

The use of social networks in scientific research with questionnaires

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Received: January 29, 2018

Accepted: June 06, 2018



Aim: The aim of this study was to determine the response rate of the SF-36 quality of life questionnaire sent and received by mail and over a social network to caregivers of individuals with epidermolysis bullosa (EB) in Brazil. **Methods:** All volunteers were first-degree relatives of patients with EB that directly spent time helping them with their basic activities of daily living. A maximum of two caregivers per patient could answer the questionnaire. Volunteers were divided into two groups: for group 1, questionnaires were sent to 53 members of a support association for the disease by mail, and for group 2, 798 members of the Facebook™ page of friends and relatives of patients with EB were invited to participate using an access link to Google Drive™ to gain access to the questionnaire. The data from both groups were analyzed 150 days after the start the study. Descriptive analysis was performed by EpiInfo8 and the return of questionnaires was evaluated according to age, sex, and time of return using the Chi-squared and Fisher's exact test. **Results:** After 150 days, 30 questionnaires were returned, 17 (56.7%) of which from group 1 and 13 (43.3%) from group 2. Approximately 12 questionnaires were returned by mail and 11 over the social network. **Conclusions:** The data collection of the SF-36 quality of life questionnaire from caregivers of individuals with EB over a social network seems to be efficient mainly when it is necessary to collect results within a short timeframe, highlighting the importance of social networks as a means for conducting this type of research. However, in our study, the most efficient method was distributing the questionnaires by mail.

Keywords: Epidermolysis bullosa. Electronic mail. Quality of life. Social support. Surveys and questionnaires.

Introduction

Questionnaires are an important tool in clinical research for outlining a situation or the way of life of a population¹⁻⁶. Usually, the forms are distributed to the public through the mail or via censuses^{3,5}. However, with the rise of the internet and the advent of electronic social networks, such as Facebook™ in 2004, distances to the target population were shortened, especially in Brazil^{1,5,7-8}. Studies have assessed the acceptability and representability of social networks in information science in Brazil¹, which led researchers to apply electronic surveys more often^{3,5,8}. In addition, the SciELO organization (online library) held a seminar in 2012 on the use of social networks in scientific communication, emphasizing the importance of this communication vehicle^{1,2,7-8}.

The distribution of questionnaires through social networks might be an effective approach to study epidermolysis bullosa (EB), which is a serious and rare dermatological genetic disorder with a prevalence of 5:100,000 live births and no racial or gender difference⁹. EB is a group of inherited connective tissue disorders characterized by the absence of a cohesion protein that results in the defective connection between epidermis and dermis, making the skin fragile¹⁰⁻¹¹. Based on the skin layer that is affected, EB can be classified into four main types: EB simplex, junctional EB, dystrophic EB, and the recently established Kindler syndrome^{9,12}. Depending on the severity of the disease, which can vary from benign to life threatening, symptoms can include skin fragility, blistering of the skin following mild friction or trauma, and blistering of mucous membranes or internal organs¹¹⁻¹³. Currently, the disease has no cure and clinical management is focused on relieving symptoms^{11,13}. Topical agents and dressings are typically used for the treatment of skin lesions, and appropriate follow-up is essential to monitor the patient and his caregivers for psychosocial problems and psychiatric symptoms¹¹⁻¹⁴.

In addition, the occurrence of problems related to mobility, self-care, and usual activities, pain, discomfort, anxiety, and depression also impact the quality of life of patients and caregivers^{12,13}. Non-professional caregivers, who are often relatives, provide informal care spending time helping the individuals with EB with their basic activities of daily living¹⁵.

Patients with EB have direct medical costs with hospital admissions, emergency visits, and outpatient care (rehabilitation, medical tests and examinations, visits to health professionals and home medical care) and non-medical costs with transportation, social care services (formal care), and caregiver's time. The time dedicated to the patient and the high informal care costs account for more than half of EB's socio-economic burden. The hidden social costs of EB are relevant and have consistent impact on the quality of life of patients and their caregivers, especially when considering the impact on family income levels¹⁵.

Thus, the aim of this study was to determine the response rate of the SF-36 quality of life questionnaire delivered by mail and through a social network to first-degree relatives of individuals with EB in Brazil. We discuss the use of surveys and questionnaires in EB caregivers, emphasizing the acceptability of social networks as an important tool for scientific research.

Materials and Methods

Sample characteristics

This study was approved by the Human Research Ethics Committee from the Federal University of Minas Gerais (protocol number ETIC 285 204). Each participant was informed about the research, and answered questions on their relationship with the individual with EB. All agreed by signing the informed consent that was sent with the SF-36 questionnaire.

The inclusion criteria for the participants were first-degree relatives that spent time directly helping patients with their basic activities of daily living. The maximum of two caregivers could answer the questionnaire and they were divided into two groups. Group 1 was selected from 83 files from the Minas Gerais Association of Relatives, Friends and Patients with Epidermolysis Bullosa (AMPAPEB), and the questionnaire was sent to 53 members by mail. Group 2 was selected from the Facebook™ page of the association, and the questionnaire was administered over this social network to 798 members, including parents, health professionals, family members, and friends of EB patients.

Study design

As recommended for cross-sectional studies²⁻¹⁶, the addresses of participants from group 1 were confirmed by telephone and 53 updated records were obtained. An envelope was sent to everyone containing the following items: 1) a letter explaining the research, 2) two informed consent forms, 3) two SF-36 quality of life questionnaires, and 4) a prepaid and labelled envelope to increase the likelihood of the questionnaire being returned.

After being accepted as a friend in the association's Facebook™ page, the researcher invited all first-degree relatives from group 2 members to participate in the study, to a maximum of two caregivers per individual with EB. The informed consent form and the questionnaire were sent through Google Drive™ software, which were filled out by an access link. Previously, a pilot study with a virtual questionnaire was performed among people not involved in this research. The pilot test was done with 5 persons (10% of the expected total sample) and included a professor and students of Dentistry.

Data collection

SF-36 quality of life questionnaire data was stored in a database. The feedback for both groups was expected to be received no more than 150 days from the start date of the study. After 30 days, the same material (letter, 2 consent forms, and 2 questionnaires) was resent to non-responders in the same way as the first delivery: by mail for group 1 and through Facebook™ and Google Drive for group 2. Additionally, the researchers had access to the date and time of the response through the Google Drive™ software in group 2.

Statistical analysis

Descriptive statistical analysis was performed with EPI INFO 8™ (Center for Disease Control and Prevention-CDC, USA). The return of questionnaires was evaluated for

groups 1 and 2 according to age, sex, and time of return. Data were analyzed using the Chi-squared and Fisher's exact test. The level of significance of the analyses was set at 5%³.

RESULTS

After 30 days, five envelopes with seven questionnaires were returned from group 1 and eight were filled out by group 2. After 150 days, 10 more questionnaires were returned by mail, and five filled out over the social network.

Thus, after 150 days from the study start date, 30 questionnaires were returned, 17 (60.0%) from group 1 (from 53 members, 32.1% return rate) and 12 (40.0%) from group 2 (from 798 members, 1.50% return rate). During the first 30 days, group 2 had a rapid return, although it did not persist until the end of the evaluation (Figure 1).

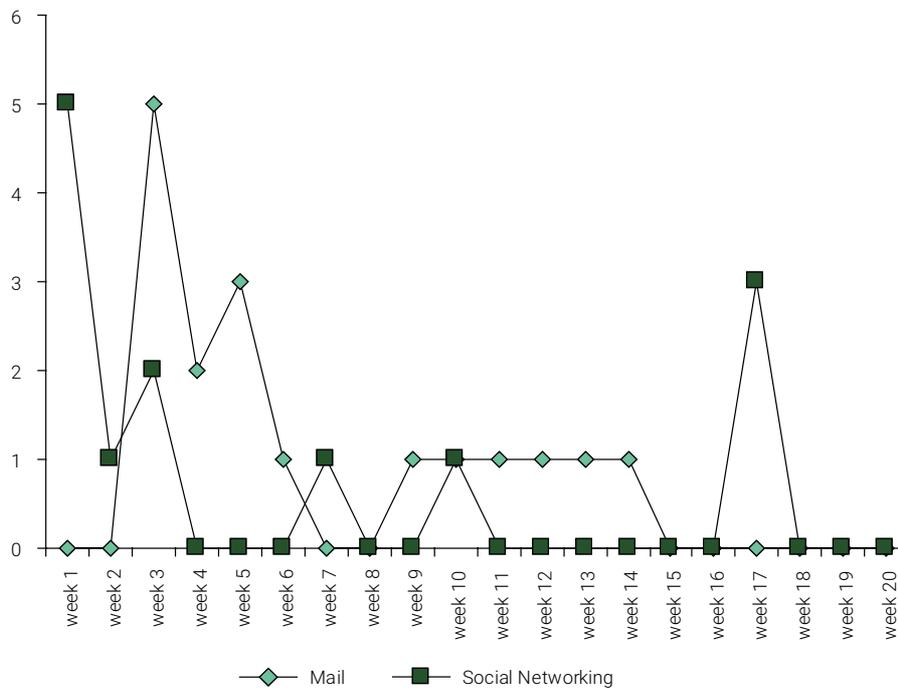


Figure 1. Return rate of questionnaires during the initial 30 days (A) and after 150 days of the start of the research (B).

Females were the majority among volunteers (23/76.7%), returning 13 (56.5%) questionnaires by mail and 10 (43.5%) through the social network. For males, questionnaire returns were more common by mail (5 questionnaires, 71.4%) than through the social network (2 questionnaires, 28.6%). No association was observed between gender and type of return ($p=0.40$) (Figure 2).

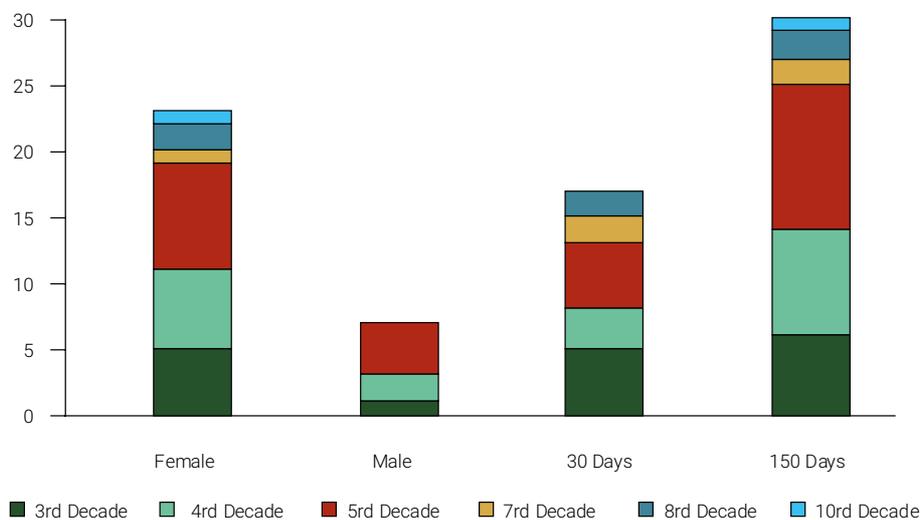


Figure 2. Relative distribution of questionnaires according to sex and age during the initial 30 days and after 150 days from the start date of the research.

Participant age ranged from 22 to 92 years (mean 39.2 years). Persons of 40 years of age or older (19–63.3%) asked questions about the questionnaire more frequently by mail (13–43.3%), and persons of 39 years of age or younger asked with almost the same frequency in both methods (5 persons by mail and 6 over the social network). No association was observed between age and type of return ($p=0.19$) (Figure 2).

The General Health score of the questionnaire for the total sample was 60.23. Among the seven domains of quality of life evaluated, the average scores obtained (ranging from 0 to 100) were: 63.66 for Social functioning, 62.83 for Physical functioning, 59.23 for Pain, 53.33 Physical role functioning, 53.33 for Emotional role functioning, 52.0 for Vitality, and 51.86 for Mental health.

Discussion

The Internet presents an opportunity for innovative recruitment modalities^{1-2,7-8,17}. Social networks were developed to bring people together and increase the sharing of information. Today, Facebook™ is one of the most used social networks and has been considered a viable recruitment option for health behavior assessment in young adults¹⁸. The use of a social network in human research has been reported; however, dental research has not yet been conducted using this recruitment method^{1,3,5}.

A systematic review found that using mailed questionnaires for health research can improve the quality of the data¹⁹. According to Leece et al.²⁰ and Kongsved et al.²¹, the prevalence of returned questionnaires via internet is significantly lower than via mail. However, the study of Frandsen et al.²² and Skonnord et al.⁸ demonstrated the opposite. The study conducted by Mazzon et al.¹⁶ showed a return of 15.1% of questionnaires by mail, while our study only observed a return of 32.1%, a high rate compared to the return by social network of only 1.50%. It is important to emphasize, however, that

many persons in the social network were friends, aunts, uncles or health professionals that did not meet the inclusion criteria. Thus, we considered that the evaluation of the method using return rate of data collected through a social network is questionable.

The social network as a means of data collection allows easy access to the caregivers of EB individuals because most Brazilians have internet access. However, the researcher needs to constantly monitor data collection since many people might not be familiar with this type of approach. Thus, new strategies should be employed in future studies to increase response rates and quality of research such as reminder system by telephone and softwares^{2,8}.

The literature demonstrates that most of the questionnaires sent by mail are returned within the first two weeks of research^{2,3,19-25}, which is corroborated by the current study. Moreover, a higher prevalence of return was observed through the social network in the first 30 days; after 150 days, however, the mailed questionnaires had a higher return rate, resulting in an overall higher rate (18 – 60.0%). This finding suggests that social networks are important tools for questionnaire-based research when data can be collected within a short timeframe²³⁻²⁵; for research in general, the most efficient way to send questionnaire and receive responses is by mail.

Women were more prevalent (76.7%) in both groups, and more men in the mail group returned the questionnaire (71.4%). These findings may be because women use social networks more frequently.

The average age of participants who returned the questionnaire was 39.2 years; those who responded over the social network were younger (43.75 years) than those who responded by mail (52.85 years). These findings show that older people tend to be more interested in participating in independent research through forms sent by mail.

Research using questionnaires is necessary and practiced widely^{2-8,23-25}. It is worth emphasizing that the internet, in addition to its technological benefits, has been asserted as a powerful research mechanism^{2,22}. Therefore, it is worthwhile to consider the expansion of social networks and their rapidly increasing number of users as a research method through sending and receiving questionnaires via the internet. These approaches may also be understood as important tools for conducting questionnaire-based-research, especially when a quick data collection is needed, to assess large samples, investigate rare cases, or decrease problems related to long distances from research centers and target population²²⁻²⁵. According to Fenner et al.¹⁷, the success of this method has worldwide implications for future research. It is worth emphasizing that our goal was to discuss the use of a social network to determine the response rate of a quality of life questionnaire sent to caregivers of individuals with EB; in this respect, social networks have become an important means of gaining access to these individuals.

The recruitment of young people for health research by traditional methods has become more expensive and challenging over recent decades¹⁷ and social networks have the potential to overcome this disadvantage, especially in terms of having a fast turnover, lower operating costs, and broad coverage. However, over a long term, mailed material still shows greater effectiveness of return.

Although we found that data collection by mail was more effective, we believe that social networks can help researchers to recruit more people and become an important tool for conducting research using questionnaires, mainly when data need to be collected within a short timeframe, people living far from the research need to be reached, and especially for investigations involving rare diseases.

References

1. Bufrem LS, Gabriel Junior RF, Sorribas TV. [Social networks in scientific research in the field of information science]. *DataGramaZero*. 2011 Aug;12(3):1-13. Portuguese.
2. Fontes KB, Benguella EA, Alarcao ACJ, Oliveira APR, Peloso SM, Carvalho MDB. [Data collection via web: supporting tool in sensitive issues approach]. *J Health Inform*. 2016 Dec;8(Compl):184-9. Portuguese.
3. Portugal FB, Campo MR, Correia CR, Goncalves DA, Ballester D, Tofoli LF, et al. Social support network, mental health and quality of life: a cross-sectional study in primary care. *Cad Saude Publica*. 2016 Dec 22;32(12):e00165115. doi: 10.1590/0102-311X00165115.
4. Reis CT, Laguardia J, Vasconcelos AGG, Martins M. Reliability and validity of the brazilian version of the hospital survey on patient safety culture (HSOPSC): a pilot study. *Cad Saude Publica*. 2016 Dec 1;32(11):e00115614. doi: 10.1590/0102-311X00115614.
5. Rivera FJU, Artmann E. Innovation and communicative action: health management networks and technologies. *Cad Saude Publica*. 2016 Nov 3;32Suppl 2(Suppl 2):e00177014. doi: 10.1590/0102-311X00177014.
6. Zhu YX, Li T, Fan SR, Liu XP, Liang YH, Liu P. Health-related quality of life as measured with the short-form 36 (SF-36) questionnaire in patients with recurrent vulvovaginal candidiasis. *Health Qual Life Outcomes*. 2016 Apr 29;14:65. doi: 10.1186/s12955-016-0470-2.
7. Hey AP, Caveiao C, Montezeli JH, Visentin A, Takano TM, Buratti FMS. [Media used by patients: information about cancer after diagnosis and during treatment]. *J Res Fundam Care Online*. 2016 Jul/Sep;8(3):4697-703. doi: 10.9789/2175-5361.2016.v8i3.4697-4703. Portuguese.
8. Skonnord T, Steen F, Skjeie H, Fetveit A, Brekke M, Klovning A. Survey email scheduling and monitoring in eRCTs (SESAME): a digital tool to improve data collection in randomized controlled clinical trials. *J Med Internet Res*. 2016 Nov 22;18(11):e311.
9. Fine JD. Epidemiology of inherited epidermolysis bullosa based on incidence and prevalence estimates from the National Epidermolysis Bullosa Registry. *JAMA Dermatol*. 2016 Nov 1;152(11):1231-1238. doi: 10.1001/jamadermatol.2016.2473.
10. Fine JD, Eady RAJ, Bauer EA, Bauer JW, Bruckner-Tuderman L, Heagerty A, et al. The classification of inherited epidermolysis bullosa (EB): report of the third international consensus meeting on diagnosis and classification of EB. *J Am Acad Dermatol*. 2008 Jun;58(6):931-50. doi: 10.1016/j.jaad.2008.02.004.
11. Williams EF, Gannon K, Soon K. The experiences of young people with epidermolysis bullosa simplex: a qualitative study. *J Health Psychol*. 2011 Jul;16(5):701-10. doi: 10.1177/1359105310387954.
12. Margari F, Lecce PA, Santamato W, Ventura P, Sportelli N, Annicchiarico G, et al. Psychiatric symptoms and quality of life in patients affected by epidermolysis bullosa. *J Clin Psychol Med Settings*. 2010 Dec;17(4):333-9. doi: 10.1007/s10880-010-9205-4.
13. Frew JW, Martin LK, Nijsten T, Murrell DF. Quality of life evaluation in epidermolysis bullosa (EB) through the development of the QOLEB questionnaire: an EB-specific quality of life instrument. *Br J Dermatol*. 2009 Dec;161(6):1323-30. doi: 10.1111/j.1365-2133.2009.09347.x.

14. Adni T, Martin K, Mudge E. The psychosocial impact of chronic wounds on patients with severe epidermolysis bullosa. *J Wound Care*. 2012 Nov;21(11):528, 530-6, 538.
15. Angelis A, Kanavos P, Lopez-Bastida J, Linertova R, Oliva-Moreno J, Serrano-Aguilar P, et al. Social/economic costs and health-related quality of life in patients with epidermolysis bullosa in Europe. *Eur J Health Econ*. 2016 Apr;17 Suppl 1:31-42. doi: 10.1007/s10198-016-0783-4.
16. Mazzon JA, Guagliardi JA, Fonseca JS. [The method of data collection by mail: an exploratory study]. In: Mazzon JA, Guagliardi JA, Fonseca JS. [Marketing: applications of quantitative methods]. São Paulo: Atlas; 1983. Portuguese.
17. Fenner Y, Garland SM, Moore EE, Jayasinghe Y, Fletcher A, Tabrizi SN, et al. Web-based recruiting for health research using a social networking site: an exploratory study. *J Med Internet Res*. 2012 Feb 1;14(1):e20. doi: 10.2196/jmir.1978.
18. Ramo DE, Prochaska JJ. Broad reach and targeted recruitment using facebook for an online survey of young adult substance use. *J Med Internet Res*. 2012 Feb 23;14(1):e28. doi: 10.2196/jmir.1878.
19. Edward P, Robert I, Clarke M, DiGuseppi C, Pratap S, Wentz R, et al. Increasing response rates to postal questionnaires: systematic review. *BMJ*. 2002 May 18;324(7347):1183.
20. Sprague S, Swiontkowski MF, Schemitsch EH, Tornetta P, et al. Internet versus mailed questionnaires: a randomized comparison (2). *J Med Internet Res*. 2004 Sep 24;6(3):e30.
21. Kongsved SM, Basnov M, Holm-Christensen K, Hjollund NH. Response rate and completeness of questionnaires: a randomized study of internet versus paper-and-pencil versions. *J Med Internet Res*. 2007 Sep 30;9(3):e25.
22. Frandsen M, Walters J, Ferguson SG. Exploring the viability of using online social media advertising as a recruitment method for smoking cessation clinical trials. *Nicotine Tob Res*. 2014 Feb;16(2):247-51. doi: 10.1093/ntr/ntt157.
23. Dainesi SM, Goldbaum M. E-survey with researchers, members of ethics committees and sponsors of clinical research in Brazil: an emerging methodology for scientific research. *Rev Bras Epidemiol*. 2012 Dec;15(4):705-13.
24. Globo. G1. [Brazil overtakes US and Bric countries in use of social networks, says research]. 2013 Jul 2 [Access 2017 Dec 28]. Available from: <http://g1.globo.com/tecnologia/noticia/2013/07/brasil-supera-eua-e-paises-do-bric-em-uso-de-redes-sociais-diz-pesquisa.html>. Portuguese.
25. Close S, Smaldone A, Fennoy I, Reame N, Grey M. Using information technology and social networking for recruitment of research participants: experience from an exploratory study of pediatric Klinefelter syndrome. *J Med Internet Res*. 2013 Mar 19;15(3):e48. doi: 10.2196/jmir.2286.