

RESEARCH | PESQUISA



Use of the Whatsapp application in health follow-up of people with HIV: a thematic analysis

Uso do aplicativo Whatsapp no acompanhamento em saúde de pessoas com HIV: uma análise temática
Uso de aplicación Whatsapp para seguimiento de salud de personas con VIH: un análisis temático

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ABSTRACT

Objective: To investigate the statements of people living with HIV during a health follow-up through the WhatsApp® application. **Methods:** A descriptive study, using a qualitative approach, was conducted with 26 people accompanied by two specialized care services for HIV/AIDS in Fortaleza, Ceará. Data were collected from September 2016 to February 2017, with participants' statements given during the online follow-up and submitted to thematic content analysis. **Results:** The following categories emerged: difficulties with treatment, antiretroviral dose delayed or missed, side effects, association between antiretroviral drugs and alcohol, use of dietary supplements and medicines, emotional changes, life habits, social rights, physical symptoms, and coping with and committing to with treatment. **Conclusion:** Follow-up over WhatsApp® improved access to health professionals, by providing an open and immediate communication channel.

 $\textbf{Keywords:} \ \mathsf{Text} \ \mathsf{Messaging;} \ \mathsf{Cell} \ \mathsf{Phones;} \ \mathsf{Communication;} \ \mathsf{Nursing} \ \mathsf{Care}.$

RESUMO

Objetivo: Analisar depoimentos de pessoas com HIV durante um acompanhamento em saúde, a partir do aplicativo *WhatsApp*®. **Métodos**: Pesquisa descritiva, abordagem qualitativa realizada com 26 pessoas com HIV acompanhadas em dois serviços de atenção especializada em HIV/Aids de Fortaleza, Ceará. Os dados foram coletados no período de setembro de 2016 a fevereiro de 2017, por meio de depoimentos de participantes durante o acompanhamento *online*, analisados a partir da análise de conteúdo temática. **Resultados:** Emergiram as seguintes categorias: dificuldades com o tratamento medicamentoso; atraso ou perda da dose do antirretroviral; efeitos colaterais; associação entre antirretroviral e bebida alcoólica; uso de suplementos alimentares e medicamentos; alterações emocionais; hábitos de vida; direitos sociais; sintomas físicos; enfrentamento e engajamento com o tratamento. **Conclusão:** O acompanhamento em saúde a partir do *WhatsApp*® promoveu a acessibilidade do paciente ao profissional de saúde fornecendo uma via de comunicação abeta e imediata

Palavras-chave: Mensagem de Texto; Telefones Celulares; Comunicação; Cuidados de Enfermagem.

RESUMEN

Objetivo: Analizar testimonios de personas con VIH durante un seguimiento en salud utilizando la aplicación WhatsApp®. Métodos: Investigación descriptiva, de abordaje cualitativo, realizada con 26 personas con VIH atendidas en dos servicios de atención especializada en VIH/SIDA de Fortaleza, Ceará. Datos recolectados durante el período entre setiembre de 2016 y febrero de 2017, a través de testimonios de participantes durante el seguimiento online, estudiados mediante análisis de contenido temático. Resultados: Surgieron las siguientes categorías: dificultades con el tratamiento farmacológico; retraso o pérdida de la dosis del antirretroviral; efectos colaterales; asociación entre antirretroviral y bebidas alcohólicas; uso de suplementos alimentarios y medicamentos; alteraciones emocionales; hábitos de vida; derechos sociales; síntomas físicos; enfrentamiento y adhesión al tratamiento. Conclusión: El seguimiento en salud a partir del WhatsApp® facilitó la accesibilidad del paciente al profesional de salud, ofreciendo una vía de comunicación abierta e inmediata.

Palabras clave: Mensaje de Texto; Teléfonos Celulares; Comunicación; Atención de Enfermería.

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INTRODUCTION

The use of information and communication technologies in health care services began in the 1990s, with the expansion of social media, also known as Web 2.0 or social networks, which are defined as a set of Internet-based tools aimed to help users connect, collaborate and communicate with other people in real time.¹

Social media has revolutionized not only the everyday life of people, but also the relationship between patients and professionals,² by providing instant communication, education in health, social support, decision-making, self-care, and also by providing support to behavior changes, with good cost-effectiveness.³

In the context of HIV/AIDS, information and communication technologies have been suggested as tools aimed to improve access to health care services, through a decrease of geographical barriers and costs that involve prevention and treatment. When they are used in combination with usual care, they allow for strengthening health care services and improving quality of care, since they mitigate the difficulties experienced by people living with HIV.⁴

Findings have shown the positive impacts of the use of cell phones on adherence to antiretroviral therapy and viral suppression, especially in the first months, whether it is done through phone calls or messages. In spite of that, studies need to be carried out in order to assess the possibilities of use and the effectiveness of social media and smartphone apps.⁵

WhatsApp® Messenger is an instant messaging application run from a mobile device which allows to communicate by sharing texts and voice messages, photos, music, and videos. The use of this application in health care has shown satisfactory results in the integration of theory and clinical practice, in both nursing and medicine. However, the use of WhatsApp® as a tool for communication between professionals and patients and of education in health is limited to a small number of publications.

Considering this gap, the present study was outlined to answer the following question: What topics are addressed during a follow-up provided to HIV patients over WhatsApp®? Studies with this approach can provide grounds to a multidisciplinary team for the identification of information needs from the perspective of people involved, giving way to the expansion of tools of communication and education in health which are used every day in care services that are specialized in HIV/AIDS, with the purpose of enabling patients to overcome difficulties related to their experience with HIV.

Therefore, we analyzed the statements given by people living with HIV during a health follow-up carried out over WhatsApp®.

METHOD

This is a qualitative study carried out from September 2016 to February 2017 with 26 people living with HIV who

were assisted by two care services specialized in HIV/AIDS in Fortaleza, state of Ceará. Both institutions are part of the Unified Health System (SUS, as per its acronym in Portuguese) and they are reference centers that provide multidisciplinary services as well as antiretroviral drugs and follow-up examinations.

Participants were selected by means of a personal invitation while they were waiting for their medical appointment. Non-probabilistic convenience sampling was adopted with the following inclusion criteria: people living with HIV/AIDS, aged over 18, undergoing treatment for one year or less, literate, who owned a cell phone with access to the internet, who used WhatsApp®, and agreed to receive messages. The exclusion criterion was having any physical, mental or visual constraint that limited the reception of messages.

Participants were first invited verbally, and then an interview was carried out in a private room within the health care service so they could fill in a semi-structured form for sociodemographic and clinical characterization. Participants were provided with information regarding the study and confidentiality of the follow-up.

After selection, subjects received individual messages every two weeks, which were sent by a nurse, from a cell phone exclusively used for this purpose, on business days and working hours, for four months. Messages were first validated by specialists ¹² and they addressed the following topics: introduction of follow-up, adherence to antiretroviral therapy, physical activity, social support, self-esteem, anxiety/depression, dietary habits, drugs and alcohol, and sexuality. In addition to the topics addressed, images with motivational messages were also sent. Throughout the follow-up, a nurse was available on WhatsApp® to clear doubts at any time.

An Excel spreadsheet was used to record chats between the nurse and participants. At the end of the follow-up, all messages sent by participants were gathered, read and submitted to thematic content analysis. The following steps were applied in the analysis: pre-analysis, material exploration or codification, result processing, inference, and interpretation.¹³

Results were presented in a chart with statements given by participants distributed over the following categories: difficulties with drug therapy, antiretroviral dose delayed or missed, antiretroviral side effects, association between antiretroviral drugs and alcohol, use of dietary supplements and medicines, emotional changes, life habits, social rights, physical symptoms, and coping with and commitment to treatment. Participants were identified by an alphanumeric code containing the letter S (for statement) and the sequence number of participants (i.e. S1).

The study derived from a clinical trial named "Effects of a telephone follow-up program to promote the health of people living with HIV/AIDS", which was approved by the Research Ethics Committee of the Federal University of Ceará, under CAAE number 53297216.8.0000.5054, in compliance with the ethical principles of Resolution 466/12.

RESULTS

All participants were men, employed (65.38%), single (73.07%), belonged to a religion (65.38%), had a mean age of 28.6 years (\pm), had an average time of diagnosis of 7.4 months (\pm 6.6), 13 years of education in average (\pm 3), a CD4 + count of \geq 500 cells/mm (53.85%) and viral load of \leq 3.000 copies/ml (76.92%).

Chart 1 lists statements given by participants during their follow-up through WhatsApp®. The following categories emerged: difficulties with drug therapy, antiretroviral dose delayed or missed, antiretroviral side effects, association between antiretroviral drugs and alcohol, use of dietary supplements and medicines, emotional changes, life habits, social rights, physical symptoms, and coping with and commitment to treatment (Chart 1).

DISCUSSION

The characterization of participants as to age and gender is in line with other Brazilian studies¹⁴⁻¹⁶ and with data from the 2016 Epidemiologic Report, which presented a higher incidence among men aged between 20 and 34 years old, homosexuals or bisexuals.¹⁷ These results suggest the need for infection prevention and care strategies aimed at young men.

Most participants have completed high school, similarly to what was found in other Brazilian^{14-15,18} and international studies. ¹⁹⁻²⁰ With regard to this particular aspect, people with higher level of education may have more access to information about HIV and greater chances of sticking to the treatment. ¹⁸

The average time of diagnosis under one year is a critical period to increase knowledge about HIV and its treatment, ¹⁶ a condition that was confirmed in the analyses of statements given by the participants. There were questions about different topics related to their condition of living with the virus, especially the forms of transmission, interpretation of the viral load examination and research on its cure.

Having been tested positive for HIV can be a traumatic experience and brings concerns about the forms of transmission and the serological examination results, situations that can interfere with the social and emotional lives of individuals.²¹ For that reason, health professionals must be ready to provide emotional support and information to people with HIV.²²

In the interactions between the nurse and participants, difficulties with the intake of prescribed antiretroviral drugs were reported, with doses being missed or delayed, as well as side effects and treatment interruption. This shows the challenges related to antiretroviral drug treatment adherence, which

Chart 1. Statements given by people living with HIV during a follow-up carried out through WhatsApp®. Fortaleza, Ceará, 2017

Category	Statement
Knowledge about HIV	Is it possible to transmit HIV by kissing? (S15) What does it mean having a viral load lower from 25 thousand to 103? (S20) If I have a complete blood count done, does it say I have HIV? (S12) What about the experiment being carried out in some British universities regarding the HIV cure? (S20)
Difficulties with drug therapy	I am going to do autohemotherapy. I don't feel good with these drugs. (S19) Doctor, it's been 3 days since I've taken my medicine, it's run out and I haven't picked it up yet. (S21) I've been taking half a pill every day, until I get used to it. (S22) I've stopped taking my medicine. (S19)
Antiretroviral dose delayed or missed	I haven't been taking them at prescribed hours, because I don't always sleep at the same time every day; does that interfere in any way? (S9) Do you know what happens when I take that pill twice a day? (S14)
Side effects	The first reaction was discomfort in the morning. Then I started to take it during the day and I got dizzy. Now I'm taking them in the evening again, before I go to bed. (S20) Is it normal to feel completely indisposed after taking the medicine? I'm having headaches frequently. (S14) I get a bad taste in my mouth, a knot in the throat, an urge to throw up. I lose sleep and appetite. Some days I don't feel like taking them. (S19) I've been feeling weak, unwell and having body aches. I think it's because of the medicine. (S18) I still have the runs when I take it. (S23) I've been urinating more often now than before I started to take it. Is that bad? (S20)

Category	Statement
Association between antiretroviral drugs and alcohol	Is it ok if I have a beer before I take my medicine? (S13) Can I drink alcohol? (S23)
Use of dietary supplements and medicines	Can I take vitamins without any trouble? (S18) I'd like to know if it's ok to use a bronchodilator without a prescription. (S14) If I ever have a headache and the pain only goes away with a pill, can I take one? (S16) Do you know anything I could take to help me sleep? (S14) Doctor, could you tell me the name of some medication that would make me stop smoking? (S20)
Emotional changes	I've been so scared lately. I'm feeling like when I found out about HIV. (S14) I've been unwell, I'm worried about myself. (S8) I just feel like sleeping, and I cry all the time. (S13)
Life habits	Now, instead of eating sweets and cakes, I've been eating fruit salad or the actual fruit. (S14) I've been working out, every two days, going to work by bicycle. (S8) I have even cut down on smoking. (S3)
Social rights	Is the pension plan for HIV-positives a complicated issue today? (S18) Am I entitled to free bus tickets? (S19) Is it possible to have a declaration from the hospital so I can get the Bolsa Familia allowance? (S21)
Physical symptoms	I've been sick all day. I got a bellyache. (S1) I had a bout of fever, but I took a pill and I'm much better now. (S13). My only problem is warts, which don't stop growing. (S2). I think I have the fever, I'm going to take a pill and then I'm going to have some sleep. I feel my eyes getting sore and have some pain in my shoulders and arms. (S17) I just have some whitish stains over my body. (S23)
Coping with and commitment to treatment	[] move on like any other person, and at each appointment, I'm happy with the results, and it's a win-win situation if I carry on with the treatment. (S10) I was afraid of the side effects, but I took heart and I'm going to take my medicine again today. (S23) Now I have medical appointments every six months. Treatment is going well and results are great. (S5) I got to read the tuberculosis exam result. There was nothing. Everything is ok. (S26) My examination result was "undetectable". (S7)

represents at least 80% of the intake of pills aimed at suppressing viruses and maintenance.²³

This low adherence to drug treatment is one of the main reasons for treatment failure,²⁴ resulting in the failure of basic treatment schemes and the need to use more complex rescue treatment schemes, which are more expensive and require a higher number of pills.²⁵ Moreover, failure to having people adhere to treatment results in personal damages such as decreased quality of life, a decrease in CD4+ cell count, viral resistance, disease progression to AIDS and death. There are also collective damages that may affect virus transmission control and which result in increased costs with treatment and hospitalizations.²⁶

As a result of these effects, it is essential to establish a therapeutic partnership between the client and health professionals, based on empathy, autonomy, and bonds, in such a way that clients feel comfortable to express their anguish, fears, and expectations with regard to their life with HIV.²⁷⁻²⁹ In this context, the follow-up through WhatsApp® represented the opportunity to communicate and clear doubts in real time, making it easier to manage difficulties associated with the treatment, with positive effects on treatment adherence.

Another matter that raised doubts among participants was the association between the use of the antiretroviral drug and alcohol intake. Although a low alcohol intake does not have negative effects on antiretroviral therapy adherence, it should be discouraged because of its harmful effects on quality of life and of the increased risk of hepatotoxicity. 15,30-31 Therefore, professionals must address the recreational use of alcohol, advising patients not to interrupt drug treatment. 17

Another doubt was related to the use of dietary supplements and other drugs, which suggests the need to inform all people

with HIV about these issues, with the purpose of preventing treatment flaws and/or side effects related to a possible interaction with antiretroviral drugs.³²

Another aspect observed among people living with HIV was the expression of emotional changes, such as fear, concern, discouragement, drowsiness and frequent crying. These complaints can be associated with a diagnosis of anxiety and/or depression, which are frequent among this group.³³ This setting points to the importance for a multidisciplinary team to continuously assess the mental health of people living with HIV and to recommend strategies to control these disorders, with the use of prescribed drugs, support groups, psychological counseling, and complementary treatment^{33,34}

A topic mentioned by participants was the search for healthy habits like having a healthy diet, doing physical activities, and reducing smoking. This is in line with a study carried out with people recently diagnosed with HIV.³⁵ These changes in life style are important to prevent the metabolic changes caused by the body's response to HIV and/or by antiretroviral drug toxicity, which can increase the prevalence of diabetes, resistance to insulin, dyslipidemia, lipodystrophy, bone alterations, in addition to early cerebrovascular and cardiovascular diseases.³⁴

Social rights such as disability retirement, right to free transportation and entitlement to allowances from the Bolsa Familia program also raised doubts among patients. Interest in these social benefits can be related to social vulnerability, 14 a typical characteristic of the HIV epidemic that may imply in difficulties in access to health services and continuity of care. For that reason, information provided by social workers after diagnosis is essential to foster knowledge about social rights guaranteed by law.

Participants consider nurses as a source of support to report physical symptoms associated with acute conditions, which was also found in a previous study. ¹⁹ This allowed for the referral to specialized emergency units and anticipation of medical appointments with an ID specialist, providing a prompter follow-up and preventing the deterioration of the clinical condition.

Communicating with nurses was also useful to share treatment adherence rates and satisfactory results of examinations, which allowed for a positive feedback of good clinical results. In the context of HIV, this partnership is crucial, since patients feel the need to be heard and get the attention of health professionals in order to cope with the disease, and in some cases, they are the only ones who patients can share their achievements with.³⁵

CONCLUSIONS

Analysis of the participants' statements showed that followup over WhatsApp® improved access to health professionals, by providing an open and immediate communication channel that made patients feel safer to overcome their difficulties with treatment, in addition to sharing their achievements and promoting healthy habits. This study also highlighted the importance of providing information and emotional support during the first months of treatment.

The use of the WhatsApp® application has proven to be useful as a health care tool for people living with HIV, and a potential channel to clear doubts and promote treatment adherence. This study can provide grounds to broaden care provided by a multidisciplinary team in HIV-specialized services with the use of an innovative technology that is little explored in the Brazilian setting.

A limitation of this study was the absence of an analysis of patients' messages responded by nurses, which made it impossible to assess the information provided by professionals.

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