Journal of Contextual Behavioral Science 10 (2018) 103–107

Contents lists available at ScienceDirect

Journal of Contextual Behavioral Science

journal homepage: www.elsevier.com/locate/jcbs

A preliminary validation of the Swedish short version of the Avoidance and Fusion Questionnaire for Youth (AFQ-Y8) for children and adolescents with cancer

Jenny Thorsell Cederberg[a,*], Sandra Weineland[b,c], JoAnne Dahl[d], Gustaf Ljungman[a]

[a] Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden
[b] Research and Development Center, Primary Health Care, Region Västra Götaland, Sweden
[c] Department of Psychology, University of Gothenburg, Gothenburg, Sweden
[d] Department of Psychology, Uppsala University, Uppsala, Sweden

ARTICLE INFO

Keywords:
Psychological inflexibility
Cognitive fusion
Experiential avoidance
Psychological flexibility
Children and adolescents
Cancer

ABSTRACT

Psychological inflexibility constitutes a generalized vulnerability for psychopathology. Children and adolescents undergoing cancer treatment are faced with numerous physical and psychological stressors throughout their cancer trajectory. Most of the survivors show resilience but some groups report psychological ill-health and poor quality-of-life long-term. Psychological flexibility has been shown to mediate improvements in psychological health for cancer patients. The Avoidance and Fusion Questionnaire for Youth (AFQ-Y) is the most frequently used measure of psychological inflexibility in children and adolescents. It correlates with a wide range of measures of mental health and long-term functional behavior. The aim of the study was to investigate norm values, psychometric properties and factor structure of the AFQ-Y8 for children and adolescents with cancer. All children and adolescents, aged 7–18 years of age, undergoing cancer treatment in Sweden at the time of the study were invited to participate. Norm values, internal consistency, test-retest reliability and convergent validity were calculated and an exploratory factor analysis was conducted. 62 children participated. The mean of the AFQ-Y8 in the sample was 10.30 (5.75). Internal consistency was acceptable ($\alpha = 0.76$), test-retest reliability was good (ICC = 0.64) and convergent validity was demonstrated ($r = 0.42$). Norm values are now available, and the psychometric properties supported, for the AFQ-Y8 for children and adolescents with cancer. This provides implications for the prevention and treatment of psychopathology for this population. However, the one-factor structure of the AFQ-Y8 was not unequivocally supported. The results from the PCA rather suggested a two-factor structure. Due to the small sample of the study, the results should be seen as preliminary and further validation is warranted, specifically with regards to factorial validity and sensitivity to change.

1. Introduction

The way a person *relates* to his/her own experiences (such as thoughts, feelings, memories and physical sensations) seems to be a better predictor of mental health and behavioral effectiveness than the experiences themselves (Hayes, Louma, Bond, Masuda, & Lillis, 2006). Cognitive fusion is the process of entanglement with the content of private experiences and the tendency to interpret this content literally, as if it was "true". This process of interpreting thoughts and feelings as true representations of reality is likely to lead to experiential avoidance (EA). EA is the process of attempting to change the form or frequency of own experiences, even when doing so leads to inconsistency between one's actions on the one hand and values and long-term goals on the other hand. EA is defined as the unwillingness to remain in contact with aversive private experiences followed by behavioral responses to avoid, alter or otherwise control those aversive experiences or events that elicit them (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). It has the paradoxical effect of sensitizing the person to the very experience he/she is trying 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 construct has been proposed as a trans-diagnostic factor (Hayes et al., 2004; Spinhoven, Drost, de Rooij, van Hemert, & Penninx, 2014) and to constitute a generalized vulnerability for the etiology, maintenance and modifications of psychopathology (Kashdan, Barrios,

* Corresponding author.
E-mail address: jenny.thorsell.cederberg@kbh.uu.se (J.T. Cederberg).

https://doi.org/10.1016/j.jcbs.2018.09.004
Received 26 April 2018; Received in revised form 6 September 2018; Accepted 20 September 2018

Forsyth, & Steger, 2006). It correlates with a wide range of measures of mental health and long-term functional behavior (Bond et al., 2011; Hayes et al., 2004). Cognitive fusion and EA are two interrelated facets of *psychological inflexibility*, the counter process of psychological *flexibility*, which 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). Psychological inflexibility/flexibility is the central target for change in acceptance and commitment therapy (ACT; (Hayes, Strosahl, & Wilson, 2012)). In ACT, the aim is not to alter the content of private experiences but rather to alter the context and function of those experiences, in order to decrease their behavioral impact. In that way, psychological inflexibility is undermined and psychological flexibility promoted, enabling a broader behavioral repertoire and engagement in vital life activities. ACT has been shown to be effective for various mental and physical health problems (A-Tjak et al., 2015). In a recent review of ACT for cancer patients, ACT was shown to improve psychological well-being and quality of life at post measurement and follow-up up to 12 months (González-Fernández & Fernández-Rodríguez, 2018). In the majority of the studies in the review the patients had finished oncological treatment, and in two of the studies the patients were undergoing treatment. Psychological flexibility has been suggested as the mechanism of change (González-Fernández & Fernández-Rodríguez, 2018; González-Fernández, Fernández-Rodríguez, Paz-Caballero, & Pérez-Álvarez, 2018) and has in one study by Arch and Mitchell (2016) been shown to mediate the improvements in eight out of nine outcomes, for example depression, life management and physical pain. One of the studies evaluated an acceptance based consultation for children and adolescents with cancer experiencing anger, which showed reductions in anger at post and one-month-follow-up (Asadi, Ghojavand, & Abedi, 2016). In another study on adolescents with chronic illness, hence not specifically cancer, psychological flexibility was positively related to well-being (Casier et al., 2013). Globally, the annual incidence rate of cancer in children and adolescents is 187 per 1 million (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). In Sweden, about 300 children and adolescents are diagnosed with cancer each year (The National Board of Health & Welfare (Socialstyrelsen), 2017). Survival rates have increased dramatically over the past decades, showing an overall five year-survival rate of over 80% (Gatta et al., 2009). However, both the disease itself and its treatment are associated with significant stressors for the children. During treatment, they suffer from multiple physical and psychosocial symptoms (Hedström, Haglund, Skolin, & von Essen, 2003; Linder, Al-Qaaydeh, & Donaldson, 2018). Common physical symptoms are pain, nausea and fatigue whereas psychosocial symptoms are commonly feelings of alienation, confinement, worry and anxiety. After treatment completion, they are at risk of late effects, depending on the type of cancer and treatment (Langer, Grabow, Steinmann, Wörmann, & Calaminus, 2017). Common late effects are cognitive impairments, sexual and reproductive problems, cardio-pulmonary derogation, thyroid abnormalities and metabolic disorders, visual and auditory problems, secondary malignancies, chronic fatigue and post-traumatic stress disorder (Landier, Armenian, & Bhatia, 2015; Langer et al., 2017; Oeffinger et al., 2006). Despite these stressors and challenges most children surviving cancer show resilience long-term – are psychologically healthy and report life satisfaction (Zeltzer et al., 2009). However, some groups of childhood cancer survivors are at risk of psychological ill-health and poor quality of life long-term (Eilertsen, Rannestad, Indredavik, & Vik, 2011). For these children and adolescents, psychological treatments are particularly important, both as preventive and therapeutic interventions. The literature suggests that psychological flexibility is a central mechanism of change for this group and interventions targeting psychological flexibility are hence of importance. In order to evaluate assumed mediators of treatments, instruments measuring those variables are necessary. The most widely used measure of psychological inflexibility in children and adolescents is the Avoidance and Fusion Questionnaire of Youth (AFQ-Y (Greco, Lambert, & Baer, 2008). The psychometric properties of the AFQ-Y has been supported and the scale has been shown to correlate positively with measures of child-reported anxiety, somatic complaints and problem behavior, and negatively with measures of quality of life. Two Swedish versions of the scale has been validated, the AFQ-Y17 and the AFQ-Y8, for adolescents 15–20 years of age. Both versions showed excellent internal consistency, temporal stability and convergent validity. The shorter version, AFQ-Y8, showed better fit of the data in a single factor structure than the longer version, and was recommended for use. The Swedish version of the scale remains, however, to be validated for children younger than 15 years of age. Furthermore, in order to be of use for children and adolescents with cancer, validation in this patient group is important. A validated scale for measuring psychological flexibility in children and adolescents with cancer would give a means to evaluate interventions targeting a central mechanism for psychological well-being in this group, and to screen for patients at risk of developing psychological ill-health long-term.

1.1. Aim

The aim of the present study was to investigate norm values, psychometric properties and factor structure of the Swedish short version of the Avoidance and Fusion Questionnaire for Youth, AFQ-Y8, in a clinical sample of children and adolescents with cancer.

2. Methods

2.1. Participants and procedures

The Avoidance and Fusion Questionnaire for Youth (AFQ-Y (Greco et al., 2008; Livheim et al., 2016)) was used as a validation measure in the development of the Pain Flexibility Scale for Children (PFS-C (Thorsell Cederberg, Weineland Strandskov, Dahl, & Ljungman, 2017)). All children and adolescents between seven and 18 years of age, undergoing cancer treatment in Sweden at the time of the study (November 2015 to May 2016) were invited to participate. Two-hundred and thirty-three children were identified by the Swedish Childhood Cancer Registry. Patient information was insufficient for one child and he was therefore excluded. Research nurses from the six pediatric oncology centers in Sweden were consulted to double-check that none of their patients had gone into palliation or died after data withdrawal, to ensure that those children were not contacted. One child was identified as undergoing palliation and was therefore excluded. Thus, 231 children were contacted and invited to participate in the study. The study material was sent out via mail to the registered address. Participants were offered inclusion in a lottery of ten movie tickets and consent was given through participation in the study. In addition, written parental consent was required for children under 15 years of age. The study material consisted of patient information, a questionnaire for background information, the test version of the scale under development, evaluation questions, and two measures for validation, of which the AFQ-Y8 was one. Three different versions of the patient information were used; one for children seven to 12 years of age, one for adolescents 13–18 years of age and one for parents. Background information included age, gender, type and date of diagnosis, date of end of treatment if applicable, and level of and discomfort of pain. A reminder was sent out two weeks after the first dispatch. The measures were sent out again a month later for test-retest analysis. All study material was coded and hence de-identified. A code key was kept during data collection for administrative purposes. Sixty-two children (27%) participated in the study, of whom 39 participated at both measurements and 23 at only one measurement. One was excluded due to insufficient completion of the measures. Data from 61 participants were included in the analyses. Due to some attrition on specific items or measures or at test-retest measurement, the number of participants vary between analyses. Three dispatches were returned by the Postal Service. Ten children declined

and no response was received from 156 children. The study was approved by the Regional Ethical Committee in Uppsala, Sweden [Dnr 2014/375].

2.2. The Avoidance and Fusion Questionnaire for Youth (AFQ-Y)

The AFQ-Y measures psychological inflexibility in children and adolescents (Greco et al., 2008). Participants rate their level of agreement with statements such as “My thoughts and feelings mess up my life” and”I’m afraid of my feelings”, on a 5-point Likert scale made up by a single factor. Score range is 0–24 and higher scores indicate a higher level of psychological inflexibility. The AFQ-Y has demonstrated excellent internal consistency, temporal stability and convergent, discriminant and construct validity. It has been shown to correlate with measures of anxiety, depression and anger. For the Swedish version of the scale the short version of eight items showed better factorial validity, for which Cronbach's alpha has been shown to be 0.90 and test-retest reliability (over two to four weeks) $r = 0.80$ (Livheim et al., 2016), and is the recommended version for use among adolescents. Therefore the short version, AFQ-Y8, has been used and evaluated in the present study.

2.3. Measure for validation

The study was part of a larger project developing a scale for measuring psychological flexibility of pain in children and adolescents with cancer (Thorsell Cederberg et al., 2017). The long-term overall aim of the project was to develop and evaluate interventions targeting psychological flexibility in order to help these patients to cope with the pain that is often associated with the cancer and its’ treatment. The Pain Catastrophizing Scale for Children (PCS-C) was therefore used to assess convergent validity (Crombez et al., 2003; Sullivan, Bishop, & Pivik, 1995). Pain catastrophizing refers to the process where pain is interpreted as very threatful (Rosenstiel & Keefe, 1983) and is characterized by an inability to divert one's attention away from pain (Crombez, Eccleston, Baeyens, & Eelen, 1998a, 1998b). It involves a highly reactive process, characterized by an unwillingness to experience pain, which corresponds to the process of psychological inflexibility. The PCS-C measures catastrophizing thoughts in children in pain and has been shown to have good internal consistency ($\alpha = 0.81$–0.89), predictive and concurrent validity and has been validated in different languages and populations (Crombez et al., 2003; Kröner-Herwig & Maas, 2013; Parkerson et al., 2013; Pielech et al., 2014; Solé, Castarlenas, & Miró, 2016; Sullivan et al., 1995). The scale consists of 13 statements with which the children rate their agreement on a 5-point Likert scale. Examples of statements are: “When I have pain, I worry all the time about whether the pain will end” and “When I have pain, I get scared that the pain will get worse”. Score range is 0–52 and higher scores indicate a higher level of catastrophizing.

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. Cronbach's alpha was calculated to assess internal consistency. Alpha values were interpreted according to guidelines (Davenport, Davison, Liou, & Love, 2015), where $\alpha < 0.50$ is unacceptable, 0.50 – 0.59 poor, 0.60 – 0.69 questionable, 0.70 – 0.79 acceptable, 0.80 – 0.89 good and $\alpha \geq 0.90$ excellent. Intraclass correlation (ICC) was calculated to examine test-retest-reliability (Terwee et al., 2007; Weir, 2005). A Two-way Random Model assessing the Single Measures value was used (Landers, 2015). According to the guidelines by Cicchetti 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-C was performed to assess convergent validity. The data on both scales were normally distributed and Pearson correlation was used. Correlation coefficients were interpreted according to the guidelines recommended by Cohen (1988), where $r = 0.10$ – 0.29 is considered a small correlation, 0.30 – 0.49 medium and 0.5 – 1.0 large. Level of statistical significance was set at $p < 0.05$. Principal component analysis (PCA) was conducted to investigate factor structure of the AFQ-Y8 in the sample. Bartlett's test of sphericity was significant and the Kaiser-Meyer-Olkin index (KMO) was 0.72 indicating suitability for factor analysis. With regards to extraction, the Kaiser's criterion and the scree plot were first assessed, then a one-factor-solution was forced. Interdependence between factors was indicated and oblique rotation was applied in the two-factor-solutions. Independent Samples *t*-test was performed to compare the means between boys and girls.

3. Results

3.1. Descriptives

Data from sixty-one participants were included the analyses, of which 33 (54%) were boys and 28 (46%) were girls. The mean age was just over 12 and a half years (SD = 3.4) and the age range was 7–18 years. The diagnoses of the children were leukemias (23), brain tumors (13) and solid tumors (25).

3.2. Factor structure

The PCA yielded two factors with an eigenvalue above 1, explaining 38.2% and 15.4% of the variance, respectively. The scree plot showed an ambiguous result with a clear break after the first factor, yet another break after the second. Table 1 shows factor loadings and communalities for a two-factor solution with Promax rotation. Table 2 shows factor loadings and communalities for a one-factor solution.

3.3. Norm values, reliability and validity

Norm values (n = 57), Cronbach's α (n = 58), the test-retest correlation coefficient (n = 37) and the correlation coefficient for the validation with the PCS-C (n = 54) are presented in Table 3. Internal consistency was acceptable and test-retest reliability was good. The correlation between the AFQ-Y8 and the PCS-C was medium, and statistically significant. The mean for boys (n = 31) was 10.8 (SD 6.3) and for girls (n = 26) 9.7 (SD 5.0), a non-significant difference in the sample (t (55) = -0.772, $p = 0.44$, two-tailed).

Table 1
Factor loadings from the structure matrix of the PCA and communalities, for a two-factor solution with Promax rotation.

Item	Communality	Factor loading	
		Factor 1	Factor 2
2) My thoughts and feelings mess up my life.	0.641	0.789	
8) I can’t be a good friend when I feel upset.	0.540	0.731	
1) My life won’t be good until I feel happy.	0.494	0.684	
5) I stop doing things that are important to me whenever I feel bad.	0.365	0.603	
6) I do worse when I have thoughts that make me feel sad.	0.390	0.547	
3) The bad things I think about myself must be true.	0.704		0.839
7) I am afraid of my feelings.	0.623		0.788
4) If my heart beats fast, there must be something wrong with me.	0.531		0.719

Table 2
Factor loadings from the component matrix of the PCA and communalities, for a one-factor solution.

Item	Communality	Factor loading (single factor)
2) My thoughts and feelings mess up my life.	0.560	0.749
3) The bad things I think about myself must be true.	0.471	0.687
7) I am afraid of my feelings.	0.454	0.674
6) I do worse when I have thoughts that make me feel sad.	0.390	0.624
8) I can't be a good friend when I feel upset.	0.351	0.593
5) I stop doing things that are important to me whenever I feel bad.	0.293	0.541
4) If my heart beats fast, there must be something wrong with me.	0.276	0.526
1) My life won't be good until I feel happy.	0.257	0.506

4. Discussion

The aim of the study was to investigate norm values, psychometric properties and factor structure of the AFQ-Y8 in a clinical sample of children and adolescents with cancer. The results showed satisfactory internal consistency, good temporal stability and a medium correlation with the PCS-C, indicating convergent validity. This strength of the correlation was expected since the PCS-C measures a related but distinct construct. The single-factor structure reported from previous studies (Greco et al., 2008; Livheim et al., 2016), was not supported in our sample. Although the scree-plot did show a break after the first factor and the factor loadings in the one-factor solutions were rather high, > 0.506, communalities were rather low (< 0.3 for three of the items), indicating low variance explained by the solution in several items and the total variance explained by a one-factor solution was only 38%. A two-factor solution rather fitted the data better. There are different facets of psychological inflexibility, which is seen as an underlying concept captured in a single-factor structure of the AFQ-Y. The question is if two different facets of the concept are reflected in a two-factor structure, such as cognitive fusion and experiential avoidance. Given the preliminary nature of this study with a small sample these results should be seen as tentative and more investigation regarding factor structure of the AFQ-Y8, particularly in clinical samples, is warranted. The mean of the AFQ-Y8 in our sample was 10.30 (SD 5.75), which is a little higher than the mean reported for a school-based sample in the US, 9.19 (SD 6.41) for girls and 7.62 (SD 6.20) for boys (Greco et al., 2008), indicating a lower level of psychological flexibility in our clinical sample. Considering the aversive symptoms and stressors that children and adolescents with cancer experience (Hedström et al., 2003; Langer et al., 2017; Linder et al., 2018) and the nature of cognitive fusion and experiential avoidance, i.e. entanglement with the content of private experiences and unwillingness to remain in contact with aversive experiences (Hayes et al., 1996, 2006), which are central aspects of psychological flexibility, it is not surprising that the mean is higher in our sample. The Swedish AFQ-Y8 has been validated previously in a clinical sample of youths, 15–20 years old, with psychosocial problems (Livheim et al., 2016). There are, however, no norm values reported for that sample. Regarding gender, in our study, the mean for the boys were higher than the mean for the girls, which is the reversed pattern compared to that reported for the school-based sample. Note that this difference was non-significant, why no conclusions can be drawn about gender differences based on these results from the present study.

The study was part of a larger project developing an instrument for measuring psychological flexibility in relation to pain in children and adolescents with cancer (Thorsell Cederberg et al., 2017). The larger study addressed children with cancer reporting pain. Pain is reported as one of the most frequent adverse symptoms of cancer treatment (Twycross, Parker, Williams, & Gibson, 2015) and is likely to affect all children and adolescents with cancer, to some extent, at one time or another. The respondents of the larger study were able to report pain retrospectively and current pain was hence not necessitated for participation in the study. Furthermore, all children, aged 7–18 years, undergoing cancer treatment in Sweden at the time of the study were offered participation. The population from which our sample is drawn is therefore considered to represent children and adolescents with cancer in general. Twenty-seven percent of the children participated in the study. Considering the demanding situation that these children and adolescents are in, the format of the study with having to fill in questionnaires, and the common percentage of participants in survey research today, this response frequency is considered expected and good enough. It is, however, something to keep in mind with regards to generalizability of the results. One could speculate that children who were sicker upon invitation to the study would not participate to the same extent. On the other hand, it may also be likely that children who were not as sick would not feel as motivated and hence not participate for that reason. Either way, the relatively low response rate does limit the generalizability of the study, along with the small sample size. The participants were evenly distributed across the age span, showing that younger children participated to the same extent as older adolescents. Another limitation of the study is that the measure used for assessing validity, the PCS-C, has not been previously validated specifically for children and adolescents with cancer. It is, however, a well-validated measure in general and has been validated for other clinical samples of children and adolescents (Crombez et al., 2003; Kröner-Herwig & Maas, 2013; Pielech et al., 2014).

The results from the present study supports the psychometric properties of the AFQ-Y8 with regards to internal consistency, temporal stability and convergent validity. The single-factor structure that previously has been reported was, however, not supported and the factorial validity of the AFQ-Y8 therefore deserves further investigation, regarding clinical samples in general and for children and adolescents with cancer in particular. Taking into the account the small sample size of the present study, further validation in general for children and adolescents with cancer is also warranted. In addition, in order to enable evaluation of mediating variables in treatments, the measurements at hand need to be sensitive to change, which remains to be assessed for the AFQ-Y8.

Table 3
Mean, standard deviation (SD), standard error (SE), confidence interval (CI) for mean, trimmed mean, median, score range and internal consistency of the AFQ-Y8 and correlation coefficients.

Mean (SD)	SE	95% CI for mean	5% trimmed mean	Median	Score range	Possible range	Cronbach's α	Test-retest (ICC, (95% CI))	Correlation with the PCS-C (*r*)
10.30 (5.75)	0.76	8.77 – 11.82	10.20	10.00	0–23	0–24	0.76	0.64 (0.40–0.80)	0.42

Note: AFQ-Y8 = the Avoidance and Fusion Questionnaire for Youth, 8-item version; PCS-C = the Pain Catastrophizing Scale for Children.

The validation of the AFQ-Y8 for children and adolescents with cancer enables evaluation of interventions targeting a central mechanism for psychological well-being in this group, namely psychological flexibility. Furthermore, available norm values provide implications not only for treatment of psychological ill-health in this group, but also for prevention. Thus, the present study takes a step further in the development towards providing psychological interventions for children and adolescents with cancer, to promote psychological well-being and quality-of-life long-term. This is particularly important for a subgroup of these patients showing a clear need for such interventions. Given the small sample size of the study, the results should, however, be seen as preliminary.

Conflicts of interest

The authors declare no conflicts of interest.

Funding

This work was supported by grants from the Swedish Childhood Cancer Foundation [PR2013-0058] and the Swedish Cancer Society [CAN2013/749].

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