



Analysis of the needs for help of men who have sex with men and live with HIV

Análise das necessidades de ajuda de homens com HIV que fazem sexo com homens
Análisis de las necesidades de asistencia para hombres con VIH que tienen relaciones sexuales con personas del mismo sexo

How to cite this article:

Farias OO, Guedes DS, Freitas PCA, Galvão MTG, Cunha GH, Lima ICV. Analysis of the needs for help of men who have sex with men and live with HIV. Rev Esc Enferm USP. 2020;54:e03650. doi: <https://doi.org/10.1590/S1980-220X2019010303650>

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ABSTRACT

Objective: To understand the needs for help of men who have sex with men and live with HIV in the light of a Prescriptive Theory. **Method:** Descriptive and qualitative study, conducted with men who have sex with men and live with HIV who were treated in a Specialized Outpatient Service in a capital in Northeastern Brazil, between the months of November 2017 and May 2018. The study used the analysis of the discourse of the collective subject. **Results:** 49 men with HIV who self-identified as men who have sex with men participated in the study. Help was described as support, welcoming, psychosocial and family support. The desire to receive assistance was related to accepting and forgetting the diagnosis. The problems experienced were related to the acceptance of the diagnosis, fear and prejudice. Professionals and family members stood out as sources of support. Nursing care was cited as significant and the main help required was psychological. **Conclusion:** The needs for help identified were mainly related to psychological support coming from health professionals and family members. Participants were willing to receive help, especially to cope with the diagnosis.

DESCRIPTORS

Men; HIV; Help-Seeking Behavior; Primary Care Nursing; Nursing Theory.

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Received: 04/17/2019
Approved: 02/17/2020

INTRODUCTION

Assessing the need-for-help of vulnerable groups is essential for implementing a culturally competent care and creating a more inclusive health environment⁽¹⁾. The advancement of science and the improvement of antiretroviral therapy (ART) have brought several benefits to people living with HIV (PLHIV), such as an increase in longevity and the consequent inclusion of these individuals in the group of people with chronic conditions. At the same time, with this event, the main difficulties experienced by most of this population have transitioned from biological to psychosocial issues⁽²⁾.

The social representations of HIV are marked by stigma, one of the main reasons that make PLHIV part of the groups classified as hard to reach, despite the high prevalence of HIV infection in the population⁽³⁾. Groups that are hard to reach are the sections of the community that are difficult to involve in public participation, due to several factors⁽³⁾. The lack of visibility and the stigma can result in serious consequences⁽³⁾, such as difficulties coping with HIV and adhering to ART, and increases in the costs of HIV care.

Men who have sex with men (MSM) are still disproportionately affected by HIV and are considered one of the key populations in HIV care in Brazil⁽⁴⁾. This group has to deal with a double burden of social stressors. In health services, caregivers of this population have been subject to increasing demands regarding their skills, especially interpersonal skills⁽¹⁾, which are necessary to provide quality care that encourages patients to face the challenges of living with HIV, particularly in more subjective aspects⁽¹⁾.

The recognition of the need-for-help is a socioemotional aspect and its identification and mutual reaffirmation, by both the patient and caregiver, are necessary conditions to reach health goals⁽⁵⁾. This identification is fundamental for health decision making, for the implementation of care strategies and for the optimization of the use of resources from health services⁽⁶⁾.

The theoretical framework of the Prescriptive Theory provides nursing professionals with tools to identify a patient's need-for-help through care-oriented practices that aim to achieve a higher purpose: provide the necessary help to the patient while contributing to the recognition of nursing as a health profession⁽⁷⁾. This theoretical model proposes three independent factors or elements: the central purpose, which is the mission that the nurse assumes as their responsibility; the prescription, which is the appropriate action to achieve the objective; and the realities, which include the challenges involved in the environment where the nursing action occurs⁽⁷⁾.

Given the opportunity to offer care according to the needs of patients and the importance of encouraging MSM who live with HIV to gain greater autonomy and assume responsibility for their health, the objective of this study was to understand the need-for-help of men who have sex with men and live with HIV in the light of the Prescriptive Theory.

METHOD

STUDY TYPE

Descriptive, qualitative study, based on Ernestine Wiedenbach's Prescriptive Theory.

SCENARIO

The study was developed from November 2017 to May 2018 in a Specialized Outpatient Service (SAE – *Serviço Ambulatorial Especializado*) of a capital in Northeastern Brazil. This SAE is a primary care unit with a multidisciplinary team composed of nurses, physicians and a social worker, who provide care for about 1,050 PLHIV in the city, its metropolitan area and the countryside of the state of Ceará, offering medical consultations, nursing care, laboratory tests, antiretroviral and prevention supplies.

The study was based on the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ)⁽⁸⁾.

POPULATION

A total of 49 MSM who live with HIV were selected by convenience sampling and participated in the study. The sample was closed according to data saturation criterion in relation to the information in the speeches. This is because, in qualitative research, the effort to see all the empirical possibilities of the object studied, considering its dimensions and interconnections, is more important than the number of subjects studied⁽⁹⁾.

SELECTION CRITERIA

The inclusion criteria were: men who identified as MSM, who were 18 years old or older, who had a positive HIV test and who were attending the SAE. Individuals with a diagnosis of a mental or cognitive disorder were excluded from the study. This information was collected in the medical records of the patients listed for assistance with a medical professional during the data collection period.

DATA COLLECTION

Data was collected through individual face-to-face interviews, conducted in a reserved room of the SAE with an average duration of 30 minutes. The interviews were conducted by two nurses from the research team, who were students of a Graduate Program and had previous experience in caring for people living with HIV.

Only the researcher and the interviewee were in the room during the interview. The interviews were audio-recorded with prior consent. The interview was based on a semi-structured form created by the researchers, with two parts: the first part addressed socio-demographic, clinical and sexual behavior data and the second part was aimed at identifying the need-for-help of MSM according to the theoretical framework of the Prescriptive Theory. The questions used in the second part of the interview were: *What does help mean to you? Do you like receiving help? Have*

you experienced problems (need-for-help) since the diagnosis of HIV? Who is the person that currently offers you help? Has any nurse helped you in the process of coping with HIV? What kind of help do you expect to receive to meet your HIV treatment needs?

Field notes were taken during the interviews to record impressions not captured in the audios. The data were manually transcribed to a Microsoft Excel spreadsheet.

DATA ANALYSIS AND TREATMENT

Data saturation in qualitative research represents an attempt to receive a quantity of information that can more closely provide the identification of the complexity of the object, understanding the broad character of these investigations⁽⁹⁾. In this study, the focus of investigation was the needs reported by men who have sex with men and live with HIV, emphasizing their own perception and the validation of those needs.

Data analysis was based on the Discourse of the Collective Subject (DCS) method, in which individual opinions or expressions with similar meanings are grouped into general semantic categories. The differential quality of this method is that individual speeches are grouped in categories according to similarities in the opinions expressed in different speeches, resulting in a synthesis report that represents the collective speech⁽¹⁰⁾.

Data was coded according to the methodological concepts of Central Idea (CI) and Discourse of the Collective Subject (DCS). The latter was represented by a sequence of six different speeches, DCS01, DCS02, DCS03, DCS04, DCS05 and DCS06, previously categorized according to each question of the data collection form. The participants were referred to by the letter E followed by a number that represented the order of the interview, ranging from 1 to 49 (Chart 1).

ETHICAL ASPECTS

The study was approved by the Research Ethics Committee of the Universidade Federal do Ceará (UFC) under Opinion no. 2.006.780/2017, according to Resolution 466/2012 of the National Health Council.

RESULTS

Of the 49 MSM living with HIV, 20.4% were between 20 and 24 years old, 79.6% were between 25 and 49 years old and the mean age was 28 years (SD = 5.5). Among the participants, 57.1% (95%CI = 42.3-70.9) were brown, 93.9% (95%CI = 79.5-97.4) were single, 58.2% (95%CI = 44.3-72.7) did not have a job, 28.6% (95%CI = 17.0 -43.5) had less than 12 years of education, 67.3% (95%CI = 52.3-79.6) had an individual income \leq two minimum wages and 69.3% (95%CI = 54,4-81,3) had a religious belief.

As for clinical data, 51.0% had been diagnosed for three years or less, 100% had an undetectable viral load with a CD4T-lymphocyte count of \geq 350 cells/mm³ and were on ART, and 61.2% reported using more than two pills a day. Regarding sexual behavior, 95.9% were sexually active, 55.1% had had two or more partners in the last three months and 59.2% did not have a steady partner. Among those who had a steady partner, 75% always used a condom. As for casual relations, 67.3% had a casual partner and 97.2% used condoms with these partners.

Regarding other Sexually Transmitted Infections (STIs), 73.5% had a past history of STI and 72.7% had a history of STI with their current partner. Most reported using alcohol (91.8%), but did not smoke (63.3%) or use illicit drugs (63.3%). As for the support network, 91.8% reported that someone else knew about their diagnosis.

Chart 1 presents the CI and the DCS in relation to the need-for-help of the participants and the role of the nurse. The main focus is the element 'realities', the third component of the three main guiding factors of the Prescriptive Theory⁽⁵⁾.

Chart 1 – Description of the Question, Central Idea (CI) and Discourse of the Collective Subject (DCS) – Fortaleza, CE, Brazil, 2019.

Question	Central Idea	Discourse of the Collective Subject
What does help mean to you?	Receiving support, welcoming, psychosocial and family support.	DCS01- <i>Having everyone's support, feeling welcome, perceiving willingness to help regardless of the problem, at any time, without wanting anything in return. Receiving support specially from family, friends and loved ones. Psychological support enhances emotional health, as the disease really affects the emotions.</i> (E1, E2, E3, E4, E6, E7, E10, E11, E12, E13, E14, E15, E16, E17, E19, E20, E21, E22, E24, E25, E26, E27, E30, E32, E38, E40, E41, E42, E43, E47).
Do you like receiving help?	Help leads to forgetting the disease and facilitates acceptance.	DCS02 - <i>It is good to receive help from everyone you like, because sometimes, when the disease comes to mind, you feel sadder and you can't talk. Then when a friend visits, the disease gets out of your mind and it is already a huge help. I think it is a fundamental thing in this moment of life. Help is essential not only for dealing with the disease itself but also for knowing how to deal with society, reducing the possibility of depression and preventing suicide.</i> (E2, E3, E4, E5, E6, E9, E10, E11, E13, E14, E15, E16, E17, E20, E22, E23, E24, E25, E26, E28, E30, E32, E35, E37, E38, E40, E44, E49).
Have you experienced problems (need-for-help) since the diagnosis of HIV?	Coping with HIV involves accepting oneself, overcoming fear and fighting the prejudice of society, family members and close people.	DCS03 - <i>The biggest issue is denying the disease, it's self-acceptance. The friends who know about it do not even mention the subject, and this is comforting, because prejudice is difficult to face. Despite of the time elapsed since the diagnosis, not all close people know about it, so that prejudice can be avoided. Living with that scar, with that disease forever, hurts. There is a fear that people will know about HIV, so pushing friends away is often inevitable. Sometimes the person living with HIV has prejudice against their own disease. Staying mentally well is a psychological struggle. They often fear death and resent their own life because they can't deal with all the bad consequences of the disease.</i> (E1, E2, E3, E4, E5, E6, E7, E8, E9, E10, E11, E12, E13, E14, E15, E16, E18, E19, E20, E21, E23, E24, E25, E26, 27, E29, E30, E35, E36, E38, E39, E42, E43, E44, E45, E46, E48).

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Question	Central Idea	Discourse of the Collective Subject
Who is the person that currently offers you help?	Help comes from health professionals, family members and close people.	DCS04 - <i>Help comes mainly from some friends and health care professionals. The service professionals are wonderful, they provide a lot of help. Friends are also great, sometimes it's possible to forget about the virus when in their company, they are trustworthy. They become psychological help. Support from family still does not exist. It would be a shock for family, as it would be a double revelation: being gay and being diagnosed with HIV, and that would be very difficult.</i> (E1, E2, E3, E4, E5, E6, E7, E8, E9, E10, E11, E12, E14, E18, E19, E20, E22, E23, E24, E25, E26, E27, E29, E30, E31, E35, E40, E42, E44, E45, E46, E49).
Has any nurse helped you in the process of coping with HIV?	The nurse's help is significant in coping with HIV.	DCS05 - <i>The professionals are wonderful, they answer questions, explain everything in detail and are very helpful. There is no help from a psychologist to cope with the disease, to go beyond physical well-being. It would be great if every routine visit had counseling, even with the clinical part, just to vent a little. The nurses helped accepting the diagnosis, offered many tips and, despite of fear, brought hope of still having a good life.</i> (E1, E2, E3, E4, E5, E6, E7, E8, E9, E10, E11, E12, E13, E14, E15, E16, E17, E19, E23, E24, E25, E26, E29, E30, E35, E36, E39, E41, E42, E44, E46).
What kind of help do you expect to receive to meet your HIV treatment needs?	Psychological help.	DCS06 - <i>More support with coping, with conversations, with life is expected, in addition to help with medication and control of viral load. It would be great to have support groups in the services, to exchange experiences with other people who are also infected, with a professional to provide support. This would even help with the family, as family members are usually pushed away. This emotional support would be very important, because there is no point in having an undetectable viral load and looking at yourself as if you were dying or feeling depressed. There is a lack of help on affective and sexual life issues. Sex is an issue that causes insecurity after diagnosis, because little is said about it. However, there is hope that advances in the medical area can lead to a cure. This would be the best help possible.</i> (E1, E2, E3, E4, E7, E9, E10, E11, E12, E13, E14, E16, E17, E18, E19, E20, E21, E25, E26, E27, E29, E31, E34, E37, E39, E41, E43, E44, E46, E47, E48).

DISCUSSION

It was found that the participants in this study were younger, brown, single and most had a low per capita income and up to 12 years of education. This data is similar to the epidemiological characteristics identified in other studies conducted in the Northeast Region and in Brazil^(4,11). Likewise, the clinical characteristics of MSM, such as undetectable viral load and satisfactory immunity reinforce the benefits of the ART, the transition in the infection scenario worldwide⁽²⁾ and the need to investigate new needs in this new setting.

The investigation of the meaning of help and willingness to receive help described in DCS 01 and 02 resulted in the identification of the needs for help, as reported by the patients themselves, and contributed to the perception and validation of these needs. In the Prescriptive Theory, help is defined as any action desired by the patient that has the potential for restoring or extending their ability to cope with situations that affect their well-being⁽⁵⁾. Therefore, it is essential to understand the need-for-help according to the individual's own perception of their situation.

According to Wiedenbach's Prescriptive Theory, to provide care, the nurse must initially identify the need, then validate this need with the patient, and only then they can carry out any action⁽⁵⁾. For MSM, the meaning of help was related to receiving support, welcoming and psychosocial and family support. These results are in accordance with what is found in other studies in the literature, which show that help is often in the bond itself. The reports show individual perceptions on the relevance of social support, the development of new social bonds, and the importance of these resources for self-care⁽¹²⁾. Having social support since the diagnosis contributes to an independent and healthier coping among people living with HIV, preventing opportunistic infections and therapeutic failure⁽¹²⁾.

The interviewees reported that receiving help leads to forgetting the disease and facilitates acceptance, which is in accordance with the literature⁽¹³⁾. For people living with HIV, receiving support is extremely significant and has a direct impact on their quality of life. Loneliness and rejection are feelings resulting from the disease that are present in the lives of these individuals, due to the fear of disclosing the diagnosis, and, consequently, the lack of psychosocial or affective support. Thus, the possibility of maintaining affective relationships with friends and family is a fundamental aspect in these lives⁽¹³⁾.

The question on coping with HIV involves exploring the reality of individuals regarding their ability to deal with the adversities of living with HIV. The assessment of the situation is part of the philosophy of nursing care for Wiedenbach. For the scholar, nurses develop a helping prescription based on the physical, physiological, psychological, emotional and spiritual reality of the subjects⁽⁵⁾. Thus, it was observed that, when asked about coping issues, the participants described situations that were predominantly social, and not biological.

The main challenges faced by MSM since the diagnosis are related to acceptance of HIV, fear and prejudice, which is in accordance with other studies in the literature. These challenges lead to denial of their condition and, sometimes, to risky behaviors that directly affect the treatment⁽¹⁴⁾. The experiences of MSM in relation to HIV go beyond the biological aspects of the infection to include the social environment of the individual⁽¹⁴⁾. It has also been pointed out that the social representations of AIDS as a serious and incurable disease associated with death has reinforced fear and stigma, which are associated with the certainty that, once the diagnosis is confirmed, it is impossible to reverse it⁽¹⁵⁾.

The perception of risk groups, mainly of the key populations of MSM, sex workers and drug users, was constructed at the beginning of the epidemic and, since then, it has generated stigma and it remains significant in the system of social representations of HIV. In addition, the anguish and fear of the unknown, the perception of HIV as a fatal disease and the plurality of perceptions of HIV transmission and prevention are directly associated with stigma and prejudice⁽¹⁵⁾. Misinformation about HIV is present in different epidemiological scenarios. Discrimination and stigma are risk factors for misinformation, while privacy and confidentiality are protective factors⁽¹⁶⁾.

One of the measures to deal with stigma and discrimination is the commitment to guarantee access to treatment, which explores social relationships and provides essential support for individuals to cope with their condition. Intervention strategies focused on coping with stigma have been shown to be effective for promoting adherence to treatment and reducing social isolation, especially when they involve multiple actions and address stigma at intrapersonal, interpersonal and structural levels⁽¹⁷⁾.

Regarding the perception of those who provide help, the role of the nurse was highlighted, which corroborates the theory of the need-for-help. The theoretical guidelines are applied in an interactive manner, based on a relationship of trust between the nurse and the patient⁽⁵⁾. In this relationship, the art of nursing must be based on a deep understanding of the needs and concerns of patients⁽⁵⁾. This process must be deliberate and can be implemented through observation and exploration of meanings, identifying in the patients the ability to achieve their own goals or the need for help.

In this study, the family stands out as one of the main forms of support, which is in agreement with a literature review that highlighted the relevance of the family as a cultural aspect in Brazil. The family represents the space for carrying out essential care, and the participation of family members is decisive in the context of health care, particularly when it comes to adherence to ART, which sometimes requires changes in the routine and habits of everyone involved⁽¹⁸⁾. However, it is important to note that most of the individuals in the study were single, which may point to a lack of affective bonds. Likewise, for people living with HIV, specially MSM, the formation and maintenance of bonds has weaknesses related to the social context in which they live.

The nuclear family was not mentioned as the main source of support, which may be related to the lack of knowledge of the patients' positive HIV status among their family members. The diagnosis is often not disclosed to family members because HIV is still associated with morally reprehensible behavior, which may lead to discrimination and exclusion in the household⁽¹⁹⁾. Thus, friends can often replace family, welcoming and supporting these individuals with no judgment. In fact, many MSM leave their families to live with friends. In this setting, help becomes voluntary and is based on reciprocal support with no mandatory repayment. Thus, receiving support from friends, who are the people who show concern, improves adherence and maintenance of treatment among PLHIV⁽¹⁹⁾.

Furthermore, professional help has a fundamental role, especially regarding the deconstruction of stigma, the development of strategies to improve adherence to ART and the reintegration of these people into society and into the formal job market, seeking to meet their needs⁽²⁰⁾. Thus, in this perspective, nurses provide a significant care, as in addition to technical knowledge, these professionals have skills for providing sensitive and humane care in their professional activities, for both patients and their families⁽¹⁴⁾. A study emphasized the role of the nurse in providing comprehensive care among other professionals working with people with HIV. In the research, nurses were twice as likely as physicians to offer comprehensive care to PLHIV (65.9% versus 34.1%; $p < .0001$)⁽²¹⁾.

However, despite the positive speeches regarding the work of nurses in this study, the literature indicates that nursing care for PLHIV needs to improve. This is because nursing practices still reflect the historical characteristics of the biomedical model, in which care management was vertical and task-centered⁽²²⁾. In addition, these professionals are part of the initial support network and, therefore, they need to be trained to maintain a relationship of empathy and trust, so that the patient feels free to express fears and anxieties⁽²³⁾.

Psychological help was highlighted among the most desired types of support in this study. This finding is in agreement with the literature, which, given the success of antiretroviral therapy, points to psychological problems as the main current concern regarding the quality of life of this population⁽²⁴⁾. This fact is confirmed by observing that 100% of the study participants had an undetectable viral load. On the other hand, another study indicated that less than half of people with HIV understand that they need psychological treatment (41%)⁽²⁵⁾, which is associated with lower chances of seeking help.

The perception of unmet needs reported by MSM living with HIV was addressed in other studies with this population carried out in countries in North America, Africa and Asia⁽²⁶⁻²⁸⁾. Overall, the needs identified in this study corroborate with others that point out the urgency of strengthening the continuity of care after the diagnosis, with regard not only to the pharmacological treatment, but also to the mental health of MSM, especially for coping with stigma, discrimination and other stressors⁽²⁶⁻²⁸⁾.

In this context, the needs of individuals can only be met if their perceptions, feelings and thoughts are known and validated. Therefore, observations and validations must be continuous⁽⁵⁾, enabling the execution of mutually agreed action plans, based on the reality and the resources available to both individuals involved in the care.

A limitation of this study was that it was conducted in a single health service. Furthermore, intervention studies should be conducted to provide a practical assessment of the viability of the theoretical framework regarding the factors of central purpose and prescription of actions.

CONCLUSION

The use of the theoretical model was appropriate for identifying the need-for-help of men who have sex

with men and live with HIV. Psychological and social needs were highlighted, with special emphasis on the support and welcoming of family members and close people. At the same time, the willingness to receive help to address issues concerning HIV was identified among the participants.

In the reality of individuals, fear and prejudice were feelings reported as negative factors, mainly regarding the prognosis and incurability of the infection. On the other hand, the significant role of nurse at the time of diagnosis was highlighted, despite reports of multiprofessional needs that were not met during follow-up.

RESUMO

Objetivo: Compreender as necessidades de ajuda de homens com HIV que fazem sexo com homens à luz de uma Teoria Prescritiva. **Método:** Estudo descritivo e qualitativo, realizado com homens com HIV que fazem sexo com homens atendidos por um Serviço Ambulatorial Especializado de uma capital no Nordeste do Brasil, entre os meses de novembro de 2017 e maio de 2018. A pesquisa utilizou a análise do discurso do sujeito coletivo. **Resultados:** Participaram do estudo 49 homens com HIV, que se autodenominaram homem que faz sexo com homem. Ajuda foi descrita como apoio, acolhimento, suporte psicossocial e familiar. O desejo de receber auxílio foi relacionado à aceitação e ao esquecimento do diagnóstico. Os problemas enfrentados aludiram à aceitação do diagnóstico, ao medo e ao preconceito. Destacaram-se como fonte de amparo os profissionais e familiares. O cuidado de enfermagem foi citado como significativo, e a principal ajuda requerida foi do tipo psicológica. **Conclusão:** As necessidades de ajuda identificadas relacionaram-se principalmente ao suporte psicológico, proveniente dos profissionais de saúde e dos familiares. Os participantes são receptivos ao recebimento de ajuda, sobretudo, no que se refere ao enfrentamento do diagnóstico.

DESCRITORES

Homens; HIV; Comportamento de Busca de Ajuda; Enfermagem de Atenção Primária; Teoria de Enfermagem.

RESUMEN

Objetivo: Entender las necesidades de asistencia de hombres con VIH que tienen relaciones sexuales con hombres, a la luz de una Teoría Prescriptiva. **Método:** Se trata de un estudio descriptivo y cualitativo, realizado entre noviembre de 2017 y mayo de 2018, entre hombres con VIH que tienen relaciones sexuales con personas de su mismo sexo y se atienden en una Clínica Ambulatoria Especializada de una capital del noreste de Brasil. La investigación utilizó el análisis del discurso del sujeto colectivo. **Resultados:** Participaron 49 hombres con VIH que declararon tener relaciones sexuales con personas del mismo sexo. La asistencia pretendida fue descrita como soporte, refugio, apoyo psicossocial y familiar. El deseo de recibir apoyo estaba relacionado con la aceptación y el olvido del diagnóstico. Los problemas enfrentados aludían a la aceptación del diagnóstico, al miedo y a los prejuicios. Se destacaron, como fuente de apoyo, los profesionales y los familiares. La atención de enfermería se citó como significativa, y la principal ayuda requerida fue la psicológica. **Conclusión:** Las necesidades de ayuda identificadas eran, principalmente, de apoyo psicológico de los profesionales de la salud y de los miembros de la familia. Los participantes están abiertos a recibir ayuda, sobre todo, en lo tocante al enfrentamiento del diagnóstico.

DESCRIPTORES

Hombres; VIH; Conducta de Búsqueda de Ayuda; Enfermería de Atención Primaria; Teoría de Enfermería.

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