.68; SE 0.56). Internal consistency (α = 0.92) and test-retest reliability (ICC = 0.86) were excellent. The SAAQ correlated moderately with the Pain Catastrophizing Scale for parents (PCS-P). Norm values are now available, and the psychometric properties supported, for the SAAQ for parents of children with cancer. This may facilitate prevention and treatment of psychopathology for this population by providing implications for interventions. First, however, sensitivity to change needs to be assessed.

1. Introduction

It has become increasingly evident in the field of psychology that mental health and behavioral effectiveness are predicted to a greater extent by how people relate to their private experiences (e.g. thoughts, feelings and bodily sensations) than by the form or content of those experiences (Hayes, Louma, Bond, Masuda, & Lillis, 2006). The construct experiential avoidance (EA) has gained attention over the last decades and been proposed as a transdiagnostic factor for psychopathology (Hayes et al., 2004; Spinhaven, Drost, de Rooij, van Hemert, & Penninx, 2014). EA has been shown to constitute a generalized vulnerability for the etiology, maintenance and modifi cations of psychopathology and to correlate with a wide range of measures of mental health and long-term functional behavior (Bond et al., 2011; Hayes et al., 2004; Kashdan, Barrios, Forsyth, & Steger, 2006). EA is described as the unwillingness to remain in contact with aversive private experiences followed by behavioral responses to avoid those aversive experiences or events that elicit them (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). It is the process where a person attempts to alter the form or frequency of private experiences even when doing so causes inconsistency between the person’s actions and his/her values and goals. EA has the paradoxical effect of sensitization to the experience one is seeking to avoid while at the same time narrowing the behavioral repertoire and hence ability to respond flexibly to different challenging life experiences (Campbell-Sills, Barlow, Brown, & Hofmann, 2006a, 2006b; Hayes et al., 2004; Wenzlaff & Wegner, 2000). The counter process of EA is “acceptance”, which is the process of willingness to experience aversive experiences in order to engage in behaviors that are consistent with one’s values and goals (Hayes et al., 2006). EA and acceptance have been incorporated into models of contextual cognitive behavior therapy (CBT), such as in mindfulness based cognitive therapy (MBCT (Segal, Williams, & Teasdale, 2002)), dialectical behavior

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therapy (DBT; (Linehan, 1993)) and acceptance and commitment
treatment (ACT; (Hayes, Strosahl, & Wilson, 2012)). ACT has been shown
to be effective for numerous mental and physical health problems (A-
Tjäk et al., 2015). Within the ACT model experiential avoidance and
acceptance are facets of the underlying process psychological flexibility
(or inflexibility), which is the central target for change. Psychological
flexibility is defined as the ability to fully contact the present moment
with consciousness, and to change or persist in behavior in accordance
with valued ends (Hayes et al., 2006). The terms acceptance and psy-
chological flexibility are often used interchangeably although psycho-
logical flexibility should be seen as the underlying, more general, pro-
cess while acceptance should be seen as an aspect of psychological flexibility (Bond et al., 2011).

The most widely used measure of experiential avoidance/acceptance is the Acceptance and Action Questionnaire (AAQ). The original
version contained nine items, such as “When I feel depressed or an-
nxious, I am unable to take care of my responsibilities” and “I’m not afraid of my feelings”, which were rated on a seven-point Likert scale
from “Never true” to “Always true” (Hayes et al., 2004). The AAQ was
found to correlate with a wide range of quality-of-life outcomes (Chawla & Ostaﬁn, 2007; Hayes et al., 2004, 2006). However, due to
low alpha levels the internal consistency of the AAQ was questioned and a second version was developed, the AAQ-II (Bond et al., 2011).
The mean alpha coefﬁcient for the AAQ-II was 0.84, which indicated good internal consistency, and it demonstrated temporal stability.
Furthermore, the AAQ-II demonstrated concurrent, predictive, conver-
gent, discriminant and incremental validity. A 10-item and a six-
item version were used. A Swedish version of the AAQ-II short version
(SAAQ) has recently been evaluated in a non-clinical (student) sample, showing good internal consistency, temporal stability and good con-
current and convergent validity (Lundgren & Parling, 2017). In order to
be of use in clinical research further validation of the SAAQ in clinical
settings, is important.

Having a child being diagnosed with cancer is one of the most in-
tense and disruptive experiences a parent can have (Vrijmoet-Wiersma
et al., 2008). Parents of children with cancer suffer from a great deal of
psychological distress elicited by numerous stressors. They see the child
very ill and suffering from adverse effects and try to support the child
through a challenging treatment and various medical procedures while at
the same time being exposed to the risk that their child might die (Bryant, 2003; Dalton, Slonim, & Pollack, 2003; Rosenman, Vik, Hui, &
Breitfeld, 2005; Williams & McCarthy, 2015). For the children, pain is reported as one of the most frequent and burdensome symptoms
throughout the cancer trajectory (Twycross, Parker, Williams, & Gibson,
2015). The causes of pain are commonly the disease itself, side
effects of the cancer treatment and/or medical procedures (Ljungman
et al., 1996). Furthermore, having a child undergoing cancer treatment infers practical challenges such as temporary residential care and se-
paration from the rest of the family (Wake et al., 2015). The causes of pain are feared in families, but also the children.

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1.1. Aim

The aim of the present study was to investigate factor structure, norm values and psychometric properties of the SAAQ in a sample of
parents of children with cancer.

2. Methods

2.1. Participants and procedures

The Swedish Acceptance and Action Questionnaire (SAAQ (Lundgren & Parling, 2017)) was used as a validation measure in the
development of the Pain Flexibility Scale for Parents (PPS-P (Thorsell
Cederberg, Weineland Strandskov, Dahl, & Ljungman, 2017b)). Parents
of all children, aged 0–18 years, being treated for cancer in Sweden at
the time of the study (November 2015 to May 2016) were offered participation in the study. The children (n = 485) were identiﬁed by
the Swedish Childhood Cancer Registry. For one child patient infor-
mation was insufﬁcient and he/she was therefore excluded. The six
pediatric oncology centers in Sweden were consulted to ensure that
parents of children who had gone into palliation or deceased after data
withdrawal were not contacted. One child was identiﬁed as undergoing
diagnosis and palliation and was therefore excluded. Parents of 483 children were thus contacted and invited to participate in the study. Information about the study was sent out via mail to the registered address, together
with two sets of the study material. Participants were offered inclusion
in a lottery of ten movie tickets. Consent was given through partici-
pation in the study. The information included that the study was part of
a larger project developing a scale for measuring acceptance of pain in
children with cancer, and their parents, respectively (Thorsell
Cederberg, Weineland Strandskov, Dahl, & Ljungman, 2017a, 2017b),
for which the overall aim was to develop psychological interventions to
help children with cancer to cope with the pain that is often associated
with the cancer and its’ treatment. The study material consisted of
background information, the test version of the scale under develop-
ment, evaluation questions, and two measures for validation, of which
the AAQ-II was one. Two weeks after the ﬁrst dispatch a reminder was
sent out. For test-retest analysis purposes, the measures were sent out
again a month later. All study material was coded and hence de-iden-
tiﬁed. A code key was kept during data collection for administrative
purposes. Two hundred and forty six parents participated in the study
of which 117 parents participated in both measurements and 129
participated at only one measurement. Parents of 160 children (34%) participated in the study. For 85 of the children both parents responded, for 75 one parent responded. Three were excluded due to incorrect
completion of the measures; 25 parents (of 23 children) declined; nine
dispatches were returned by the Postal Service and no response was
received from parents of 291 children. Data from 243 three parents, of
158 children, were included in the statistical analyses. The study was
approved by the Regional Ethical Committee in Uppsala, Sweden [Dnr
2014/375].

2.2. The Swedish Acceptance and Action Questionnaire (SAAQ)

The SAAQ is the Swedish version of the AAQ-II which measures a
general level of experiential avoidance (Bond et al., 2011; Hayes et al.,
2004). Participants rate their level of agreement with statements such
as “My painful experiences and memories make it difﬁcult for me to live
a life that I would value” and “I’m afraid of my feelings”, on a 7-point
Likert scale. Higher scores indicate a higher level of experiential avoidance. In previous studies Cronbach’s alpha for the AAQ-II has been
shown to be 0.78–0.88, test-retest reliability over three months 0.81 and
it has been shown to correlate with a range of measures of mental
health. The SAAQ is the Swedish short version of AAQ-II, with six items
(Lundgren & Parling, 2017), which has shown good internal consistency
(α = 0.85), temporal stability (r = 0.80), good concurrent and
convergent validity and for which a one-factor structure has been supported.

2.3. Measure for validation

Due to the aims of the larger project, to develop a scale for measuring psychological flexibility in relation to pain for parents of children with cancer and to develop psychological interventions to help children with cancer to cope with the pain that is often associated with the cancer and its’ treatment, the Pain Catastrophizing Scale for Parents (PCS-P) was used to assess convergent validity. Pain catastrophizing refers to the process where pain is interpreted as being very threatening (Rosenstiel & Keefe, 1983) and infers an inability to divert one’s attention away from pain (Crombez, Eccleston, Baeyens, & Eelen, 1998a, 1998b). Pain catastrophizing implies a highly reactive process, characterized by an unwillingness to experience pain, which can be conceptualized as experiential avoidance. Pain catastrophizing is associated with disability in both pain patients (Severeijns, Vlaeyen, van den Hout, & Weber, 2001; Turner, Jensen, & Romano, 2000; Turner, Jensen, Warms, & Cardenas, 2002; Turner, Mancl, & Aaron, 2004) and the general population (Severeijns, van den Hout, & Vlaeyen, 2005). The PCS-P is a 13-item scale measuring catastrophizing thoughts in parents of children in pain (Goubert, Eccleston, Vervoort, Jordan, & Crombez, 2006; Sullivan, Bishop, & Pivik, 1995). Parents rate their level of agreement with statements such as “When my child is in pain, I can’t stand it anymore” and “When my child is in pain, I can’t keep it out of my mind”, on a 5-point Likert scale. Higher scores indicate a higher level of catastrophizing thoughts. Crombach’s alpha for the PCS-P has been shown to be 0.93 and the scale correlates with measures of parental distress and of child functioning and disability (Goubert et al., 2006).

2.4. Statistical analyses

All statistical analyses were performed in IBM SPSS Statistics, version 24 (IBM, 2016). Descriptive statistics were used to calculate norm values. Principal Component Analysis (PCA) was performed to investigate factor-structure of the measurement in the present sample. Bartlett’s test of sphericity was significant and the Kaiser-Meyer-Olkin index (KMO) was 0.88 indicating that the data set was suitable for factor analysis. Regarding extraction, the Kaiser’s criterion and the scree plot were assessed. Crombach’s alpha was calculated to assess the internal consistency of the scale for this population. To examine test-retest-reliability, the intraclass correlation coefficient (ICC) was calculated, which has been reported as the method of choice (Terwee et al., 2007; Weir, 2005). A Two-way Random Model assessing the Single Measures value was used (Landers, 2015). An ICC of less than 0.40 indicates poor inter-rater-agreement, between 0.40 and 0.59 fair, between 0.60 and 0.74 good and greater than 0.75 excellent (Cicchetti, 1994). Correlation with the PCS-P was performed to assess convergent validity. The scale data was not normally distributed and hence Spearman’s rho was used. Correlation coefficients were interpreted according to Cohen (Cohen, 1988), where $p = 0.00–0.19$ was considered very weak, $0.20–0.39$ weak, $0.40–0.59$ moderate, $0.60–0.79$ strong and $0.80–1.0$ very strong.

3. Results

3.1. Descriptives

Two hundred and forty three parents participated in the study, of which 147 (60.5%) were mothers and 96 (39.5%) fathers. The mean age of the children was just over seven and a half years (SD = 5.1) and the age range was 0–18 years. The diagnoses of the children were leukemias (81), brain tumors (20) and solid tumors (57). The parents reported their child’s current level of pain and discomfort as well as average level of pain and discomfort during the last week. The mean of these ratings ranged from 1.25 to 1.58 (SD = 1.85–2.05) on a scale from 0 to 10, indicating low levels of pain and discomfort.

3.2. Factor structure

The PCA revealed one factor with an eigenvalue above 1, explaining 72.6% of the variance. The scree plot also showed a clear break after the first factor. In a one-factor solution, communalities were high (0.659–0.827) as well as factor loadings (0.812–0.909). Hence, a one-factor structure of the SAAQ was supported. Factor loadings are presented in Table 1.

3.3. Norm values, reliability and validity

Norm values, Cronbach’s α ($n = 240$), the test-retest correlation coefficient ($n = 116$) and the correlation coefficient for the validation with the PCS-P ($n = 236$) are presented in Table 2. Internal consistency and test-retest reliability were excellent. The correlation between the SAAQ and the PCS-P was moderate.

4. Discussion

The aim of the study was to investigate factor structure, norm values and psychometric properties of the SAAQ in a clinical sample of parents of children with cancer. A one-factor structure of the SAAQ has previously been found to best represent the data and was supported in the sample. The mean of the SAAQ was 16.69 (SD 8.68), which is higher than the mean reported for a student sample, 14.84 (SD 6.24), indicating a higher level of EA in our clinical sample (Lundgren & Parling, 2017). (The standard error of the mean, .56, and the confidence interval, 15.59–17.80, indicate that this difference is valid). This is not surprising considering the challenges that parents of children with cancer face, which may very likely trigger EA, compared with a non-clinical population. The results showed excellent internal consistency and temporal stability. A moderate correlation with the PCS-P was shown, which was expected since the PCS-P measures an adjacent but clearly distinct construct.

The study was part of a larger project developing a scale for measuring acceptance of pain in children with cancer, and their parents, respectively (Thorsell Cederberg et al., 2017a, 2017b), for which the overall aim was to develop psychological interventions to help children with cancer to cope with the pain that is often associated with the cancer and its’ treatment. Parents of all children undergoing cancer treatment in Sweden at the time of the study were invited to participate. The larger study addressed children with cancer reporting pain, and their parents respectively, and one could wonder if the population in the current study therefore rather would be parents of children with cancer reporting pain. Pain is reported as one of the most frequent adverse symptoms of cancer treatment (Twycross et al., 2015) and highly likely to affect all children with cancer, to some extent.
Furthermore, the respondents of the larger study were able to report pain retroactively and current pain was hence not obliged. Taken together, the sample of the current study is considered representative of children with cancer in general. Parents of one third of the children participated in the study, which is considered an expected answering frequency in research today and also realistic given the stressful situation that these families are in. Yet, it is something to keep in mind with regards to generalizability of the results. It is possible that the most distressed parents declined to participate, or did not respond. On the other hand, it is also possible that the least distressed parents did not participate due to lack of motivation. Either way, with a substantial part of the parents not participating, there is a risk that the sample is not quite representative of the whole population.

The AAQ-II, the English version of the SAAQ, is well validated, which along with the validation of the SAAQ in a student sample and the results of the present study support the psychometric properties of the SAAQ. However, further psychometric evaluation to investigate its reliability and validity would be important in general. Moreover, further evaluation of the SAAQ in clinical samples would be important to assess experiential avoidance and psychological flexibility for certain populations. Experiential avoidance has been proposed as a generalized vulnerability for psychopathology (Kashdan et al., 2006) and to predict psychological ill-health long-term and that EA constitutes hand, which remains to be evaluated for the SAAQ. Interventions fostering psychological flexibility have the potential of promoting psychological health and well-being for this population. In a pilot study evaluating an ACT intervention for parents of children with a life-threatening illness (who were either diagnosed with cancer or who had life-saving cardiac surgery), parents reported improvements in psychological flexibility and reductions in post-traumatic stress symptoms and emotional impact from their child’s illness post intervention. (Burke et al., 2014) These improvements were maintained at 6-month follow-up. The results warrant further evaluation of psychological flexibility enhancing interventions for parents of children with life-threatening diseases. In order to evaluate processes of change in different interventions sensitivity to change needs to be assessed for the measure at hand, which remains to be evaluated for the SAAQ.

In sum, considering that a subgroup of parents of children with cancer report psychological ill-health long-term and that EA constitutes a generalized vulnerability for the etiology and maintenance of psychopathology and has been shown to predict psychological ill-health in parents of children with cancer, the SAAQ has the potential of being useful in the prevention and treatment of psychopathology for this population by providing reliable implications for interventions. Interventions fostering psychological flexibility and promoting psychological well-being would not only benefit the parents who struggle to cope with their child's disease but also the children.

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### Table 2
| Mean (SD) | SE | 95% CI for mean | 9% trimmed mean | Median | Score range | Possible range | Cronbach's α | Test-retest (ICC) | Correlation with the PCS-P (γ) |
|----------|----|----------------|----------------|--------|-------------|---------------|--------------|---------------|----------------|------------------|
| 16.69 (8.68) | 0.56 | 15.59 – 17.80 | 16.17 | 16.00 | 6–42 | 6–42 | 0.92 | 0.86 | 0.57 |

Note: SAAQ = the Swedish Acceptance and Action Questionnaire; PCS-P = the Pain Catastrophizing Scale for Parents.

### Conflicts of interest
The authors declare no conflicts of interest.

### References


