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Title

Perceptions of Patients with Primary Nonadherence to Statin Medications

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14   **Perceptions of Patients with Primary Nonadherence to Statin Medications**
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16 **INTRODUCTION**
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18   Cardiovascular disease (CVD) is the United States' leading cause of morbidity, mortality,

19 and rising health care costs,[1] but proven population-based CVD risk reduction strategies are

20 often not fully used. Many organizations seek to reduce CVD risk factors such as high

21 cholesterol.[2-8] Patients not meeting goals after lifestyle modification are prescribed HMGCoA

22 reductase inhibitors, commonly referred to as "statins," for CVD prevention.[9,10] But patients

23 often do not take statins as prescribed. Secondary nonadherence (stopping or taking a

24 medication differently than prescribed) is a recognized problem,[11,12] but it is less well recognized

25 that 13-34% of people never fill a new statin prescription (primary nonadherence).[13-18]

26   While existing studies have identified the incidence and demographics associated with

27 primary nonadherence, none have exclusively explored the reasons, attitudes and beliefs behind

28 primary statin nonadherence. This study aims to address this gap in understanding. Previous

29 studies in the United States, all from one managed care healthcare system, suggest that patients

30 with primary nonadherence tend to be English-speaking, younger, black, on no other

31 medications, and have fewer comorbidities,[17-19] suggesting that they were prescribed statins for

32 primary prevention. One study showed that most respondents had "general concerns" about

33 statins, were scared of side effects, or failed to understand why statins were prescribed or their

34 purpose.[17] Outside of these findings, the literature lacks a deeper understanding of the attitudes

35 and beliefs of patients with primary statin nonadherence, the information patients consider before

36 deciding not to start statins, or how primary statin nonadherence might be avoided. This focus

37 group study was designed to investigate attitudes, beliefs, and perceptions of patients who chose

38 not to fill their first prescription for a statin.

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41 **METHODS**
42
43 *Participant Identification and Recruitment*

44   Participants were recruited from: 1) lists of patients with primary nonadherence at

45 [Institution Name, de-identified] identified by querying electronic health records linked to

46 Surescripts medication fill data;[20] 2) placing internet advertisements on *Craigslist.com* in 22

47 United States metropolitan areas over a 6-month period; and 3) a large internet-based CVD

48 cohort (the Health eHeart Study). Advertisements contained a link to a study information sheet

49 and to an eligibility screening questionnaire; the study team contacted potentially eligible

50 participants.

51   Eligibility criteria were: aged 18 and older, received a new statin prescription within 2

52 years prior to contact, and did not start taking the prescription. We oversampled for minority

53 patients. The [Institution Name, de-identified] Institutional Review Board (IRB) approved the

54 study protocol, and served as the IRB of record for [Institution Name, de-identified]. No written

55 informed consent was required, but participants gave verbal consent prior to the focus groups.

56
57 *Data Collection*

58   Focus groups were conducted between February and July 2018 by two project

59 coordinators with psychology backgrounds who were experienced interviewers. We chose

60 interviewers without medical backgrounds to lead the focus groups so that patients would not

61 feel inhibited sharing their honest opinions about their medical care. To minimize variation in

62 technique, both interviewers were thoroughly oriented to the research problem, participated in

63 developing the interview guide and potential probes, and engaged in debriefing sessions after

64 each focus group. A physician-investigator with expertise conducting focus group interviews

65 concerning patient medication use[21-24] was present for all but one focus group discussion, and

66 worked with the interviewers to probe participant perspectives. To avoid influencing patient

67 responses, this investigator was introduced only by first name, and patients were informed only

68 that the investigator was a research team member. Focus groups lasted a mean of 80.2(SD=11.1)

69 minutes and were audio-recorded and transcribed verbatim.

70   Interviewers used a focus group discussion guide to lead conversations and probed

71 participants as needed for detailed answers. Interviewers met with two of the investigators

72 (XXX [a cardiologist] and XXX [a family physician]; initials de-identified) after each focus

73 group to reflect on interview findings, put them into context of earlier focus group discussions,

74 and to modify the focus group guide as needed to prompt greater depth of responses (**Table**

75 **1**).[25,26] All participants were surveyed about their demographics; history of heart disease/heart

76 attack, stroke, or diabetes; and number of prescription medications taken. Participants received a

77 $60 gift card for participating.

78 *Focus Group Analyses*

79   Four investigators with different backgrounds (family physician with expertise in

80 physician-patient communication, medical sociologist, cardiologist, and project coordinator with

81 psychology background) formed the coding team. On completion of data collection, they

82 independently reviewed a subset of two focus group transcripts, using inductive content

83 analysis,[27,28] existing literature,[29] and clinical expertise to generate themes. The coders used open

84 coding to identify comments in focus group discussions that related to patient decisions about not

85 starting a prescribed statin. Themes were classified as "major themes" if they emerged in every

86 focus group discussion, and as "minor themes" if they were raised in only a subset of

4

87   discussions. Subthemes (specific themes within major and minor themes) also were identified.

88   The coding team engaged in discussions about the themes, resolved disagreements via

89   consensus, and generated a codebook describing the themes. After theme generation, 3 coders

90   performed focused coding using the codebook, with at least 2 coders analyzing each transcript.

91   Coding discrepancies were resolved through discussion. ATLAS.ti 8.0 (Scientific Software

92   Development GmbH) was used for coding. Theoretical saturation, when no new themes can be

93   generated from the data, was reached after eight transcripts. This was assessed by using

94   ATLAS.ti to track the codes applied to each transcript.

95   **RESULTS**
96
97   Ten focus groups were conducted with 61 total participants. Participants were mostly

98   middle-aged and without CVD **(Table 2)**. All participants met screening criteria for primary

99   nonadherence to statins within the past 2 years, but it became apparent during the discussions

100   that 4 participants (in 3 focus groups) had taken statins in the distant past.

101   Four major themes describing patient perspectives about starting a statin medication

102   emerged from all focus group discussions: 1) desire for alternative treatments; 2) worry about the

103   risks of statins; 3) perceptions of good personal health; and 4) uncertainty about the benefits of

104   statin use. We also present "minor themes" that emerged from some but not all focus group

105   discussions, as well as themes related to provider-patient relationships and interactions that

106   influenced patient decisions about starting a statin. Below we describe each of the major themes

107   in detail.

108

109   **Major Themes Related to Primary Statin Nonadherence (Table 3)**

110 *Desire for Alternative Treatments*

111   Almost all participants expressed a desire to pursue alternative treatments before starting

112 a statin. Alternatives ranged from lifestyle changes (e.g., exercise, dietary changes, weight loss)

113 to dietary supplements and "home remedies." Participants often mentioned wanting 'natural'

114 treatments such as red yeast rice, vitamin E, and cinnamon. One participant noted: "…as an

115 alternative, I have bought an over-the-counter plant sterol gummy and I've been taking the

116 gummies for awhile." [FG8:P3] Another participant's experience involved visiting: "a health

117 food store, and they recommended some herbs to take, like garlic, fenugreek, turmeric, ginger,

118 omega-3, flaxseed...I'll make a smoothie every other day and include the herbs." [FG4:P7]

119 Home remedies included boiling avocado leaves and drinking the resultant tea. Other approaches

120 included yoga and following a holistic lifestyle.

121   Participants mostly felt no urgency to start statins. In addition to wanting alternatives,

122 some wanted to repeat their cholesterol test, do other additional testing, or get more information

123 about statins. Many stated they were willing to start a statin if alternative treatments were

124 ineffective.

125 *Worry about the Risks of Statins*

126   Almost all focus group participants worried about statin side effects (e.g., liver damage,

127 muscle pain), which they typically read about on the internet or heard about from friends or

128 family. Participants also had concerns about worsening existing medical issues and about

129 potential interactions with other medications, for example: "Because if you're on a lot of

130 medications…it seems like it conflicts a bit." [FG9:P4]. Some were apprehensive about creating

131 new problems, for example: "Problem that I see, it causes like a domino effect. You take one

132 medication for one thing, and it causes something else to happen, so then you have to take

133 another medication to counteract the problem that the side effect is causing." [FG2:P5] Those

134 with a family history of diabetes were particularly concerned about statin use leading to diabetes.

135 *Perceptions of Good Personal Health*

136   There were several subthemes describing participant perceptions of personal health. A

137 few participants felt that statins were unwarranted because they had no medical problems or were

138 too young. Others noted they had a healthy lifestyle, no family history, or no symptoms. Some

139 said immediate statin use was unwarranted because their cholesterol was only slightly above

140 normal, for example, "I found myself healthy. Just a little change in the cholesterol. It doesn't

141 mean I have to start [a statin]." [FG7:P4]

142   Almost all indicated they would start a statin in a "life or death" or "life-threatening"

143 situation. Some said they would consider a statin if their cholesterol became "really high," if they

144 had worsening health, or they started eating more unhealthy foods. One participant noted, "If I

145 knew that I was in serious probability of having [a heart attack], I would probably think twice

146 about taking it." [FG9:P2] Many said they would take a statin if they had a heart attack, stroke,

147 or heart disease.

148 *Uncertainty about the Benefits of Statin Use*

149   Some participants seemed to have a poor understanding about the benefits of statins. For

150 example, a participant with heart disease revealed a disconnect: "If there's a medication that I

151 could take that would help with my heart problem and prolong my life, you know, that's a no-

152 brainer. You take it." [FG7:P5]

153   Some participants correctly noted that statins lower cholesterol levels. But many

154 questioned the benefits of statins, with some asserting that statins are not that helpful or

155 important, and others suggesting that the evidence for use is unclear: "even though medical

156 studies say that…the benefits will be such in such, what it turns out that in many cases that is

157 wrong, and on later stud[ies] that information is wrong" [FG3:P6]. A handful were unconvinced

158 that 10-year cardiovascular event risk calculators appropriately incorporated their personal

159 characteristics. A minority questioned the link between cholesterol and CVD. Several also felt

160 that cholesterol treatment cutoffs were arbitrary. Participants mostly failed to understand the

161 concept of personal risks for CVD; discussions often turned to the risks of statins when the term

162 "risk" was mentioned.

163

164 **Minor Themes Related to Primary Statin Nonadherence**

165 *Participant Hesitation about Medication Use*

166   Many participants generally resisted taking medications. Those already taking

167 medications hesitated to add another prescription. Some felt that taking too many medications

168 was detrimental. Those naïve to chronic medications were resistant to starting one. Two

169 patients conceded they were in denial; one acknowledged: "I'm kind of like more in denial. By

170 taking [a statin], I'm admitting I have a problem." [FG10:P2] One patient mentioned: "I wanted

171 to avoid having that stigma of having to go on Lipitor. I mean, to me, there's a stigma, maybe

172 kind of some type of judgment that others make when they would find out." [FG7:P3] Some felt

173 that medications were overprescribed, with doctors tending to pursue a "quick fix" [FG6:P7].

174 Other participants talked about not wanting a daily medication, feeling hesitant about taking a

175 medication for the rest of their life, or dosing regimens that were difficult for them to follow.

176 *Prior experiences contributed to hesitation to take statin*

177   Prior experiences that influenced participants included experiencing adverse medication

178 effects, hearing about others' negative experiences with medications, or having prior success

179 lowering cholesterol with non-pharmaceutical therapies. As one participant noted: "there's other

180 drugs that I've taken that have had side effects, and so I just don't need another drug that has side

181 effects." [FG1:P2]

182 *Mistrust of pharmaceutical industry*

183   Participants in 8 of 10 groups voiced concerns about pharmaceutical companies

184 influencing prescribing: "I'm inclined to think…that some doctors are paid commissions for

185 prescribing medicines, their medicines, by their pharmaceutical companies." [FG8:P2] Another

186 participant noted: "I can be cynical enough to think that the pharmaceutical marketing may

187 actually impact the guidelines. You and I all know that they've been milking millions of dollars,

188 pouring into vacations and cars…and I don't know who writes those ever-changing opinions

189 about when should somebody start [a statin]..." [FG1:P2]

190
191 *Medication Cost*

192   Only a handful of participants cited cost as the primary reason they failed to fill their

193 statin prescription. High costs mostly served to reinforce participants' hesitation, for example: "I

194 had to come out-of-pocket for $75.00. I was like, no, I'm not going to do that. I think that if I go

195 natural, I will feel much better. I will put less side effects on my body and I will have to pay

196 less." [FG10:P3]

197

198 **Themes Related to Provider-Patient Relationships and Interactions**

199 *Mistrust of prescribing provider*

200   Several participants felt unsure about starting a statin because it was prescribed by a

201   provider they had never seen. Others wanted their primary care provider's approval before

202   starting the statin: "I didn't feel like the hospital cardiologist was equipped or knew enough

203   about me to prescribe medication to me other than my PCP." [FG10:P2] Poor provider-patient

204   relationships and mistrust also contributed to primary nonadherence.

205   *Inadequate provider communication about statins*

206   Communication lapses were important. One patient shared that his doctor "…didn't even

207   say anything, just told that they were sending me the pills." [FG5:P5] Lack of shared decision-

208   making deterred patients from filling statins, as did patient perceptions that providers did not care

209   or were not very worried about a patient's cholesterol. Two patients did not realize their

210   provider prescribed a statin until their pharmacy notified them. As one described: "I got a notice

211   on my cell phone, a text message, that I had another prescription and I was confused. He had

212   sent, this doctor, which I'd never seen before, had sent a prescription for Lipitor [to the

213   pharmacy], which I didn't fill because I felt like I wasn't informed. I didn't know what it was for."

214   [FG7:P2]

215

216   **Participant Comments on Disclosing Nonadherence to Providers**

217   During focus group discussions, not all participants commented about disclosing their

218   nonadherence, but 20 of 61 participants stated that they had not told their providers about their

219   primary nonadherence. Half of these participants were planning on telling their provider, but a

220   few believed it was disrespectful to question their provider's recommendations, and were

221   hesitant to bring up their primary nonadherence. Of 26 participants who told a provider about

222   their primary nonadherence, 19 (73.1%) did so at the time of prescribing and the rest during a

223   follow-up visit.

224

225   **"We're Not All the Same"**

226   One focus group participant summarized the need for providers to individualize

227   approaches when prescribing statins, by addressing aspects of the major themes that might

228   prevent patients from starting a statin:

229   "Some people just get that prescription, go and pop the pill, and they're done. Other

230   people need an explanation…need to understand what all the ramifications are if I do this

231   and if I don't do that and so on. And so you have to, as a medical professional, adjust the

232   way you approach your patient. And so, if you see someone's reluctant, you have to be

233   able to either explain it in a way – if you really believe that this would benefit the person,

234   explain it in a way that they are, let's say, convinced, which is maybe too strong a word,

235   or demonstrate it by doing other tests and giving some more data because…we're not all

236   the same. Different people need different information." [FG1:P4]

237

238   **DISCUSSION**

239   The focus group interviews in this study elucidated why adults might choose primary

240   nonadherence to statins. Participants discussed four major themes influencing their decisions: 1)

241   desire for alternative treatments; 2) worry about the risks of statins; 3) perceptions of good

242   personal health; and 4) uncertainty about the benefits of statin use. Existing literature shows that

243   patients in general do not wish to take new medications, and may go to extremes to avoid using

244   them.[30] Many themes identified in this study echoed those found in other studies examining

245 patient perspectives towards statins and on reasons underlying nonadherence to other

246 medications such as anti-hypertensive drugs.[31,32] However, with its focus on primary

247 nonadherence to statins (mostly for primary CVD prevention), this study goes beyond the

248 existing literature by illustrating that primary nonadherence to statin medications reflects a

249 decision-making process that is weighted toward belief in individual ability to alter lifestyle, diet,

250 or exercise to reduce cholesterol levels, and minimization of personal risk and the potential

251 benefit of a statin in the absence of symptomatic conditions/disease. Laboratory cutoff points

252 and guideline-based risk assessments did not appear to convince participants that a statin

253 medication was necessary.

254 It makes intuitive sense that people who perceive themselves to be at low risk for an

255 adverse medical outcome may want to delay starting a newly prescribed chronic medication and

256 to first try alternative measures. While we did not examine participant medical records or

257 calculate CVD risks, limited medication use and young mean age of participants support their

258 lack of reported CVD. Participant preferences for lifestyle or dietary modifications align with

259 most guidelines recommending initial primary prevention in people with high cholesterol

260 without CVD.[3,6] It is reassuring that most participants would reconsider statin use if their efforts

261 failed to lower their cholesterol, if their cholesterol levels increased, or if they developed CVD.

262 Thus, this decision may be mutable but may require time for individuals to process information

263 or try alternatives. Providers need to find better ways to convey concepts regarding CVD risk,

264 achievable goals from lifestyle modification, and the lack of evidence for dietary supplements in

265 improving CVD risk, as well as the evidence of benefits of statins. Discussions about 10-year

266 risk calculators may need proper context and framing for patients who worry mostly about their

267 immediate risks for adverse outcomes.

268   One-third of all focus group participants did not inform their providers about their

269   nonadherence to the statin. This finding is limited and requires additional exploration because

270   not all participants commented on this topic. In the absence of this communication, there is no

271   opportunity to address poor understanding about the role of statins for primary prevention of

272   CVD, the risks of statin therapy and ways to monitor or minimize them, or the opportunity to

273   develop a plan to reduce their cardiovascular risk over time.

274   Previous studies have shown lapses in provider communication around newly prescribed

275   medications.[33,34] In this study, some participants revealed that gaps in communication

276   contributed to their unwillingness to start a statin. Providers often are reluctant to question or

277   confront patients about nonadherence,[23] but our data suggest that it is important to assess a

278   patient's stance toward statins at the time of prescribing, to make sure patients know providers

279   are considering their individual situations, to tailor discussions to address individual patient

280   concerns, and to ensure that patients have follow-up appointments to assess adherence.

281   Reluctant patients would likely benefit from a trial of lifestyle or dietary changes, or other

282   preferred treatment modalities. Providers could employ discussions regarding the duration and

283   goals of the trial. Follow-up visits would ascertain success in meeting goals, address individual

284   patient concerns about the benefits and risks of statins, and help patients better understand their

285   personal risks for cardiovascular events.[35] If goals were met in the short-term, a plan for future

286   reassessment could be established.

287   Mistrust was commonly raised during the focus group discussions. Mistrust of the

288   pharmaceutical industry led some participants to question the validity of scientific guidelines,

289   and even their providers' motives for prescribing statins. This erosion of trust likely influences

290   people's ability to trust that population-based guidelines apply to individuals, and to accept that

291 the benefits of statins outweigh the risks. Thus, for some patients, restoring trust in the

292 pharmaceutical industry or strengthening trust in their physician may be crucial to their

293 acceptance of treatments that are beneficial to their health.

294   Study limitations include those inherent to focus group studies, such as potential lack of

295 transferability due to participant self-selection.[36] EHR identification of patients with primary

296 nonadherence was inaccurate and yielded insufficient numbers of patients for purposive sampling

297 based on patient characteristics. Thus most of our participants were recruited from online

298 advertisements, and the majority of the participants used the internet. However, internet usage is

299 growing, with 87% and 66% of adults aged 50-64 and aged 65+, respectively, using the internet

300 in 2018.[37] We discovered during focus group discussions that a small number of participants in 3

301 focus groups had secondary, rather than primary nonadherence. All of the themes raised by these

302 patients were consistent with those mentioned by patients with primary nonadherence. The

303 majority of patients in this study were prescribed a statin for primary, rather than for secondary

304 CVD prevention, so additional studies may be needed to assess potential differences in attitudes

305 of those prescribed a statin for secondary prevention.

306   In conclusion, this study describes patients' wishes to choose their own lifestyle or

307 dietary changes, their concerns regarding the risks of statins, and their lack of understanding of

308 personal risks necessitating statin use and potential benefits of statin therapy as major

309 contributors to primary nonadherence to statins in people without CVD. In addition, we found

310 that patients often do not communicate their decision not to take a statin to their providers. The

311 work identifies promising targets for improvement that could help reduce cardiovascular risks.

312

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FIGURE LEGEND

438 Figure 1. Framework describing major categories of information patients consider when newly

439 prescribed a statin medication

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441   Table 1. Sample Focus Group (FG) Interview Guide
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• Think back to why you didn't get your statin medicine. What sorts of things kept you from getting it?
• Tell us about your interaction with your doctor when s/he prescribed the statin.
• What would have led you to fill the statin prescription when your doctor prescribed it?
• What might lead you to get the statin medicine in the future?
• Where do you get most of your information about statin medicines?

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444   Table 2. Focus group patient characteristics; n=61
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Characteristic	n (%) or mean (SD)
Age, mean (SD), range	53.0 (10.2), 25-75
Female, n (%)	33 (54.1)
Race/ethnicity, n (%)	
White	20 (32.8)
Black	18 (29.5)
Hispanic	16 (26.2)
Asian	5 (8.2)
Mixed race	2 (3.3)
History of diabetes, n (%)	10 (16.4)
History of heart attack, n (%)	4 (6.6)
History of stroke, n (%)	0
Prescription medications taken, mean (SD), range	1.4 (1.8); 0-7
Not taking any prescription medications	27 (44.3)

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461   Table 3. Sample Quotations Depicting the Subthemes Associated with Each Major Theme
462   Influencing Primary Statin Nonadherence

Major Themes and Associated Subthemes	Sample Quotes
Desire for Alternative Treatments	
Lifestyle changes (diet and exercise)	"I actually informed my doctor that I wasn't gonna take it, but he can prescribe it to me first, but I wanted to go to changing my diet first to see if that would help." [FG5:P1]
Dietary supplements / alternative treatments	I think if you look up a bunch of your herbs, herbs that you can eat…that will also help. Natural herbs. [FG6:P1]
Risks	
Risks of statins worry patients	
Side effects and interactions	"I don't [want to] have liver and kidney problems, and muscle cramp[s], and all those crazy side effects." [FG5:P4]
Worsening of existing problems	"Some of my friends and…me, I have asthma. They had took statin and they had more symptoms. It worsened their lung functions… yeah, it made it worse. Worsened their lungs." [FG6:P3]
Creating new medical problems	"The last thing I wanted to do was to get type 2 diabetes while trying to lower my cholesterol. So it just seemed counterproductive [FG9:P1]
Causing addiction or dependency	" I didn't know if this is something that you can get addicted to or something like that." [FG6:P4]
Perceptions of Good Health	
Too healthy or young to start a statin	"Made me feel old, you know. I always thought statins would be for older people like, retirees, versus someone in their 40s." [FG3:P2]
Good family history	"My mother had the same lipid profile I have, and they wanted to put her on a statin. And I think she did it for a while, but – without it, though, she hit 93." [FG1:P3]
Cholesterol slightly high or not that high	"I'm not that over the scale that I

	should have to be taking [a statin] ... I'm only eight points over." [FG2:P4]
Correctable reason for high cholesterol	"…my cholesterol was just over the normal, and I had lost my mother so I gained some weight…" [FG3:P5]
High cholesterol is genetic	"I heard my family mention that they also have the same issue with the high cholesterol. They were told that it was genetic and basically they were told that it didn't matter if they took the medication…Basically, the medication wasn't going to help. So I figure if it's a genetic thing, why even take the medication?" [FG10:P1]
Benefits – Uncertainty about benefits	
Scientific evidence not definitive	"…the other key point from that [JAMA] article was that there was not as strong evidence that it really...that everybody would really need it even though it was being recommended under the new guidelines." [FG7:P6]
Risk calculator does not look at people as individuals	"…we're being treated by a medical profession that sees us sort of as a statistic. I mean, statistically speaking, you have a 10 percent chance of having a cardiac event in the next blah-blah-blah. And we're not all the same." [FG1:P4]
Link between cholesterol and CVD is uncertain	"…it's not really clear how important is it to take statins, in spite of having a so called high level of bad cholesterol." [FG2:P1]
Cholesterol cutoffs for treatment are arbitrary	"I'm not going to take [a statin] for what could be just an arbitrary number." [FG4:P5]
Statins do not cure	"…we have to make changes in our life…Medication is not a cure. It's just a band aid." [FG4:P7]

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