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CASE REPORT

Support, attention and distant guidance for chronic pain patients. Case report

Apoio, acolhimento e orientações à distância para pacientes com dor crônica. Relato de caso

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ABSTRACT

BACKGROUND AND OBJECTIVES: Mutual help among patients and distant support tools – such as phone calls and online discussions – are promising strategies to manage chronic conditions, however still poorly explored in the context of pain. This study aimed at evaluating two different remote guidance methods able to help chronic patients: (I) phone calls and (II) engagement in online discussion groups for patients.

CASE REPORT: To evaluate these two assistance models, a qualitative research model was used. Investigations have started as from practical needs of a Support Group for chronic pain patients in São Paulo. To evaluate approach (I), 15 semi-structured interviews were carried out with specialists working with telephone guidance. For approach (II), the ethnographic method was used where a Facebook fibromyalgia discussion group was followed up for three months.

CONCLUSION: Both studied initiatives have positive results but still lack well structured and uniform protocols. Interviews have shown that distant support practices for chronic patients could be expanded for a larger number of diseases.

Keywords: Chronic pain, Self-help group, Social network, Social support, Telemedicine.

RESUMO

JUSTIFICATIVA E OBJETIVOS: A ajuda mútua entre pacientes e as ferramentas de apoio à distância - como telefonemas e discussões online - são estratégias promissoras no manuseio das condições crônicas, mas ainda pouco exploradas no contexto da dor. O objetivo deste estudo foi analisar duas diferentes formas de orientação remota capazes de auxiliar pacientes crônicos: (I) ligações telefônicas e (II) engajamento em grupo de discussão online para pacientes.

RELATO DO CASO: Para analisar esses dois modelos de assistência utilizou-se um modelo qualitativo de pesquisa. As investigações surgiram a partir de necessidades práticas de um Grupo de Apoio para pacientes com dor crônica de São Paulo. Para analisar a abordagem (I) foram feitas 15 entrevistas semiestruturadas com especialistas que trabalham com orientação telefônica. Para a abordagem (II) utilizou-se o método etnográfico, em que um Grupo de discussão para fibromialgia presente no *Facebook* foi acompanhado por 3 meses.

CONCLUSÃO: As duas iniciativas investigadas têm mostrado resultados positivos, mas ainda carecem de protocolos bem estruturados e uniformes. As entrevistas conduzidas mostram que as práticas de apoio à distância para pacientes crônicos poderiam se estender para um maior número de doenças.

Descritores: Apoio social, Dor crônica, Grupo de autoajuda, Rede social, Telemedicina.

INTRODUCTION

Support groups are characterized for offering support to a certain group of people with stresses related to crisis situations, life transitions, personal difficulties or specific diseases. They are in general targeted to individuals with similar problems willing to share personal experiences, which results in cohesion and mutual support process[1].

These groups provide educational strategies and psychosocial support to contribute to better adherence to proposed therapies. It is important for these groups to encourage self-determination and independence, aiming at improving self-esteem, affection and autonomy of participants. Among other positive effects referred by members of such communities, there are: better use of social resources, improved capacity of coping with life situations, improved self-confidence, emotional relief and less hopelessness. Support groups work based on reciprocity and sociability principles, where the sharing of experiences contributes to create a common memory which strengthens participants[2-4].

Studies have shown satisfactory results with the implementation of such groups in different health conditions, such as in autoimmune diseases, cancer, dementia and chronic pain[5,6]. However, many of these groups face difficulties with regard to management and communication. In a previous survey, aiming at characterizing support groups and associations of rheumatic patients in Brazil, it was identified that from a total of 45 existing groups, more than 70% had no website and approximately 50% were difficult to be accessed (character-

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ized by undisclosed e-mail associated to a telephone number not corresponding to the internet record or phone calls which were not answered after three attempts in different days and business hours)[6]. In spite of these differences, such groups are in general reference in information support to other places, which often need telephone or e-mail guidance and, more recently, Facebook discussion groups[6,7].

However, although being a promising field, distant support approaches still lack studies to define best working methods highlighting major benefits, challenges and criticisms related to each approach. Such problems will then be discussed as from the case report of difficulties of a chronic pain support group of São Paulo. This group received contacts from different Brazilian states and had difficulties in guiding people of other places. As a way to work around the problem, the study aimed at evaluating two different remote guidance methods: telephone calls and online discussion groups.

CASE REPORT

A Support Group was created in 2008 in São Paulo for chronic pain patients that meet every week to perform activities such as experience sharing, group therapy, relaxation exercises and e-mail guidance, among other educational experiences.

Among results of this group, more than 2.6 thousand e-mails were answered and national and international events were organized. However, frequent questions have been raised in recent years about how to maximize the impact of the group by offering support to people of other states/cities who often get in touch with questions and different requests. With this, the team started to call some patients who reported more severe cases in their e-mails, to know how they were and for simple guidance. Although not having a specific protocol for such end, patients in general reported the importance of the contact and of the brief emotional support they received.

So, the team started to investigate ways to enhance this type of remote assistance. Literature surveys and visits to other institutions were carried out to understand the models used. In addition, in this investigation, two specific methodologies were used:

I) for telephone follow-up, 15 interviews were carried out with specialists working with this tool to monitor patients' evolution;

II) for the analysis of online discussion groups, a participative ethnography was used. A fibromyalgia support community was followed-up for three months, which was very active and present on Facebook, with weekly immersions to evaluate elements such as: usual interests, engagement, behaviors and reported difficulties.

Both described remote follow-up methods have promising results, with evidences of clinical, financial and institutional image benefits. Each approach has outstanding features, but a common element is the need for a better defined protocol, because practical conduction of such initiatives significantly varies as a function of organization capacity, available infrastructure and dedication of people involved.

DISCUSSSION

I) Telephone follow-up

Those working for decades with such approach are groups specialized in chronic patients management[8], who record calls, work with goals to decrease absenteeism, audit interaction, work with around-the-clock centers and softwares pointing to the periodicity needed for each phone call. These phone calls are usually made by nursing teams. Even so, the director of one of those groups has reported that unfortunately the focus of many of these programs in Brazil ends up being just hypertension, diabetes and cancer, and that unfortunately there is no project directed to autoimmune diseases, mental health and pain.

In the 15 interviews with specialists, it was identified that major Brazilian hospitals have this type of intervention to follow-up some patients, but are just able to offer such initiatives to small groups or specific diseases.

Some hospitals have reported that are starting this service to build a loyalty relationship with their patients. In this sense, nurses following up patients during the hospitalization period even give their personal phone number, have post-discharge call protocols and use the tool to visualized parts of patient's body. For such, technologies such as Skype (to promote better contact and visualization, in addition to voice) are used. Integrated communication interfaces, such as personal medical charts to follow up the evolution, and warning messages for medical consultations are also used.

The answers of two senior nurses portraying part of the described scenario are presented below.

Q: - "How does the hospital work with patients after discharge (Monitoring via phone call, new technologies and social media)"?

A: - "Hospitals' Outcomes Cell was created for the first time in Brazil in 2011. Objectives are: get information about clinical outcome, adherence to treatment and assuring the continuity of care. Currently, patients inserted in strategic programs of cardiology, locomotor, neurology, surgery and oncology are followed-up. Contacts are made via telephone or e-mail, with periodicity of 30, 90 days, six months, 1, 2, 3, 4 and 5 years".

A: - "Until the beginning of this year, continuity of post-discharge care was made by phone contact. However, the hospital has acquired in January a communication platform that works as videoconference. For such, it is necessary that patients have a computer with access to the internet and a camera or smartphone. This resource has been currently the most widely used, but if patients prefer they may be contacted by telephone. The system offers encryption to assure secrecy and safety standards".

Major target audience of this program are oncologic and oncohematologic patients (hospitalized and in ambulatory treatment), being that for hospitalized patients the contact is made after one week and for ambulatory patients it is made during the week and before the next visit to the ambulatory. In robotic gastroenterology, urology and gynecology surgeries the contact is made after 1, 2, 4 weeks, 2 months, 4, 6, 9 and 12 months. Diabetes mellitus patients (insulin-dependent and oral hypoglycemic agents) were contacted three days after hospital discharge or even the day after, if necessary – continuity depends on patients' needs. Patients with complicated wounds and ostomies are contacted according to individual needs".

Although having contacted hospitals with pain management reference centers, none of the 15 institutions where interviewed professionals worked had a specific group for chronic pain.

Some respondents talked about the importance of such programs with regard to preventing new hospitalizations.

Reports showed that protocols vary a lot according to the disease. It is possible to mention other studies with the same goal. Chaves & Oyama[9] stress the need for more specific protocols for such programs. In their study, the interval between calls was between one and two months, with the special aim of changing behavior. In another review[10], authors mention studies with quite different protocols, one of them with an active telephone exchange were calls are made in general every three months, with major objective of supporting weight control, the practice of physical activities and of generating adherence to drugs. These might be relevant data for applicability in chronic pain cases, where exercise is a structuring therapy.

It is also stressed the need for future guidelines for telephone approach in cases of pain, such as that existing for cardiology[11].

II) Online discussion groups

In previous surveys, with query filter just for fibromyalgia, more than 50 virtual support groups via Facebook were found, with more than 8 thousand members. In face of such data, the question was raised about the challenge of offering a good support to so many users. How to improve the impact on those groups and promote further engagement among participants?

Following one of those groups, it was identified that there environments are numerous times mentioned by different participants as the only place they can disclose their feelings. Such communities are considered also important support and information sources, with characteristics similar to those described for face-to-face support groups. Disease aid is one of the most requested topics for discussion.

Among studies suggesting possible initiatives for the success of such virtual communities, there is the study of Uden-Kraan et al.[12] which mentions that moderators must dedicate 10 to 15 weekly hours for the group to have a better chance of being successful. Camerini, Camerini & Schultz[13] have mentioned the importance of tailored contents and individualized attention. There are still contradictory data about the relationship among more active individuals being directly related to higher satisfaction with the group or better clinical results[14,15].

As encouragement to this line of care, a Cochrane systematic review has shown that the mere identification of similar cases or symptoms among patients with similar problems in discussion groups could be an excellent tool to handle chronic conditions[16], offering health improvements and promoting better autonomy and proactivity. In this line of action, there are also benefits such as improved social life, decreased hopelessness, better knowledge about the disease, expansion of behavioral strategies and better clinical results in diseases such as fibromyalgia, rheumatoid arthritis and cancer[16,17]. Many consulted studies have mentioned the importance of further studies in this area.

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