What Does It Take to Get Post-Discharge Data?

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Abstract

As the field of outdoor behavioral healthcare amplifies research efforts, reaching study participants post-discharge is essential. This paper analyzes follow-up efforts in an outcome study with 844 participants that achieved high 6-month follow-up response rates. The researcher coded each completed questionnaire to reflect the effort required to receive it. While 72% of parents responded after initial emails, 81% of adolescent and 61% of young adult responses required a moderate to high level of effort. This analysis found that an interactive process, collaboration with other treatment programs, and persistence are critical to a successful follow-up.

Keywords: outdoor behavioral healthcare, post-discharge data, methodology

Over the last decade, a wave of enthusiasm for research has hit the field of Outdoor Behavioral Healthcare (OBH). Many wilderness and residential treatment programs are implementing research and evaluation as their own independent initiative, or as a membership expectation and "best practice" in the National Association of Therapeutic Schools and Programs (NATSAP) and the Outdoor Behavioral Healthcare Research Cooperative (OBHRC). The OBHRC founded in 1999 to deliver an active, comprehensive research program for the field, can be largely credited for growing the literature base for OBH. Since its inception OBHRC has developed and evolved into the OBH Center at the University of New Hampshire. To date, researchers for OBHRC and the OBH Center have produced over 200 studies in the last 15 years. NATSAP Practice Research Network (PRN), established in 2007, was created to respond to the call for research on program effectiveness of private residential treatment centers (NATSAP, n.d.). These initiatives, as well as other independent projects, have created a research corpus that suggests that OBH is a promising treatment for adolescents (Behrens, Santa, & Gass, 2010; Gass, Gillis, Russell, 2012; Hoag, Savicki, & Burlingame, 2001; Lewis, 2007; Magle-Haberek, Tucker, & Gass, 2012; Russell, 2003, 2005).

OBH literature shows promising outcomes over the course of treatment. However, it is also riddled with problems of non-representative samples, inconsistent data collection, and a shortage of post-discharge data (Russell, 2007; Scott & Duerson, 2009; Tucker, Zelov, & Young, 2011). This paper speaks to the latter issue. While multiple studies provide strong data on positive change made over the course of treatment (Behrens et al., 2010; Magle-Haberek et al., 2012; Russell, 2003), quantitative data on clients after they leave programs is sparse (Behrens et al., 2010; Russell, 2003). As the OBH field grows and research efforts increase, it is essential to gather post-discharge data. Furthermore, in order to continue to advance OBH research there is a need to understand how to best collect post-discharge data.

Method

We invited adolescent clients and their parents to participate in an outcome study from May 2011 to July 2012 at four different wilderness therapy locations across the United States. Eighty-three percent of families entering the wilderness program voluntarily participated in the study (792 adolescents entered the program, 46 were excluded due not finishing the program, and 88 declined to participate). We invited young adult clients to participate from May 2011 to June 2012 at one wilderness therapy program in southern Utah; 77% of young adults participated (241 young adults entered the program, 27 were excluded due to not finishing the program, and 28 declined to participate). While in the wilderness therapy program, study participants completed the appropriate measures from the Outcome Questionnaire® (OQ®) Family of Instruments in addition to several measurements of life effectiveness, dysfunctional attitudes, alliance with therapist, and treatment expectancy. At six months post-discharge, participants were asked to complete their respective OQ® again. Parents of

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adolescents completed the Youth Outcome Questionnaire-2.01 (Y-OQ® -2.01); adolescents completed the Youth Outcome Questionnaire–Self Report® (Y-OQ-SR®); and young adults completed the Outcome Questionnaire–45.2 (OQ®-45.2). Response rates at intake, discharge, and post-discharge are shown in Table 1.

Participants

The mean age for adolescents was 15.8 with 32% reporting female, 17% were adopted, and 65% had parents who lived together. The mean age for young adults was 20.3, 18% reported female, 14% were adopted, and 73% had parents who lived together. The average length of stay for young adults and adolescents was 10 weeks. Seventy-eight percent of young adults and 83% of adolescents went to a residential treatment center, boarding school, or another type of aftercare (AC) program upon discharge. The most common primary diagnoses for both adolescents and young adults were Mood Disorders, followed by Substance-Related Disorders and Anxiety Disorders. For adolescents, Behavior Disorders tied with Anxiety Disorders as the third most common primary diagnosis.

Data collection

During the program, clients were given questionnaires in the field, while parents received their questionnaires through an automated email sent by Outcome Tools, an online research system (Outcome Tools, 2012). If a parent did not respond to the two automated emails at intake and discharge, the researcher sent the parent a personal email to make sure that the automated email was received.

For the 6-month follow-up, the researcher sent an email to parents with links to both the parent's and the adolescent's questionnaire. The parent was asked to forward their child's questionnaire to their child or to provide contact information so that the researcher could send it to the adolescent. If the questionnaires had not been completed after one week, the researcher sent a reminder email to the parent; if another week passed, the researcher called the parent. Parents often directed the researcher to their child's residential treatment program or AC program. In this case, the researcher contacted the program and gave up to two reminders. If there was no response from the parent, the researcher would contact an adolescent's AC program, given there was a release to do so.

Young adults' personal email addresses were collected upon discharge. At the 6-month follow-up, the researcher sent an email to the young adult. If the young adult did not have an email address or did not respond to the emails sent to their personal email address, the researcher emailed their parent(s). Parents often referred the researcher to the young adult's AC program, provided a current email address, or forwarded the message to their young adult child. If there was no response from the parent, the researcher would contact the young adult's AC program, given there was a release to do so.

Coding

The researcher utilized Excel spreadsheets to track the 6-month follow-up protocol, as well as emails with parents and clients. This tracking was used to determine the level of effort needed to obtain each response. Each completed questionnaire was given a code that reflected how many and what type of contacts were needed. The codes fell into three categories: low, moderate, and high effort. Those coded as low effort were questionnaires completed with two or less emails to the initial contact. Responses coded as moderate effort required more than two personal emails to the initial contact, or needed to be sent to a secondary contact. The secondary contact most often being an AC program. High effort codes reflected responses requiring redirection to a secondary contact, and multiple emails and a phone call to the initial and/or the secondary contact.

Results

Of the 363 adolescent questionnaires completed at the 6-month follow-up, AC programs administered 70.5% and parents administered 29.5%. Figure 1 shows the level of effort breakdown for adolescent clients. For the 452 parents who completed the YOQ-2.01, 49% completed it after the first email and another 28% after the second email. Only 23% of responding parents required multiple emails and/or

phone calls.

Of the 82 young adult clients that responded, 40% did so after just two emails to the initial, or original, contact. We obtained 61% of the young adult responses with help from secondary sources - parents and AC programs (Figure 2). Parental help included reminding young adults to complete the questionnaire and providing correct or alternative contact information. This category ranged from a moderate to a high level of effort. Since the process was to first contact the young adults and then their parents, questionnaires that were obtained through an AC program generally reflected a long line of efforts.

Discussion

This paper analyzes the effort required to obtain post-discharge responses and what strategies were most effective in following up with OBH study participants. We conducted an outcome evaluation and enrolled participants for one year, investing heavily in a 6-month post-discharge follow-up. As a result, response rates for clients and parents were high.

This analysis found that follow-up from a wilderness therapy program (post-discharge) is an interactive process requiring investigative and persistent efforts. Following up with parents of adolescent clients is simpler and more straightforward. With 72% of parents responding to the initial emails, parent participation is the "low hanging fruit" in post-discharge follow-up. Conversely 81% of adolescent responses and 61% of young adult responses required more than two emails after the initial contact. While parents were invaluable in connecting the researcher to clients, relying on parents to deliver a client's questionnaire was not sufficient as most clients were living away from the parent's home. We saw success in offering to direct our message to another party who could more easily deliver the questionnaire to the client. This analysis provides several recommendations for OBH programs specifically Wilderness and Residential programs. When conducting a 6-month post-discharge follow-up: integrating technology and personal interaction, collaborating with other treatment programs, collecting young adult email addresses, and being persistent could ensure greater response rate.

An interactive follow-up process that includes various forms of contact methods was effective in this study. Being able to redirect messages to another email address, call a parent or AC program, and respond to questions yielded high response rates. This study's follow-up did not use any automated emails; however, automated emails could have minimized administrative time and, in theory, reached those in the low effort category with less effort. For parents of adolescents, this could have been a significant portion of the respondents. Technology, and specifically automated online data collection service, such as Outcome Tools, has changed the way the field of OBH collects data and has made the process easier and more reliable. This is an enormous advantage as it decreases administrative work and makes participation easier. It does not remove all of the tedious work that comes with follow-up though. It is possible that relying entirely on technology or an automated system will not yield representative client samples.

Collecting young adults' personal email addresses and collaborating with AC programs proved to be effective strategies. Young adults proved to be the hardest group of participants to reach and had the lowest response rate, though 51% of young adults who responded were successfully reached through their personal email address. This method was not as effective for reaching adolescent participants. As most OBH clients go on to another level of treatment, collaborating and coordinating with other programs in data collection was critical, especially with adolescents. Staff at AC programs administered 71% of adolescent questionnaires and 29% of young adult questionnaires. This difference between adolescents and young adults may be due to adolescents attending AC programs for longer periods of time and having placements that are more restrictive. In addition, parents of adolescents were more likely to direct the researcher to an AC program, while parents of young adults were more likely to provide the young adult's personal contact information. These implications may be limited to a 6-month follow-up, as clients at a 12-month or longer follow-up are likely to have different circumstances. The clear message is that without engaging aftercare programs and parents of young adults, a significant proportion of participants would have been missed.

From this analysis we learned the value of developing a follow-up process that balances technology

and persistent personal interaction. While parents of adolescents responded easily to initial emails, young adult and adolescent clients did not. The majority of client questionnaires were not returned after the initial emails, and secondary contacts that helped deliver questionnaires often needed multiple reminders. Several other keys to success were utilizing young adults' personal contact information, engaging parents of young adults, and collaborating with other treatment programs.

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Table 1

Sample size and response rates at intake, discharge, and 6-months post-discharge

	Intake: n(%)	Discharge: n(%)	6-months post: n(%)
Young adults	159 (85%)	131 (70%)	82 (44%)
Adolescents	619 (94%)	534 (81%)	363 (55%)
Parents of adolescents	501 (76%)	398 (60%)	452 (69%)

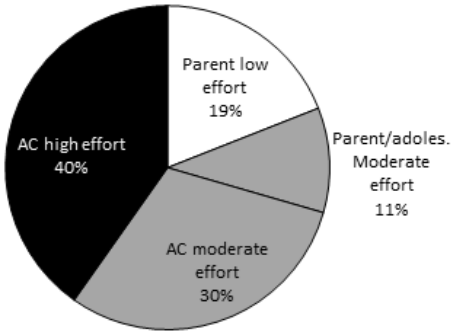

Figure 1. Pie chart reflecting adolescent responses requiring low, moderate, and high effort, and how the questionnaire was delivered at the 6-month follow-up.

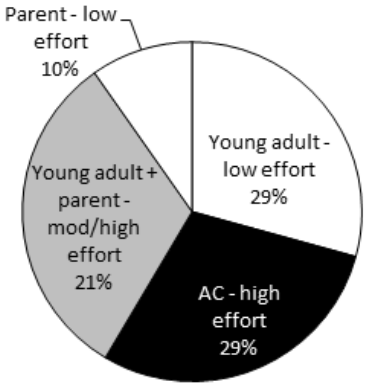

Figure 2. Pie chart reflecting young adult responses requiring low, moderate, or high effort, and how the questionnaire was delivered at the 6-month follow-up.