

## Adherence to antiretroviral therapy: a qualitative study with physicians from Rio de Janeiro, Brazil

Aderência à terapia anti-retroviral: um estudo qualitativo com médicos no Rio de Janeiro, Brasil

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### Abstract

*Brazil provides free antiretroviral (ARV) therapy to some 150,000 individuals living with HIV/AIDS). ARV regimens require optimal adherence to achieve undetectable viral loads and to avoid viral resistance. Physicians play a key role to foster ARV adherence, but until now little is known about the communication between physicians/people living with HIV/AIDS in this setting. In-depth interviews were conducted with 40 physicians treating people living with HIV/AIDS at six public reference centers in Rio de Janeiro, Brazil. Interview topics included: experiences in the treatment of people living with HIV/AIDS, relationship and dialogue with patients, barriers/facilitators to adherence, and effectiveness of available services. Barriers to ARV adherence were mainly related to the low quality of patient-provider relationship. Other barriers were related to "chaotic" patients' lifestyles, and inadequate knowledge and/or negative beliefs about HIV/AIDS and ARV effectiveness. It is necessary to improve networking between services, establish agile referral systems, and improve health professionals' integration. These structural changes could contribute to improved adherence, resulting in improved quality of life for people living with HIV/AIDS.*

*Acquired Immunodeficiency Syndrome; HIV; Highly Active Antiretroviral Therapy*

### Introduction

The HIV/AIDS epidemic continues to expand globally; an estimated 40 million people are now infected with HIV, and projections suggest that an additional 45 million people will become infected in developing countries between 2002 and 2010 <sup>1</sup>. Access to treatment, care, and support for people living with HIV/AIDS remains grossly inadequate. At the end of 2001, fewer than 4% of people in need of antiretroviral treatment in low- and middle-income countries were receiving it, and fewer than 10% of people living with HIV/AIDS had access to palliative care or treatment for opportunistic infections <sup>1</sup>. Unaffordable prices remain the most commonly cited reason for limited access to antiretroviral drugs; however, insufficient capacity of the health sector, including infrastructure limitations and shortage of trained personnel, is also a major obstacle to ART delivery in many countries <sup>2</sup>.

The Brazilian response to the HIV/AIDS epidemic is both unique and exemplary in several respects. In 2000, there were an estimated 600,000 people living with HIV/AIDS in Brazil <sup>1</sup>, in contrast to the 1.2 million the World Bank had projected a decade earlier <sup>3</sup>. The comprehensive set of prevention and care initiatives implemented by the Brazilian National STD/AIDS Program, State and Municipal health secretariats, and non-governmental organizations

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is thought to have played a large role in altering the course of the Brazilian AIDS epidemic 1,4,5,6,7.

Provision of antiretroviral therapy (ART) is a central piece of the Brazilian AIDS Program. Brazilian Federal law established free universal access to ART in 1996<sup>8</sup>, making Brazil unique in the developing world. Currently, about 150,000 persons receive ART in Brazil<sup>9</sup>. In the years following introduction of universal access, AIDS mortality rates declined by approximately 50% and inpatient hospital days due to HIV declined by about 60%<sup>10</sup>.

The Brazilian health system has succeeded in expanding access to ART. However, in addition to providing drugs, a successful HIV/AIDS treatment program must offer a comprehensive set of care and support services, including promoting early entrance into care, facilitating adherence to ART, integrating psychosocial support services with care, promoting protective behaviors, and providing ongoing training to medical personnel and psychosocial support staff<sup>3,5</sup>. Patient adherence to treatment and clinical follow-up plays a particularly crucial role in allowing patients to achieve better outcomes<sup>11,12</sup>.

A recent paper by Nemes et al.<sup>13</sup> presents data from a cross-sectional survey conducted with 1,972 persons living with HIV/AIDS in Brazil. The study found that 75% of participants were adherent to ART. According to the authors, the main predictors of non-adherence were: services with 100 patients or less, missed appointments, more complex treatment regimens, high number of daily pills, and patients with less than 2 years of formal education. Another recent study by Hofer et al.<sup>14</sup> found high rates of immunological response and adherence to ART among persons living with HIV/AIDS in Brazil: 82% of 211 patients enrolled in the study achieved virologic/immunologic response to ART. According to data from both studies, the proportion of patients who presented good adherence levels and/or who achieved optimal biological outcomes due to ART was similar to reports from developed countries, suggesting that ART can be successfully implemented in developing countries' settings<sup>13,14</sup>.

Patient adherence is a complex phenomenon that can be affected by a number of variables, including the difficulty of the treatment regimen, patients' access to social support, and patients' beliefs about the efficacy of the treatment<sup>7</sup>. Several studies suggest that physician-

patient communication has a particularly powerful effect on patient adherence to medication regimens<sup>11,15,16,17,18</sup>. Patients who receive comprehensive information about their ART regimens, who have access to culturally sensitive health services, and who have an open and non-judgmental dialogue with their health providers are more likely than others to be adherent to both ART regimens and clinical follow-up<sup>11,19,20</sup>. Good communication between patient and provider about patient lifestyle and preferences can improve ART adherence by aiding in the selection of an ART regimen tailored to the patient's lifestyle<sup>16</sup>, with lower pill burden, more convenient dosing, and more tolerable side effects<sup>11</sup>.

On the other hand, patients who receive inadequate information from their physicians and/or do not understand their physicians' prescriptions/recommendations are unlikely to adhere to therapy<sup>15,21</sup>. Physicians' use of specialized/technical language, low literacy of patients, and other language barriers between patients and providers present a particular barrier to patient adherence<sup>15,22</sup>.

Although these studies suggest a crucial role for physicians in fostering adherence, to date little is known about how physicians communicate with their patients about ART adherence. We conducted an exploratory study using in-depth qualitative interviews with physicians to improve understanding of how, from the physician's perspective, the patient-provider relationship can influence adherence to HIV treatment and care in Brazil.

## Methods

### Study population

Participants were recruited from physicians involved in the treatment and care of people living with HIV/AIDS at six public HIV/AIDS reference centers located in different areas of Rio de Janeiro, Brazil. All reference centers offer inpatient and outpatient HIV/AIDS treatment using multidisciplinary teams, and serve primarily low-income individuals from diverse racial/ethnic backgrounds. There were no formal clinic policies in place for communicating with patients about adherence at the time of the study.

### Data collection

Qualitative research aims to describe social phenomena and behaviors using rich contextual data that emphasize the subjective experiences of social actors. In-depth interviews provide a flexible tool to collect narrative data describing interviewees' perspectives<sup>23</sup>. This type of data can be difficult to assess using quantitative methods, particularly in the exploratory stage of research, before hypotheses can be clearly articulated. The value of a qualitative perspective has gained favor in social and behavioral health research, and in HIV/AIDS research in particular, where many of the social phenomena being studied are personal, intensely private, and sometimes illicit<sup>23</sup>.

For the current study, in-depth qualitative interviews were conducted with 40 physicians between 2001 and 2002. Interviews were semi-structured and used a script that focused on attitudes about AIDS, experiences in the daily treatment of HIV-positive patients, thoughts about available treatments for HIV/AIDS, difficulties related to clinical practice, relationships with patients, barriers to and facilitators of patient adherence to treatment, and effectiveness of available services. Each physician was interviewed once, for about 60-90 minutes. All interviews were tape-recorded and later transcribed into an Atlas.ti database<sup>24</sup>.

All interviews were conducted in Portuguese. Selected quotes were translated into English and included in this paper to illustrate common barriers to ART adherence reported by the interviewees. The selection of quotes aimed to cover all expressed viewpoints while avoiding redundancy.

### Analysis

Transcripts of the interviews were coded and the data analyzed for patterns of consensus, contrast, and variability. Data were analyzed using standard qualitative techniques, including contact summary sheets, inductive generation of coding categories, marginal remarks, and memos<sup>25,26</sup>. Each of these techniques is described below in more detail.

Contact sheets are used to summarize interviews or other field contacts, and to focus subsequent contacts<sup>26</sup>. After each interview in this study, a contact sheet was filled out that answered the following questions: (i) What was the physician's approach to communicate about ART adherence with patients? (ii) How did the physician try to assess and encourage patient adherence to ART? (iii) What was the non-ver-

bal context of the interview? (iv) Which areas of inquiry in the initial study framework – patient-provider ART adherence communication – did the interview bear on most centrally? (v) What new hypotheses or speculations were suggested by the interview? (vi) What changes, if any, should be made in subsequent interviews?

Transcripts of each interview were also analyzed line-by-line, and codes were developed to label key themes in the data. Codes were generated inductively, using "open coding" methodology, in which investigators break down, conceptualize, and categorize the data<sup>25</sup>. Concepts are created when investigators place a label on "*happenings, events, or other instances or phenomena*"<sup>25</sup> (p. 61).

Atlas.ti, a software program for computer-based text search and retrieval, was used to help to manage data during the coding process. Specifically, all coded segments of data were entered into Atlas.ti and the program was then used to print all data corresponding to each individual coding category, allowing a better analysis of specific themes such as ART communication barriers/facilitators collected among different participants. These data were then again reviewed on a line-by-line basis and sub-codes were developed for each category (e.g. communication barriers include sub-codes such as insufficient time to talk with patient and lack of training).

In addition to coding, remarks were noted in the margins of interview transcripts and were further developed into memos during the analysis process. In qualitative methodology, marginal remarks reflect comments that occur to a researcher as coding proceeds<sup>26</sup>, while "*memos represent the written forms of our abstract thinking about data*"<sup>25</sup> (p. 10). Memos are used for analytical purposes; they do not simply summarize data, they make sense of it.

### Ethical procedures

The study was undertaken with the approval of the Rio de Janeiro State University Research Ethics Committee. Participants were given verbal and written information about the project and signed an informed consent form before being interviewed. No personal or identifying information was retained within transcripts. All interviewees participated on a voluntary basis and no financial incentives were provided.

## Results

Interviewee characteristics are summarized in Table 1. All interviewees had at least 3 years of experience working in the field of HIV/AIDS.

All interviewees cited patients' poor adherence to ART and clinical follow-up as a frequent and relevant problem in their practice. According to the interviewed physicians, every patient has some "non-adherence (skip) moments". Barriers to adherence identified by physicians were diverse, and related to patients' lifestyles, beliefs, and the quality and characteristics of the patient-provider relationship. Barriers to adherence identified in in-depth interviews are summarized below.

### Barriers to ART adherence related to patient-provider dialogue

- **Insufficient time**

The majority of physicians interviewed felt that a positive patient-provider dialogue helps to increase and maintain patient adherence. However, physicians often reported being overwhelmed, with insufficient time to assess patient needs or concerns that might affect ART adherence. Some physicians addressed this difficulty by referring their patients to other health professionals, such as counselors or nurses, who they felt were better equipped with the time and skill necessary to engage in dialogue with patients.

*"Well, you know. Some patients need more support, they come here and want to talk about their lives and problems, and you've got to be patient. Sometimes I'm really overwhelmed, and there's a huge line waiting for me outside. So I usually ask for help. There's a nurse who works with me, and she's really a good listener (...) [who] will listen to his/her problems carefully, and my nurse feels more useful than if she were doing bandages all day long (...) If there's no one available [to listen] to their unmet needs it can become a big problem. It's also a way to prevent relapses, non-adherence, and all those problems".*

- **Difficulty discussing adherence**

Some participants expressed uncertainty about how to discuss ART adherence with their patients, and as a result, either avoided discussing adherence all together or adopted a judgmental tone, as illustrated below.

*"Well, I'm not proud of it at all, but I've got to confess something to you. I'm the worst coun-*

Table 1

Basic descriptive data for the 40 physicians enrolled in the study. Rio de Janeiro, Brazil, 2001/2002.

Physicians characteristic	n	%
<b>Gender</b>		
Male	32	80.0
Female	8	20.0
<b>Ethnic background</b>		
White	36	90.0
Non-white	4	10.0
<b>Age (years), mean</b>	42 (range 30-52)	
<b>Number of years of experience in HIV treatment</b>	7 (range 3-10)	
<b>Specialized training</b>		
Board-certified in infectious disease	19	47.5
Board-certified in psychiatry	10	25.0
Board-certified in pulmonary disease	8	20.0
Board-certified in oncology	3	7.5

*selor you could ever find, and I really don't feel comfortable in asking my patients about adherence (...) I mean, I feel like it's something invasive to keep asking them all the time: How many doses did you skip last month? I also don't know how to start this kind of conversation, it seems like I'm always a kind of 'cop' trying to find something wrong, you know? It's really hard for me; I was never trained to be a counselor or anything like that (...) So, every time I can I prefer to skip this kind of conversation, it's better for all of us".*

*"I have some drug-using patients, and I know that they keep using drugs because they want to, they don't care at all. If they really wanted to quit, I'm sure that they would succeed. So, I kind of 'push-hard' with those patients. If they give me any excuse for skipping (ART) doses, I always tell them that this is all about a weak character and their drug-using habits. It's nothing about feeling sad or lonely, it's just a lack of perseverance; they just don't want to stop using drugs. And that's it. I don't want to talk for hours and hours with those guys, they don't deserve it. They've got to use the (ART) pills every day, and that's it. Am I being judgmental? Sure, but who doesn't judge other people's behaviors, thoughts and so on? ... So, is it better not to talk about this? Or is it better to argue? I don't know..."*

- **Lack of dialogue about adverse effects**

Patient-provider dialogue about medication side effects also presented problems. Although participants were generally aware of the importance of discussing possible adverse effects with their patients, physicians did not usually engage in a comprehensive dialogue about adverse effects before starting their patients on a new ART regimen. Some physicians, despite knowing that all ART regimens can cause side effects, preferred to avoid discussing the issue entirely, as follows:

*“Yep, we all know that you’ve got to spend a lot of time talking about meds, side effects, prescriptions and so on before starting the therapy. But I’ve got to tell you the truth, sometimes I feel that I shouldn’t scare my patients that much, you know? I mean, what’s the point of telling a young woman that she might have lipodistrophy, that her body might change and stuff like that? I mean, she needs to take the meds, no matter what. I don’t want my young and good-looking patients to freak out, man! Let’s deal with side effects when they appear – if they really appear someday...”*

Some physicians remained reluctant to discuss side effects even after they had appeared, as illustrated in the following quote:

*“A patient of mine told me he couldn’t go on with his medicine, Viracept. He told me he had diarrhea, he couldn’t swallow the pills, and that his leg vessels were getting ugly. But what am I supposed to do?(...) I mean, they’ve got to handle it, or they can die of pneumonia, tuberculosis, or another opportunistic infection. When they come to me with this kind of explanation for quitting their treatment, I just say: OK, you don’t want to have diarrhea, just stop your meds. But when you get pneumonia or other stuff, please don’t look for me. It’s better to have an ugly leg and diarrhea, but still to be alive...”*

#### **Barriers to ARV adherence related to patients’ characteristics**

- **Patient lifestyle**

Some physicians cited difficulties with adherence caused by patients’ social habits and routines. As illustrated by the following quote, some physicians felt that improved understanding of an individual patient’s lifestyle can increase adherence by guiding development of a regimen to fit the patient’s specific needs.

*“I had a patient who was working as an airline crewmember, and she traveled a lot. She was using a medication that had to be taken*

*three times a day. Once, she came to me and said: ‘Doc, I just can’t handle it anymore. I’ll never be able to follow your prescription, you know? At 3pm I’m always working, it’s just impossible!’ And then we talked a lot about the importance of taking her meds on time, about her quality of life and many, many other things. Then I presented her all other treatment choices we had, and together we chose a regimen she could take twice a day. Also I asked her to use a beeper as a kind of reminder tool. Thanks to our open dialogue, we made it. Nowadays she’s more adherent and healthy”.*

- **Patient beliefs about HIV/AIDS and ART effectiveness**

According to participants, patients’ inadequate knowledge and negative beliefs about HIV disease and treatment effectiveness present an important barrier to ART adherence. Again, providers felt that an open dialogue with their patients played a key role in overcoming such difficulties. Below we present two quotes in which physicians tried to clarify their patients’ misunderstandings about treatment, with different outcomes. These quotes highlight the importance of using a culturally sensitive approach to discussing adherence.

*“A patient of mine told me that she needed a drug holiday. She told me that even her traditional healer agreed with her. This guy told her she had taken so many pills that she had a kind of ‘superpower’ inside her. I just wanted to kill myself! I was so angry that I even shouted at her. So I told her that this healer knew nothing about AIDS, that I was her doctor and I knew what was best for her. I also told her this superpower doesn’t exist at all, and that all this theory was completely stupid. I explained (...) all the problems she could face if she really decided for a drug holiday. So I wrote her prescriptions, made her next month’s appointment, and begged her to forget this crazy idea and keep taking her pills as usual. After that she never came back...”*

*“Once a young patient of mine told me something like this: ‘Doc, I’ve already taken too much AZT. I’m done. If I keep taking those pills, I’m going to get sick (...). I saw Cazuza [a Brazilian rock star who died from AIDS in 1989] die from taking AZT...’ Quickly I thought: I’ve got to be careful here. Then I explained that (...) when Cazuza was sick, we had only one medicine available – AZT. I also told him that he [the patient] was taking three different meds, and not only AZT (...) and how his therapeutic regimen was effective. Then I explained to him the possi-*

*ble consequences of a drug holiday (...) We also talked about side effects and how we could manage them (...) now he is still taking the same meds, we achieved an undetectable viral load, and he's getting better and better".*

- **Patient perception of disease severity**

According to all interviewees, patients who have experienced AIDS-related symptoms they perceive as serious are usually more adherent than patients who have never had symptoms, or who consider their symptoms unimportant. The influence of self-perceived vulnerability on ART adherence is illustrated in the following quotes:

*"I had a patient, an old man who almost drove me crazy (...) He was always drunk, skipped pills all the time, and his treatment was a big mess. Then he got pneumonia and was hospitalized for a few months. You won't believe it, but after this pneumonia he became a kind of perfect patient. He's adherent, he never skips pills or misses an appointment, and he even looked for help to quit alcohol with AA meetings. It's strange, but sometimes they just change after a painful experience, when they really feel their lives are vulnerable. I mean, it's completely different to listen to someone telling you what will happen if you keep skipping your pills, and to really feel what happens".*

*"I have a patient, a young good-looking girl. She's pretty, 23 or 24 years old, and never had any disease symptoms. She got her HIV diagnosis when she came here with her fiancé, looking for a kind of check-up before they got married (...) But I guess that HIV is something really far away from her. I mean, she's a young, good-looking girl and doesn't want to think about her HIV infection every time she takes a pill, you know? She is always telling me that she sees a perfect and healthy person in her mirror. So she's always skipping doses, and she travels and forgets her meds at home, it's a mess. So, what am I supposed to do? I just can't change the way she feels and thinks about it..."*

## Discussion

According to the international literature, adherence should be recognized as a complex behavioral process influenced by factors including medication regimen<sup>12,27</sup>, provider-patient relationship<sup>16,28</sup>, and patients' attitudes and beliefs about medication-taking and disease<sup>29,30</sup>. We found that discussions between patients and physicians about the patients' con-

cerns and well-being can encourage or, if absent or misguided, discourage adherence to drug regimens and retention of patients for follow-up, as well as helping to mediate the impact of patient beliefs on adherence.

Guidelines for ART care, including those issued by the Brazilian Ministry of Health<sup>31</sup>, recommend that physicians discuss treatment-related issues with their patients. We found that this recommendation was often not appropriately translated into clinical practice by the physicians in our study. Several physicians in the study did not feel that they were communicating effectively with their patients about ARV adherence and the issues surrounding it. Some physicians expressed uncertainty regarding how to broach the topic of adherence with patients, while others were simply not willing to discuss such issues with patients, or felt that they lacked adequate training and/or counseling skills. Others tried to engage their patients in a discussion about lifestyle and ARV adherence, but did not maintain an open and non-judgmental dialogue.

Insufficient time also played a major role in limiting participants' communication with their patients. Mainly due to understaffed services, the physicians interviewed were generally overwhelmed and had high caseloads. As a result, many physicians had to limit the amount of time they devoted to discussing treatment-related issues with their HIV-positive patients. These findings agree with those of a qualitative study conducted by Roberts<sup>32</sup>, which found that time constraints impaired physician-patient dialogue about adherence, and illustrate the barriers to adherence that can be posed by resource limitations and staff-constrained services.

Although adverse effects of medications may be inevitable, we found that insufficient provider responsiveness to patient concerns about ART side effects may increase the barrier these effects present to adherence. In contrast, effective communication and responsiveness to conflicts between patients' lifestyle and the requirements of medication regimens can act to improve patient adherence.

Corroborating the findings of a previous study by Gao et al.<sup>33</sup>, our results suggest that patients who have experienced more health complications perceive a stronger relationship between poor adherence and AIDS-related symptoms, and are more adherent to their medication regimen, when compared to patients with no prior complications. An open and culturally sensitive dialogue between patient and provider about the importance and effectiveness of ART

may have the potential to improve adherence among patients who report they are “feeling healthy” and are therefore skipping doses. On the other hand, conflicts between physician and patients’ beliefs can aggravate existing barriers to adherence, and may lead to the loss of patients for follow up.

Results of this study indicate that physicians in Rio de Janeiro may benefit from additional training about adherence counseling<sup>23</sup>. Given the potential for health care providers to increase (or jeopardize) HIV treatment adherence, it is imperative that patients have access to additional sources of information and support. Physicians should be trained and have the resources to refer patients to different services and/or colleagues. The health care system should develop a referral network of low-threshold services, including mental health facilities, drug treatment centers, and social support facilities such as shelters, and monitor to ensure that individuals are able to access the services to which they are referred.

Our findings reiterate the importance of individualized care for achieving optimal patient adherence. Improved collaboration between NGOs, community-based organizations, and health services could help provide targeted support for adherence, including peer education, adherence groups, and information and educational materials, to specific populations. Such collaborations could also provide a more culturally sensitive environment to meet the needs of specific vulnerable populations, such as women, drug users, and the homeless.

Our recommendations of improved training, increased collaboration with NGOs, and establishment of a referral network should be feasible within the resource constraints of the

Brazilian health care system, as their implementation would not require the creation of new health services or expensive health infrastructure. An increased role for collaborations and referrals could also reduce the caseload of physicians at overstrained health reference centers, allowing them to offer better treatment and care.

Some limitations of the present study should be noted. We assessed a sample of physicians recruited only in reference centers in Rio de Janeiro. Future studies should explore the patterns of adherence communication in settings such as primary health care centers, which serve fewer HIV-infected patients and are staffed by physicians who do not specialize in treating AIDS. By including patients, future studies should also examine an alternative perspective on the patient-provider relationship.

In addition, the study relied solely on interview data. Further research, including participant observation, is needed to capture actual interactions between physicians and patients. In addition, associations between styles of physician-patient communication and behavioral and clinical outcomes should be assessed using quantitative methods.

In conclusion, adherence to ARV therapy is likely to remain of utmost importance for years to come. Effective adherence strategies can improve viral suppression and health outcomes for people living with HIV/AIDS<sup>22,34,35</sup>. Achieving optimal adherence requires the commitment of both patient and provider. Physicians can best serve their patients by providing thorough information and open discussion about ART adherence beginning prior to the initiation of therapy and extending throughout the patient’s lifetime.

## Resumo

O Brasil fornece gratuitamente terapia anti-retroviral (ARV) para cerca de 150 mil pessoas vivendo com HIV/AIDS. A terapia ARV requer aderência ótima, visando alcançar carga viral indetectável e evitar resistência viral. Os médicos desempenham papel central quanto à aderência à ARV, mas há escassa informação sobre a comunicação entre médicos/pessoas vivendo com HIV/AIDS. Entrevistas em profundidade foram realizadas com 40 médicos assistentes de seis hospitais de referência do Rio de Janeiro, Brasil. Tópicos da entrevista incluíram: experiências relativas ao tratamento de pessoas vivendo com HIV/AIDS, relacionamento/diálogo com pacientes, barreiras/facilitadores para aderência aos serviços disponíveis e eficácia destes. As barreiras para aderência à ARV se referiam, principalmente, ao relacionamento médico-paciente. Outras barreiras estavam relacionadas a estilos de vida "caóticos" de alguns pacientes, conhecimento inadequado/crenças negativas sobre HIV/AIDS e a eficácia da ARV. É necessário melhorar as redes de serviços de saúde, com encaminhamento mais ágil e maior integração entre diferentes profissionais de saúde. Essas mudanças estruturais podem melhorar a aderência e a qualidade de vida das pessoas vivendo com HIV/AIDS.

*Síndrome de Imunodeficiência Adquirida; HIV; Terapia Anti-retroviral de Alta Atividade*

## Contributors

M. Malta planned and conducted the study under the supervision of F. Freitas. The empirical data were analyzed jointly by M. L. Petersen, S. Clair, and F. I. Bastos. All the authors participated in drafting the article.

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