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Retention Strategies in Longitudinal Studies with Emerging Adults

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Abstract

Purpose/Objectives—The purpose of this report is to describe retention strategies that were useful and those that were not in a longitudinal study of emerging adults.

Background of Project—A longitudinal study examining the transition to young adulthood among emerging adults with type 1 diabetes, which had success in retention, provided the context for describing retention strategies.

Rationale—A challenge in longitudinally designed studies is retention of participants since their loss decreases power for statistical analysis. Given that emerging adulthood is a period of instability, retention is particularly challenging among this population. However, longitudinal studies are the best way to understand developmental changes, and it is also important to increase our knowledge of health outcomes during emerging adulthood.

Description—Retention strategies used in the study are described, including promoting a positive relationship with participants, maintaining contact with participants, having a study staff with good interpersonal skills, using incentives, conveying respect for participants, and employing user-friendly data collection.

Outcomes—Useful strategies to promote a positive relationship included sending cards and newsletters to participants, maintaining consistency of contact person, and expressing appreciation for participant's time and effort. Useful strategies for maintaining contact with participants included obtaining contact information at every data collection point, maintaining birthdates and chart numbers in tracking data bases, monitoring returned mail, and using Web search engines. Other useful strategies were providing incentives to participants, employing staff with good interpersonal skills, providing participants with choices when appropriate, and employing user-friendly data collection. One strategy, using contests, was not found useful.

Conclusions—Despite the challenges of conducting longitudinally designed studies with emerging adults, multiple retention strategies can be employed that are useful to retention.

Implications—It is feasible to conduct longitudinal studies with emerging adults despite the challenges.

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Keywords

Recruitment; Retention; Longitudinal Study; Emerging Adults

Retention of participants over time is a challenge in longitudinal studies,[1] and it is especially challenging in the emerging adult population. Across several longitudinal studies with emerging adults, retention rates varied from 45% to 88%,[2–6] decreased the longer the length of the study,[5] and were relatively lower during emerging adulthood than for earlier periods of adolescence.[2] Participants who are transient and difficult to locate are a challenge to retaining participants in longitudinal studies,[7] and these characteristics are relatively more common in emerging adults. These youth are in the developmental period of emerging adulthood, from 18 years of age to the mid and late twenties, a time known for many changes.[8] For example, these youth may be graduating from high school,[9] moving out of parental homes, enrolling in college,[10] and/or entering the job market, and those with a chronic health problem are transferring from pediatric to adult health care providers.[11] All these changes contribute to challenges in maintaining contact with these youth, an important aspect of retention in longitudinal studies.[7] Addressing retention of participants over time is important because low retention rates contribute to reduced sample size and power for statistical analysis,[12] and they also result in potential bias in the sample because those who drop out may be different from those who do not.[1] Because longitudinal studies are the best way to understand developmental changes,[1] professionals who conduct such studies with youth in this developmental period would benefit from a description of useful and non-useful retention strategies. Thus, this paper describes the range of retention strategies that we found useful or not in our longitudinal study of emerging adults with type 1diabetes, for which we had relatively good retention rates.

The Diabetes Study: Emerging Adults with Type 1 Diabetes

We conducted a longitudinal study to examine the transition to young adulthood among emerging adults with type 1 diabetes, specifically the first year after high school graduation. The rationales for the study were that little evidence exists to guide clinical practice for these youth;[13] this transitional developmental time is proposed to contribute to poor health outcomes;[14] and longitudinal studies are the best way to understand developmental changes.[1] For example, it is important to increase our knowledge of health outcomes such as poor glycemic control for which these youth are known[15, 16] because poor control contributes to serious short and long-term health complications.[17]

The study was conducted after IRB approval, and consent was obtained from youth 18 years of age or older; for youth under age 18, consent from parents and assent from youth were obtained. Study procedures, described elsewhere,[18] included recruitment of participants in four waves or consecutive years during their last six months of high school. Recruitment was from a regional university medical center, a private hospital, and a regional center providing outpatient diabetes care. At baseline, the sample, described elsewhere,[18] consisted of 204 participants. Guided by the transition framework for emerging adults with diabetes,[14] the study examined health, behavioral and developmental outcomes such as glycemic control, diabetes management, and autonomy in diabetes care. In addition, guided by Hanna's[14] framework, the study examined influential transitional events and individual and environmental characteristics such as living situation in relation to parents, diabetes-specific self-efficacy, and diabetes-specific support from parents, friends, and romantic partners. This study could be considered relatively high in terms of burden on participants; they were asked to self-report on multiple variables, and data collection for most variables occurred every three months from the last semester of high school through one year post-high school.

In addition, this study was challenging to study staff who tracked participant for all five years of the study so that a final report newsletter could be sent.

Despite the considerable time and effort asked of study participants in this transient age group, the study was quite successful in retaining participants. At completion of the study, we only had 3% (N = 7) who were considered definitely lost to follow-up, with 3 having requested to be withdrawn, 2 having died, and 2 who could not be contacted after the 6- or 9-month data collection points. This category of lost-to-follow-up did not include those who missed particular data collection points because after missing one point, many completed the next data collection point. Thus, we also calculated a non-completion of data collection rate. On average, 82% of participants completed follow-up collection points over the course of the study.

Retention Strategies Implemented

Several procedures were used to increase retention with this longitudinal study of emerging adults. We used various strategies to promote a positive relationship between participants and staff and to maintain contact with participants. In addition, retention strategies included having a study staff with good interpersonal skills, using incentives, conveying respect for participants, and employing user-friendly data collection. We found most of these strategies useful, although one was found not useful.

Useful Strategies for Maintaining a Positive Relationship

Strategies to promote and maintain a positive relationship between participants and the study team are important in longitudinal studies.[19] We sent holiday cards, birthday cards, and brief annual newsletters over the course of the five-year study. The ongoing newsletters provided pictures of and general information on the research team members and ways to contact them, as well as encouraging commitment to the study. The final newsletter provided a brief summary of study results. In addition, efforts were made for consistency in which study staff contacted participants. Data collectors expressed appreciation to participants for their time whenever there was personal contact.

Non-useful Strategies for Maintaining Positive Relationships

Periodic contests were held because such strategies have been found by others to increase participation.[20] In one contest, we asked participants to voluntarily provide captions to a picture depicting discussion among peers eating together. In another, we asked participants to voluntarily complete a diabetes-specific cross-word puzzle. However, this strategy was not continued because there was minimal participation in either contest despite the different formats.

Useful Strategies for Maintaining Contact

A major problem in longitudinal studies is tracking patients.[21] Given the mobility of the emerging adult age group, we specifically focused upon maintaining contact information. We gathered this information at the initial enrollment visit and updated it at each data collection point, as recommended by others.[19] Contact information included a current address, telephone numbers (home and/or cell), and e-mail address of each participant, as well as the address and telephone numbers of one or two persons (parents, relatives, friends) who would always know participants' whereabouts. The principal investigator had previously been successful with this strategy in studies with adolescents on the sensitive issue of contraceptive use.[22] Participants indicated preferred modes of contact as well as best days and times to contact them. Medical charts and the Postal Service have been suggested as sources for tracing lost participants;[23] thus, contact information also included

birthdates and chart numbers as well as monitoring returned mail from the newsletters, birthday cards, and December holiday cards sent. If participants could not be contacted via the contact list, Forwarding Address Requests through the Postal Service and Web search engines were used to obtain current addresses. Mailed incentive checks also provided motivation for keeping contact information up to date. The information in the tracking data bases was kept in locked and password-protected files.

Useful Strategies: Staff with Good Interpersonal Skills

Interpersonal skills of study personnel are also vital to successful retention in longitudinal studies.[21] The study staff was in fairly frequent contact with participants, reminding them of the availability of the next questionnaire and making follow-up telephone calls encouraging completion of surveys. As has been suggested by others,[24] especially in relation to participants who miss a follow-up data collection, it is important for study staff to emphasize the need for complete information in the study. Although some studies specify a certain number (up to nine have been reported) of attempts that must be made to contact participants who miss data collection,[25] our staff, in an attempt to be respectful, adjusted the number of calls based upon the tenor of the response of the participants. A detailed log was kept of all contacts and responses. In addition, study staff members were flexible in their work hours, often calling participants during evening hours.

Useful Strategies: Respect for Participants

We implemented several strategies that conveyed respect for participants, a key for retention in longitudinal studies.[21] The strategies included: 1) providing participants a choice about where they wished to complete the questionnaires; 2) providing a choice of completing questionnaires via a WEB-based program or by paper and pencil; 3) contacting participants via their preferred mode of contact; 4) and sending mailed questionnaires with return envelopes to those who chose the paper-and-pencil option. Respect for participants' commitment to the study was conveyed, as mentioned, with expressions of appreciation to them for their time whenever there was personal contact with study staff. In addition, as noted above, study staff conveyed respect by limiting the number of reminder calls made to participants based upon their responses.

Useful Strategies: Incentives

A major strategy was the provision of incentives in recognition of the considerable time and effort needed for completion of instruments every three months in this study. The participants received a $50 gift certificate or a mailed check as compensation for completing the baseline survey. After they completed each of the questionnaires, they were mailed $25 checks for the 3 to 15-month questionnaires and $25 for the 18-month questionnaire. However, if the baseline-through-18-month questionnaires had all been completed they were mailed $100 for the 18-month questionnaire as a special incentive. This incentive system was explained to participants ahead of time. This is common practice in research with adolescent samples; payment is provided in more than half of such studies,[26] and these incentives are known to increase participation.[27, 28]

Useful Strategies: User Friendly Data Collection

Finally, we had strategies around data collection that were aimed at this particular age group. Questionnaires were self-completed predominately by Web-based entry by these emerging adults, who were well acquainted with computers. Web-based data entry has advantages similar to Computer Assisted Self-Interviewing (CASI), documented to be easy to use,[29] to be equivalent to data collected via written questionnaires[30] or telephone interviews,[31] to provide privacy,[32] and to increase reliability of self-report of sensitive

information relative to written questionnaires and face-to-face-interviews.[33–35] The Web program also decreased participant burden by providing standard directions and by allowing one to move to the next relevant item and skip non-relevant items. In addition, the Web program allowed participants to take breaks in the data collection session and to access their questionnaire more than once within a one-week period of time.

Several other procedures were used to increase usability of the Web-based data collection program. The study was given a "catchy" title, the Young Adult Diabetes Assessment (YADA), for consistent recognition on the WEB page. For accessing the Web-based program, we purchased a study domain name with YADA as part of it. In addition, participants were able to choose their own username and password. Finally, ways were provided for participants to contact study staff if help was needed for usernames or passwords that had been forgotten.

Discussion

We found that, with the implementation of a range of retention strategies, it was feasible to conduct a longitudinal study with youth in the challenging time of emerging adulthood. Only 3% of the participants were lost to follow-up in this longitudinal study of emerging adults with type 1 diabetes. Despite the mobility of this age group, contact strategies were successful, with only two participants in the follow-up period lost because they could not be contacted. This is a very low lost to follow-up rate given that contact was maintained over 5 years of the study. It needs to be kept in mind that not all participants completed all 3-month data collections. However, the 82% average completion rate over all the data points was relatively high in comparison to the 45% to 88% range noted in other studies with emerging adults[2–6] and was particularly good considering the participant burden of every 3-month collection of multiple variables over the course of 18 months.

Most strategies that we used for addressing retention were found useful in this study. Consistent with promoting positive relationships with participants,[19] we employed a number of useful strategies such as sending holiday and birthday cards as well as newsletters. In addition, we used strategies that conveyed respect for participants, found by others to be important for retention[21] such as providing participants a choice in the format of the questionnaires and mode of contact. Conveying respect may be especially useful for emerging adults, who are developmentally working toward autonomy and self-identity.[8] Finally, promotion of positive relationships with participants was also likely enhanced by study staff with interpersonal skills, proposed to increase retention in longitudinal studies.[21] Study staff also limited the number of reminder calls made to participants based upon the tone of their previous responses.

Several useful strategies are particularly salient for this age group. Because a major challenge to retention is maintaining contact with participants,[21] especially for those who are transient,[7] multiple strategies were used with this sample of emerging adults who were in a period known for many changes.[8] These strategies included updating contact information at every data collection point; tracking birthdates and chart numbers; monitoring returned mail from the newsletters, cards, and incentive checks; and, when needed, using Postal Service and Web search engines. Consistent with other studies,[27, 28] incentives were a useful retention strategy. The limited finances for which emerging adults are known[36] likely contributed to the usefulness of incentives as a retention strategy.

Employing user-friendly data collection such as a Web-based data collection program was also found useful for this age group, which is very familiar with computers. The Web program decreased participant burden by the ease of navigating through the questions,

ability to take breaks in the data collection sessions, and allowing access to the questionnaire more than once within a specified period of time. In addition, ease of use was enhanced by giving the study a catchy and easy-to-remember title, having the study name as part of the domain name to access the data collection system, allowing participants to choose their own username and password, and providing participants with access to study staff if usernames or passwords had been forgotten.

A retention strategy not found useful was the use of contests. This strategy was implemented as a way to promote a positive connection with the study. However, there was minimal participation in the two contests tried even though they had different formats. This is not consistent with some[20] who found that contests did increase retention. Our participants often conveyed to study staff that they were very busy, and the voluntary contests may have been seen by them as just one more thing to do for which they did not have time.

In conclusion, we found that conducting a longitudinal study of emerging adults with type 1 diabetes was feasible in relation to maintaining retention of the participants. In any context, similar retention strategies may prove useful to address the challenges of a longitudinal design as well as the particular characteristics of this age group. Although the strategies discussed did require considerable staff time and effort, in terms of the outcomes of our study, they were very worthwhile.

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