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1 **A qualitative view of the HIV epidemic in coastal Ecuador**

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18

19 **Abstract:**

20 In 2013 approximately 37,000 people were living with HIV in Ecuador (prevalence
21 0.4%), representing a generalized epidemic where most new infections arise from sexual
22 interactions in the general population. Studies that examine attitudes towards people
23 living with HIV (PLWH), individual risk perception of acquiring HIV amongst
24 Ecuadorians, and the ways in which levels of risk perception may affect risk behaviors
25 are lacking. This qualitative study aimed to fill this gap in the literature by investigating
26 these issues in the rural, coastal community of Manglaralto, Ecuador, which has among
27 the highest incidence of HIV in Ecuador. We conducted interviews with 15 patients at
28 Manglaralto Hospital. Analysis of interview transcripts revealed widespread negative
29 attitudes towards PLWH, prevalent risk behaviors such as multiple sex partners and lack
30 of condom use, and low individual risk-perception of contracting HIV. These findings
31 underscore the need for increased efforts to prevent further growth of the HIV epidemic
32 in Ecuador.

33

34 **Keywords:** HIV/AIDS, Ecuador, HIV risk behavior, HIV risk perception, HIV attitudes

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36

37

38 **Introduction:**

39 Available data show that the HIV epidemic in Ecuador affects heterosexual people living in
40 the coastal regions of the country. In 2013 there were approximately 37,000 people living
41 with HIV (PLWH) in Ecuador, representing a prevalence of about 0.4% of adults ages 15
42 to 49 (UNAIDS, 2013). The majority of cases of HIV were among people ages 20-44 and
43 more than 80% were in the heterosexual population as of 2007 (UNGASS Ecuador, 2008).
44 A 2008 report from the Ministry of Public Health reported that 99% of cases were spread
45 through sexual contact, defining the primary route of transmission of HIV in the country
46 (CARE, 2008). The Pan American Health Organization estimates that 74% of the cases of
47 HIV/AIDS are concentrated in coastal regions (PAHO, 2012). Santa Elena province, the
48 site of the current study, is a coastal province with the third highest HIV incidence in
49 Ecuador at 10.87 cases per 100,000 inhabitants (Ministerio de Salud Pública del Ecuador,
50 2010). Recent evidence indicates that HIV prevalence in coastal regions of Ecuador may
51 even exceed 1% among pregnant women (Sánchez-Gómez et al., 2013). The available
52 evidence suggests that Ecuador faces a generalized HIV epidemic that is concentrated in
53 coastal regions and predominantly sexually transmitted among the general population
54 (Sánchez-Gómez et al., 2013; UNAIDS, 2008).

55

56 The current scope of research on HIV in Ecuador is limited. Prior research has primarily
57 focused on specific populations such as men who have sex with men (MSM) and
58 commercial sex workers (Bautista et al., 2008; Grant et al., 2014; J.-P. Gutiérrez, Molina-
59 Yépez, Morrison, Samuels, & Bertozzi, 2006; J. P. Gutiérrez, Molina-Yépez, Samuels, &
60 Bertozzi, 2006; Jacobson et al., 2014; Solomon, Smith, & del Rio, 2008). While several

61 studies of HIV knowledge, attitudes, and behaviors have been conducted elsewhere in the
62 country, little is known about rural, coastal regions where prevalence rates are among the
63 highest in the country, and general healthcare is less readily available (Cabezas,
64 Fornasini, Dardenne, Borja, & Albert, 2013; Chedraui, Van Ardenne, Wendte, Quintero,
65 & Hidalgo, 2007; Dearborn, Lewis, & Mino, 2010; PAHO, 2012; Park, Sneed, Morisky,
66 Alvear, & Hearst, 2002) .

67

68 Specifically, research is needed to better understand the potential social and ecological
69 factors influencing the spread of HIV in the general population. Of the models that exist
70 to describe HIV prevention and risk behaviors, several have demonstrated that
71 interpersonal factors, perceived social norms, and social environmental factors
72 substantially influence HIV risk (Ajzen, 1991; Ewart, 1991; Fisher & Fisher, 1992).
73 However, there is also very little known about individual risk perception amongst
74 Ecuadoreans. A deeper understanding of these issues can provide information about
75 factors that might influence the spread of HIV, and in turn might elucidate the most
76 relevant content for HIV prevention initiatives in the area.

77

78 Accordingly, this qualitative study aimed to develop new knowledge about HIV attitudes,
79 risk behaviors, and risk perceptions in the rural, coastal community of Manglaralto,
80 Ecuador. This study was nested within a larger quantitative investigation that broadly
81 sought to understand the Manglaralto community's knowledge about and behaviors
82 concerning HIV and HIV testing. A sub-set of those who completed the quantitative
83 survey was invited to participate in in-depth interviews to explore these issues further and

84 understand possible individual and contextual factors not easily captured by quantitative
85 surveys. The goal of the current study was to generate insight into actions that could be
86 taken to improve regional HIV prevention, diagnosis, and treatment efforts in this setting.

87

88 **Methods**

89

90 *Setting*

91 The study was conducted from May to August of 2013 at the Manglaralto Hospital, a
92 public hospital in the town of Manglaralto in the Santa Elena province on the
93 Southwestern coast of Ecuador. It is the smaller of two hospitals in the province and
94 serves residents of the northern portion of the province. The Manglaralto Hospital
95 provides anonymous and free HIV testing and counseling to anyone who requests it. This
96 site was selected because the Santa Elena province has the third highest HIV/AIDS
97 prevalence in Ecuador, the hospital is easily accessible by public transportation, and the
98 hospital administration and staff were interested in the issue of HIV in their community.
99 Interviews were conducted at the hospital in a private setting in which participants could
100 openly discuss sensitive issues such as HIV/AIDS and their own possible HIV-associated
101 risk behaviors.

102

103 *Study Sample*

104 The sample for the qualitative sub-study comprised 15 out-patients (7 men, 8 women)
105 who visited the Manglaralto Hospital. They were recruited during medical clinic hours
106 and selected by purposive sampling based on demographic information obtained through

107 the larger study's quantitative survey. Inclusion criteria for both the main study and this
108 sub-study were that participants be (1) over 18 years old and (2) a resident of the Santa
109 Elena province. Recruitment continued until no additional themes emerged (i.e.,
110 saturation).

111

112 ***Study Procedures***

113 Following their completion of the quantitative survey (n=343), purposive sampling was
114 used to select patients selected for inclusion in this study based on gender, age and
115 education, and invited by a member of the research team to participate in an interview.
116 Approximately 15% of those asked to participate in the interview refused, either for
117 logistical reasons (e.g., did not have time) or unease in being interviewed. All interviews
118 were conducted individually and anonymously. The interviews were audio-recorded and
119 typically lasted 60 minutes. The interviews were conducted in Spanish by a trained
120 interviewer who was not a native Ecuadorian but had lived in the region for many years
121 and was culturally competent. One other member of the research team (AB, MW, VP or
122 NS), with language proficiency in Spanish, was also present during each interview.

123

124 All study participants provided written informed consent prior to the audio-recorded
125 interview. The recordings were subsequently transcribed in Spanish. Any identifying
126 information was removed and replaced with pseudonyms.

127

128 In addition to receiving HIV/STI prevention brochures as part of the main study,
129 participants in the qualitative sub-study were also reimbursed for their time in the form of

130 a gift equivalent to US\$2 and given a Certificate of Study Completion. The research
131 study was approved by the Human Subjects Committee at Yale University (HSC Protocol
132 #1304011872) and the Board of Directors of the Manglaralto Hospital.

133

134 *Interview Guide*

135 A draft interview guide, based on existing literature and previous studies in the region,
136 focused on knowledge about HIV, attitudes towards HIV and PLWH, and sexual risk
137 behaviors. Prior to beginning study recruitment, the guide was modified based upon input
138 from local medical staff and patients from Manglaralto Hospital. The guide was further
139 modified to improve cultural sensitivity based on the initial interviews, and additional
140 questions were added to reflect emergent themes.

141

142 The domains in the final interview guide were: (1) HIV knowledge; (2) source of HIV
143 knowledge; (3) condom use; (4) HIV risk behaviors; (5) HIV risk perceptions; (6) HIV
144 prevention behaviors; (7) HIV attitudes and stigma; (8) friendships and social interactions
145 with PLWH; and (9) specific suggestions to improve local HIV prevention efforts.

146

147 *Analytic Methods*

148 Prior to arriving in Ecuador, the research team developed a preliminary coding scheme
149 based on the research questions. During data collection the research team (AB, MW, VP
150 and NS) met daily (and weekly with LG via skype) to review and analyze the data. Codes
151 were added based on emergent themes, and existing codes were refined, clarified, or
152 collapsed. This process was done iteratively until the codes were clearly defined and

153 similarly understood by all members of the research team. The first two transcripts were
154 then translated into English, independently coded in ATLAS.ti (version 1.0.2) by two bi-
155 lingual members of the research team (MW, AB) and discussed in meetings with the
156 senior author. Any coding discrepancies were resolved by consensus during these
157 meetings. Once inter-coding reliability was judged to be acceptable, the remaining
158 interviews were then coded in Spanish by MW and AB. A third transcript was translated
159 into English and reviewed (by MW, AB, LG) midway through the coding process to
160 ensure that coders continued to reliably assign codes. Quotes from the transcripts selected
161 for inclusion in the manuscript were translated into English. Given the community's
162 small size, participants are identified by only an arbitrary participant number, an age
163 range, and gender to protect their anonymity.

164

165 Analytical induction and comparative analysis were used to identify common patterns
166 and themes relevant to the research aims (Braun & Clarke, 2006; Clarke, Braun, Clarke,
167 & Braun, 2013). We sought out “negative” instances (i.e., comparative analysis that may
168 not fit initial constructs) in order to expand, adapt, or restrict the original conceptual
169 scheme. Coding and analysis was an iterative process and continued until saturation was
170 reached (i.e., no new themes or information emerged).

171

172 **Results**

173 *Study sample*

174

175 Table 1 provides demographic information about the study sample. The total sample can
176 be characterized as fairly young and minimally educated. The mean age for the total
177 sample was 38.9 years (11.5 SD), although males were approximately five years older
178 than females (41.6 vs. 36.1 years) (data not shown). Half of the total sample had
179 completed only a primary education. Two participants (one male, one female) reported
180 being college educated. Slightly fewer females had secondary education (data not
181 shown).

182

183 **[Insert Table 1]**

184

185 The major themes to emerge from the interview data were perceived negative
186 consequences of being infected with HIV, sexual behaviors that increased the potential
187 for HIV infection, and a tendency to minimize personal risk of infection.

188

189 *Negative consequences of being infected with HIV*

190 *Fear of discrimination and isolation*

191 Interviews revealed a consistent expectation that contracting HIV would lead to isolation
192 and retribution. Participants generally believed that society treats people with HIV
193 poorly. All participants noted the high levels of societal discrimination against PLWH.
194 Participant 1, a male in his 20s, stated that he would not tell other people that he received
195 an HIV test, explaining:

196

197 Because you know how society is here...They discriminate against those people
198 [with HIV]...Here in Ecuador the people discriminate a lot against people with
199 those types of sicknesses.

200

201 Many participants spoke specifically about their fear of abandonment and discrimination
202 by friends and family if they were to disclose a positive HIV test result. When asked how
203 a positive HIV test result would affect his friendships, Participant 2, a man in his 30s,
204 responded that “My friends, well, one always has friends in the street, but when one most
205 needs them they are no longer friends.” Similarly, Participant 3, a female in her 20s,
206 stated:

207

208 [My family would react in] a really bad way. [And friends would react] much
209 worse. Because they would leave you. And, family always protects you and with
210 time maybe they would come to understand...In contrast, friends would always
211 abandon you.

212

213 Participants also spoke of their community as being afraid of people with HIV.

214 Participant 4, a male in his 60s, elaborated on the notion of being afraid of people with
215 HIV and consequently leaving them in isolation, explaining:

216

217 A person who is infected...We, or most of us, are afraid to go near them because
218 they can infect you...And, I have seen in the press, in the movies, that someone

219 who is infected is not treated as important by anyone, so those people are left all
220 alone...And here it is even worse because no one will help you.

221

222 As a result of all the negative associations with HIV, some participants reported that they
223 would want to die if they were diagnosed with HIV. For example, Participant 5, a female
224 in her 30s, noted that suicide was preferable to the abandonment she would face by
225 having the disease.

226

227 As exemplified by these quotes, the majority of participants anticipated social isolation
228 and discrimination that would accompany being diagnosed with HIV. The general
229 attitude towards HIV can be summarized as one of perceived suffering and social
230 isolation.

231

232 *HIV as a deadly disease*

233 Almost all participants viewed HIV as an illness that involves much physical suffering
234 and tantamount to receiving a death sentence. As Participant 6, a male in his 40s, noted:

235

236 For me...in my case...or for the person that gets detected with the HIV virus...it
237 means to die slowly. I say this because it is a sickness that takes its course. From
238 what I have seen, you fall [ill] and you begin the symptoms bit by bit and, once
239 you realize that, you are already in the terminal stage...I have had some friends
240 with this disease, and I have seen that they are suffering.

241

242 ***Sexual behaviors that increase risk for HIV infection***

243 *Multiple sex partners*

244 Many participants, both male and female, described their culture as one in which
245 infidelity is pervasive and the primary way that HIV spreads within the community.
246 Specifically, they identified men as the ones most often engaging in extramarital sex
247 because it was an accepted phenomenon within the culture. No participants stated or
248 suggested that females in this community are unfaithful to their male partners. Typical of
249 others' opinions, one female participant referred to this practice as "the disobedience of
250 the men." Other participants elaborated on this theme:

251

252 Someone told me that these questions are confidential, so in that case...I have
253 also cheated on my wife, because I am a man. But I don't want to share more
254 about this. (Participant 6, a male in his 40s)

255

256 It's not that I have had sex with others...It's that my husband is a man, and the
257 men sometimes, you know, are going to have...[Pause.] Even with trust, one can
258 always walk on another path [*colloquial expression suggesting extramarital sex*]
259 and is going to have sex with someone else, and this person has had sex with
260 another person, and from that you can get infected. (Participant 5, a female in her
261 30s)

262

263 Infidelity was an acknowledged common occurrence, and participants did not believe that
264 there was anything to be done to counteract it. Interviewees viewed infidelity as a firmly
265 entrenched cultural practice.

266

267 *Lack of Condom use*

268 Condom use varied by type of sexual partner. The perception of trust within a
269 relationship often influenced the decision to use or not use condoms. Some men reported
270 using a condom with commercial sex workers or extramarital or casual partners. For
271 example, a Participant 1 (male, in his 20s) reported that he would use a condom in the
272 brothels, but that he would not use a condom with his wife since he trusts her.

273

274 Many women reported not using condoms with their husbands because of the trust in
275 their marriage and despite infidelity of males being commonly acknowledged. Female
276 participants who believed their husbands were cheating on them hoped that, but were
277 unsure if, their spouses used condoms in their extramarital affairs.

278

279 Both male and female participants described a variety of reasons why men prefer not to
280 use condoms. These reasons included issues of decreased sensation and the belief that a
281 female's desire for a male to use a condom was an indication that she was unfaithful.

282 Participant 7, a woman in her 30s, contextualized the situation for women by saying,
283 "...the truth is, here it is very difficult for you to say to your husband or your boyfriend,
284 'Use a condom.'"

285

286 *Perception of personal risk of HIV infection*

287 Many women identified females like themselves as at risk for contracting HIV because of
288 their husbands' sexual infidelities and the fact that they do not frequently use condoms
289 with their husbands.

290

291 I always hear on the television them talking about this sickness [HIV], and I think
292 that, they say that there are thousands of housewives [*“amas de casa”*] who are
293 the most infected because of the men who are unfaithful and are walking around
294 places where they don't need to be [*expression for extramarital sex*]. So, I think
295 we are the most affected. (Participant 8, a female in her 30s)

296

297 Acknowledging her vulnerability to infection, Participant 9, a female in her 40s, similarly
298 said that women are at increased risk for acquiring HIV because of their husbands' sexual
299 behavior. She believed she was at risk of contracting HIV because her husband is a
300 fisherman who is often away for periods of 15 days, and she believes he is unfaithful
301 during those absences.

302

303 Contrary to women's risk perceptions, men who stated that they engaged in extramarital
304 sex and did not use protection with their wives still considered themselves to be at low or
305 no risk for infection. They sometimes acknowledged that in general people who engaged
306 in these same activities were at risk, but they did not identify themselves as such. One
307 man, Participant 6 (male in his 40s), exemplified this attitude. He had previously
308 identified himself as having sex outside of his marriage and not using a condom with his

309 wife. However, he said he was confident that he was not at risk for HIV although later
310 noting that other men who are unfaithful are at increased risk of contracting HIV. He
311 recognized the theoretical risk associated with having multiple partners but did not
312 recognize his personal risk—even after acknowledging his own infidelity.

313

314 **Discussion**

315 To our knowledge, this is the first qualitative study to assess HIV attitudes, risk
316 perceptions, and risk behaviors in an open-ended fashion in a rural, coastal region of
317 Ecuador where HIV prevalence is among the highest in the country (Ministerio de Salud
318 Pública del Ecuador, 2010). The data indicated that a positive HIV test result was
319 considered by participants to be a lethal diagnosis, and participants were concerned about
320 potential isolation, discrimination, and erosion of their support system, particularly
321 friendships. Nonetheless, a few participants indicated that family would play an
322 important, positive role in helping PLWH cope. These results regarding community
323 isolation are consistent with other findings in Ecuador and parts of Latin America, which
324 reported isolation and discrimination on the basis of HIV status (Aggleton, Parker, &
325 Maluwa, 2003; Ayarza, R. & Reyes, B., 2002; Manji, Peña, & Dubrow, 2007; UNAIDS,
326 2013). The reported individual- and community-level negative attitudes towards those
327 with HIV are particularly concerning as it may discourage PLWH from disclosing their
328 status to sexual partners and negatively affect their quality of life, as is observed in other
329 parts of the world with high levels of HIV stigmatization (Brooks, Etzel, Hinojos, Henry,
330 & Perez, 2005; Centers for Disease Control and Prevention (CDC), 2000; Chesney &
331 Smith, 1999; Goldin, 1994; Herek, Capitanio, & Widaman, 2003; Weiser et al., 2006). If

332 lack of disclosure is accompanied by lack of condom use, the risk of transmission
333 increases, posing a serious public health threat.
334
335 Addressing negative attitudes towards those living with HIV should be a major part of
336 ongoing HIV testing and educational campaigns in Ecuador. Recommended strategies
337 include implementing educational campaigns that provide explicit information about
338 disease transmission and prevention, reframing HIV/AIDS as a chronic disease with
339 effective treatment options and providing consistent pre- and post-test counseling for
340 HIV screening tests (Mahajan et al., 2008; Obermeyer & Osborn, 2007). It is also
341 essential to fold HIV care and prevention into neutral and confidential healthcare and
342 community settings (Nyblade, Stangl, Weiss, & Ashburn, 2009). Given the negative
343 perceptions about HIV disease, one potential method could be to ensure that HIV services
344 are offered within the framework of general healthcare services, thus allowing patients to
345 request HIV-related services in a discreet manner. Finally, policy makers might want to
346 further investigate the ways in which HIV-related attitudes in the Santa Elena province
347 and throughout the country are inhibiting HIV testing and prevention.

348
349 Another major theme that emerged from the interviews was the high prevalence of risk
350 behaviors. Consistent with reports of *machismo* trends in other parts of Latin America
351 (Nyblade et al., 2009; Sternberg, 2000) participants viewed male infidelity as
352 commonplace in their community. Similar to other studies in Ecuador (Cabezas et al.,
353 2013; Park et al., 2002), some participants in our study minimized their risk of HIV,
354 despite engaging in HIV-associated risk behaviors. Since some men in the community

355 appear to be engaging in sex with multiple partners and having unprotected sex with their
356 spouses, our results demonstrate the need for condom use campaigns that focus
357 particularly on the importance of men always using condoms with new or casual sex
358 partners. To prevent men from transmitting STIs to their spouses, assertiveness and
359 condom negotiation training may be helpful for women whose husbands are suspected of
360 having multiple partners. Healthcare providers in Ecuador should also be trained to
361 consistently screen for risk behaviors in a way that will elicit truthful responses. As of the
362 time of this study, Ecuador was routinely testing only pregnant women for HIV
363 (Ministerio de Salud Pública del Ecuador, 2010). However, the current findings suggest a
364 need for providers to test all patients that report high-risk behaviors. To prevent the HIV
365 epidemic in Ecuador from growing, healthcare providers need to identify, treat and
366 counsel patients with HIV. Expanding HIV testing could also reinforce efforts to combat
367 negative attitudes, since increased testing is associated with reduced marginalization
368 (Weiser et al., 2006).

369

370 This study had some potential limitations. First, it is possible that a larger sample size
371 may have generated further insights into the topics we investigated; however, by the
372 fifteenth interview no new codes or themes were emerging, and therefore no additional
373 interviews were conducted. Second, these interviews were not conducted specifically
374 with PLWH, and their voice is lacking from the analysis. Nonetheless, this study aimed
375 to understand attitudes within the general population, and future research is needed to
376 understand these issues from the perspective of PLWH. Third, since this qualitative study
377 was nested inside a quantitative study, participants could have been influenced by the

378 questionnaire they completed prior to the interview, as it asked questions about HIV
379 attitudes, stigma, and risk. Finally, this study was conducted within a hospital setting, so
380 it is not necessarily applicable to those who are not accessing medical care in this
381 community. However, it does reflect the target population for any hospital-based
382 interventions.

383

384 This qualitative study is the first to examine HIV attitudes, risk perceptions, and risk
385 behaviors in a coastal region of Ecuador. The epidemic can currently be classified as
386 small but at risk of growing. The combination of high levels of negative attitudes towards
387 HIV, prevalence of risky sexual behaviors, and low perception of personal risk identified
388 in this study suggests a dangerous risk profile for the expansion of the HIV epidemic in
389 Ecuador. These findings thus suggest a need for increased education about HIV among
390 the general population in Manglaralto, specifically focused on promoting testing,
391 recognizing personal risk and how to reduce that risk, and condom negotiation skills.
392 Efforts in these areas may allow people to better understand the connections between risk
393 behaviors and transmission as well as to counter negative attitudes toward PLWH.
394 Finally, more accurate and updated prevalence estimates by region are needed to more
395 effectively monitor the epidemic in Ecuador. Given the limited data from this region, we
396 recommend epidemiological and social network studies to identify specific at-risk and
397 bridge populations. Studies similar to our own are also needed in other parts of the
398 country to test whether the major themes we identified generalize to other regions and
399 whether HIV prevention interventions developed for the Manglaralto region are relevant
400 to other parts of Ecuador.

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409

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519 **Tables:**

520 **Table 1. Characteristics of the Study Sample (N = 15)**

Male	46.7%
Age (years)*	
Mean (SD)	38.9 (11.5)
Education*	
Primary	50%
Secondary	35.7%
College	14.3%

521 * Data missing for one female participant.

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