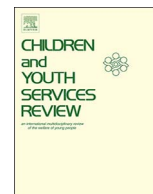




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## “I am no longer alone”: Evaluation of the first North American camp for youth living in families with Huntington's disease

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### 1. Introduction

Affecting over 30,000 people, with approximately 200,000 at risk in the United States, Huntington's disease (HD) is often called a disease of the family (Huntington's Disease Society of America, 2015). HD, with its complicated, stigmatizing symptoms (involuntary movement, slurred speech and cognitive impairment), commonly manifests during ones 30's and 40's during which children are often present in the home. Living with a parent or family member with HD can be emotionally charged, particularly given the knowledge of the 50% inheritance rate (Forrest Keenan, Miedzybrodzka, Teijlingen, McKee, & Simpson, 2007), manifesting concern about whether they will inherit and when they might test for the disease (Driessnack, Williams, Barnette, Sparbel, & Paulsen, 2012).

Moreover, many children and youth participate, at often-intense levels and complexity, in caregiving for the parent or family member (Kavanaugh, 2014). With inconsistent knowledge of HD and attention paid to HD families by health and social service providers (Helder et al., 2002; Lowit & van Tiejlingen, 2005), youth in HD families describe secrecy (Williams et al., 2013), isolation, and little support from peers and other adults (Kavanaugh, Noh, & Studer, 2015). Youth in families with HD are infrequently presented with an opportunity to explore what they know about HD, how it affects them and their well-being, while connecting with “like peers” in similar situations.

In families with illness, youth well-being is often influenced by what they are or are not told about the parent's illness (Muckherjee, Sloper, & Lewin, 2002). While many families struggle with what to tell their children, it is clear children and youth need support in helping them deal with a parental illness (Spath, 2006). Youth in families with HD desire information about the disease process and the possibility they themselves might be at risk – while clearly stating the need to be in supportive environments with other “like youth” where they feel normal and less “othered.” (Kavanaugh et al., 2015). Yet, these youth may be kept in the dark about their risk of inheritance and HD in general, as many parents struggle with how, what, and when to tell

them (Forest Keenan, Teijlingen, McKee, & Miedzybrodzka, 2009).

Addressing the gap in youth services and support, the Huntington's Disease Youth Organization (HDYO), an international non-profit for youth in families with HD, developed a series of programs and supports for these isolated and vulnerable youth, including a youth respite camp.

#### 1.1. Youth respite camps

Health related youth respite camps traditionally target youth living with an illness or disability (cancer, diabetes, Downs syndrome etc.). The majority of camps seek to improve campers self-perception (Wong et al., 2009), while providing disease education and management, in the context of peer support and professional health care expertise (Hunter, Rosnov, Koontz, & Roberts, 2006; Moola, Faulkner, White, & Krish, 2013). Disease-based camps serve to reduce isolation and develop youth goal setting in dealing with the illness, while increasing disease knowledge (Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1990; Harkavy et al., 1983). Campers report increased positive attitudes towards illness, self-concept, and internalizing symptoms (Briery & Rabian, 1999; Zimmerman et al., 1987) as well as self-esteem (Dawson, Knapp, & Farmer, 2012). A review of 31 camp evaluations for youth with chronic illness, the authors found small improvements in self-perceptions after attending camps (Odar, Canter, & Roberts, 2013).

Despite the efficacy of these disease-based camps for youth, little published evaluation data exists on the effect of camps that serve youth with a parental or other family member illness. While they are not the ones with an illness, these youth live with and are daily impacted by illness in the home. While the mechanisms may differ, living in a family with chronic or acute illness similarly impacts child well-being, stress levels and isolation from youth not tasked with dealing with an ill family member. We know youth living with an ill parent experience depression, stress and social isolation (Barkmann, Romer, Watson, & Schulte-Markwort, 2007; Beardslee, Versage, & Gladstone, 1998; Diareme et al., 2007; Faulkner & Davey, 2002; Hilton & Elfert,

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1996). Therefore, the utility of camps targeting youth who have an ill family member might be similarly beneficial as camps designed for youth with an illness, providing support, education and a normalizing environment.

### 1.2. Social comparison in camp settings

Theories of social comparison have been used to frame disease-based youth camps (Dawson et al., 2012; Meltzer & Rourke, 2005), highlighting the importance of surrounding youth with youth in similar situations, proving an avenue for improved well-being by reflecting and sharing experiences in a “normalized” setting with “like” peers. The provision of supportive and educational environments in camps may provide an opportunity to develop positive self-esteem, resilience for future adversity, greater satisfaction with life after supportive environment and increased capacity for understanding the disease with which they live due to parental illness. In a study of youth cancer survivors in camp, Meltzer and Rourke (2005), adolescents feel more similar to their camp peers than to their home peers regarding greater self-competence in terms of social acceptance and global self-worth. Given the often chaotic and stressful home life of youth in HD families (Korer & Fitzsimmons, 1985), living with unpredictable symptomology, and the knowledge of genetic inheritance as they “watch and wait” for when it may happen to them (Sparbel et al., 2008), the provision of a camp may provide respite from home and develop a new normal and opportunity for support from those “like” them. The opportunity to develop a positive social comparison is particularly crucial in this population given the stigma and isolation associated with a genetic disorder which they may one day inherit. This paper provides evaluation data on one unique camp in North America, targeting children and youth who have a family member with Huntington's disease (HD). Specific research questions addressing improved well being across several measures including resilience, self-esteem, life satisfaction and disease specific knowledge addressed include: 1) Across genders, do youth report an increase in knowledge about HD and support in dealing with HD after attending the camp; 2) Are resilience, self-esteem and life satisfaction improved across genders as a function of attending the camp? 3) How do youth feel after attending camp?

## 2. Methods

### 2.1. Camp participants

The camp was spearheaded by the HDYO, with support from the Huntington's Disease Society of America (HDSA), and the Huntington Society of Canada (HSC). Fig. 1 details outreach to potential camp participants, application procedures, and acceptance rates. The camp was staffed by experienced HD health practitioners, including 3 social workers, one nurse and one psychiatrist. The 4-day camp content was decided upon after a short list of potential topics was included in the application for camp. The final list of topics included: grief and loss, being the best version of myself, testing, communication, relationships with family and/or friends, support, caregiving, and science and research. The staff also worked to weave the theme of “living positively” into all sessions to build social connectivity and positive social comparison among the campers. The primary focus of camp development was to create a peer supportive environment, which youth can learn to support each other, with the goal of improving self-esteem, resilience, life satisfaction and living with HD in relation to others going through the same experience. Campers were broken out into groups by the camp staff prior to arriving; no siblings in the same group, and campers from similar geographic regions were often placed together to facilitate future support and bonding.

#### 2.1.1. Data collection

A repeated measure evaluation was conducted over four time

points. Participants were invited to partake in all waves of the survey, but was not a condition of attending the camp. The baseline survey was sent 6 weeks prior to the camp, to avoid any prior interaction with the camp director or support staff. The second wave (pre) was given when campers arrived at the camp, prior to any camp activities. The third wave (post) was administered the last day of camp, during wrap up. The final and fourth wave was sent out 6 weeks post camp. Each survey was coded with a three-digit code, connected to the master list only accessed by the study PI and camp director. During camp, the surveys were handed out according to coded number by the camp director, and locked in a cabinet only accessible by the camp director. All wave one (baseline) and wave four (6 weeks post) surveys were mailed directly to the study PI, while completed waves 2 (pre) and 3 (post) surveys were mailed in a packet by the camp director, directly to the study PI. IRB approval was obtained by the PI institution. Prior to camp, all attendees were mailed evaluation information. All campers provided consent if they were 18 and over. For campers under the age of 18, all provided assent, while their non-HD affected parent provided consent.

### 2.2. Measures

All measures were chosen to reflect the goals of the camp and social comparison theory: Improving youth well-being through the provision of a peer supportive, professionally led respite camp.

#### 2.2.1. Self esteem

Rosenberg's self-esteem scale (Rosenberg, 1965) was used to assess self-esteem. The 10 items are answered on a four-point scale, ranging from 1 = strongly disagree to 4 = strongly agree. The scale ranges from 10 to 40, with 40 indicating the highest score possible. Scores are reported using average of the ten items, whereby higher summary score indicates higher self-esteem. (Alpha's range from 0.85–0.92).

#### 2.2.2. Resilience

The brief resilience scale (Smith et al., 2008) was used to assess child/adolescent ability to respond to difficult situations. The scale is a six item measure asking about the child/adolescent's ability to “bounce back” in the face of difficulty. The scale ranged from 1 = strongly disagree to 5 = strongly agree. Scores represent an average of six items, with higher summary score indicating higher satisfaction with life. (Alpha = 0.80–0.91).

#### 2.2.3. HD knowledge and support

A nine item scale was developed based on the PI's prior research in youth providing care for and living with a parent with HD (Kavanaugh, 2014; Kavanaugh et al., 2015). The measure includes two subscales, HD knowledge (four items) and family and friends (five items). Scale items ranged from 0 = strongly disagree to 4 = strongly agree. We obtained scores by taking average of five items, whereby higher summary score indicates higher knowledge and support. The measures are being tested for this project, so wave 1 was used for the alpha. (full scale alpha = 0.86; HD knowledge subscale = 0.84; friends and family = 0.81).

#### 2.2.4. Satisfaction with life

The satisfaction with life scale (Deiner, Emmons, Larsen, & Griffon, 1985) was used to assess life satisfaction and how they view the conditions of their lives. The five item measure has response options ranging from 0 = strongly disagree to 4 = strongly agree. Higher summary scores indicate a higher sense of satisfaction with life. We obtained score by taking average of five items, whereby higher summary score indicates higher satisfaction with life. Initial reliability showed Alpha ranges from 0.66–0.81.

#### 2.2.5. Qualitative questions

Two questions were asked at waves 3 and 4 (post and 6 week post)

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