

Using Virtual Social Networks for Case Finding in Clinical Studies: An Experiment from Adolescence, Brain, Cognition, and Diabetes Study

Abstract

Background: One of the main usages of social networks in clinical studies is facilitating the process of sampling and case finding for scientists. The main focus of this study is on comparing two different methods of sampling through phone calls and using social network, for study purposes. **Methods:** One of the researchers started calling 214 families of children with diabetes during 90 days. After this period, phone calls stopped, and the team started communicating with families through telegram, a virtual social network for 30 days. The number of children who participated in the study was evaluated. **Results:** Although the telegram method was 60 days shorter than the phone call method, researchers found that the number of participants from telegram (17.6%) did not have any significant differences compared with the ones being phone called (12.9%). **Conclusions:** Using social networks can be suggested as a beneficial method for local researchers who look for easier sampling methods, winning their samples' trust, following up with the procedure, and an easy-access database.

Keywords: Case finding, clinical studies, diabetes, sampling, social network

Introduction

Following the expansion of internet usage in societies, countless efforts have been made to use this opportunity, expanding human communications as well. For example, using cyberspace to create social networks to establish an easier connection.^[1] In recent years, a number of various social networks are created online, which a significant number of people are registered in now. Participation in these networks has been highly demanding, that in 2018, the number of users is predicted to reach more than 2.5 billion all around the world.^[2]

However, social networks have been problematic too; internet addiction and social networks is considered to be one.^[3] For example, in Hong Kong, internet addiction among high school students has been on rise, involving for about 17%–26.8% of the students. Despite the problems, cyberspace has not been always bad. In some fields, though, it has been sufficiently helpful.

Using online techniques by therapists, to offer psychological therapy on Facebook (as one of the biggest social networks) has

been under research for a while. Moreover, it had results.^[4] Making phone applications to control and stabilize chronic diseases such as diabetes has been very effective too.^[5]

One of the main usages of social networks in clinical studies is facilitating the process of sampling and case finding for scientists. Social networks with endless features offer a stable and mutual connection through vocal, visual, and textual means. They ease finding new samples that are eligible for clinical studies and play a crucial role in connecting researchers and patients before and after the research.

Adolescence, Brain, Cognition, and Diabetes study, which is dedicated to investigating cognitive changes and its consistency with brain structures in children and adolescents, is one of the clinical studies that is approved by Endocrinology and Metabolism Research Institute - Tehran University of Medical Sciences.^[6] However, it requires a vast connection with children and youths who are the samples of this study. In this study, 300 children with diabetes are under cognitive evaluation. At first, researchers made phone calls to collect samples and invite their

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families to the project. Later, they started using telegram application as a communication tool. Telegram is a social network developed in 2013. Moreover, it had more than 60 million users as far as September 2015. There are about 12 billion messages sent daily through telegram.^[7] Based on local data, there is about a population of 20 million Iranian users on telegram, and so it is among the most popular social networks in Iran.^[8] In this article, the focus is on comparing two different methods of sampling the children and adolescents with diabetes for study purposes.

Methods

From October to the end of September 2015 (about 90 days), one of the researchers started calling 214 families of children with diabetes ages 6–12. After a brief introduction of himself and the project, he invited the parents and the child for cognitive evaluation and brain mapping (if needed) to the institute’s clinic.

However, January 2016 beginning, the phone calls stopped, and the team started communicating with families through Telegram (version 0.9.18). To begin with, the families were all invited to a telegram group dedicated to this purpose, and then they were all provided with thorough information about the project, and a brochure for further reading.

Next, an expert in the field went online and answered the families’ questions about diabetes. In total, they were two experts answering the questions. During this period, there were four questions brought up by the researchers, in the form of a periodic competition. The families participated by answering to these questions. Later on, the right answer was given by the researcher. Beside Q and A, the group would get a break every week, in which the members would share jokes and unrelated material to what the group was created for. Even once, on a virtual festival called “sweet children” in the group, each group member shared a photo of its child with diabetes.

Every 3–4 days, information related to the research, introduction brochure, and invitation to the research would be shared again on telegram.

Results

In the project’s first 90 days, the researchers called 80 families, which 62 of them (77.5%) answered. Moreover, among these 62 families, 11 were convinced to visit the clinic for a cognitive evaluation (17.7%). Three patients missed, but eight visited the clinic (12.9% of invitees) and were evaluated within 90 days [Table 1].

In the second phase, part one (after creating the telegram group), 96 of 214 families were added to the group (44.8%). After a month (telegram phase), the group had reached a number of 102 members, 480 pictures, 60 videos, 34 audios, 32 texts, and 50 links. The maximum number of online member was 14.

This group was active for only 30 days, and 14 families decided to participate in the research (13.7% of group members). From 14 that were supposed to visit, 5 patients missed the visit and 9 were evaluated. From these 9 cases, 6 patients were among the 34 patients that the researchers had their numbers but had never called them, and 3 patients were families who were invited by other members to the telegram group.

Finally, 8 patients (with a mean age of 9.2 years) out of 64 successful calls, visited the clinic during 90 days. While after using telegram within only 30 days, 6 patients (with a mean age of 9.8 years) out of 34 remaining contacts (ones which the researchers hadn’t called) visited the clinic. Using Chi-squared test, researchers showed no statistical significance, while there were more participants from telegram (17.6%) than the ones being phone called (12.9%) though the telegram method was 60 days shorter than the other method ($P < 0.05$) [Figure 1].

Discussion

In this experiment, the researchers tried to compare two different methods of case finding in clinical studies. Considering that there was no statistical significance in the ratio of participants to invitees, it seems that social networking by consuming less time (of the researcher) and responding in a shorter period of time (by the patients) can be used as a common tool for sampling.

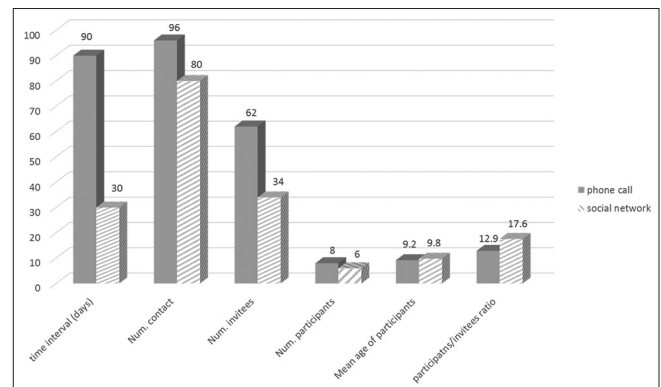


Figure 1: Comparison between two study groups in invitation time interval, numbers, and ratios of invitees and participants

Table 1: Statistical data from participants in two methods

	Number of invitees (people)	Time interval (days)	Participants (people)	Participants’ mean age (years)	Ratio of participants to invitees (%)
Phone call	62	90	8	9.2 (5-12)	12.9
Social network (Telegram)	34	30	6	9.8 (5-13)	17.6

Researchers also believe that social networks such as telegram have the potential to help with case finding and establishing a mutual connection with patients. This method, if used instead of older methods (like retro clinical databases and phone calling), could speed up the process of sampling, and while establishing a mutual connection by the researchers would win the patient's trust easily. As well, would make a network for further information exchange between researchers and their patients.

Using cyberspace in different stages of a clinical study has been very common since it was born at the first place; as well as preventing and diagnosing different types of diseases. Wiecha *et al.* in a research about asthmatic children used a network-based method. Moreover, in their research, they considered the method to increase the patient's knowledge about asthma and fidelity to medication.^[9] Thrul *et al.* too had a similar experiment, in which used Facebook for youth's smoking awareness.^[10] Using cyberspace and mobile applications proved useful once again, when Sze *et al.* decided to do a research on youth's weight based on a family spectrum and found those applications to be helpful.^[11] Spasic *et al.*, who used web-based applications to improve self-management in patients with knee problems, were happy with the results as well.^[12] Some more examples include Muller who investigated the effects of web-based programs on children physical activities.^[13] Chieug whom used WhatsApp for smoking relapse prevention in a group of patients and reduced probabilities to a significant level.^[14] Yet, despite all the researches dedicated to investigate the effects of cyberspace on medical interventions, there is not much done to facilitate the job for the researchers sampling and case finding. Maybe this recent study is to take an initial step forward. Sampling, case finding, and preserving the samples are the most complicated parts of the research, so using this method opens up a possibility of decreasing the hardships dramatically. Our researchers hope to use social networks to preserve connections with samples for future studies.

Conclusions

It seems that using social networks considering each country's cultural capacity, could a sufficient method for local researchers; who look for easier sampling methods, winning their samples' trust, following up with the procedure, and an easy-access database. However, along with these benefits, authors should consider some issues such as selection bias when using this method of sampling and case finding. Authors will examine the long-term results of this method related to sampling in later studies.

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Conflicts of interest

There are no conflicts of interest.

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