



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 ($\alpha = 0.92$) 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; Spinhoven, Drost, de Rooij, van Hemert, & Penninx, 2014). EA has been shown to constitute a generalized vulnerability for the etiology, maintenance and modifications 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 therapy (ACT; (Hayes, Strosahl, & Wilson, 2012)). ACT has been shown to be effective for numerous mental and physical health problems (A-Tjak 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 psychological flexibility are often used interchangeably although psychological flexibility should be seen as the underlying, more general, process 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 anxious, 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, convergent, 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 concurrent 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 intense 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 separation from the rest of the family (Wakefield, McLoone, Butow, Lenthen, & Cohn, 2011). Despite these stressors, most parents of children with cancer show resilience long-term (Phipps et al., 2015). A subgroup, however, report high levels of psychological distress long-term (Ljungman et al., 2014, 2016). EA has been proposed as a maintaining factor for psychological ill-health in parents of children with cancer (Cernvall et al., 2016). The validation of the AAQ-II for this population would therefore be of great use, both in research and clinically. In addition, how parents feel and behave in challenging situations affect level of distress and type of coping in the child (Blount et al., 1989; Fuemmeler, Brown, Williams, & Barredo, 2003; Perrin, Ayoub, & Willett, 1993; Phipps & Mulhern, 1995; Phipps, Long, Hudson, & Rai, 2005; Robinson, Gerhardt, Vannatta, & Noll, 2007) and acceptance in parents has been shown to predict lower levels of depression and anxiety in the children (Garthe, Sullivan, & Kliever, 2015; Moyer & Sandoz, 2015). Therefore, the use of a measure of EA in parents of children with cancer would not only benefit the parents per se, but also the children.

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 (PFS-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 information 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 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 participation 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 development, 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-identified. 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 ($\alpha = 0.85$), 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, Warm, & 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. Cronbach'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. Cronbach'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 $\rho = 0.00$ – 0.19 was considered very weak, $.20$ to 0.39 weak, $.40$ to 0.59 moderate, $.60$ to 0.79 strong and 0.8 – 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

Table 1
Factor loadings of the items from the principal component analysis of the SAAQ.

Item	Factor loading
4) My painful memories prevent me from having a fulfilling life.	0.909
2) I'm afraid of my feelings.	0.862
3) I worry about not being able to control my worries and feelings.	0.854
6) Worries get in the way of my success.	0.839
5) It seems like most people are handling their lives better than I am.	0.831
1) My painful experiences and memories make it difficult for me to live a life that I would value.	0.812

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.

Table 2

Mean, standard deviation (SD), standard error (SE), confidence interval (CI) for mean, trimmed mean, median, score range, possible range and internal consistency of the SAAQ and correlation coefficients.

Mean (SD)	SE	95% CI for mean	5% trimmed mean	Median	Score range	Possible range	Cronbach's α	Test-retest (ICC)	Correlation with the PCS-P (ρ)
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.

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 to represent parents 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 not quite represents 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 in parents of children with cancer (Cernvall et al., 2016). By providing norm values, the study enables the prediction of experiential avoidance and psychological flexibility for parents of children with cancer, in the natural course. Furthermore, interventions targeting 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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Conflicts of interest

The authors declare no conflicts of interest.

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