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Abstract: This article describes the pilot evaluation of two Positive Youth Development (PYD) programs for youth with child onset chronic illness (COCI), reporting how the programs influenced participants' character development. College students with COCI led high school students with COCI through activities pertaining to different aspects of growing up with a chronic illness. Participants completed the Positive Youth Development Inventory-Short Form (PYDI-S), which measures seven domains of youth perceptions of the contribution to their development from the program. Participants reported that both programs helped them the most with personal standards, which corresponds well to character development on the full version of the Positive Youth Development Inventory (PYDI). They also had high scores on prosocial behavior and future orientation, both important domains for character development. We discuss the idea that interventions promoting character development for youth with COCI are critical for promoting a positive narrative for chronically-ill youth, their parents, and society.

Introduction

Over the past 40 years there have been dramatic improvements in the health outcomes of youth growing up with childhood-onset chronic illness (COCI), such as cancer, diabetes, and sickle cell disease, among others. Approximately 90% of youth with COCI are expected to survive to adulthood, yet many struggle to transition to adult independence, and even more struggle with tasks of self-management including medication adherence and navigating the health system (Blum, 1995; American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002). In particular, youth with COCI are less likely to graduate college (18% vs. 32% for healthy peers) and less likely to be employed in adulthood (Maslow, Haydon, McRee, Ford, & Halpern, 2011; Gledhill, Rangel, & Garralda, 2000). Character-based interventions that promote Positive Youth Development (PYD) can increase youth hope for the future, promote personal standards/prosocial behavior, and provide youth with an opportunity to contribute to society (Eccles & Gootman, 2002). These programs are of particular importance for youth with COCI because they are at increased risk of poor adult outcomes and are, anecdotally, often unable to participate in community-based youth development programs secondary to their health conditions.

Lerner and Lerner's PYD model has three core program components: sustained youth adult relationships, skill-building programming, and youth involvement in leadership; and five main outcome components (the Five Cs): Connection, Competence, Confidence, Caring, and Character (Lerner, Lerner, Bowers, & Geldhof, 2015). In a 2013 review of the medical literature investigating group programs for youth with COCI, we identified only three programs that included all three PYD program components (Maslow & Chung, 2013).

Over the past 10 years we have been involved in creating and disseminating a PYD intervention for youth with COCI to promote character development and other positive adult outcomes. The original program, called Steps Towards Adult Responsibility (STAR), started in 1998 at the Dartmouth-Hitchcock Medical Center and brought together college mentors from Dartmouth with adolescent patients at Dartmouth's hospital. Subsequently, based on this model, we started The Adolescent Leadership Council (TALC) at Brown University and then five years later Adolescents Transitioning to Leadership and Success (ATLAS) at Duke University. More recently, other programs have been started at Stanford University and Indiana University. These programs bring together on a regular basis youth and college-aged mentors with COCI. The programs provide young adults with the opportunity to discuss illness, participate and lead group activities and engage in leadership opportunities in the community. In 2013 a program evaluation of TALC at Brown was published and demonstrated that participants had decreased loneliness and increased healthcare self-advocacy following participation (Maslow et al., 2013).

With the goal of evaluating and improving these types of programs, we administered a PYD survey to elicit feedback from youth about how the program has influenced their character development. This paper describes this pilot evaluation of two PYD programs for youth with childhood-onset chronic illness.

Method

Curriculum

TALC was created in 2005, while ATLAS was created in 2010. Both programs have the goal of fostering resilience and independence in adolescents and young adults with chronic illness, using PYD principles. Table 1 provides the domains of PYD program criteria and Figure 1 provides the logic model for the programs. The TALC Leadership Council and the ATLAS program meet monthly during the academic year, with each session lasting two hours. During meetings, college students with COCI lead high school students with COCI through activities around different aspects of growing up with a chronic illness (e.g., interacting with doctors, communicating with friends, school issues and resources, college and career preparation, transition planning, and family relationships). Programming ranges from group discussions about the experience of illness, to art projects, to skill based programming like health coaching, to leadership projects aimed at educating doctors and nurses about youth experiences. One of the central themes throughout the program is the importance of education and staying in school, as the college mentors describe the value of their own education and provide concrete advice regarding how to navigate the challenges of completing high school while living with a COCI.

Table 1

Domains of PYD Program Criteria for each program

CRITERIA	*TALC*	*ATLAS*
1. Intentionally create a place for youth to experience physical and psychological safety	Monthly meetings held on Rhode Island Hospital Campus. Program's medical staff provide assistance for participants with medical concerns.	Monthly meetings regularly held on Duke University Campus. Program's medical staff provide assistance for participants with medical concerns.
2. Provide intentional and appropriate structure for participating youth	Monthly agendas for Leadership Council are developed by mentors with youth feedback.	Mentors develop monthly agendas using one of the 9-month curriculum topics
3. Emphasize supportive relationships; particularly youth-adult relationships	Mentors with chronic illness meet regularly with youth with chronic illness and act as role models.	Mentors with chronic illness meet regularly with youth with chronic illness and act as role models.
4. Create a place for youth to belong and to matter	Program specifically designed for youth with chronic illnesses	Program specifically designed for youth with chronic illnesses
5. Develop and enforce clear social norms, with clear expectations for youth	Higher education, work, or greater independence established as norms	Higher education, work, or greater independence established as norms
6. Provide opportunities for the development of mastery and efficacy	Adolescents develop improved communication skills and self-awareness regarding health.	Adolescents develop improved communication skills and self-awareness regarding health
7. Provide distinct opportunities for youth to build specific skills	Adolescents also serve as a hospital youth advisory committee. Adolescents develop leadership skills by participating in leadership projects related to chronic illness. Mentors develop leadership skills by facilitating monthly programs.	Mentors develop leadership skills by facilitating monthly programs. Youth become leaders in the program over time.
8. Intentionally seek to integrate youths' family, school, and community	Parents are involved in a parent group simultaneously.	Parents are involved in a parent council simultaneously. Effort made to connect youth to community educational resources.

Figure 1

Logic model for ATLAS and TALC program

Inputs	Outputs *Activities*	Outcomes -- Impact *Short*	*Long*
• High school age mentees and their parents with Childhood Onset Chronic Illness • College age mentors with Childhood Onset Chronic Illness • Medical staff and volunteers	ATLAS & TALC Programs based on Positive Youth Development Principals: • Youth participation in and leadership of activities • Emphasis on development of life skills in general and related to illness • Environment with sustained and caring adult-youth relationships	Positive Youth Development Outcomes: • Connection • Competence • Confidence • Caring • Character • Contribution	Educational Outcomes: • High school graduation • College attendance Vocational Outcomes: • Employment • Career choice Healthcare Outcomes: • See pediatric or adult PCP • See pediatric or adult specialist • Have a healthcare transition mentor

The general format involves small group programming bookended by large group discussion. Program staff and volunteers, often including physicians, nurses, social workers, psychologists, and medical students, provide a safe structure and supervision of the medical aspects of the program. This structure, along with unstructured time built into each meeting, allows the mentors to focus on speaking with the mentees about their lives and experiences. Currently the mentors are not actively paired individually with mentees in either program. Following the principles of youth-initiated mentoring, the open structure allows adolescents the opportunity to meet each mentor and most find they connect more strongly with one or two of the mentors and are in contact with them outside of the monthly programs (Schwartz, Rhodes, Spencer, & Grossman, 2013).

Mentor training includes an initial workshop that reviews important information regarding confidentiality and how to approach facilitating group discussions. Mentors then meet on a monthly basis separate from the mentees to discuss and plan the program activities. This monthly meeting provides the opportunity for mentors to support one another and to receive support from program staff. During the mentor meetings the mentors and staff actively discuss each mentee and strategies for engaging and supporting the mentees.

At each session, parents of participants meet separately, led by either a social worker or psychiatry resident, with the goal of supporting and learning from each. Lastly, both programs include a few social events per year, a team-building event and an optional overnight residential summer program on the respective college campuses. Both TALC and ATLAS adhere to PYD criteria, outlined in Table 1, as set forth by Eccles and Gootman (2002).

Although similar, the programs do have differences. First, TALC is the official youth advisory council for the Children's Hospital and so youth are involved actively in leadership activities on a consistent basis. Second, ATLAS frequently connects youth with community members around educational/vocational opportunities, but has less direct leadership opportunities than TALC.

Participants

Thirteen youth participants from the TALC 2014-2015 program period were recruited to this study by the Brown University study team; mentors were not recruited for the study at Brown. Seventeen youth participants, including five mentors, from the ATLAS 2014-2015 program period were recruited to this study by the Duke University study team. All participants had childhood-onset chronic illnesses.

Adolescent participants, aged 13-18 years old, are recruited to the ATLAS and TALC programs through pediatric clinics and referred by physicians, social workers, other staff or family members. At each site adolescent participants are screened through an in-person meeting with a site coordinator, and a brief mental health screening is performed to confirm that the program is appropriate. Youth with mental health concerns are able to participate but are expected to be in concurrent mental health treatment.

Mentors are young adults, aged 17-25 years old, with chronic illness and are recruited from hospital clinics and local universities. Each site has a relationship with the host university and the majority of the mentors are college students. Mentors are screened by completing an application in which they describe their own experience growing up with an illness and reasons for wanting to serve as a mentor. Program staff reviews these applications and mentors are interviewed.

Procedures

Each program conducted the evaluation separately, but using the same measures. Both ATLAS and TALC obtained consent from parents for youth under 18 with minor assent and directly from participants over 18. For study inclusion, participants had to be able to read and understand written English.

This study was approved by the Duke University Institutional Review Board for ATLAS, and the TALC evaluation followed a similar procedure with the study approved by the Rhode Island Hospital Institutional Review Board. For both programs, participation in the study was not required for participation in the program; no compensation was provided for study participation.

Measures

Program participants completed the Positive Youth Development Inventory-Short Form (PYDI-S) at the end of the intervention while in attendance at the final meeting of the year. The PYDI-S consists of 34-items and measures youth perception of the contribution to their development from a program across seven domains: Prosocial, Future Orientation, Emotional Regulation, Personal Standards/Values, Adult Support, Friendship, and Contributions using a 4-point Likert Scale ranked from strongly disagree (1) to strongly agree (4) (Arnold et al., 2012b). The mean values are calculated for each subscale according to the scoring guide (Arnold, Nott, & Meinhold, 2012a). Demographic data were collected at study entry, including age, year in school, race, and sex.

Analyses

Descriptive analyses were conducted to calculate sums, averages, and percentages of data collected from the PYDI-S. Association between demographic factors and scores was completed using t-tests for categorical variables and ANOVA for continuous variables in Stata v14 (College Station, TX).

Results

A total of 30 youth in the two programs completed the exit pilot program evaluation, including 13 high school participants from TALC at Brown and 17 participants from ATLAS at Duke (12 high school participants plus five mentors). There were no significant differences between the groups in terms of average age, grade, or sex distribution (Table 2).

Table 2

Demographic description of participants in both programs

	Overall N=30	ATLAS N=17	TALC N=13
Age in years (range)	16.7 (12-21)	17.1 (12-21)	16.2 (14-17)
Sex			
Male	8	3	5
Female	22	14	8
Mentors	5	5	0
Grade in school mean (range)	10.7 (8-16)	11 (8-16)	10.4 (8-12)
Race (%)			
White	25 (83%)	14 (82%)	11 (85%)
Black	2 (7%)	2 (12%)	0
Hispanic	1 (3%)	1 (6%)	0
Other	2 (7%)	0	2 (15%)
Medical Conditions			
Asthma	2	1	1
Autoimmune diseases (ie Lupus, Arthritis)	4	3	1
Congenital Heart Disease	5	2	3
Cystic Fibrosis	1	1	0
Epilepsy	4	2	2
Gastrointestinal syndromes	4	2	2
Hematological (blood disease)	1	1	0
Other Heart disease	2	2	0
Thyroid Disease	2	1	1
Type 1 Diabetes	5	2	3

The domains that most closely correlate with character development on the PYDI-S were the highest rated from both programs and there were no significant differences between the two programs (Table 3). The personal standards domain of the PYDI-S corresponds best to character development, as measured on the well-validated PYDI, and was the highest rated domain from both programs surveyed. Four of the five personal standards questions on the PYDI-S are identical to four of eleven Character domain questions on the PYDI: “It is important for me to do the right thing,” “I try to do the right thing, even when I know that no one will know if I do or not,” “It is important for me to do my best,” and “If I promise to do something I can be counted on to do it.” The next highest scores were in pro-social values which has some overlap with character development on the PYDI, and future orientation, which is viewed as contributing to character development. The statement "I am able to stand up to peer pressure when I feel something is not right to do" is on the PYDI under character development and the PYDI-S under the domain pro-social values.

Table 3

Character and PYD outcomes

	OVERALL	ATLAS	ATLAS	ATLAS	TALC
	Total N=30 Mean(SD)	Total N=17 Mean(SD)	Youth N=12 Mean(SD)	Mentor N=5 Mean(SD)	Youth N=13 Mean(SD)
Personal Standards	3.6 (0.09)	3.6 (.13)	3.7 (.15)	3.5 (.3)	3.5 (0.14)
Future Orientation	3.4 (0.10)	3.4 (.17)	3.4 (.19)	3.3 (.35)	3.4 (0.20)
Prosocial	3.3 (0.11)	3.4 (.15)	3.4 (.19)	3.5 (.36)	3.2 (0.15)
Friendship	3.2 (0.10)	3.3 (.13)	3.2 (.15)	3.4 (.28)	3.2 (0.16)
Adult Support	3.2 (0.10)	3.2 (.17)	3.2 (.15)	3.3 (.37)	3.1 (0.16)
Contribution	3.2 (0.10)	3.4 (.15)	3.2 (.18)	3.6 (.2)	3.1 (0.14)
Emotional Regulation	3.0 (0.13	3.2 (.14)	3.2 (.17)	3.1 (.33)	2.7 (0.23)

For the mentors in the ATLAS program, the contribution score was the highest. All domains across groups had means above three (corresponding to "agree" that the program helped them on that domain), except for emotional regulation for the TALC program, which averaged 2.7.

In addition, subgroup analyses were conducted comparing scores on PYDI-S based on age, sex, and type of condition. Female participants had higher scores across all domains, but these differences were not statistically significant. There was also no significant difference in scores by age or type of condition. However three youth with genetic conditions had the lowest scores across all domains and those with congenital heart disease and gastro-intestinal conditions had the highest scores.

Discussion

This pilot evaluation provides preliminary evidence that participants view the programs as contributing to their character development. In particular, participants in both programs most highly rated personal standards, pro-social values and future orientation domains as areas of growth resulting from the program, which correspond to character development and are consistent with role modeling provided by successful college-aged mentors. These programs are different than traditional support groups because emphasis is placed on adolescents' interactions with college-aged mentors who are thriving while living with their own chronic illnesses. It is also important to note that mentors rated the Contribution domain highest, which fits with the role of the mentor in supporting the growth of other youth with childhood-onset chronic illness (COCI). All together, the strengths that participants report gaining from ATLAS and TALC align with those reported by Eccles and Gootman (2002): hope for the future, personal standards, prosocial behavior, and contribution to society.

Both ATLAS and TALC have curricula that include issues common to adolescents with a variety of medical conditions, including how chronic illness affects their lives, how to talk about illness with friends, and how to take more active roles in their healthcare. Meetings provide an opportunity for skill building in a safe environment. The various activities give participants the chance to find and express their own strengths while learning from one another. Hence, the sense of contribution and community was a very real and empowering experience for the adolescents. It is useful to see that participants are perceiving benefits that align with the intended Positive Youth Development components of the program: sustained youth adult relationships, skill-building programming, and youth involvement in leadership (Lerner et al., 2015).

ATLAS, TALC, and similar programs at other institutions differ slightly in their structure and curriculum, based on the program size and other logistics. The similar character and PYD outcomes between ATLAS and TALC, despite differences in structure and curriculum, are a preliminary demonstration that programs utilizing PYD principles can be deployed to support the development of youth with COCI. Camps, churches, community centers, and other non-medical organizations could adapt the structure and logistics to these programs based on their resources, while still providing similar opportunities for character and positive youth development through mentorship for youth growing up with a chronic illness.

As a pilot study, there are several limitations that we hope to address in a subsequent evaluation study of TALC, ATLAS, and two additional mentoring programs for youth with COCI across the United States, that form the Positive Youth Development-Chronic Illness (PYD-CI) Mentoring Collaborative. This study is an important first step in the process of designing a larger, more robust program evaluation examining these character development programs. The first limitation is that the data are based on self-reported beliefs about the effect of the program on aspects of PYD, and responses were only gathered at the end of the program. However, our success with collecting survey data from a high percentage of intervention participants during regularly scheduled meetings makes the feasibility of collecting more thorough outcomes data in a similar model very likely. Future evaluations should include a control group and measure pre- and post-test data on youth character development, self-regulatory strengths, PYD, Contribution, risk and problematic behaviors, and school and career motivation and achievement using reliable and valid measures. Observational measurement of the quality of the setting created by the programs would also add to our understanding. The Youth Program Quality Assessment is such a validated tool (Granger, 2010) .

Another major limitation of this study is the small sample size, which limits our ability to detect differences in effect across age, race, sex, duration of condition, disability, and type of condition. Some of the interesting but nonetheless non-significant differences involving condition, sex, and age suggest the need for further study in a larger sample. For the future PYD-CI Mentoring Collaborative evaluation our goal will be to increase the number of mentors and mentees recruited and retained across sites. The current study was further limited by a lack of evaluation of implementation fidelity, particularly important in the context of mentorship because mentor background and the quality of training and support provided to mentors have been linked to mentor relationship quality, the backbone of our intervention (Dubois, Holloway, Valentine, & Cooper, 2002). Rhodes' model of youth mentoring, in turn, presents this strong and meaningful connection as the catalyst for youth psychosocial development such as the Five Cs and, ultimately, youth outcomes such as academic and career success (Rhodes, 2005). In order to address this issue in future studies, site program coordinators supervised by the overall program coordinator will guide sites in evidence-based on-site mentor training sessions and regular support meetings and fidelity will be monitored in an ongoing manner.

Implementing a mentorship program for youth with chronic illness and carrying out such a program based in a medical setting make delivering a mentorship program with fidelity across multiple sites particularly difficult. Mentorship continuity can be regularly disrupted by illness and hospitalization of both mentors and mentees. In addition, participants are often traveling long distances to receive medical care and having the program sites in or near the medical center can make community formation more challenging. Moreover, there are challenges associated with participants having different conditions.

Despite these challenges the shared experience of growing up sick and having to interact regularly with the medical system allows the mentors and participants to form a powerful community. The connections between the mentors and youth provide a setting for character development for youth as they learn from the mentors and also contribute to the development of the mentors themselves. In many ways the youth who participate in these character development programs develop their capacity for agency. As a group these youth often are not able to be in control of their lives or even of their own bodies and working with adults who have navigated these challenges successful provides them with models and examples of how to develop their own agency and strengthen their character. As noted by Lerner and Callina (2014, p. 332) "Indeed, across time and place, good character may involve the content and structure of particular functions that enable the person to reliably and coherently contribute positively to the context that is supporting him or her and, as we have stressed, in particular, other individuals within the ecology." These programs strive to promote character development in this way through the development of mutually beneficial mentoring relationships promoting the ability of youth with chronic illness to positively interact with their own context.

This pilot evaluation has provided the research team with important information regarding the logistics of conducting a study of these programs that will shape a future larger study with a control group. The team has identified strategies for recruiting youth with illness and mentors that can be deployed for a larger study and identified the character development domains that youth identify as benefits of the program. This information will guide the measurement of character development in future study and inform the type of control group used. To more rigorously evaluate the specific character development effects of this mentoring intervention future studies will need a control group that receives some form of educational intervention, but does not receive the mentoring or peer support that are believed to be the active character development component.

While some might consider the differences in curricula between TALC and ATLAS to be a limitation, the similarities in results from both programs indicates that curricular specifics are likely not critical to the effect of the program; in many ways, this highlights the flexibility, adaptability, and expandability of this type of mentoring-based program for youth with COCI. Our ability to interpret the lack of significant difference between the outcomes of the PYDI-S for the two programs, however, is limited by our small sample size, and this may be one area in which we could see a difference in a larger study.

Youth with COCI are seen as vulnerable and based on anecdotal, clinical feedback may be excluded from other youth development programs because of their condition. While they are at risk for worse educational and vocational outcomes, youth with COCI have the potential to thrive in adulthood and to contribute to society broadly. Interventions that promote character development for youth with COCI, such as the two described in this study, are critical to changing the narrative for youth, their parents, and a society that may not value the character strengths and potential of youth growing up sick.

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