Published in final edited form as:

J Pediatr Health Care. 2014 ; 28(6): 478–485. doi:10.1016/j.pedhc.2014.02.008.

Development of a Positive Psychology Intervention to Improve Adherence in Adolescents with Type 1 Diabetes

Sarah S. Jaser, Ph.D.,

Associate Professor, Department of Pediatrics, Vanderbilt University, Nashville, TN

Niral Patel, MPH,

Research Analyst, Department of Pediatrics, Vanderbilt University, Nashville, TN

Rebecca Linsky, BA, and

Research Assistant, School of Nursing, Yale University, New Haven, CT

Robin Whittemore, PhD, APRN, FAAN

Associate Professor, School of Nursing, Yale University, New Haven, CT

Sarah S. Jaser: sarah.s.jaser@vanderbilt.edu; Niral Patel: niral.patel@vanderbilt.edu; Rebecca Linsky: rebecca.linsky@yale.edu; Robin Whittemore: robin.whittemore@yale.edu

Abstract

Introduction—Novel interventions are needed to improve adherence to treatment in adolescents with type 1 diabetes. In this paper, we describe the development, feasibility, and acceptability of a positive psychology intervention for this population.

Method—Adolescents and their parents (n=39) were randomly assigned to either a positive psychology intervention or an attention control group. Quantitative and qualitative data were collected on feasibility and acceptability. Descriptive and content analysis methods were used.

Results—Recruitment was successful, participation and satisfaction were high in both groups, and retention was excellent over 6 months. In the positive psychology group, adolescents and their parents noted benefits related to increased positive communication and thinking more about diabetes care. We also identified challenges to implementation.

Discussion—While more research is indicated, a positive psychology framework emphasizing positive emotions and strengths, rather than problems, may be beneficial to adolescents living with a complex chronic illness.

Keywords

Type 1 diabetes; medical treatment adherence; adolescent; intervention development

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Correspondence may be directed to Sarah Jaser at 2200 Children's Way, 11136 Doctors' Office Tower Nashville, TN 37232-9170, USA. Phone: 615-343-6775. Fax: 615-875-7633. sarah.jaser@vanderbilt.edu.

Conflict of Interest: The authors have no conflict of interest to report.

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Type 1 diabetes is a common childhood chronic illness, and incidence appears to be rising (Gale, 2002; Liese, 2006). Currently, 1 in every 400 individuals under the age of 20 is affected, with a peak age of onset in adolescence (Liese, 2006). The recommended treatment regimen for type 1 diabetes involves frequent monitoring of blood glucose levels, administering and adjusting daily insulin injections (3–4/day or pump), and monitoring and controlling carbohydrate intake and activity level (American Diabetes Association, 2014). Adherence to this regimen is linked with better glycemic control, reducing the risk for acute and long-term medical complications (Hood, Peterson, Rohan, & Drotar, 2010). However, this intensive level of responsibility is likely to increase stress (Anderson et al., 2002) and negatively impact quality of life in adolescents (DCCT Research Group, 1996). Perhaps not surprisingly, problems with adherence are common among adolescents with type 1 diabetes, with rates as high as 93% (Rapoff, 2010). Previous studies aimed at improving adherence in youth with type 1 diabetes have shown modest to moderate effects; however, many were time-intensive and expensive (Anderson, Svoren, & Laffel, 2007). Thus, there is a need for novel approaches to improve adherence among adolescents with type 1 diabetes, with the goal of achieving better glycemic control (Borus & Laffel, 2010).

Positive Affect

In recent years, there has been an emerging focus on positive affect, defined as feelings that reflect pleasurable engagement with the environment (e.g., interested, proud, or content), and favorable health outcomes (Pressman & Cohen, 2005). A review of the effects of positive affect on health suggests that it has the strongest impact in conditions in which behavioral factors play a large role, such as diabetes (Pressman & Cohen, 2005). The broaden-and-build hypothesis posits that by providing a respite from chronic stress, positive affect increases individuals' attention and motivation, thereby leading to improved coping and problem solving (see Figure 1) (Fredrickson & Branigan, 2005). This improvement in coping, in turn, is likely to have a positive impact on treatment adherence. Given that type 1 diabetes requires the adolescent and his/her family to take on the majority of treatment management, and that coping is related to self-management in this population (Jaser et al., 2012), enhancing positive affect could have a large impact on adherence to diabetes management.

The application of positive psychology principles to induce positive affect and improve adherence has been successful in adults with chronic illness; randomized controlled trials of positive affect interventions have been shown to increase adherence to medical regimens in adults with hypertension (Ogedegbe et al., 2012) and cardiovascular disease (Peterson et al., 2012), and these improvements were sustained over time (Peterson et al., 2012). In these studies, researchers asked patients to notice things that made them happy (exercise in gratitude), report on sources of pride (self-affirmations), and choose small gifts to induce positive affect (Charlson et al., 2007). To our knowledge, no studies have examined the effects of positive affect induction on adherence behaviors in pediatric populations. In this article, we describe the development, feasibility, and acceptability of the positive psychology intervention for adolescents with type 1 diabetes and their parents aimed at improving adherence to the intensive treatment regimen.

Method

Overview of Study Design

The study was a randomized pilot study with 6 month follow-up that used quantitative and qualitative methodology to evaluate the intervention. Adolescents were eligible for the study if they were between the ages of 13–17, were able to speak and read English, had no other major medical conditions, and had been diagnosed with type 1 diabetes for at least six months. Parents or guardians were eligible if they lived with the adolescent and were able to speak and read English. Adolescents were approached in an outpatient pediatric diabetes clinic. Of the 73 families approached, 9 were ineligible, 16 refused (most common reasons were time and lack of interest), 8 expressed interest in participating at a future date, and 40 were enrolled in the study. One adolescent was later determined to be ineligible due to an additional medical condition. Thus, 39 adolescents were included in the analysis. In line with University IRB requirements, the study was explained to adolescents and their parents, and consent/assent was obtained. After completing questionnaire data, adolescents were randomly assigned to either the positive affect (PA) or attention control Education (EDU) group. See Table 1 for demographic characteristics.

Development of the PA Intervention

Development of the Check It! intervention was guided by the work of Charlson and colleagues on positive affect interventions for adults aimed at improving adherence to medical regimens (Charlson et al., 2007). Our intervention for adolescents with type 1 diabetes used positive psychology exercises in gratitude, self-affirmations, and small gifts to induce positive affect. To make the adult intervention protocol more developmentally appropriate for adolescents, we also asked parents to provide tailored messages of positive affirmations to adolescents. In addition, we increased the frequency of contact by providing bi-weekly phone calls to remind adolescents to use exercises in gratitude and self-affirmations (vs. bi-monthly in the adult protocol).

Interventions

Those in the PA group met with trained research assistants to complete a short positive affect interview, in which they identified topics for gratitude (what are some things that make you happy, even for a moment?) and self-affirmation (what's something that you are proud of?). This interview included a worksheet with examples of each. Adolescents also indicated their preferences from several small gifts (e.g., water bottles, picture frames), with an average cost of \$3.00 per item. Parents of adolescents in the PA group were asked to provide weekly positive affirmations to their child verbally or by sending a short text message. Parents were given a worksheet to take home, reminding them to provide positive affirmations, and giving examples of specific praise (e.g., I'm proud of you for studying so hard for your math test). Preferred gifts were mailed every 2 weeks, for 8 weeks.

Adolescents in the EDU group were mailed diabetes educational materials every 2 weeks for 8 weeks (on the same schedule as the PA condition). The educational materials consisted of 3-page packets, with topics related to diabetes: 'Checking Your Blood Sugar,' Exercise, Sports, and Diabetes,' 'Hypoglycemia,' and 'Type 1 Diabetes.' All packets included

illustrations and simple language to provide developmentally-appropriate, educational information that was relevant to the participants—encouraging them to realize that blood glucose monitoring is an important aspect of diabetes management.

Adolescents in both groups received phone calls from a trained research assistant every 2 weeks for 8 weeks, for data collection on mood and diabetes self-management. Those in the PA group were asked to report on something that they noticed in the last week that made them happy. They were also reminded of the self-affirmation that they reported during the PA interview during phone calls. Phone calls lasted an average of 5 minutes, and the number of attempts to reach participants ranged from 1–4.

Data Collection

Data for the pilot study included psychosocial, behavioral, and clinical data to determine preliminary efficacy. All data were collected at baseline, 3 month, and 6 month follow-up visits. Adolescents and parents were compensated for completing questionnaires (\$10) at each time point. In addition, teens were asked to complete short surveys, every 2 weeks of the 8-week intervention, which included questions from the Self Care Inventory (SCI, La Greca, 2004) and Positive and Negative Affect Scale (PANAS, Clark & Watson, 1991). Parents provided demographic data at baseline on age, race/ethnicity, marital status, annual family income, child age and gender, and date of diagnosis. Feasibility data consisted of recruitment yield, participation (receipt of gifts or education packets and completion of phone calls) and retention. Acceptability data consisted of a satisfaction survey and a semi-structured interview. Frequency of blood glucose monitoring (previous 7 days) was collected via meter downloads at each time point. The satisfaction survey, completed by adolescents, was a 10-item questionnaire administered at the completion of the study. The survey questions were designed to measure participants' perceptions of how helpful, enjoyable, and interesting the intervention was, and to provide ideas for possible adaptations to improve the program. Six questions were formatted in a Likert scale ranging from 1 (not at all) to 5 (very), and four questions were open-ended. The semi-structured interviews were conducted with parents and adolescents by a trained research assistant after 6-month data collection was completed. An interview guide was developed with open-ended questions on parent/adolescent interest in the study; satisfaction, and ease of participation. Parents and adolescents of the PA group were also asked how and when they used the positive affect exercises. Lastly, we asked both groups their opinion on the use of text messages vs. phone calls for intervention delivery. Interviews were completed with 30 parents (25 mothers and 5 fathers) and 38 adolescents (85% of parents and 100% adolescents in PA group; 74% parents and 95% adolescents in EDU group). The research assistant recorded participants' responses on a form, using the exact words of parents/adolescents as questions were answered. Data from the interviews were linked with participants' demographic data, including age and gender.

Analysis

Data were entered into a Microsoft Excel 2010 spreadsheet and checked for accuracy. Quantitative analysis of the satisfaction survey and demographic data were conducted with SAS 9.3, and treatment effects were calculated using repeated-measures analysis.

Qualitative analysis was conducted using a content analysis method (Elo & Kyngas, 2008). Each question was coded individually, and each parent/adolescent statement was coded with a phrase that captured the meaning of the statement. Codes for each question were collapsed into categories with other codes of similar meanings. When appropriate, codes were counted to substantiate the number of participants that endorsed a particular code. The coding process was completed by one of the investigators (RW) and verified by another investigator (SJ).

Results

There was no significant difference between groups on the primary adherence outcome (average daily blood glucose monitoring (mean difference = -0.5 , 95% CI = -1.5 – 0.5 , $p = .324$). The means for blood glucose monitoring were as follows: for the PA group: baseline = 3.8; post-intervention = 3.5 (3 month follow-up visit) and 3.4 (6 month follow-up visit), and for the EDU group: baseline = 4.4; post-intervention = 4.4 (3 month follow-up visit) and 4.1 (6 month follow-up visit). In addition, positive affect (measured on the PANAS) increased in the PA group from baseline (mean = 35.3) to post-intervention (mean = 38.9), and decreased in the EDU group from baseline (mean = 41.2) to post-intervention (mean = 31.4), $F = 3.76$, $p = .061$. As this was a pilot study, we did not have sufficient power to detect significant results. We were interested in obtaining estimates of effect sizes and information on feasibility and acceptability to guide future intervention development.

Feasibility

As noted above, interest in the study was high (75% of eligible adolescents expressed interest in participating, and 63% enrolled. Participation in all components of the intervention was also high. With respect to the mailings, 90% of adolescents in the PA group reported receiving all 4 gifts, and 89% of adolescents in the EDU group reported receiving all 4 packets. Completion of phone calls was also very feasible. Seventy-five percent of adolescents in the PA group ($n=15$) and 90% of adolescents in the EDU group ($n=17$) completed at least 3 of 4 phone calls. Retention was also excellent; 95% of adolescents ($n=37$) completed follow-up data at 3 months, and 95% completed follow-up data at 6 months.

Acceptability

Interest in the Study—Parents and adolescents were interested in the study for different reasons. Parents thought that it would be helpful to improve diabetes outcomes ($n=5$). Several parents expressed that the timing was good as they were “struggling in this area with [adolescent].” Parents were also interested in learning more about diabetes ($n=6$) and positive affirmations ($n=9$). As one parent stated, “I was interested in learning about positive affirmations and trying to be more positive in general.” Several parents had never participated in a study like this and were curious about the outcome. Lastly, parents were interested in participating in this study for altruistic reasons, as they felt that the results could be helpful to others ($n=5$), and that they are generally interested in participating in studies ($n=5$). With respect to adolescents, the majority were interested in the study due to the incentives – the money for completing surveys ($n=8$) or the gifts they might receive

(n=7). A few adolescents were interested in learning, helping others, or changing “bad habits.” One adolescent stated, “I was curious about what group I would be assigned to and how the gifts and positive affect or education would affect me.”

Satisfaction (Survey)—Participants rated the intervention positively, with an overall satisfaction score of 11.1 out of 15.0, with 15 being most positive. As noted in Table 2, adolescents reported that they found the study to be helpful (mean = 3.5 out of 5), enjoyable (mean = 3.8 out of 5), and interesting (mean = 3.7 out of 5). There were no significant differences between groups on satisfaction scores.

Satisfaction (Interview)—Qualitative data from the follow-up interviews further support that satisfaction with the study was high in both groups. In the PA group, 90% spoke very positively about the study and the positive psychology exercises (n=18). The majority of adolescents enjoyed the gifts, reporting that they were “great,” “fun,” and a source of positive anticipation. Adolescents also reported that self-affirmations were helpful. One adolescent stated that when he was upset, he “thought about what he was proud of or what made him happy, which helped him to calm down and be happy again.” Another stated that she usually used self-affirmations “when things were getting me down or feeling stressed.”

Parents reported that delivering positive affirmations to adolescents was “special;” as one parent reported, “I liked reminders to say something nice. It was an opportunity to bring out dialogue.” One adolescent stated that the study “helped relationships within the family because everyone became more positive.” Lastly, parents and adolescents both reported that positive affect helped with diabetes self-management. As one parent stated, “reminders and gifts helped remind her about taking care of diabetes and helped make it habitual.” Any dissatisfaction with the PA intervention was primarily related to the data collected via phone calls or questionnaires completed in clinic.

In the EDU group, 72% spoke very positively about the study (n= 13), 17% were mostly positive (n=3); and 11% (n=2) expressed dissatisfaction. Overall, parents and adolescents felt that the education packets were informative. As one adolescent stated, they “helped her to learn things that she didn’t know.” The packets also helped to remind adolescents to check their blood glucose more frequently. As one reported, “it made me realize to keep checking (blood glucose) in the back of my mind.” One adolescent, however, expressed that the information in the education packets “was not new.” It is important to note that several adolescents reported that completing the questionnaires on mood and diabetes management caused them to reflect on their feelings or made them take more responsibility for diabetes (i.e., checking blood glucose), thus demonstrating a testing effect. Similar to the PA group, parents’ or adolescents’ dissatisfaction was primarily with the data collection on the phone or questionnaires in clinic.

Positive Affect used by Adolescents and Parents

Parents and adolescents of the PA group reported that they incorporated positive affect exercises into daily life. The majority of parents reported that they provided positive affirmations throughout the duration of the study (n=16/17 interviewed) which were provided verbally (n=7), both verbally and with text messages (n=7), and with text only

(n=3). One parent provided messages initially, but lapsed over time. Many parents continued to use the positive affirmation exercises upon completion of the study (n=13/17 interviewed). Over half of adolescents reported that they used positive affect exercises during the course of the study (n=11/20 interviewed), primarily when upset, stressed, sad, or when checking blood glucose. Two adolescents reported that they only used the positive affect exercises when reminded, otherwise they “forgot about it,” and two adolescents reported that they did not use the positive affect exercises. Five adolescents did not respond to this question.

Difficulty and Ease of Participation

The predominant challenge to participation reported by adolescents and parents was completing the phone calls for data collection (also used in the PA group for reminding adolescents of PA exercises). Despite setting up phone appointments, schedules could change, and they would miss phone calls. Adolescents who had after-school jobs reported difficulty in scheduling calls or “playing phone tag.” Technical problems were also reported, such as poor cell phone service at home, or having the phone turned off. Two adolescents reported that they lost their cell phones during the study, and one parent reported that she took her adolescent son’s cell phone away for discipline. Other factors that made it difficult to participate in the study were personal reasons (e.g., family health problems) and time.

Suggestions for ease of participation included modifying the data collection process (e.g., less surveys, mailing surveys vs. completing in clinic, online data collection). Over half of parents and adolescents stated that they would prefer text messaging over phone calls for intervention delivery (n=20); however, ambivalence was also expressed, as many parents/adolescents liked the phone calls or thought that it may be too difficult to respond to questions via text (n=11).

Discussion

Adolescents with type 1 diabetes are a high-risk population, and novel approaches are needed to improve their adherence to treatment management (Borus & Laffel, 2010). Adolescents often report missing blood glucose checks due to concerns about fitting in with peers and not wanting to stop enjoyable activities (e.g., sports practice) to check their blood sugar (Davidson, Penney, Muller, & Grey, 2004). Given adolescents’ concerns about the social context (Borus & Laffel, 2010), they may require greater motivation than adults to perform diabetes management tasks. Positive affect has been linked with an increased ability to see the connection between one’s efforts and positive outcomes (Isen, Daubman, & Nowicki, 1987), thereby increasing effort and motivation (Erez & Isen, 2002). By using exercises in gratitude and self-affirmation, small gifts, and parent-affirmations, we attempted to boost adolescents’ positive affect, thereby increasing their motivation for diabetes management.

The PA intervention was delivered per protocol, with parents and adolescents reporting when and how they used the positive affect strategies. Inexpensive gifts were a source of enjoyment for adolescents. The majority of parents and adolescents incorporated the positive affect strategies into daily life, with reminders. Further, the high retention rates over 6

months (95%) support that the study was highly feasible. Adolescents in the PA group were receptive to the use of self-affirmations and reported that it improved their mood and/or stress level.

One key adaptation to the positive affect protocol developed for adults was the inclusion of parents in the intervention. The literature strongly supports the need for ongoing parental involvement in diabetes management (Anderson et al., 2002), but as children enter adolescence and strive for autonomy, parents' attempts to monitor treatment may be viewed as intrusive (Weinger, O'Donnell, & Ritholz, 2001). Further, blood glucose monitoring is one of the most common sources of conflict between adolescents and parents (Schilling, Knafl, & Grey, 2006), and family communication often focuses on diabetes care. In the positive affect intervention, we attempted to take some of the focus of parent-child communication away from diabetes management by asking parents to provide positive affirmation statements to adolescents. Parents were overwhelmingly positive on the use of positive affirmations that were unrelated to diabetes self-management with their adolescent. There was also some indication that the use of positive affirmations favorably influenced the family environment.

Adolescents and parents indicated that the positive psychology intervention was very acceptable to them. In the recruitment process, many were curious as to what the intervention would entail and the effect it would have on the family. Findings from the satisfaction surveys and follow-up interviews suggest that adolescents and their parents felt that the intervention was interesting, enjoyable, and relevant to address challenges of diabetes self-management. Parents and adolescents who received educational packets were also very satisfied with the intervention, which was somewhat surprising. Providing diabetes education in a simple, albeit engaging format (visually appealing graphics and fonts) targeted for adolescents appears to be acceptable to adolescents as they transition to more autonomous diabetes self-management.

Strategies to improve future interventions

Challenges to protocol implementation were identified, and participants provided important insights to guide future intervention development. The primary challenge was the individual telephone calls, used to collect intermediate data on mood and adherence and to remind adolescents in the PA group to use positive affect exercises. These calls were difficult to schedule around adolescents' busy lives. Based on feedback from parents and adolescents, one possibility for future interventions is to evaluate alternate delivery methods, such as an automated text-messaging version of the intervention. This delivery method has been used effectively in other studies of adolescents with type 1 diabetes and may be more feasible than telephone calls in an adolescent population (Franklin, Waller, Pagliari, & Greene, 2006). However, many participants indicated that they did like the phone calls, due to the personalized attention they received from the caller. Comparison of an automated text message delivery system vs. personalized phone calls may aid in determining which delivery system is most effective and convenient for the participants.

Further, several adolescents reported that they only used the exercises when reminded, or not at all. This suggests that more frequent contact (e.g., weekly) or "booster" sessions may

improve the dose of the PA intervention. Additional training and materials may also improve adolescents' and parents' use of the PA exercises. By providing mobile-based or automated interventions, increased frequency of contact and rates of participation may occur without additional time for research staff. In addition, some adolescents in this study did not like the phone data collection process or the time spent in clinic completing questionnaires; thus, electronic data collection on tablets or laptops could be considered. Lastly, mailing the personalized small gifts was time-consuming and required additional costs for postage and mailing supplies; thus, future studies could explore the use of e-gift cards as an alternative to personalized gifts, which could be used to purchase music or games for to be played on electronic devices.

Limitations

The current study was a pilot study, which may limit the generalizability of the findings. The rate of participation and retention was quite high, however, suggesting that there may be less bias than in studies with low rates of participation. The findings are limited by the characteristics of the diabetes clinic, which serves a relatively high socioeconomic status population with little racial diversity and has a high percentage of children on insulin pumps. It will be important to see if findings differ in a larger, more diverse population. While we completed interviews on the majority of adolescents and parents, those not interviewed may have had a different experience. Further, we did not collect objective data on mood over the course of the study, or systematic data on treatment fidelity, which may impact results.

Conclusion

Behavioral and psychosocial interventions need to be developed systematically, based on a strong theoretical foundation identifying mechanisms of behavior change with feedback from the targeted user (Whittemore & Grey, 2002). Collecting quantitative and qualitative data in this study provided rich data that has the potential to strengthen the intervention acceptability and efficacy in subsequent testing. Qualitative methods are particularly useful in developing the intervention protocol, evaluating the delivery of the intervention, determining who benefits most from the intervention, and assessing which components of the intervention can be adjusted (Monaghan, Sanders, Kelly, Cogen, & Streisand, 2011). Results of this study demonstrate the feasibility and acceptability of providing a positive psychology intervention to adolescents with type 1 diabetes and parents.

This study is the first to evaluate the feasibility and acceptability of a positive psychology intervention to promote adherence in a pediatric population. Findings from this pilot study indicated that a positive psychology approach (Seligman & Csikszentmihalyi, 2000), which emphasizes positive emotions and strengths rather than problems, is appealing to adolescents and their parents. Thus, providers may want to inquire about positive aspects of adolescents' lives (e.g., "What makes you happy? What are you proud of?"), rather than focusing only on diabetes-related challenges and outcomes. In a larger study, we will be able to test the associations between positive affect with coping, family conflict, and quality of life. Further, the response to parental affirmations was largely positive, suggesting that providers should encourage parents to find ways to affirm their adolescents and praise their efforts -- not only at diabetes management -- but other accomplishments. Future research is

indicated to examine the effect of positive psychology interventions using alternative delivery modalities on psychosocial adjustment, quality of life, and adherence to diabetes self-management tasks in adolescents with type 1 diabetes.

Acknowledgments

This research was supported by grants from the National Institute of Diabetes and Digestive and Kidney Diseases [K23 NK088454] and a Yale School of Nursing Intramural Pilot/Feasibility Grant.

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Figure 1.
Proposed Mechanism of Intervention, based on the Broaden-and-Build Hypothesis (Fredrickson, 2001).

Table 1

Comparison of Demographic and Clinical Characteristics by Group

<u>Variables</u>	<u>Positive Affect (n=20)</u>	<u>Education (n=19)</u>
Gender		
Male	8 (40%)	11 (57.9%)
Female	12 (60%)	8 (42.1%)
Race/Ethnicity		
White, Non-Hispanic	13 (65%)	17 (89.5%)
Non-white	7 (35%)	2 (10.5%)
Annual Family Income (USD)		
<\$40,000	7 (36.8%)	1 (5.6%)
\$40,000–80,000	4 (21.1%)	3 (16.7%)
>\$80,000	8 (42.1%)	14 (77.7%)
Therapy Type		
Insulin Pump	13 (68.4%)	16 (84.2%)
Injections	6 (31.6%)	3 (15.8%)
Age (years)	15.3 (1.4)	15.0 (1.6)
Duration (years)	7.3 (4.3)	6.5 (3.5)
A1C at baseline (%)	8.5 (1.1)	8.2 (1.0)

Table 2

Satisfaction Survey Results

Group	n	Variable	Mean	SD
Education	19	Helpful	3.7	1.2
		Enjoyable	4.0	0.91
		Interesting	3.9	0.94
Positive Affect	20	Helpful	3.3	1.1
		Enjoyable	3.7	1.0
		Interesting	3.6	0.68