Psychosocial issues of the adolescent PI patient and the development of the PI Teen Outreach Program

Wendy Shama^{a*} and Brenda Reid^b

ABSTRACT

Background: The effects of disruptions in the lives of the adolescent Primary Immunodeficiency (PI) patient require psychosocial staff involved in their care to find unique approaches to treatment. The demands of living with PI in adolescence complicates this already turbulent life cycle transition. Absence from school due to infections and treatment can lead to social isolation and in turn issues of self-esteem, creating challenges for teenagers with chronic diseases. The importance of maintaining social support with peers and developing a new network of social supports with teens with similar diagnoses is highlighted in the literature as an important factor in helping teens successfully cope with the demands of chronic illness.

Methods: To best meet the complex needs of this population, the PI Teen Outreach Program was created in 2010. The goal was to connect teens with PI to one another in an environment that engages them in “normal” activities while providing an opportunity to discuss diagnosis, coping, and the impact of living with PI. The program consists of group teen events that involve an activity for peers to connect followed by a meal for sharing of life experiences. Community peers are invited to assist teens in demystifying their PI disease to their community friends.

Results: At the conclusion of each outreach event, teens were given an anonymous evaluation utilizing both Likert scales and qualitative narrative comments. The positive feedback highlights the importance of providing creative and unique programs for this population.

Conclusion: A diagnosis of PI can be difficult for teenagers as they cope with the developmental tasks of adolescence alongside a chronic illness. The Teen Outreach Program has been successful in enhancing the psychosocial support and normalizing the experience of teenagers with PI.

Statement of novelty: There is a paucity of literature addressing the psychosocial issues that the PI teen population face and any novel programming to address their unique needs.

Introduction

Adolescence is a period of rapid physical, psychological, emotional, and social development during which young people develop a sense of an independent identity, focus on peer acceptance, make plans for the future, and develop romantic and intimate relationships. Young people with chronic disease have the same developmental issues as healthy young people, however, their

development may be arrested by the impact of the disease (Taylor et al. 2008). A framework for positive youth development for all teens includes focusing on the strengths of the teen and resources in the settings that surround them to promote positive outcomes. From this framework’s perspective, successful youth outcomes include the development of attributes such as competence, confidence, character, social connection, and compassion. The development of these skills allows

^aHospital for Sick Children, Department of Social Work; Factor-Inwentash Faculty of Social Work, University of Toronto, Toronto, ON; ^bThe Hospital for Sick Children, Nursing and Immunology/Allergy, Toronto, ON

*Corresponding author: Wendy Shama/wendy.shama@sickkids.ca

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for both healthy and chronically ill teens to cope with life challenges as they progress into their adult life (Maslow and Chung 2013).

The importance of social support in affecting human behaviour, via its influence on human beliefs and attitudes, has been increasingly recognized in health psychology (Owen Yang et al. 2010). Studies have shown the benefit of peer support programs for teens with a variety of chronic diseases, including diabetes, asthma, cystic fibrosis, sickle cell, and mixed groups of a variety of illnesses (Maslow and Chung 2013). The benefit of these programs in promoting positive outcomes for chronically ill teens has been credited to the opportunity to share activities and discussions, as well as providing empathy and promoting positive health behaviours through modelling (Olsson et al. 2005). Others have identified the positive benefits of peer support as providing assistance with daily self-management through the sharing of experiences, giving social and emotional support through empathetic listening, promoting health seeking behaviours by the sharing of health care experiences, and providing ongoing social support (Baumann and Dang 2012). The lack of support during adolescence by either parents or peers has been associated with poor psychological adjustment and behavioural problems, which further stresses the need for such programs for chronically ill teens (Owen Yang et al. 2010).

For rare diseases, such as primary immunodeficiency (PI), patients often need to take a very proactive role in managing their care and become experts in their disease management. Patients and families are often responsible for aspects of their care, such as self-infusion of gammaglobulin, medications, and other treatments at home. The ability to manage these treatments is complicated by many antibody deficient patients presenting in adolescence and being challenged to cope with the onset of their illness and learning care self-management skills, while also facing the competing challenges of the adolescent developmental stage (Burton et al. 2010). This challenge is further complicated by many PI patients receiving aspects of their care from health care providers who have minimal experience with PI diseases. Their access to immunodeficiency specialists may also be limited. Our clinical experience in working with teenagers with PI identified that these teens do not often have opportunities to meet other teen PI patients during clinic visits, and many have expressed the feeling

that they are the only one dealing with this diagnosis. The Teen Outreach Program was developed after review of the literature, in conjunction with our direct work with teenagers to address the needs of teen PI patients for peer support. We provided them with opportunities to meet each other in the setting of fun activities organized by staff (Social Worker & Clinical Nurse Specialist) with expertise in PI diseases.

PI teen outreach program

The effects of disruptions in the life of the adolescent PI patient require psychosocial staff involved in their care to find unique approaches to treatment. Absence from school due to infections and treatment can lead to social isolation and in turn issues of self-esteem, creating challenges for teenagers with chronic diseases. The importance of maintaining social support with peers and developing a new network of social supports with teens with similar diagnoses is an important factor in helping teens successfully cope with the demands of chronic illness. In an effort to better meet the complex needs of this population, a PI Teen Outreach Program was created in 2010 to connect teens with PI to one another in an environment that encourages the development of interpersonal skills, and to engage them in “normal” activities with a focus on having fun and feeling good about themselves. From 2010 through 2014, events were run yearly; 1 for teen girls and 1 for teen boys. In 2015 and 2017, combined events were run for both boys and girls. In all teen boy events, as well as joint boy/girl events, each participant was invited to bring a friend. The community peers were chosen by the PI patients and were those who they felt comfortable sharing their health care experiences with. Successful applications to the Patient Events Grant Program through Immunodeficiency Canada has continued to fund this outreach program.

Participants

All teen patients between the ages of 12 to 19 with confirmed diagnosis of PI, and within a 2 hour driving distance of SickKids were invited to participate in the PI Teen Outreach Program. Those who were able to take part in the event were usually within 90 minutes of the Greater Toronto Area. Email invitations were sent out and followed up by an individual telephone call to discuss the event and its objectives. PI diagnoses included combined immune deficiency, agammaglobulinemia,

common variable immune deficiency, chronic mucocutaneous candidiasis, and selective antibody deficiency. The majority of participants were on gammaglobulin replacement therapy. A list of teenagers that were eligible for each event was compiled. Many teens were eligible for multiple events. Most participants had not met each other prior to the third event. Consent was obtained at each event for photography for educational and conference purposes.

Outreach program description

PI teen girl events

The objectives for the PI Teen Girl Events were to (i) enhance their perception of body image and self-esteem, and (ii) to facilitate the introduction of all teen girls with PI. Five events were run for girls beginning in 2010; with the first 3 taking place at a spa, the fourth a combined event with teen boys at a trampoline facility, and the fifth a combined event at an Escape Room. These last 2 events provided the opportunity for the girls to bring a friend. The first 3 events involved a morning at a local spa with manicures, pedicures, skin cleansing, and makeup application. The spa was opened exclusively for this group and took great care to make the girls feel pampered and special. The trampoline facility allowed the teens to participate in team sports as well as free jumping. The Escape Room had the teens working together to solve clues in order to get out of a locked room within a prescribed time. All events were followed by lunch where a support group was run by the PI Social Worker and Clinical Nurse Specialist. This support group allowed the girls to share thoughts and feelings about their diagnosis, discuss coping with PI, and its impact on day-to-day life. At the conclusion of the day, girls were given an anonymous evaluation to complete which utilized both Likert scales and an opportunity to provide narrative comments.

PI teen boy events

The objectives for the PI Teen Boy Events were to (i) facilitate the introduction of boys with PI to one another, and (ii) reduce their social isolation and engage them with their peers. Six events were run for boys beginning in 2010; 4 included the boys with their friends and the last 2 events combined them with the teen girls. The events included a combination of rock climbing, laser tag, trampoline, cosmic bowling, cyber-sport, whirly ball, and an Escape Room. In each event, the activities were open just for our group of teens with

a private room for a meal at the end of the activity. During the meal, a support group was run by the PI social worker and Clinical Nurse Specialist that, similar to the girls' event, allowed them an opportunity to discuss their thoughts and feelings about their diagnosis, their experience living with PI, their coping with illness, and impact on day-to-day life.

Program evaluation and results

At the conclusion of each event, all teens were given anonymous evaluations to complete reflecting on their experience. All teens (100%) that participated in each event completed an evaluation. These evaluations utilized both Likert scales and qualitative narrative comments. Basic statistics were used in calculating mean scores on Likert scales as well as content analysis of narrative comments. The Likert scales were numbered from 1 to 5, with 1 being "very dissatisfied/very uncomfortable/very unimportant" and 5 being "very satisfied/very comfortable/very important". A total of 31 evaluations were analyzed in total over all events.

PI teen girl events

The girls completed a total of twelve evaluations over the 5 different events (Table 1). All girls (100%) were "very satisfied" with each and every event. All girls (100%) stated that every event "definitely" or "far exceeded" their expectations of the days. In attempting to assess whether the event had served as a catalyst to connect teens to one another, it was asked whether they had met each other prior to the events. None of the girls had met each other at each of the first 2 events, and 2 girls had met one another by the third event. When asked whether they felt it was important to be connected with other girls with PI, 10 girls (83%) felt it was "somewhat" to "very important". Although more than half the girls stated that they would be uncomfortable approaching a teen prior to this event, all girls stated that they would be comfortable now approaching a teen they had met at a future hospital visit. When asked whether the event was beneficial in helping them cope with their diagnosis, 8 girls (73%) replied "for the majority" or "definitely" and all girls (100%) stated that they would be interested in participating in a future teen event. There were several opportunities for the girls to write their thoughts about why it would or would not be important to be connected with other teens with PI, and what they enjoyed or did not enjoy about the event.

Table 1: Likert ratings for teen girl events.

Likert ratings for teen girl events	1	2	3	4	5
Satisfaction with event	0	0	0	0	12
Did event meet expectations	0	0	0	7	5
Importance of connecting to others with PI	0	0	2	3	7
Comfortable now in approaching teen at future hospital visit	0	0	0	0	12
Event beneficial in helping cope with diagnosis*	1	0	2	7	1
Would you want to attend a future event	0	0	0	0	12

Note: 1, very dissatisfied/very uncomfortable/very unimportant/not at all; 3, neither important nor unimportant/somewhat; 5, very satisfied/very comfortable/very important/far exceeded/definitely; *, not all respondents answered the question.

Table 2: Likert ratings for teen boy events.

Likert ratings for teen boy events	1	2	3	4	5
Satisfaction with event	0	0	0	3	16
Importance of connecting to others with PI	0	0	1	14	4
Importance of sharing event with a friend*	0	0	0	2	15
Comfortable now in approaching teen at future hospital visit	0	0	0	0	19
Event beneficial in helping cope with diagnosis*	0	0	4	4	7
Would you want to attend a future event	0	0	0	0	19

Note: 1, very dissatisfied/very uncomfortable/very unimportant/not at all; 3, Neither important nor unimportant/somewhat; 5, very satisfied/very comfortable/very important/far exceeded/definitely; *, not all respondents answered the question.

The individual comments were organized and analyzed and a thematic analysis was performed and reviewed for consistent experiences and perception. The following themes emerged; (i) relaxing and having fun meeting and connecting with girls the same age, (ii) sharing the experience with girls who know what you are going through and how you may feel since they have a similar health problem, (iii) an increased comfort in getting to know girls so you can talk to them about what you are dealing with. There was also an opportunity to elicit feedback for future events. The activities were therefore modified year to year based on the teen’s suggestions. The last 2 events included both boys and girls to allow for a variety of empowering experiences.

PI teen boy events

The boys completed a total of 19 evaluations over the 6 different events (Table 2). Sixteen boys (84%) were “very satisfied” with each and every event. In looking at the importance of allowing the boys to invite a peer from their local community, and in response to the question of whether it was important for them to share this with a friend, 15 boys (88%) stated it was “very important”. Ten of the boys (67%) had met one or 2 other boys prior to the third event and all boys stated they would be comfortable approaching a teen they met at an event at a

hospital visit in the future. When asked about the importance of being connected with other teens in the Immunology program, 18 boys (95%) stated that it was “somewhat important” to “very important”, and all boys stated they would definitely attend another event in the future. The boy’s individual comments were analyzed and the themes that emerged were; (i) meeting new people, (ii) having fun, and (iii) the importance of talking with kids that are going through the same experience.

Conclusions

A diagnosis of PI can be difficult for teenagers as they cope with the normal developmental tasks of adolescence in addition to the complexities of dealing with a chronic illness. Creative interventions are needed to best engage adolescents with the ultimate goal of promoting their ability to cope with chronic illness. The feedback we have received from the teens themselves as well as the staff that have participated in our events have been overwhelmingly positive, and has illustrated the significant impact it has had on PI adolescent’s psychosocial well-being and coping. It has provided opportunities for them to connect with others like themselves which has helped to normalize their experience, promote compliance with treatment, increase their feelings of self-efficacy, and

provide ongoing support. Events will continue yearly, as our goal remains to provide the highest quality of care to enhance the psychosocial support and normalize the experiences of teenagers with PI.

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