



Psycho-social and Care Delivery Challenges of HIV/AIDS in the Dominican Republic: Impairment of Patient Outcomes

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Abstract

Objective: The aim of this pilot study was to identify HIV/AIDS care delivery gaps from both caregiver and patient perspectives, in a high risk region of the Dominican Republic. Furthermore, the study hopes to establish baseline data on psychosocial issues of HIV/AIDS in the Dominican Republic. The study further analyzed these factors in the context of current national policies.

Methods: The study, conducted at Boca Chica HIV/AIDS Clinic in the Dominican Republic, consisted of two parts: 1) a retrospective review of 300 patient clinical charts and 2) personal interviews with 52 patients, 15 physicians, 7 nurses, 5 social workers and 11 hospital administrators.

Results: Major barriers to accessing care identified were patient education, training for healthcare professionals, lack of funds, transportation and inconvenient clinic hours. Over half of patients believed that supernatural means to healing could be utilized as a sole path to disease management. Only 21% indicated they had continuous access to medication. Although patients trusted the clinic in terms of confidentiality, 60% expressed a fear of inappropriate information. Social workers, physicians, and nurses identified stigmatization as a major healthcare barrier, but this view was held by only 17% of patients. Administrators identified documentation and equipment as major areas that need improvement. All 300 records were missing some piece of data such as follow-up dates for appointments, medication histories, social histories, income information, or psychiatric histories, and 33% had no record of a physical exam. Only 62% of physicians, nurses, social workers, and medical administrators were aware of national programs that collect HIV/AIDS information and how they function.

Conclusion: Our results warrant new programs and development of a robust and coherent multidisciplinary approach to HIV/AIDS care delivery as a capacity-building national policy. Furthermore, our observations indicate that the lack of effective implementation programs adds to the complexity of HIV/AIDS care services.

Keywords: HIV/AIDS; Psycho-social challenges; Multidisciplinary care approaches; Capacity-building needs; HIV policy; Barriers to HIV/AIDS care; HIV/AIDS dominican public

Introduction

The incidence of HIV/AIDS in the Dominican Republic is 1.7%, with rates in urban areas exceeding 10% [1]. Its increased levels of tourism, coupled with its low income per capita, make the Dominican Republic an important site for research on HIV/AIDS care delivery and outcomes [2]. Tourism areas such as the Boca Chica district have been linked to an elevated vulnerability to HIV/AIDS infection and high prevalence of risky sexual behaviors, with sex workers exhibiting disease prevalence five times higher than individuals that don't engage in for profit sexual activities [2,3]. Despite the high prevalence among sex workers, the government has neglected implementation of HIV/AIDS prevention programs geared toward the realities of the tourism sector. Thus, the lack of strong policy increases the exposure of the local population to the virus [3]. While this might explain the high

prevalence of HIV/AIDS in tourism areas such as Boca Chica, conceptualization of contributing psychosocial factors must be further examined to gain a full understanding of the situation.

Psychological issues faced by HIV/AIDS patients include the anticipation of losses, shame and stigmatization [4]. Concurrently, major social issues such as poverty and poor education levels are encountered in the Dominican Republic [5]. Such factors indicate the need for sustainable psycho-social treatment infrastructure. Other studies have demonstrated that transportation costs and distance, staff shortages, long waiting times, drug side effects, and the need to take time off work were major social factors in poor treatment outcomes [6]. Further, social risk factors that affect medication adherence in Dominican patients were studied, including lack of social support and appropriate cultural interventions [7]. The absence of a framework for psycho-social counseling, monitoring, and evaluation is an impediment to patient well-being.

While national policies in the Dominican Republic guarantee free care, the system is overwhelmed by high patient numbers and is

incapable of meeting population needs due to state institutions hampered with political patronage-driven hiring practices, unnecessary bureaucratic steps, and inadequate financial management [8]. The issue of overcrowding is further exacerbated by the inappropriate surveillance system and a shortage of healthcare professionals devoted to non-discrimination [9]. Regulations have not been established to register and accredit providers, set minimum standards for healthcare facilities, and establish quality control to protect consumers, in spite of such measures having been mandated by legislation [10]. The absence of adequate monitoring undermines the efforts to control endemic diseases. Additionally, patients complain of insufficient antiretroviral (ART) medication supply despite governmental assistance [11]. A lack of social services is evident, as social workers perform their duties without institutional support [2].

Materials and Methods

Overview

This research is based on a previous study [2] conducted by the Michigan State University Institute of International Health in the Boca Chica HIV/AIDS Unit. Our approach had two components: 1) a retrospective and quantitative review of 300 clinical charts, and 2) interviews of hospital staff members and patients. It is generally similar to other clinical settings in the rest of the Dominican Republic, outside Santo Domingo due to its lack of delivery systems, location in a high HIV setting, and low government funding of healthcare resources such as TB and Retroviral drugs. Similar clinical settings are widespread in the countryside in areas such as Bateyes and San Pedro de Marcoris where the prevalence of HIV/AIDS is high but low income clinics, such as the one in Boca Chica, are unable to provide care [11]. Furthermore, the Boca Chica HIV/AIDS clinic is the sole provider of care in the area. The latter ensures that the sample studied was representative of the afflicted local population.

Data comparisons utilized chi-square analysis, either with or without the Yates correction depending on expected cell frequencies. Two-by-two tables with very small expected cell frequencies were analyzed using the two-tailed Fischer Exact Test.

Clinical Chart Review

We conducted reviews of all the clinical charts available at the clinic (300 total), covering a period from 2005 to 2012. Of the 300 charts, 90 belonged to males, 109 to females, and the remaining 101 did not have gender information available. The purpose of this chart review was to assess the services that were being provided by the clinic and how frequently they were used by patients. To ensure accuracy, the researchers created a systemic framework on objective characteristics. Based on already existing templates [12,13] to act as a checklist for thorough revision of the available paper-based medical charts. Each patient's record was reviewed by the investigators for presence or absence of documentation of 20 items including physical exam forms, social history, sexual history, bloodwork orders, and other health concerns. The charts were reviewed by the first two authors of this study. Items for review, and coding of those items, were agreed on beforehand based on what relevant data were contained in the medical records.

Interviews

The approval for this investigation was granted by the Institutional Review Board at Michigan State University and by the Boca Chica Hospital. This pilot study conducted interviews on a series of 52 patients over 2 weeks (28 males and 24 females). All participants were required to sign informed consent forms.

We also interviewed 15 staff physicians, 5 social workers, 7 nurses, and 11 administrative staff. These numbers were not predetermined and represent the maximum number of individuals that were available during the study. Twenty two patients were questioned regarding religious psychosocial barriers with a gender division of 11 males and 11 females. The difference in sample size (from 52) is due to the later addition of 3 religious questions which dealt with beliefs in being cured through supernatural entities, practitioners who perform supernatural curing rituals, and their adherence to those methods only while disregarding medical treatment. This question was added at the suggestion of our unit liaison halfway through the study as it was an important factor that he observed through his work in the area. Non-HIV/AIDS status patients, inpatients, and staff members not regularly providing HIV/AIDS care were excluded from the interviews. The content of each questionnaire varied among subgroups (i.e. patients, physicians, nurses, social workers, and administrators, as the questions were intended to match the responsibilities and lifestyle of each subgroup. Each survey lasted 25-30 minutes and no personal identifiers were documented. Participants were interviewed individually with closed-ended questions in a setting that ensured privacy. Since the researchers were fluent in Spanish, no interpreters were utilized. All materials utilized during the study were in Spanish, the official language of the Dominican Republic [14-16].

Since this was a pilot study, and since we did not have any real basis to estimate anticipated differences in the variables surveyed, we did not attempt a statistical power analysis to determine the sample size. Hence, the sample size for this study was somewhat arbitrary and dictated by time and resources available.

Survey questions were generated based on literature review and suggestions from observed psychosocial healthcare barriers in the Boca Chica clinic from previous trips performed by the Institute of International Health at Michigan State University. Themes such as transportation, poverty, social stigma, and information disclosure were identified in the literature as major barriers to care in resource-limited settings and transformed into questions for the survey [17-31]. Examples of questions included:

- Does your physician inspire trust in allowing you to tell him personal information relating to your illness (please indicate in HIV unit and in main hospital)?
- What barriers usually prevent you from getting care at the clinic (indicate all that apply)? Please indicate distance travel to clinic in kilometers.

In addition, insufficient provider education, difficulties imposed by a lack of resources, and lack of culturally guided public health approaches were found to be barriers in the literature review [10,23] and incorporated into survey questions. Culturally guided health approaches were defined as the manner in which healthcare is delivered to patients in a familiar setting to them in terms of the behaviors and beliefs shared by the individual and his or her community. Studies have shown that health care delivered in a culturally guided manner tends to increase patient adherence [35]. Guidelines for conducting and structuring survey research were

obtained through the Institute of International Health and suggestions in the literature [34].

Results

Psycho-Social Barriers

The response rate among all five subject subgroups was 100%. Survey results showed that more males than females sought care every month, while relatively more females came once a week or for emergencies. Subjects were self-described as originating from low-income brackets and native to the Caribbean, except for one male patient who was Italian. Chart review results revealed that 63.9% of patients had medical visits two to six months apart, while 15.6% had visits every 1-4 weeks, and a small fraction (4%) visited in intervals greater than 6 months. The remaining 16.5% of patient charts lacked dates.

Overall, transportation and funding were the main obstacles to care identified by patients. A noticeable example of an obstacle to care was the long distance travelled by patients, an average of 31.7 km among study participants (Table 1). Transportation and home/work duties were barriers expressed equally by both genders. However, males expressed lack of funds, inconvenient clinic hours, and fear of HIV/AIDS stigma in greater proportion than females while females expressed long waiting times in greater proportion than males.

Furthermore, patients reported discontent with the limited clinic hours of operation and length of waiting times. During the duration of our study, the Boca Chica HIV/AIDS clinic was opened daily from 8 am to noon. Waiting times averaged between two to three hours. Moreover, we noticed that the physician-to-patient, and the nurse-to-patient ratios were on average 1:10.

Social Barrier Identified	Male (n=28)	Female (n=24)	Total (N=52)
Lack of Transportation	17	18	35 (67%)
Lack of Funds	21	18	39 (75%)
Inconvenient Clinic Hours	9	7	16 (31%)
Home/Work Duties	9	9	18 (35%)
Long Waiting Times	5	9	14 (27%)
Fear of Stigma Associated with HIV/AIDS	6	3	9 (15%)

Table 1: Social Barriers. Percentages of male and female distribution of patients who were interviewed for barriers that prevented HIV/AIDS care. No gender difference was significant by chi square analysis at $p \leq 0.05$.

In understanding religious beliefs as approaches to cultural disease causation models, 86% (19) of the 22 patients interviewed believed that a supernatural entity (Deity/God) could cure them of their illness. Furthermore, 72% (16) of these 22 patients believed that a supernatural/religious cure was all that was required for their disease to be healed. Only six patients believed that medical intervention was necessary. It was also found that only 36% [4] of females interviewed

believed in shamans, witch doctors, and spiritualists as methods of curing the illness. No males interviewed held this belief.

Patient access to medication such as antiretroviral and multivitamins was assessed. For the purposes of this study, access to medication was defined as the ability of a patient to obtain prescribed medications either at the Boca Chica HIV/AIDS Clinic or an outside location. We found that only 21% of the patient pool (N=52) always had access to medication. In contrast, 65% of patients reported to having access only some of the time, while 14% stated that they rarely or never had access to medication. Lack of income was offered as the main reason for inadequate access to medication by patients.

Results from the chart review showed lack of documentation of medication administered, follow-up, and compliance in all 300 charts. Additionally, only 31% charts indicated illegal drug use.

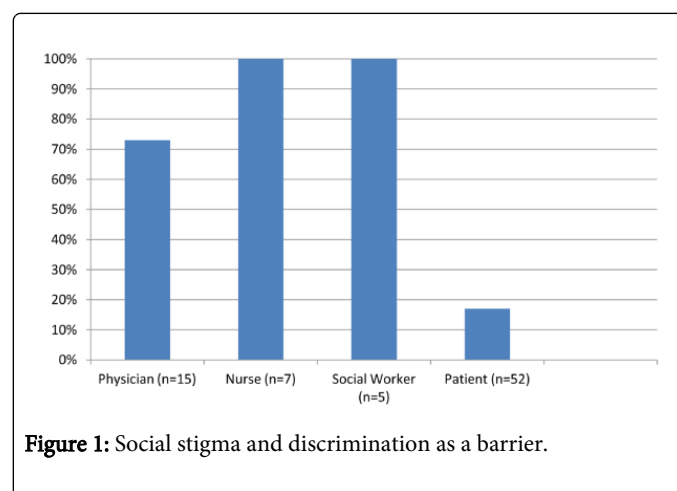


Figure 1: Social stigma and discrimination as a barrier.

Patient Information Disclosure

We further investigated lack of trust by requesting 52 patients to compare their trust levels in HIV/AIDS care physicians outside the unit via interviews. Our investigation showed 95% patients trusted the HIV/AIDS healthcare providers in the clinic while only 60% trusted providers outside of the unit. Nurses and social workers identified fear of social stigma and lack of confidentiality to be the most pressing issues affecting patient information disclosure.

We extended our investigation by asking the social workers about specific social stressors that they felt that patients experienced. Results showed they believed that social stigma and discrimination were major barriers in pursuing treatment, followed by inability to provide for the household, abandon sexual tourism and prostitution, and pay for treatment. It follows that social workers were much more likely (100%) than patients (17%) to identify stigma and discrimination as a major barrier to medical care (Two-tailed Fischer Exact Test $p < 0.001$). Both patients and social workers were asked directly. When comparing patient responses about stigma to pool staff responses, the chi square is 33.98, indicating a statistical significance at $p < 0.00001$.

Of 15 physicians interviewed, 11 identified fear of social stigma as a major barrier to full medical information disclosure (Figure 1). Other barriers identified by physicians included lack of proper staffing and inability of patients to understand the nature of their disease. Inability to understand the diseases was defined as either lack of knowledge of acquisition, pathological disease progression, disease management, or transmission to others.

Capacity Building Needs

The responses of eleven hospital administrators regarding funding needs for HIV/AIDS care are summarized in Figure 2. Administrators expressed concerns with record keeping, clerical needs, and hospital and laboratory equipment. These concerns revolved mainly around lack of funding and manpower on these areas.

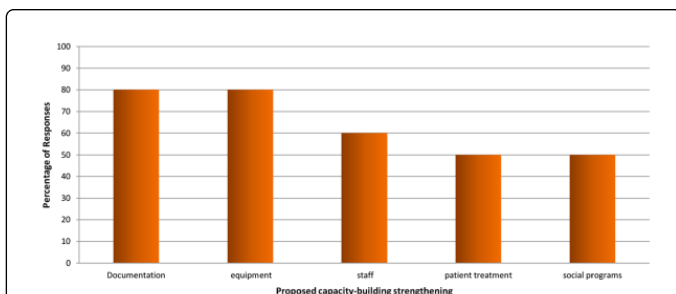


Figure 2: Proposed capacity-building strengthening.

According to clinic physicians, HIV/AIDS units in the Dominican Republic receiving governmental funding are mandated to maintain a specific set of data for the state for Public Health and Social Welfare (SESPAS), 68.5% (207) of the clinical charts in the Boca Chica Clinic failed to follow this standard. The given format is mandated by the government to assure proper collection of epidemiological data for statistical purposes, determine need of the clinical site, allocate funds, and evaluate use of those funds.

None of the charts reviewed contained income information or social history. All 300 records were missing follow-up dates on appointments and 33% had no record of a physical exam. 34% failed even to indicate the gender of the patient. Additionally, it was noted that the SESPAS form did not have a field for psychiatric history.

Medical care workers were also asked about their knowledge of national programs that collect HIV/AIDS information. This included physicians, nurses, social workers, and medical administrative staff (N=37). Results are shown in Figure 3 (Figure 3).

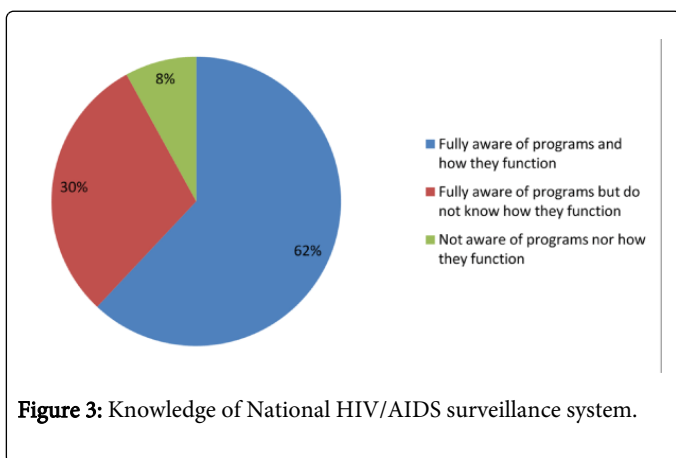


Figure 3: Knowledge of National HIV/AIDS surveillance system.

Discussion

Social Factors

Assistance with travel and finances, clinic hours, and wait times were frequently suggested as necessities by the data from both patients and caregivers. Responses from patients in our study suggested that the limited clinic hours of operation from 8am to noon made it challenging to seek care. Furthermore, patients reported waiting times of 2 to 3 hours. In other resource-limited countries, transportation limitations, low frequency of visits and limited clinic hours have been found to significantly prevent access to care [14]. In a pilot study, also conducted in Boca Chica, patients often failed to undergo HIV/AIDS testing because of the related costs in terms of transportation, safety issues and work or home duties [2]. To further complicate the issue, the patients are within an hour of distance by car to the closest laboratory capable of running genotype/phenotype testing. Without the means to obtain these tests, national program efforts are weakened and the probability of increasing resistance becomes higher [15]. Inaccessibility of genotype/phenotype testing, combined with an increased reliance on anti-retroviral therapy, contributes to the steadily increasing development of anti-retroviral resistant strains [16].

Financial limitations were problematic for several patients, as testified by field researchers. Many patients voiced lack of money for a taxi cab as an obstacle to access certain labs in the capital city, while others sold their shoes to obtain money for rides to the clinic. Economic and financial barriers have implications on antiretroviral drug resistance and poor health outcomes. Also contributing to the development of drug resistance in Boca Chica is limited access to medications, clinic hours, and low frequency of visits. Studies have shown that changes in both pharmacological accessibility and quality of care, which are generated by these factors, have a tendency to increase and influence drug resistant patterns in HIV-1 individuals [36]. Our study found that most patients (n=52) only visit the clinic once a month (68.52%) with 20.37% of patients visiting once every 6 months or only on emergencies. Additionally, our study found that 79% of patients had access to medication either some of the time or none of the time. Inconsistent access to medication and follow-up visits predisposes patients to ART therapy reversal and the development of opportunistic infections. Consequently, such patients have limited drug options for future treatment [17]. This inconsistent access contradicts the principles of the HIV/AIDS Dominican National Program, which guarantees the universal provision of medication at no cost. It was learned during the study that the reason for limited medication access was mainly stock-outs.

Inadequate epidemiological surveillance policy is another issue in the Dominican Republic and it is attributed to inefficient countrywide data collection [18]. This was demonstrated by the use of outdated government forms as well as over 1/4 of providers' lack of awareness regarding national surveillance program. Despite WHO guidelines [19] indicating that HIV/AIDS patients require a physical exam during each visit, many lacked documentation of such an exam. Moreover, lack of computer access in the rural clinics created inconsistencies in submission to national surveillance databases. Given that disease trend surveillance is crucial for tackling the underestimation of HIV/AIDS rates and proper allocation of resources, our findings warrant policy changes [9]. Without a proper surveillance system, it is impossible to generate accurate policies that answer the needs of the population with evidence-based approaches.

Our results indicate that the current governmental provision of free treatment unaccompanied by transportation support for improved access to care is ineffective. Many patients voiced that they live far from the unit of care making it a challenge to keep up with follow-up visits and medication refills. Consequently, we recommend that HIV/AIDS clinics implement home visitation programs. The AIDS Relief Program has demonstrated such programs can significantly improve transportation barriers [20]. Incorporation of home visits would further ameliorate the issues of inconvenient clinic hours and geographical barriers found during our study.

As seen in other studies, use of alternative medicine methods correlate with decreased antiretroviral adherence and therapy discontinuation [21]. In fact, 72% of interviewed patients believed they could be cured without medical intervention. Such practices have been associated with decreased condom use, as well as less intention to engage in safe sexual practices [22]. In addition, many who find themselves infected with HIV/AIDS seek supernatural treatment and shy away from modern medicine. Such behaviour leads to disease progression and future infection of other individuals [23]. Interestingly, our study found that a belief in shamans, witch doctors, and spiritualists was only associated with the female gender in our sample while males believed that their illness could be cured solely by a supernatural intervention. This warrants gender-specific intervention and the inclusion of religious leaders in the treatment plan, as they are capable of shaping social values and influencing attitudes [24]. In Uganda, similar approaches, such as incorporating religious beliefs in educational campaigns and counselling sessions have led to increased knowledge of HIV/AIDS, increased contraceptive use, and decrease in multiple sexual partners at the community level [25]. Alternatively, interventions geared to males could incorporate sports as a means to increase HIV/AIDS knowledge [26].

The World Bank [27] states that in 2011 42.2% of residents lived in poverty and that during 2010, 10% of the population lived in extreme poverty. These figures make it apparent that low socioeconomic status due to unemployment, low wages, or poor education is relatively common in the Dominican Republic. HIV/AIDS has been the greatest burden on poor populations, impacting livelihood and development at the individual, household, and country levels [28]. Despite this, all reviewed charts lacked information regarding patients' social history. Lack of proper documentation prevents resource allocation, weakening the sustainability of the HIV/AIDS national response. However, before any of these implementations can take place, a structured social support system must be built. During our investigation, it became apparent that the Dominican Republic does not currently have an adequate number of social programs available for food, clothing, and housing. Despite this finding, only 50% of the interviewed administrators indicated social programs as an underfunded area. A report published by the International Development Bank showed that the Dominican Republic had one of the lowest levels of social expenditure in Latin America [29]. Low social expenditures and persistent rural poverty warrant reforms with more focus on social programs.

Psychological/Psychiatry

Social stigma is a major stressor experienced by HIV/AIDS patients [30]. Dominican Law 135-11 calls for the penalization of those who discriminate based on HIV/AIDS status. However, there is a lack of enforcement as the staff in the clinic stated that fear of social stigma continues to be a barrier to medical disclosure. According to the

survey responses, only a few patients seemed to be concerned with stigma, but many admitted to the social workers that they did not want to reveal they were discriminated against. The social worker further mentioned that some providers outside the unit refuse to provide treatment. These findings agree with studies showing that in the Caribbean, healthcare professionals have been found to make treatment decisions based on HIV/AIDS status rather than mental health needs [31].

Studies have reported that individuals experiencing high levels of stigmatization are more prone to depression and compromised immune systems [32]. Additionally, depression negatively affects medical adherence, developing drug resistant strains [33]. This serves as justification for the development of mental health services. In 2006, law 12-06 on mental health was endorsed, making mental health a right. Additionally, the Dominican Republic engaged in a ten-year plan that involves improving mental health services [29]. In spite of this, our study found that none of the records contained evidence of providing mental health counselling. As a response, it is suggested that healthcare professionals be trained in the early treatment and recognition of mental health deterioration. Furthermore, development of special certificate programs targeting HIV/AIDS and mental health in collaborations with universities was suggested.

Currently, little literature is available on the topic of psychosocial HIV/AIDS factors and their association with national policies in low income areas of the Dominican Republic. Findings of this pilot study may serve as baseline data for future studies.

Conclusion

The results of this study are broadly consistent and expand on previous literature. Our results show that transportation and finances are larger obstacles to treatment for patients than stigmas and discrimination. They also highlight the prevalence of potentially maladaptive health beliefs (e.g. belief in cure of HIV/AIDS without medication). Furthermore, this pilot study explored factors relevant to HIV/AIDS care from perspectives of caregivers and patients in the context of current policies. We have found that the social ecology system provides a positive framework for understanding relationships between individuals and social factors. Extra-familial factors such as communication with caregivers and treatment adherence issues indicate a lack of structured social and psychological support system. It is necessary to cultivate a professional and integrated approach to HIV/AIDS care to effectively establish communication networks in the Dominican Republic. This strategy should be an essential element of capacity-building at the national level.

For HIV/AIDS-diagnosed patients, counseling, including psychological and social support from trained individuals, is highly recommended. This step may be crucial to ensure the patient's well-being. Public education on HIV/AIDS and its treatment is also important. It is necessary to educate patients and families on the importance of medical care, regardless of beliefs in divine intervention. Strengthening the HIV/AIDS care system through CMEs, targeted training, specialty recruitment, and retention of health-care workers is imperative to building a strong national commitment and achieving optimal standards of care.

Limitations

The conclusions of this study are limited by small sample size, lack of extensively validated interview schedules, and lack of questions on

important issues such as mental health status. The poor quality of medical records reviewed is a weakness of this study, as well as of the care being provided at this time. In addition, the conduct of this study at only one site may limit its generalization.

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