HEALTH-RELATED INDEPENDENCE AND QUALITY OF LIFE OF YOUTH WITH BOWEL AND/OR BLADDER DYSFUNCTION ATTENDING A ONE-WEEK RESIDENTIAL PROGRAM

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ABSTRACT

In order to foster effective transitions to adulthood, it is necessary for youths with chronic healthcare conditions to have access to training and support. When the condition is one that is rare and potentially stigmatizing such as incontinence, these opportunities can be difficult to find locally. Camps and special weekends have been used to provide training and support to youth with various rare chronic conditions. However, the impact of these programs has not often been measured within the context of facilitation of health-related independence or quality of life issues. A study of the impact of a one-week residential program on 89 youth with bowel and/or bladder dysfunction was conducted to determine if significant, lasting change was effected in these areas. While no statistically significant impact was found on the larger constructs, the health-related independence domain of *Knowledge of Your Condition* and the quality of life domain of *Self* were significantly impacted and was sustained 2-4 months after the program. Implications for programs for this and other populations with chronic illness are discussed.

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Youth with special health care needs experience physical and psychological effects as a result of their conditions which may affect their quality of self image, understanding of peers, and other life experiences. These youth often seek out experiences such as camps or special weekend events to learn more about their conditions and develop relationships with others experiencing the same illnesses. Programs that offer an opportunity for youth to learn about their conditions, develop relationships with others with the same diagnoses, and develop skills to be successful in managing their conditions can foster better outcomes and increased independence (Geist, Grdisa, & Otley, 2003; Hughes, Wood & Smith, 2009; Michalski, Mishna, Worthington, & Cummings, 2003). Ensuring these youth attain quality knowledge and skills to more independently manage the physical and psychological impact of illness is needed for effective transitions into adulthood (Clay, 2004). This study investigated the impact of a one-week residential program for youth with bowel and/or bladder dysfunction resulting in some level of incontinence. More specifically, health-related independence and quality of life were studied to determine if there were improvements after the program ended, and if those changes were maintained two to four months later.

Making the transition into adulthood is challenging to all adolescents. A major component of effective transitions is ensuring that young adults have the proper knowledge and skills to direct their own lives effectively. When the adolescents have special health care needs, this transition must also include helping them take charge of their own health care needs (Scal, Evans, Blozis, Okinow, & Blum, 1999). Transition encompasses not only the typical changes of adulthood, but also the complex transition from pediatric to adult health services. This should include the successful transfer from pediatric to adult care providers and establishing workable relationships with those providers (Betz & Telfair, 2007).

The 1990's saw much reform across multiple federal agencies concerned with the outcomes of federal programs and services. In 1992, transition planning and services were required by all schools providing special education services to children with disabilities. Similarly, in 1996, the US Department of Health and Human Services and other federal agencies began to focus on the transition of children with special health care needs (Betz, 2004).

Through the Maternal and Child Health Bureau's Division of Services for Children with Special Health Needs, states received funding through "Healthy and Ready to Work" initiatives designed to build support systems for the transition needs of this population, as well as the funding of a Healthy and Ready to Work (HRTW) National Resource Center (Healthy and Ready to Work Center, n.d.).

The term "quality of life" has been used to describe one's overall well being, and encompasses both internal and external factors. While health status can certainly impact quality of life, there is general agreement that the individual's response to the condition is also a major influence (Guyatt, Naylor, Juniper, Heyland, Jaeschke, & Cook, 1997). There is consensus in the field that quality of life includes mental, physical, and social functioning (Smith, Avis, & Assmann, 1999). Quality of life has long been a concern of medical professionals and is much reported in the literature. However, defining and measuring quality of life in children with special health care needs is not as well explored. The measurement and evaluation of quality of life in this population is difficult given their developmental maturity, the variability in their health status, and the scarcity of research-supported tools to use in such studies (Topolski, Edwards, & Patrick, 2009).

PURPOSE OF THE STUDY

This study was designed to investigate the impact of a one-week residential program on youth and young adults with various special health care needs that impact bowel and/or bladder function. Participants spent one-week on a college campus and engaged in both structured and unstructured sessions facilitated by young adults with these conditions and/or medical professionals. Sessions focused on both physiological and psychological issues, including strategies for home, school, and medical settings. Social activities designed to facilitate development of social relationships among peers were also conducted. See Figure 1 for a description of the program content.

Reported levels of health-related independence were studied to determine any changes in skills needed for successful transitioning from pediatric to adult health care. Additionally, data were collected on a more holistic construct, quality of life, in order to provide more global information about this population. Results may inform the field about the needs of young adults with these conditions and the efficacy of one approach to meeting these needs.

Figure 1. Features of the Program Studied.

Program Features	
Location:	Each year a college campus is chosen for the program based on its proximity to a major hospital, airport, and recreational activities.
Duration:	The program lasts five days.
Residential Living:	Each participant lives in a dormitory with a same-gendered roommate, and has meals in the on-campus dining hall.
Program Staff:	The program is staffed by volunteer counselors and medical professionals, many of whom were former program participants. By prioritizing staff with the same diagnoses and experiences, the program intends to provide mentorship from those with similar medical, personal, and social differences and experiences experienced by participants.
Educational Sessions:	Educational sessions focus on issues relating to living with some form of incontinence. Topics included self-esteem, fitting in at school, medical issues, and the psychological effects of dealing with personal differences and medical diagnoses. During the program period studied, approximately seven hours were devoted to educational sessions relating to physical and psychological well-being.
Facilitated Discussions:	Following each educational session, participants engage into discussion groups by diagnosis, age, and gender. These groups are facilitated by program staff and provide an opportunity for participants to have their specific questions answered, receive focused attention to their specialized needs and concerns, and hear other stories, from both other campers and counselors, about confronting and dealing with adversity. During the program period studied, approximately five hours were devoted to facilitated discussions.
Structured Recreation:	There are several structured recreational activities designed to facilitate interaction among participants, and among participants and staff. This includes games, themed nights, dances, a fitness morning, a day-trip to a local attraction, and a dance and graduation ceremony on the final night of the program. During the program period studied, approximately twelve hours were devoted to structured recreation.

Unstructured Recreation:	There are also times during the schedule in which participants have unstructured time to interact with one another. This included time to explore the college campus, swim, make crafts, shop in campus bookstore, or just hang out with others. During the program period studied, approximately thirteen hours were devoted to unstructured recreation.

METHODS

PARTICIPANTS

Participants and counselors-in-training under the age of 21 who attended a one-week residential program specifically designed for youth with bowel and/or bladder dysfunction resulting in some level of incontinence were included in the study. Of the 142 potential participants, 89 agreed to participate (63% participation rate) in the study. The mean age for participants was 17 (18%, range 11-18 years); the most frequent age reported was 17 (18.0 %, n = 16). Participants from various races participated, with Caucasians being most frequently represented (49.6%, n = 64) (see Table 1).

Table 1.

Age and Race of Participants in Sample

	%	n
Age		
11	7.9%	7
12	10.1%	9
13	12.4%	11
14	15.7%	14
15	14.6%	13
16	16.9%	15
17	18.0%	16
18	2.2%	2
Did not report	2.2%	2
Race		
Caucasian	49.6%	64
African American	5.4%	7
American Indian or Alaskan Native	4.7%	6
Hispanic	2.3%	3
Did not wish to report	10.1%	9

Table 2.

Number of Times Attending Program Represented in the Sample

Times in Attendance	%	n
1	44.9%	40
2	19.1%	17
3	18.0%	16
4	6.7%	6
5	3.4%	3
6	2.3%	1
7	1.1%	1
Did not respond	4.5%	4

Note. "1" indicates a first-time participant.

Many of the participants had attended this program in the past. Average number of times attended was 2.02 with first-time attendance indicated most frequently (44.9%, n = 40) (see Table 2).

Participants were asked to identify medical diagnoses. The medical diagnosis most frequently indicated by participants was Imperforate Anus (13.5%, n = 12). Bladder Exstrophy, Crohn's Disease, and Hirschprung's Disease were each identified by 12.4% of participants (n = 11 for each diagnosis). "I Don't Know" was reported by 10.1% (n = 9) and no response was given by 3.4% (n = 3). Frequency data for other diagnoses are given in Table 3.

PROCEDURE

Prior to the beginning of the study, this project was reviewed and approved by the university's Human Subjects Protection Review Committee which ensures that research projects involving human subjects follow federal regulations. Informed consent to participate was attained from the parents and/or legal guardians of minor participants prior to administration of the instruments via a consent form included in the registration packet. The signed consent form described the purpose of the study and explained participation was voluntary. Additionally, on the demographics page completed by the participant, there was the statement, "Your parents have agreed for you to answer some surveys that will help [. . .] If you feel uncomfortable and do not want to complete the survey, you can stop."

Two instruments were used in order to measure health-related independence (*Transitioning to Independence: How Ready Are You?*) and quality of life (*Youth Quality of Life Instrument-Research Version*). These instruments were

Table 3.

Medical Diagnoses Represented in the Sample

Medical Diagnosis	%	n
Imperforate Anus	13.5%	12
Bladder Exstrophy	12.4%	11
Crohn's Disease	12.4%	11
Hirschsprung's Disease	12.4%	11
Colitis	10.1%	9
Neurogenic Bladder	9.0%	8
Cloaca	5.6%	5
Renal Defects	5.6%	5
VATER/VACTERL	4.5%	4
Spina Bifida	4.5%	4
Ileostomy	2.3%	2
Anal Stenosis	1.1%	1
Scoliosis	1.1%	1
Stretched Spinal Cord	1.1%	1
Tracheo-Esophageal Fistula	1.1%	1
I Don't Know	10.1%	9
No Response	3.4%	3

Note. Diagnoses reported are not mutually exclusive and do not add up to 100 percent.

administered during registration on the first day of the program (pre-test) and during out-processing on the last day of the program (post-test). Delayed-post data collection (follow-up) was conducted between 2 and 4 months post-rally. At follow-up, instruments were mailed to participants by program staff, ensuring anonymity of responses. Reminders were sent to participants by program staff via email and an additional packet was sent to non-responders two months following the initial mailing in an effort to maximize returns. Additionally, a separate entry card was included in the packet which, if returned, would enter the respondent's name into a drawing for free registration at next year's program. Upon receipt of the instrument packets, an independent third party removed the entry cards from the packets and placed them into a secure envelope prior to giving the instruments to the researchers. After all packets were received, the third party mailed the entry cards to program staff who selected the recipient of the incentive.

Two administrations of the instruments were given (post-test and follow-up) in an attempt to ensure accuracy of the results of the impact of the program, which may or may not be apparent during the post-test administration only. It was necessary to assess again after some time had passed in order to allow for any therapeutic regressive processes to occur. Regressions are often necessary in healing and may occur after treatments that have psychological impact in which the participant may actually appear to have no improvement or even regress after experiencing a therapeutic process. These levels of regression and subsequent periods of progression that may occur are said to be necessary for psychological growth and maturation (Applegate & Bonovitz, 1995). By conducting both a post-test immediately after the program and follow-up administration 2-4 months later, true effects were more likely to be seen as participants had time to integrate what was experienced and learned. A delayed post-treatment assessment is also helpful to determine if any benefits were maintained over time after the treatment ends.

MEASURES

Shriner's Hospital for Children in Northern California developed *Transitioning to Independence: How Ready Are You?* as a brief screening/assessment tool to identify if youth have the skills to proactively manage their own health and health care needs (Shriner's Hospital for Children, n.d.). It contains 34 statements within the following four sections: *Staying Healthy*, *Knowledge of Your Health Condition*, *Education and Work*, and *Adult Health Care*. In this study, participants were presented with these statements and asked to respond using a Likert-type scale of 1 to 10 with 1 indicating "not at all/I have no idea", 5 indicating "kind of", and 10 indicating "absolutely". See Table 4 for a description of the scales included.

While this tool has content validity as evidenced by inclusion in the tools disseminated by the Healthy and Ready to Work National Resource Center, there is no information on the reliability of the tool. Because of this, reliability was evaluated post hoc using Cronbach's alpha prior to accepting data from this instrument for this study. Analysis of data from all three administrations of the instrument revealed internal reliability well above the commonly-accepted level of .70 (pretest $\alpha = 0.904$; posttest $\alpha = 0.939$; and follow-up $\alpha = 0.920$).

Quality of life instruments typically are developed in a manner that facilitates comparisons of the population being studied to the typical population. However, most instruments were developed for and normed with adult or

Table 4.

Description of Scales/Subscales:
Transitioning to Independence: How Ready Are You?

Scale or Subscale	Description
Overall Independence	
Staying Healthy	General ability to manage health; making medical appointments; managing insurance and records; general wellness.
Knowledge of Condition	Specific knowledge of condition and its implications; manage medications and treatments.
Education and Work	Attending school and/or work; participating in accommodation planning and meetings; basic advocacy skills.
Adult Health Care	Knowledge of medical doctors and facilities to be used when an adult; scheduled appointments with adult adult health providers; insurance.

even geriatric populations. The Youth Quality of Life Instrument-Research Version (YQOL-R) was developed specifically for youth, attending to the unique social relationships, environments, and sense of self of this age group. It has well established content validity (both convergent and discriminant) as extensively documented in the technical manual for the instrument. Additionally, reliability was established by the instrument's developers using Cronbach's alpha, with coefficients above the .70 accepted level (Topolski, Edwards, & Patrick, 2009).

The YQOL-R consists of 57 items addressing both contextual and perceptual areas and uses two different types of Likert-type response scales. The response scale used in the *Describing Your Life* (contextual items) uses frequency modes consisting of *Never* (1), *Almost Never* (2), *Sometimes* (3), *Fairly Often* (4), *Very Often* (5). The response scale used in all other sections (perceptual items) consisted of rating options of 0-10 with *Not at all* corresponding to a 0 rating and *Completely* or *A great deal* corresponding to a 10 rating. In addition to a total score for quality of life, domain scores are generated based on perceptual items in the domains of *Self, Relationships, Environment,* and *General Quality of Life*. See Table 5 for a description of the scales and subscales.

Table 5.

Description of Scales/Subscales: *Youth Quality of Life Instrument-Research Version*

Scale or Subscale	Description
Overall Quality of Life	
Self Domain	Sense of self or how the youth feels about him/herself in regards to belief in self, being oneself, mental health, physical health, and spirituality.
Relationships Domain	Social relationships with others. Includes the youth's perception of his/her adult support, ability to care for others, family relations, freedom, friendships, participation, and peer relations.
Environment Domain	Personal opportunities and obstacles including engagement in activities, quality of education, satisfaction with neighborhood, monetary resources, personal safety, and outlook of future.
General Quality of Life	General enjoyment of life, feeling life is worthwhile, and satisfaction with one's life.

DATA ANALYSIS

For each scale and subscale, descriptive statistics were generated to show the overall number, mean, and standard error. While statistically significant conclusions cannot be drawn from descriptive statistics alone, they can provide valuable information regarding each area, showing general changes in scores. For each scale and subscale, a repeated measures analysis of covariance (ANCOVA) was conducted to determine if participation in the program had a statistically significant impact on anxiety, health-related independence, and/or quality of life. ANCOVA is warranted when attempting to statistically control for an extraneous variable. In this study, some participants had prior experience at the program, and therefore the potential for error variance in the results was present. Because a control group (youth who were not attending the program) was not used in this study, experimental control could not be attained. However, in the absence of experimental control, statistical control was attained by using number of times attending the program as a covariant, resulting in a smaller error variance, and increased accuracy of results (Huck, 2008). When using such an analysis, it is necessary to determine if the assumption of sphericity has been violated and correct when such a violation occurs. Mauchly's test was used to test for sphericity and the Greenhouse-Geisser correction was used when the assumption of sphericity was violated (Abdi, 2010; Huck, 2008). In this study, the independent variable was attendance at the program; the dependent variables were reported health-related independence and quality of life; and number times attending the program was the covariate. When a statistically significant result was found for any scale or subscale, further analysis of the data was conducted for the planned contrasts of pre-test vs. post-test and pre-test vs. follow-up to determine specifically where results were seen.

RESULTS

In an effort to determine the impact of the program on the health-related independence of participants, data generated from three administrations of the instrument, *Transitioning to Independence: How Ready Are You?* were analyzed. Data on the corrected means and standard error for the total instrument, as well as each scale, is first provided. Next, an analysis of covariance (ANCOVA) procedure was used to determine if attendance had an impact on the total score or any scale scores. When statistical significance was found in the ANCOVA procedure, further planned contrasts were examined to determine if the effect was seen in the pre- and post- program administrations and/or the pre- and follow-up administrations. These results are presented along with relevant data tables in the sections below.

HEALTH-RELATED INDEPENDENCE

Mean scores, standard deviation, and numbers of participants for whom data is available at each administration are provided in Table 6. While there are no data to use as a comparison for what may be reasonably expected, generally speaking, higher scores are more desirable and indicate greater levels of independence. The overall mean scores increased over time, as did *Staying Healthy*, *Knowledge of Health Condition,* and *Education and Work.* Mean scores did not increase for *Adult Health Care.*

While visual analysis of mean scores generated for each administration of *Transitioning to Independence: How Ready Are You?* revealed change over time for all but one area, statistical significance was tested via the use of the analysis of covariance (ANCOVA) procedure. Despite these mean increases, attendance at the program was not found to impact overall health independence levels. Statistical significance was found for only one of four scales, *Knowledge of Health Condition* (F(2, 106) = 3.209 p = .044). Results of all scales are provided in Table 7, with the scale demonstrating statistical significance highlighted in bold.

Table 6.

Means and Standard Deviations:
Transitioning to Independence: How Ready Are You?

	Pre-Test		Post-Test		Follow-up	
	Mean	Std. Error	Mean	Std. Error	Mean	Std. Error
Overall Independence	5.85	.22	5.88	.25	6.04	.24
Staying Healthy	5.35	.27	5.46	.30	5.53	.29
Knowledge of Condition	7.67	.24	7.94	.27	8.05	.26
Education and Work	6.69	.23	6.67	.21	6.73	.21
Adult Health Care	2.10	.41	1.72	.40	1.94	.37

Note. Corrected means and standard errors are reported based on calculations using the covariate "Years at Program".

Table 7.

ANCOVA Results: *Transitioning to Independence: How Ready Are You?*

	SS	*df*	*MS*	*F*	*Sig.*	*error*
Overall Independence	.261	2	.131	.340	.713	96
Staying Healthy	.183	2	.092	.100	.905	106
Knowledge of Health Condition	**5.329**	**2**	**2.665**	**3.209**	**.044**	**106**
Education and Work	.358	2	.179	.206	.814	.004
Adult Health Care	.433	2	.217	.117	.889	94

Note. Statistically significant results are given in bold.

In an attempt to determine if the statistically significant effect was found between pre- and post-testing, pre- and follow-up testing, or both, further analysis of within-subjects contrasts was conducted. A statistically significant result was found for *Knowledge of Health Condition* and is reported in Table 8. Improvements at levels approaching significance were shown between the pre- and post-test administration, and levels with statistical significant at the pre- and follow-up administration.

QUALITY OF LIFE

The impact of the program on the quality of life of participants was determined from, data generated from three administrations of the instrument,

Table 8.

Planned Comparisons for Statistically Significant Results: *Transitioning to Independence: How Ready Are You?*

	SS	*df*	*MS*	*F*	*Sig.*	*error*
Knowledge of Health Condition						
Pre-test vs. Post-test [a]	5.567	1	5.567	3.944	.052[a]	53
Pre-test vs. Follow-up	9.821	1	9.821	4.497	.039	53

[a] This planned comparison did not meet the criteria for statistical significance (p < .05), but is considered to be approaching significance and therefore included in this table for reference.

Youth Quality of Life Instrument-Research Version (YQOL-R) Data on the corrected means and standard error for the total instrument, as well as each scale is first provided. Next, results of the analysis of covariance (ANCOVA) were used to determine if attendance at the program had an impact on the total score or any scale scores. When statistical significance was found in the ANCOVA procedure, further planned contrasts were examined to determine if the effect was seen in the pre- and post- program administrations and/or the pre- and follow-up administrations. These results are presented along with relevant data tables in the sections following.

The means and standard errors for all three administrations of the instrument are provided in Table 9. In addition to the data generated in this study, means and standard errors are reported for a “no condition” group which was provided in the technical manual for the YQOL-R. (Topolski, Edwards, & Patrick, 2009). While not enough is known to determine if comparisons may be made with confidence, these data are provided for a general frame of reference regarding what scores for a typical population may be.

Preliminary examination of the mean scores for total quality of life and the four domains measured comparing “no condition” group and the pre-test administration for participants. The pre-test mean total score and the *Relationships, Environment,* and *General Quality of Life* domain scores for participants were all reasonably similar to the “no-condition” group. However, the *Self* domain appeared much lower for participants as compared to the “no condition” group.

Additionally, while the overall mean score and the domain scores all appeared to improve, albeit slightly in some areas, many returned to pre-program levels or even below at follow-up. While mean scores in the *Self* domain were lower at follow-up as compared to post-test, they were still noticeably higher than pre-test levels.

Statistical significance for changes in quality of life was tested via an analysis of covariance (ANCOVA). Attendance was not found to impact overall

Table 9.

Means and Standard Deviations:
Youth Quality of Life Instrument-Research Version

	Comparison[a]		Pre-Test[b]		Post-Test[b]		Follow-up[b]	
	Mean	Std. Error	Mean	Std. Error	Mean	Std. Error	Mean	Std. Error
Total Score	82.20	1.14	81.26	1.55	83.00	1.74	80.95	1.73
Self Domain	78.77	1.28	70.17	1.32	74.25	1.41	72.16	1.71
Relationships Doman	80.79	1.43	79.09	1.71	79.85	1.94	75.55	1.89
Environment Domain	87.56	1.14	87.24	1.74	88.05	1.87	87.52	1.87
General Quality of Life	86.85	1.58	87.45	2.25	88.76	2.84	85.95	2.69

[a] Comparison data is provided from the YQOL-R user's manual, Table 2 which provides data for a comparison group of subjects with "no condition".

[b] Corrected means and standard errors for pre-test, post-test and follow-up are from the present study and reported based on calculations using the covariate "Years at Program".

quality of life levels, nor the *Relationships, Environment,* or *General Quality of Life* domains. Statistical significance for the *Self* domain was (F(1.664, 86.516) = 4.896 p = .014). Results of all scales are provided in Table 10, with the scale demonstrating statistical significance highlighted.

Table 10.

ANCOVA Results for Quality of Life

	SS	*df*	*MS*	*F*	*Sig.*	*error*
Overall Quality of Life[a]	81.614	1.606	50.834	1.219	.294	98
Self Domain[a]	**488.097**	**1.664**	**293.368**	**4.896**	**.014**	**86.516**
Relationships Domain[a]	22.640	1.614	14.024	.259	.725	82.332
Environment Domain[a]	10.467	1.691	6.192	.134	.840	87.907
General Quality of Life[a]	214.698	1.383	155.219	1.236	.285	67.76

Note. Statistically significant results are given in bold.

[a] Data reported are reflective of the values obtained via the Greenhouse-Geisser correction when the assumption of sphericity was violated.

Table 11.

Planned Comparisons for Statistically Significant Results for Quality of Life

	SS	*df*	*MS*	*F*	*Sig.*	*error*
Self Domain						
Pre-test vs. Post-test	551.740	1	551.740	9.927	.003	52
Pre-test vs. Follow-up	875.370	1	875.370	7.617	.008	52

To learn if the statistically significant effect on the *Self* domain was found between pre- and post-testing, pre- and follow-up testing, or both, further analysis of within-subjects contrasts was conducted. Statistical significance was shown both between the pre- and post-test administration, and pre- and follow-up administration (see Table 11).

DISCUSSION

While the program has been in existence for many years, this was the first formal study of its impact. In more traditional program evaluation efforts, researchers primarily evaluate the attainment of program-specific goals and objectives (Royse, Thyer, & Padgett, 2010). The stated goal of the program studied is to provide a positive atmosphere of support, learning, and personal growth for youths with bowel and/or bladder dysfunction. As this is very broad, the specific areas of potential impact to be studied were identified by the researchers after a review of the literature to include quality of life and health-related independence. While program staff were aware of the general areas studied, they were not informed of the specific areas measured (i.e., the domains studied) nor did they have prior information about the areas of knowledge and reported skill measured by the instruments. As such, this study included areas that were not specific areas of focus during the program agenda (i.e., teaching participants how to schedule medical appointments, etc.). This was purposefully done in order to not influence the results of the study. Further, this approach was intended to provide an overall picture of the areas of strength of the program as it is, and generate areas of potential change in the future.

When reviewing the results relating to health independence, it is not surprising that a program designed to teach participants about their health condition shows significant improvement in the area of *Knowledge of Health Condition.* The program is designed to not only teach about the condition and its management, but often provides the first time that the young adult must take control over his/her care without a parent. This experience can promote a deeper understanding of that condition and build competence. Similarly, it is not surprising that significance was not found among the pre- and post-test administration, as some of the items targeted very specific activities that the participants did not have an opportunity to change during the week (i.e., "I call to schedule my own doctor and dental appointments."; "I participate in meetings about me at school."; etc.). However, there was also no significant improvement in these areas between the pre- and follow-up administration when participants would have had an opportunity to engage in these activities at a more independent level.

The low levels of independence reported could also be attributed to the age of the respondents. While the mean age of respondents was 17 years, it is possible that they have not yet started thinking about or practicing these skills. It is also possible that parents and service providers have not afforded the young adults opportunities to learn and practice skills for independence. However, as most formal transition planning begins around this age, particularly for children receiving special education services, it is important for the development of these skills to begin. Also, because independence develops over time, it is necessary to teach and support these skills as soon as possible in this population.

Overall quality of life is considered a longitudinal outcome with many contributing factors both within and outside the individual's control. While there is considerable debate as to how to specifically define and measure quality of life, there is general agreement that it is a construct designed to measure the holistic condition of one's life (Fayers & Machin, 2007). As such, it was not surprising that the gains seen immediately following the program for most areas returned to pre-test levels.

For the *Self* domain, which was the only domain found to have a significant, lasting impact, the scores increased markedly over the week of the program. The pre-program mean score was 70.17 rising to 74.25 at the measure taken immediately at the end of the program. As is often seen in many studies, the treatment effect is often lessened over time. While there was some regression from the mean score of 74.25 found immediately at the end of the program to a 72.16 mean score at the delayed post-program measure, the difference in the pre-program and delayed post-program measure remains statistically significant. This indicates that participants developed an increased sense of self and comfort with being oneself as a result of the program. Education and increased knowledge of diagnoses can empower youth with special health care needs, and in turn may improve overall mental health, including self-esteem. The changes seen in the *Self* domain may also be due to challenges offered by the program, which can provide opportunities for success in activities with peers and adults. The development of new skills can increase self-esteem and confidence, which can be transferred to life at home and in the community.

There was not a significant impact of the program on *Relationship*, *Environment*, and *General Quality of Life* domains. The program studied provides an opportunity for participants to interact with a wide range of peers from different backgrounds and who have had similar life experiences. If participants had limited relationships in their home communities, attendance at this program can help foster the establishment of new relationships among peers with shared experiences. However, as participants come from all over the nation, it may be difficult to maintain those relationships after the program to such a degree that would impact the scores on the *Relationships* domain of this instrument, particularly during the follow-up administration. Similarly, because the program takes place on a college campus in the summer, away from participants' community and school, it may be beyond the scope of the program to impact the *Environment* domain which measures day to day interactions in their home communities.

IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE

This study evaluated the impact of a one-week residential program on the health-related independence and quality of life of youth with bowel and/or bladder dysfunction. Because only those choosing to attend this particular program were studied, it would be helpful for future studies to use a comparison group not attending the program. Even though results of impact on the population from this study can be viewed with confidence because of the time-series design used (pre-, post- and follow-up), more information could be attained by using a comparison group in future research.

Because the participants are of the age when developing skills for independence is critical, it is recommended that programs consider more actively incorporating content designed to teach information and build skills in the area of medical self-management and independence Particular sessions on managing one's own health care, moving from pediatric to adult doctors, discussing insurance issues, and understanding school and work accommodations are all potential areas of need.

Having knowledge of these areas, however, may be insufficient. Participants must also be taught self-advocacy skills so that they can put their new knowledge into action. Beyond building these skills in young adults, parents must also be made aware of the need for early planning and explicit teaching in order to develop skills for independence in their children. Program staff may consider providing information to parents of participants on the areas of knowledge and skill needed by their children if they are to be successful in their transition. In addition to sharing the items listed on the instrument used in this study, program staff may want to consider the more comprehensive listing developed by California's Healthy and Ready to Work Project (Betz, 2000). This list is unique in that it describes skills that can be fostered in children from birth and its citation is provided in the reference section.

While it is difficult to impact the day to day life of participants, it is still important to think about their lives holistically and to design opportunities for participants to become empowered to impact their lives once they return home. Program staff may consider providing information to parents regarding skills to help improve the overall quality of life of their children. Informational sessions for parents could be offered in conjunction with other groups, or via webinars. Helping families extend learning beyond the program may have a more significant impact on the day to day lives of participants. By continuing to provide activities to increase self awareness, expanding activities designed to foster more self-advocacy and independence in participants, and providing information to families to assist in continuing these activities throughout the year, it is anticipated the program may impact the overall quality of life of its participants over time.

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