Systematic Review of Positive Youth Development Programs for Adolescents With Chronic Illness

abstract

BACKGROUND AND OBJECTIVE: The Positive Youth Development (PYD) framework has been successfully used to support at-risk youth. However, its effectiveness in fostering positive outcomes for adolescents with chronic illness has not been established. We performed a systematic review of PYD-consistent programs for adolescents with chronic illness.

METHODS: Data sources included PubMed, CINAHL, and PsychINFO. Guided by an analytic framework, we searched for studies of PYD-consistent programs serving adolescents and young adults aged 13 through 24 with chronic illness. References were screened iteratively with increasing depth until a focused cohort was obtained and reviewed in full. The authors separately reviewed the studies using structured analysis forms. Relevant study details were abstracted during the review process.

RESULTS: Fifteen studies describing 14 programs were included in the analysis. Three comprehensive programs included all 3 core components of a PYD program, including opportunities for youth leadership, skill building, and sustained connections between youth and adults. Four programs were primarily mentoring programs, and 7 others focused on youth leadership. Programs served youth with a variety of chronic illnesses. The quality and type of evaluation varied considerably, with most reporting psychosocial outcomes but only a few including medical outcomes.

CONCLUSIONS: The PYD-consistent programs identified in this review can serve as models for the development of youth development programs for adolescents with chronic illness. Additional study is needed to evaluate such programs rigorously with respect to both psychosocial and health-related outcomes. PYD-consistent programs have the potential to reach youth with chronic illness and promote positive adult outcomes broadly. Pediatrics 2013;131:e1605–e1618
Over the past 40 years, advances in pediatric medicine have decreased the mortality rate of many once uniformly fatal chronic diseases. Children who previously would have died early in life are now living well into adulthood. For example, in 1970, the life expectancy for a child born with sickle cell disease was only 14 years; today it is >40 years.\(^1,2\) This and other similar increases in life expectancy have give rise to new challenges as youth with chronic illness often struggle with transitions into adulthood related to health, education, vocation, and finance. They are less likely to graduate from college and to be employed as adults, and they have lower annual incomes than their healthy peers.\(^3-5\)

To date, studies of the development of youth with chronic illness and their transition to adulthood have focused on the problems youth encounter as they become adults, instead of examining pathways to positive adult outcomes. The Positive Youth Development (PYD) perspective is a framework for examining thriving in youth and has been useful in promoting positive outcomes for other at-risk youth.\(^6\) As typified by the statement “problem-free is not fully prepared,” the PYD perspective is a strength-based approach that sees youth as resources to be nurtured and focuses on the alignment between the strengths of youth and resources in the settings that surround them as the key means of promoting positive outcomes.\(^7,8\) From the PYD perspective, successful youth outcomes include the development of attributes such as competence, confidence, character, social connection, and compassion.\(^7\) The development of these positive attributes is thought to foster positive outcomes during adolescence such as improved self-care, greater academic achievement, higher quality interpersonal relationships, and overall improved well-being. Although development of these PYD attributes during adolescence is important in itself, these attributes are also believed to be critical in promoting successful adult development and improved health outcomes.

Youth programs consistent with PYD principles have been linked to positive adult outcomes, although these programs have not been systematically examined for youth with chronic illness.\(^7,8\) Richard M. Lerner and colleagues have examined the features of youth programs that promote the development of PYD attributes for youth.\(^10\) They identified the “Big Three” components of effective youth development programs, including (1) opportunities for youth participation in and leadership of activities, (2) emphasis on the development of life skills, and (3) a context of sustained and caring adult-youth relationships.\(^10\) Thriving in youth is promoted by programs that include these features of youth participation, skill building, and adult mentorship.\(^11\) Programs using the “Big Three” components could be harnessed to promote positive youth development outcomes for youth with chronic illness, including the development of specific self-management and other health behaviors. These behaviors and skills could be the focus of the life skills portion of such a program. Ultimately, >85% of youth with chronic illness become adults and youth programs have the potential to support such youth as they transition to adulthood.\(^12\)

Each year in the United States, an estimated 500 000 adolescents with special health care needs turn 18 years old, but there are few effective strategies to promote positive adult outcomes for this group.\(^13\) The goal of this review is to systematically identify and examine published studies that describe or evaluate programs for youth with chronic illness that deploy principles of positive youth development to support their transition to adulthood.

**METHODS**

**Analytic Framework**

The analytic framework for this systematic review was based on a non-categorical approach to childhood chronic illness and the principles of the PYD perspective described earlier.\(^10,14\) The noncategorical approach to childhood chronic illness is a common approach to studies of the psychosocial effects of chronic illness. Studies have consistently demonstrated that although there are disease-specific effects of chronic illness, most psychosocial effects of chronic illness in childhood are similar across conditions. This perspective shaped the broad definition of “youth with special health care needs” that is used to examine the outcomes of youth with a wide array of chronic conditions.

By using the PICO (population [participants], intervention, comparator, and outcomes) approach to evidence-based medicine, this review started with identification of the population of interest, youth with childhood-onset chronic illness (Fig 1). A comprehensive list of childhood-onset chronic conditions was compiled to include in the search. Then the relevant interventions were defined and organized into 3 categories that have been linked to positive youth development: (1) youth actively involved in the design and/or implementation of the intervention or serving in other leadership capacities, (2) youth learning some form of life skill, and (3) youth being involved in sustained mentoring relationships with ≥1 adults.\(^7\) Programs that included ≥2 of these categories were deemed consistent with the PYD perspective. Because the goal of this study was to identify as many programs as possible, we used this broader definition of a PYD-consistent program. This decision was made a priori. The authors planned to review each study and independently identify
whether each of the 3 elements were present. This process started with the program features listed in Fig 1 serving as examples of each of the 3 components. During the review process, the authors were given leeway to identify other activities that were not included on this list but that were consistent with the “Big Three” components of PYD programs.

Relevant comparison groups and potential outcomes were included in the analytic framework but were not used as part of the search strategy because it was believed that this would narrow the search prematurely. Potential outcomes of youth programs for youth with chronic illness presented in Fig 1 include medical outcomes, broad psychosocial outcomes, and health-transition-related outcomes. Medical outcomes included traditional health outcomes such as weight, hemoglobin A1c, or lung function. Psychosocial outcomes included measures of psychological function, social interaction, and quality of life. We conceptualized the 5Cs of PYD as a type of psychosocial outcome. Studies that evaluate self-esteem would be evaluating 1 component of the 5Cs, namely, confidence; however, no study used a specific measure of PYD, such as that developed by Lerner’s group. Improved chronic disease self-management and empowerment are examples of medical transition outcomes. These outcomes were a part of the analytic framework and were abstracted during article review but were not a part of the search strategy or article selection process.

**Data Sources**

The contents of the Medline, PsycINFO, and CINAHL databases from inception through November 2011 were searched by using a search strategy developed collaboratively with library staff. The search strategy included chronic illness terms that were combined with key words relevant to the interventions examined in this review and terms specific to different study designs (see Fig 1 for partial list of search terms including illnesses included). Additional complementary search strategies included searching the reference lists of relevant review articles. The searches were limited to English language publications with participants 13 to 24 years of age. The full search strategy is available from the corresponding author.

**Study Selection**

Two reviewers (GM and RC) independently reviewed all titles produced by the initial searches and excluded those that were definitively irrelevant to the search intent. Any titles that were insufficiently clear to make such a determination were retained for review at the abstract level. The remaining abstracts were then independently screened for the following inclusion criteria: (1) the publication was a descriptive or evaluative study of a discrete program; (2) the population studied included adolescents and/or young adults with chronic illness; and (3) the program included at least 2 of the following 3 core elements of PYD interventions: there were opportunities for youth participation and leadership of program activities, programs had an emphasis on the development of life skills, and youth were involved in sustained and caring relationships with one or more adults. If determination surrounding these criteria was not possible at the abstract level, publications were retained for full review.
These same inclusion criteria were then applied at the full article review level to yield the final cohort of articles included in this review. Figure 2 shows the numbers of titles, abstracts, and articles reviewed at each stage.

**Article Review**

Full articles were independently reviewed by both authors using structured analysis forms. Conflicts were resolved through consensus with agreement required between both authors. The structured review forms allowed the authors to systematically identify the presence or absence of the core PYD program components and to abstract comprehensive descriptions of the interventions including participant demographics, intervention specifics, evaluative methods, and outcomes. The elements were examined and placed into evidence tables, available outcome data were assessed for quality and implications, and unifying themes and concepts were formulated.

**RESULTS**

We identified 15 studies of 14 programs for youth with childhood-onset chronic illness that applied principles of the PYD perspective (1 of the programs was studied twice). Three broad categories were identified based on whether a program had all 3 PYD program components or some combination of 2 components. Three of the programs included all 3 of the features of effective youth development programs and were categorized as Comprehensive youth development programs (Table 1). Of note, all 14 programs included the life-skills development component, and programs that were not deemed Comprehensive lacked either the mentoring or youth leadership component. Five programs were characterized as Mentoring programs in that they promoted sustained youth-adult relationships in combination with the development of life skills but did not involve youth in program leadership. Six programs were characterized as Youth Leadership programs because they involved youth actively in leadership of the program but did not involve sustained youth-adult relationships.

**Program Descriptions**

**Comprehensive Programs**

All 3 Comprehensive youth development programs had multiple interlocking components that were designed to serve a wide range of youth. For example, the Chronic Illness Peers Support program (ChIPS) from Australia started with a peer support group intervention for youth with chronic health conditions. This program included

**Leadership:** Youth leaders, peer counselors

**Life skills:**
- Transition preparation
- Chronic illness self-management skills
- Educational, vocational, financial or social program focus

**Youth-adult relationships:**
- Mentoring programs
- Clinic-based programs with particular personnel with youth development role
- Peer support

**Diabetes, cancer, epilepsy (seizures), cystic fibrosis, inflammatory bowel disease, obesity, burns, arthritis, asthma, celiac disease, cerebral palsy, deafness, blindness, hemophilia, HIV, neurofibromatosis, muscular dystrophy, sickle cell anemia, migraine headaches, spina bifida, congenital heart disease, and others with special health care needs.**

**FIGURE 2**

Logic model guiding systematic review for PYD programs. Search terms included diseases and features of programs (upper two boxes). Outcomes were not included in the search but were abstracted as part of the review.
<table>
<thead>
<tr>
<th>Medical Condition/ Country/Duration</th>
<th>Program Description</th>
<th>PYD Components of Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Youth Leadership</td>
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<td></td>
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<td>Comprehensive</td>
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<tr>
<td><strong>Bettencourt</strong>17 HIV/USA/ongoing</td>
<td>Program: The Bay Area Positives, Inc. organization is a peer-run organization founded and directed by HIV-positive youth that addresses key needs of HIV-positive adolescents and young adults up to age 26 y, focusing on sexual minority youth, youth of color, and young women. Through provision of emotional and practical supports, the organization seeks to empower HIV-positive young people to thrive. Structure/Staffing: Key components of the program include peer-based support and mentorship, guidance in accessing appropriate services, and individualized support and development. Professional staff and a board of directors, including some program alumni, oversee the program. Youth run the organization and serve as peer supporters. Education and guidance regarding health services and self-advocacy. Professional staff serve as mentors to youth leaders and youth leaders support other HIV+ participants over time.</td>
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<tr>
<td><strong>Bourdon</strong>18 HIV/USA/ongoing</td>
<td>Program: The Youth Health Initiative is a community outreach program designed to enhance the quality of life of HIV+/at-risk youth in San Francisco. Structure/Staffing: Community outreach program with 1-time events and ongoing programs for youth with HIV and youth at risk for contracting HIV. Staff include some youth who are HIV+. The program is overseen by an administrative team including the program director, a communications team that provides outreach, and a young women’s health team. Programs include a 2-wk leadership training program for HIV+ youth, health and advocacy trainings, conferences, and other educational programs. Youth participate in planning, running, and evaluating programs. Programs focus on teaching self-advocacy and health promotion. Professionals on the administrative team serve as mentors; HIV+ staff and participants in ongoing programs develop sustained relationships.</td>
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<tr>
<td><strong>Olsson</strong>16 Multiple/Australia/ ongoing</td>
<td>Program: The ChIPS is a multilevel intervention for youth with various chronic illnesses in Australia. Structure/Staffing: The program involves 8 weekly group meetings led by a psychologist and a peer mentor with chronic illnesses. After participating in this group, youth can choose to participate in social, educational, recreational, and leadership activities. Youth are supervised by professional staff including a psychologist and physicians. Youth become cofacilitators of support groups and participate in a monthly leadership group that organizes a camp, fundraising, and advocacy activities. Group sessions focus on important skills for living with a chronic illness. Participants develop sustained relationships with peers and staff through leadership groups and year round programs.</td>
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*TABLE 1 Program Descriptions*
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<tr>
<td><strong>Youth Leadership</strong></td>
<td><strong>Skill-Based Activities</strong></td>
<td><strong>Youth-Adult Sustained Relationships</strong></td>
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<tr>
<td><strong>Mentoring</strong></td>
<td>Focus of intervention was on developing various skills including social skills in preparation for becoming a successful adult with a disability.</td>
<td>Longitudinal program with sustained relationships with mentors over 25 wk.</td>
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<tr>
<td>Stewart(^{21}) Cerebral palsy and spina bifida/ Canada/6 months</td>
<td>Program: An online support intervention for youth with spina bifida and CP. In weekly online sessions, youth interacted with mentors and peers who all had either spina bifida or cerebral palsy. Structure/Staffing: Five peer mentors were supervised by two psychologists in providing this pilot online intervention. Youth participated in a weekly online chat room for 60–90 min. Topics discussed included living independently, bullying, making friends, career planning, relationships, and health concerns.</td>
<td>Youth learned how to navigate their communities and work environments. Parents learned how to support youth.</td>
</tr>
<tr>
<td>Powers(^{40}) Disability/USA/5 mo</td>
<td>Program: Take Charge was an intervention designed to promote self-determination in adolescents with a variety of chronic illnesses and disabilities through coaching in self-determination skills and peer-based mentorship. Structure/Staffing: Mentors were adults with disability living in the community who met monthly with youth and their parents. The program was run by teachers and educators familiar with working with youth with disabilities. Youth and parents also met weekly with program staff for self-determination coaching sessions and there were monthly workshops for all participants (youth, parents, and mentors).</td>
<td>Mentors taught about diabetes during teachable moments that arose during meals and activities.</td>
</tr>
<tr>
<td>Daley(^{29}) Diabetes/USA/10 mo</td>
<td>Program: The Sponsorship Program for Adolescents With Diabetes matched adolescents (12–16 y) with diabetes with mentors with diabetes who were aged 25 to 43 y. Structure/Staffing: The mentor and youth spent time together twice a month for 10 mo doing social and recreational activities.</td>
<td>Mentors focused on teaching social and recreational skills and activities.</td>
</tr>
<tr>
<td>MacDonald(^{20}) Cystic fibrosis/UK/ 18 mo</td>
<td>Mission: This “Befriending” program from Great Britain was a mentoring program for youth with cystic fibrosis matched with adult mentors without illness. Structure/Staffing: Mentors met with youth at least monthly for a year and a half. Mentors in their 20s were described as “between education and employment.”</td>
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### TABLE 1 Continued

<table>
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| O’Mahar\(^2\)
Spina Bifida/ USA/1 wk            | Program: The intervention that was deployed at Camp Ability, a camp for youth with spina bifida, taught campers specific skills related to independent self-management. Structure/Staffing: Camp counselors were trained by research staff to implement the independence intervention. Parents and campers collaboratively developed goals, which staff helped campers to implement. | Focused on spina bifida self-care skills and general problem-solving skills. Youth with spina bifida had sustained relationships with adult counselors because it was an annual camp. |

**Youth Leadership**

| Hillson\(^2\)
Diabetes/UK/2 wk                  | Program: British Outward Bound course for youth with type I diabetes. Program designed for participants to learn to manage their diabetes in varied conditions through outdoor activities including climbing, mountain expeditions, canoeing, swimming, and other activities. Structure/Staffing: Medical staff and Outward Bound instructors led participants on a 2-wk program in the wilderness. | Participants served as leaders and supported each other through the challenging activities. Youth learned diabetes self-management skills and problem solving. |

| Herskowitz\(^2\)
Diabetes/USA/ 5–10 d              | Program: Outward Bound program in Maine for youth with type I diabetes. Program designed for participants to learn to manage their diabetes while participating in outdoor activities, including sailing, a ropes course, rock climbing and swimming. Structure/Staffing: Multiday program for small groups of participants, run by medical staff from their diabetes clinic and Outward Bound staff in Maine. | Participants served as leaders and supported each other through the challenging activities. Youth learned diabetes self-management skills and problem solving. |

| Kessel\(^2\)
Multiple/USA/ 2 wk                | Program: Adventure, Etc. combined wilderness and urban Outward Bound experiences for youth with a variety of chronic illnesses. Program included elements such as rock climbing, white-water canoeing, portaging, camping, map and compass orienteering, an overnight solo experience, a city component, and a mini-marathon. Goals of the program were to promote attainment of appropriate separation from parents, achievement of mastery, development of social skills, and attainment of a positive body image. Structure/Staffing: Two-week programs for 10 youth per trip led by a physician and Outward Bound instructor. Program was a joint effort of the University of Minnesota Adolescent Medicine Program and Outward Bound. | Participants acted as leaders for the group throughout the program and participated in group decision-making. Youth learned outdoor skills, as well as social skills and skills related to being an independent adult. |
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<td></td>
<td>Youth Leadership</td>
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<tr>
<td>Shah &amp; Gibson (27) Asthma/Australia/5 mo</td>
<td>Program: The Adolescent Asthma Action program was a peer leadership based program that provided asthma education in schools. Structure/Staffing: The program was implemented as part of a research study, and youth were supervised by research staff. First, volunteer students in the 11th grade were trained to be peer leaders. Then teams of 3 to 4 peer leaders conducted three 45-minute lessons for 10th-grade students. The 10th-grade students then developed an asthma education lesson that they presented at an assembly of seventh-grade students. All participants learned about asthma self-management.</td>
<td>10th- and 11th-grade students participated in teaching younger students.</td>
</tr>
<tr>
<td>Rhee (26) Asthma/USA/3 wk</td>
<td>Program: Peer-based intervention, implemented as part of a 1-d asthma summer camp. Peer leaders with asthma implemented an asthma self-management program after a 3-wk training. Structure/Staffing: Peer leaders with the support of research staff implemented a curriculum that included basic asthma education, psychosocial components, and self-management elements. Youth served as asthma peer educators.</td>
<td>Participants learned about asthma self-management.</td>
</tr>
<tr>
<td>Jelalian (25) Obesity/USA/6 mo</td>
<td>Program: In this clinical study of a multicomponent weight loss program, all youth received cognitive behavioral treatment of 6 mo. The intervention group participated in a weekly peer-based adventure therapy program and the control group received weekly aerobic exercise training. Structure/Staffing: Research staff and staff at an outdoor education facility ran the peer-based adventure therapy program. It included weekly peer-based problem solving activities, culminating in 2 half days at a ropes course where participants worked together to navigate outdoor challenges. Youth participated as leaders in team-based problem solving.</td>
<td>Youth learned about weight management and about problem solving and cooperation.</td>
</tr>
</tbody>
</table>
Mentoring Programs

The Mentoring programs were deployed in a diversity of settings including online, in a hospital setting, at a summer camp, and in local communities. The mentoring programs had 2 distinct focuses, with some focused on specific skills such as spina bifida self-care and others focused on general support and enjoyment such as a sponsorship program for youth with diabetes and a British “buddying program” for youth with cystic fibrosis.18 Some mentoring programs matched individual youth with a specific mentor; whereas others used a group setting in which a small number of mentors interacted with youth with illness. For example, an online mentoring program for youth with either spina bifida or cerebral palsy included 22 youth and 5 mentors interacting through weekly online group sessions.21

Youth Leadership Programs

Three of the Youth Leadership programs involved collaboration with an Outward Bound school. These programs were staffed by medical clinicians from the program and by instructors from Outward Bound schools in Minnesota, Maine, and Great Britain. Other Youth Leadership programs included camp- and school-based asthma programs and an obesity program that was paired with a cognitive-behavioral therapy intervention. Some programs in this category were among the most rigorously evaluated including a randomized controlled trial and school-based studies with well-designed control groups.

Program Evaluation

Medical Outcomes

Table 2 summarizes the program evaluation data presented in these studies broadly divided into medical outcomes, psychosocial outcomes, and health care transition outcomes. Only 4 programs measured discrete medical outcomes, and the only study that showed significant changes in a medical outcome was a study of a weight loss program that used a Youth Leadership component. In this study, there was greater weight loss in the intervention group compared with controls, and 33% of youth from the intervention group maintained weight loss as compared with only 12% of controls ($P = .04$). In contrast, the 1 diabetes program that looked at changes in glycemic control between participants and controls found no difference. In addition, 2 studies evaluating asthma programs found no difference in lung function between participants and controls. Finally, related to issues of medical safety, programs that involved significant physical exertion did include data regarding the safety of these programs for youth with medical issues and indicated that with appropriate planning and precautions these programs could be run safely.

Psychosocial Outcomes

All of the studies in the review presented psychosocial outcomes included several with both qualitative and quantitative outcome data. Key outcome categories included disease-specific knowledge, illness management behaviors, social outcomes, and psychological adjustment/well-being. With respect to disease-specific knowledge, the Adolescent Asthma Action program demonstrated improved knowledge for students with and without asthma, compared with controls. In addition, all 3 of the Comprehensive programs qualitatively described ways in which their programs contributed to greater illness-related knowledge. In terms of illness management behaviors, the programs for youth with diabetes and youth with spina bifida targeted illness management behaviors, but only 1 study rigorously assessed these. This study at a camp for children and youth with spina bifida found that there was an increase in spina bifida goal setting and a slight increase in independence with spina bifida tasks for participants. Meanwhile, all programs for youth with diabetes qualitatively reported improvements in self-management as a result of participation from the perspectives of participants and parents.

Social outcomes were examined in 2 studies for youth with disabilities and were found to have improved in both. In the online program described earlier for youth with either spina bifida or cerebral palsy, there was an increase in contact with peers and a greater sense of community, although there was no corresponding change in loneliness or social acceptance. In the other study of a camp program for youth with spina bifida, there was an increase in social goal setting. Finally, the ChIPS program was described qualitatively as decreasing isolation.

Psychological adjustment and well-being were examined through a variety of measures in 7 studies. Quality of life improved for youth with asthma who participated in a school-based program and also for the intervention group in a
<table>
<thead>
<tr>
<th>Medical Condition</th>
<th>Subjects (Total M/F)</th>
<th>Age, y (mean)</th>
<th>Study Design</th>
<th>Medical Outcomes</th>
<th>Psychosocial Outcomes</th>
<th>Transition Outcomes</th>
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<tbody>
<tr>
<td><strong>Comprehensive</strong></td>
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<tr>
<td>Bettencourt17 HIV</td>
<td>21 n/a</td>
<td></td>
<td>Qualitative: semistructured interviews</td>
<td>Satisfaction: Participants were most satisfied with trainings and recreational events. Emotional support: Participants indicated the program was a source of emotional support. Knowledge: Participants identified increased knowledge as a positive outcome of participation.</td>
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<tr>
<td>Bourdon18 HIV</td>
<td>136 M/169 F; HIV+ 45 M/20 F</td>
<td>M: 22.3; F: 19.6</td>
<td>Qualitative: focus groups</td>
<td>Knowledge: Qualitative increase in participants’ knowledge of resources.</td>
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</tr>
<tr>
<td>Olsson16 Multiple</td>
<td>&gt;500 n/a</td>
<td></td>
<td>Qualitative</td>
<td>Social: Qualitative description of a decrease in isolation for participants. Knowledge: Increased knowledge for young women participants.</td>
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<tr>
<td><strong>Mentoring</strong></td>
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<tr>
<td>Stewart21 Cerebral palsy/ SB</td>
<td>22 (12 M/10 F); 11 with cerebral palsy, 11 with SB</td>
<td>12–18 (14.6)</td>
<td>Single group longitudinal observational study: pre, post, and delayed post (3 mo)</td>
<td>Social: Increased contact with peers and greater sense of community. No change in loneliness, social acceptance, or coping. Qualitative data suggested benefits not captured quantitatively by small sample</td>
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<tr>
<td>Powers41 Disability</td>
<td>20 (10 M/10 F); 10 control, 10 intervention</td>
<td>12–18 (14)</td>
<td>RCT</td>
<td>Well-being: Improved psychosocial adjustment. Self-efficacy: Greater empowerment and sense of personal accomplishment.</td>
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<tr>
<td>Daley28 Diabetes</td>
<td>54 (21 M/3 3F); 27 control; 27 intervention</td>
<td>12–16</td>
<td>RCT</td>
<td>No difference in HbA1c. Intervention group tested blood sugar more frequently.</td>
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<tr>
<td>MacDonald20 Cystic fibrosis</td>
<td>24 interviews: 7 youth, 7 parents, 7 hospital staff, 3 “buddies”</td>
<td>8–18</td>
<td>Qualitative semistructured interviews</td>
<td>Satisfaction: Mentoring described as positive for all parties. Challenges: Challenges identified included ending the relationship and negative effects of a mentor not committed to the process.</td>
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<tr>
<td>O’Mahar19 SB</td>
<td>76 (33M/43F)</td>
<td>8–37 (18.8)</td>
<td>Single group longitudinal observational study: pre, post, and delayed post (10 mo)</td>
<td>Self-efficacy: Increase in SB goal setting. Social: Increase in social goal setting. Marginal increase in independence with SB tasks</td>
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<tr>
<td><strong>Youth Leadership</strong></td>
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<tr>
<td>Hillson22 Diabetes</td>
<td>39 (28 M/11 F)</td>
<td>14–20</td>
<td>Qualitative</td>
<td>Safety—outdoor education program for youth with diabetes can be run safely. Self-efficacy: Satisfaction: Qualitative description of enjoyment, satisfaction, self-efficacy.</td>
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<tr>
<td>Herskovitz24 Diabetes</td>
<td>8</td>
<td>14–42</td>
<td>Single group observational pre- and postevaluation; qualitative evaluation</td>
<td>Safety: outdoor education program for youth with diabetes can be run safely. Self-efficacy: No change in self-esteem or locus of control. Well-being: No change in diabetes adjustment. However trend toward a decrease in problem scores on Achenbach self-report profile. Qualitative reports of improving self-confidence and better control of diabetes</td>
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# DISCUSSION

This review identified a wide range of programs for youth with chronic illness in the camp-based asthma program. Participation in the camp-based asthma program also expressed more positive attitudes toward asthma after intervention. Self-esteem was qualitatively reported to have improved in a diabetes mentoring program, while it remained unchanged in another diabetes-specific program in an Outward Bound setting. In addition, psychosocial adjustment and empowerment improved in a mentoring program for youth with disabilities. Other studies found no change in self-worth, coping, and diabetes adjustment. Overall, the quality of the assessment of changes in well-being and psychological adjustment was poor and most studies lacked an adequate control group or sufficient follow-up to ascertain whether any changes observed were sustained.

## TABLE 2 Continued

<table>
<thead>
<tr>
<th>Medical Condition</th>
<th>Subjects</th>
<th>Medical Outcomes</th>
<th>Psychosocial Outcomes</th>
<th>Transition Outcomes</th>
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</thead>
<tbody>
<tr>
<td>Shah[^12]</td>
<td>Asthma</td>
<td>251 (114 M/137 F); 138 control, 113 intervention</td>
<td>No change in lung function. More asthma attacks in control group.</td>
<td>Well-being: Quality of life improved for 25% of intervention group, as opposed to 12% of control group (P &lt; .01). Decrease in school absences for intervention group, but not the control group.</td>
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<td>Gibson[^6]</td>
<td>Asthma</td>
<td>92 (0 M/92 F); 30 control, 62 intervention</td>
<td>Controlled trial with intervention and control schools</td>
<td>Knowledge: Significant improvement in asthma knowledge in students with and without asthma.</td>
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<td>Rhee[^26]</td>
<td>Asthma</td>
<td>112 (48 M/64 F); 53 control, 59 intervention</td>
<td>No significant difference in spirometry.</td>
<td>Well-being: Intervention group with a more positive attitude toward illness at 6 mo and higher quality of life at 6 and 8 mo. Self-efficacy: Both groups with greater self-worth post-intervention and at 10 mo.</td>
</tr>
<tr>
<td>Jelalian[^25]</td>
<td>Obesity</td>
<td>76 (22 M/54 F)</td>
<td>14.5</td>
<td>RCT</td>
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CBCL, Child Behavior Checklist; F, female; M, male; RCT, randomized controlled trial; SB, spina bifida.
that use principles of the PYD perspective. All of the programs aimed to promote youth development through participation in activities that targeted important skills. The approaches varied, however, in terms of their scope from the most comprehensive programs that sought to promote positive youth development across an entire community of youth with a particular illness to more focused programs targeting a specific skill, such as self-catheterization for youth with spina bifida. All 14 programs described in this review sought to promote the positive development of youth with chronic illness and not just prevent negative outcomes.

Although none of the programs described in this review explicitly discussed the PYD perspective, the programs focused on developing positive youth outcomes through the application of some combination of the core PYD program principles of equipping youth with life skills, involving them in active leadership of the program, and fostering sustained youth-adult relationships. Although this systematic review does not demonstrate conclusively that a PYD approach is effective at promoting positive outcomes for youth with chronic illness, it does describe a wide variety of strategies for deploying PYD-consistent principles in support of their development.

The PYD perspective has been used in health promotion and risk prevention for at-risk youth broadly. Multiple programs have used the PYD model to mitigate negative sexual health outcomes for youth including pregnancy and acquisition of sexually transmitted infections. For example, 1 program demonstrated improvements in sexual risk behaviors through an intervention that specifically highlighted peer leadership groups. Another after-school youth development program demonstrated positive effects on attitudes toward substance use and actual substance use behaviors using a curricular approach focused on decision-making skills. Yet another recent application of PYD highlighted mentorship as a way to improve social acceptance and resilience against future substance use. These program evaluations, as well as analyses of longitudinal cohorts of adolescents, indicate that well-being in adolescence is associated with better general health and decreased health risks in young adulthood. The development of rigorous evaluations of PYD programs for youth with chronic illness can build on these efforts by both adapting study designs and examining similar outcomes.

Although many of the programs described in this review had the potential to promote positive youth outcomes, few were evaluated rigorously. In particular, none of the comprehensive programs that integrated all 3 key PYD components were studied by using a control group. Even for studies that did use a control group, most were small and with limited duration of follow-up, making it difficult to generalize the findings beyond the particular group and setting studied, such as youth with spina bifida attending a spina bifida camp. Still, despite these limitations, this review may serve as a stimulus for considering the future role of youth development programs in the lives of youth with chronic illness.

First the comprehensive programs take a community-based approach to supporting youth with chronic illness. Often youth with chronic illness are not fully integrated into the community. This happens as a result of school absence due to illness, as well as a lack of after-school programs that can accommodate youth with complex illnesses secondary to logistical issues or parental or child anxiety. The comprehensive programs described in this review sought to change this dynamic and promote the integration of youth with chronic illness into the community or, as in the case of the Australian ChIPS program, create a community out of whole cloth. Such programs at a community or hospital level might be able to reach a large population of youth with chronic illness.

Second, this review points to the importance of using youth development theory in designing programs for youth with chronic illness and to the opportunity to improve the quality of youth programs using PYD theory. In the future, developers of programs for youth with chronic illness could consider Lerner’s Big Three components of successful PYD programs as they work to design new PYD programs and improve existing programs. For example, programs that focus on mentoring might add in a youth leadership component to augment the program’s effects. Such additions could also be coupled with quality improvement efforts to provide a particularly rigorous application of youth development principles. The Youth Program Quality Intervention (YPQI) is a systematic quality improvement process that could be deployed to improve the quality of a program for youth with chronic illness. The YPQI has been rigorously studied and used to evaluate youth programs and subsequently make improvements. Studies using the YPQI process, including 1 examining implementation of after-school programs in Nashville, Tennessee, indicated that this type of structured assessment and quality improvement framework improves positive youth development settings. Such a quality improvement approach could be used to improve programs for youth with chronic illness through improvements in staff training, participant safety, and the ways in which programs promote positive adult-youth relationships.

Third, with 500,000 youth with special health care needs turning 18 each year, there is a pressing need to understand
how to promote successful adult outcomes broadly for such youth. To date, few effective programs for health care transition have been developed. The PYD perspective has not yet been extensively applied to the promotion of positive health outcomes for youth with chronic illness. Its application in this context carries vast potential for promoting the health of youth with chronic illness, both in general and specifically with respect to health care transitions. As more and more youth with chronic illness survive to adulthood, the health care system needs to adapt. The PYD perspective offers a framework to address the critical objective of developing and strengthening programs that can help youth move smoothly from the pediatric to the adult health care system.

CONCLUSIONS

PYD programs transcend disease-specific issues and provide access to programs that promote development in a more holistic manner to youth with illness. Many of the youth development programs identified in this review enable youth not only to manage their particular disease but to seek their own health promotion more broadly. Successful health care transitions will require that youth with chronic illness not only learn to manage their disease but also develop into skillful and capable adults in general. Indeed, the centerpiece of the PYD approach is that it is not enough to ensure that youth with chronic illness avoid flares or worsening symptoms but rather that they develop into adults with chronic illness who thrive in all areas of their lives. This review may serve as a starting point for applying the PYD perspective to the development of youth with chronic illness. Future research is needed to examine the short- and long-term effects of PYD programs on the adult development of youth with chronic illness. This would include examining educational, vocational, and health-related outcomes.

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