

Table 2. Exemplary quotes from all stakeholder groups around the five major focus group themes

Theme	Exemplar Quotes
Long-term side effects of medication	<p>I want to add something, the general thing about aging, is—I don't know whether my aging process is accelerating or not, um, my doctor never comments about it. I am a retired nurse, and basically uh, a hypochondriac, but it seems to me that there are certain things that are happening to my body awfully quickly at my age—I'm 67. I don't know, you know, I don't know what else to attribute it to besides that I'm HIV-positive. <i>(67-year-old White male living with HIV)</i></p> <p>...No one's ever taken these drugs. You know, the studies ended in 90 days and they were taking them for decades. You have no idea what's in these drugs and what they're doing long-term, or what's gonna happen as far as just being HIV-positive one day. <i>(72-year-old White male living with HIV)</i></p> <p>I've been on drugs for so long and a lot of us have been on these drugs for, you know, a long time, and we are surviving, uh, but in the end when, you know, what's the price we're gonna pay for, you know, living this long and taking these drugs and the effects they're gonna have on parts of our bodies? <i>(69-year-old Hispanic male living with HIV)</i></p> <p>So, it's what's gonna happen—is something else gonna happen to me before I die of family diseases? ... But, uh, yeah is something else gonna happen or show up or something else to—because of these drugs or because of the virus itself? <i>(72-year-old White male living with HIV)</i></p> <p>Fatigue has been an issue for me quite a bit, too, and it's when I bring it up to the doctor, they don't usually—I mean my labs look fine, so there's—and the doctor doesn't really know what do to about it. So I don't know if it's just because of the medications I'm on, I've been on them for so long. And actually I recently changed my regimen to a newer, you know, generation of HIV medications after having been on Sustiva and [unintelligible] for like 20 years. And uh, I do seem to, um, have less fatigue than I did before so it could've been the medications I was on. <i>(57-year-old White male living with HIV)</i></p> <p>I realize age is just a number but it's curious because I really [unintelligible]. I really am curious to see how much older I am health-wise than I am numerically. You know, what has impact been the impact of the drugs, the constant inflammation, the other things that happened and where do I really fit in things because if I don't have a long period of time, that changes how we might want to approach things versus, "Oh, you'll be around quite a while." <i>(62-year-old White male CBO representative)</i></p> <p>I was just gonna say on the issue of anxiety that it's true for me, too. I mean even small changes in my health will cause me to have a lot of anxiety more than I did, you know, 10 years ago, or 15 years ago, or 20 years ago. It's like you know—just</p>

	<p>recently I got my labs. My creatinine numbers had spiked up. So I don't know if it's due to one of the new medications in my regimen, um, but it indicates a possible kidney issue and of course that's causing me a lot of anxiety. So yeah um, I don't feel as resilient as I used to on all sorts of things.</p> <p><i>(57-year-old White male living with HIV)</i></p>
Social determinants of health	<p>I feel so—I'm so glad I got an apartment over there at Vista Sunrise. When I got really sick in 2014, it took me 'til 2015—that secured me. I felt okay, I was so thankful I got in there.</p> <p><i>(59-year-old White male living with HIV)</i></p> <p>I don't know. My T-cells are only around 210. I used to be up in the 600's but I lost Medi-Cal. And back in 2005 I was off my meds for 3 years. When I went back on it again, I was down to 24 T-cells, now I seem to hover around 200 and it just won't go any more—so maybe that's it, I don't know—but that's one thing that happened to me.</p> <p><i>(59-year-old White male living with HIV)</i></p> <p>All those things that DAP offers are um, you need to pursue them and find out about them, and pursue them. But I think a very tangible benefit that is often overlooked in our community is the thousands of people who get help by the AIDS Assistance program, giving us the grocery store coupons to go get actual food. And that's a very real tangible benefit for many people.</p> <p><i>(66-year-old White male living with HIV)</i></p> <p>Um, this is kind of strange for me but I uh I eat at Mizell probably at least three or four times a week. It's \$3, I mean it's very inexpensive, you can park right there—uh, easy parking—and they always have like, you know, it's a small meal but it's mixed, you know you have a salad and you have, uh, whatever else to make it a balanced meal. And living as I do as a single person and living in a house, um, it's so much easier to do that if I—it's better than skipping a meal altogether. I can go there and I can meet people and socialize and so it has a combination kind of effect. And I know they have Meals On Wheels and I'm so fortunate to be—you know, I don't need that. But um, it's nice to know that it's there, I think it's a big support for the community to not have to worry about that issue so much—that you could have it if you need it—the Mizell—or I mean, the Meals On Wheels thing so.</p> <p><i>(76-year-old White male living with HIV)</i></p> <p>Um, there's a lot of um, uh, ill feeling—if you will—uh, folks uh, often put off or avoid health care altogether because um, they don't feel comfortable in the presence of doctors or nurses and support people. Um, you hear about things like misgendering, uh, just outright rudeness, uh, asking inappropriate questions. And if people don't feel comfortable they won't go back or they'll get to a point where their situation is really desperate before they seek health care. And uh also mixed in with that would be uh insurance issues.</p> <p><i>(69-year-old Black transgender CBO representative)</i></p> <p>I'd like to, uh, expand on that, uh, idea about, uh, community support. Um, you know when we talk about, you know, fixed resources and things like that. Um, I</p>

	<p>suspect that what that means is that a lot of folks may be living relatively close to the edge in terms of, uh, financial stability. And, uh, having, uh, some support to prevent people from just falling off the cliff, um, is a good thing. Um, and I don't think there's a substitute for it because odd things will happen, you know. And it's time-sensitive, you know. If it happened this month that may have been fine, but if it happened three months later with one or two other events, then, you know, you're looking at disaster. So, you know, trying to avoid those kinds of situations is very important for people. That's why, uh, we have a, uh, an emergency fund for the trans community, you know, for those kinds of things to, you know, keep people from falling into the abyss.</p> <p><i>(69-year-old Black transgender CBO representative)</i></p> <p>I think uncertainty about all of it, at least for me since the election, it's been very uncertain as to whether the safety net that I counted on is gonna be there. Are we gonna still have social security that's gonna be paid to where it's appropriate? What about Medicare, which I rely on, or Medicaid that others—or Medi-Cal, here—that other people rely on? [Undistinguishable] money, housing money, all these areas that we thought were gonna be safe and there for us—we just don't know.</p> <p><i>(62-year-old White male CBO representative)</i></p> <p>And [unintelligible], that engenders in the community is that—are the places that you go to not feel that stigmatization or some feeling or, you know, something is wrong with you. It's this welcoming feeling that makes you want to do things or makes you feel more comfortable in those places. And that's a good thing. And, um, a lot of places that I've been to—you know—some places were really bad, some places were really good. Here in Palm Springs area, I've found that it's been really good. I'm feel very glad that I, um, was fortunate to be in LKA and gone to Borrego to their Stonewall Clinic. And all of it was good. So I felt very comfortable being there. But it would have been something else if—I went to another doctor, which I'm not gonna say, and she was not great at all. I felt, like, stigmatized, I felt really bad about myself. I felt dirty, and they made me feel that way. So, there was a big difference in how they treated people and that made a difference in how I felt about myself.</p> <p><i>(57-year-old Hispanic male caregiver)</i></p> <p>They—related to a lot of that is seeing a lot of uh, co-infection with STDs, particularly syphilis, in this—the Palm Springs area. And repeated co-infection—um, treated and then re-infected. So then there's, you know, continuing, uh, health issues with that. And then, I think sort of the more like social/epi—social/epidemiological standpoint. I get worried about a lot of the social determinants of health issues. So there's a lot of things that we know are issues for, um, our aging population in general and then it's amplified with an HIV, uh, diagnosis and you know—being if you're a gay male and HIV-positive and aging. So this cross-section of all of these things with, um, you know, housing and income and, uh, social isolation, and transportation. Um, all of these things having an impact on people's well-being and health overall. So I'm seeing—that's something that I spend some time worrying about.</p> <p><i>(48-year-old White male academic researcher)</i></p>
Mental health	<p>You know, and uh, so I go over to his condo and he's on the bedroom floor, and he hadn't eaten in 3 or 4 days. And he couldn't even get off the floor. Uh, we ended up</p>

	<p>having to call an ambulance and then transport him to the hospital. And then, he was a retired nurse and, uh, he didn't want to, uh, he didn't even want to finish his test and I finally took him home. And then, uh, for two weeks I got him, uh, you know, the uh, like Pediacare, uh, for his electrolytes and Ensure for his—so he could eat. But this really, this kind of issue bothers me because—we talked about this issue, too, at the pos life series—that it would be nice to have a support group here that looks in on people that are isolated. And—and he's doing better now, I still check on him every once in a while but, it's—he has two sons—they don't care about him—and he just got depressed and stopped eating. (76-year-old White male living with HIV)</p> <p>Isolation, I guess, you know. [Unintelligible]. Well, isolation from all your friends who've died. Uh, you have, uh—my partner and I are, uh, nearly—I'm over 70, he's nearly 70, and we have no close friends. They all died. So um, loss of supportive circles, you know—a supportive circle of friends—everybody is dead. (76-year-old White male caregiver)</p> <p>Just another aspect of the grief: coping. I've had several people say, 'it's like living in the 80s and 90s all over again. Everybody I know is dying.' They're not dying of AIDS but they're dying. So it's almost PTSD—um, like, 'cause the people that are alive now survived that epidemic at that point. (76-year-old White male HIV provider)</p> <p>As a caregiver the folks that I've been with have a sense of loss and what will come next. Um, you know, loss of mobility, loss of pets, loss of, uh, health, loss of energy, you know, just a combination of what will come next, "I've lost all these things, what's next?" (64-year-old White male caregiver)</p> <p>Um, uh, concern over, uh, the possibility in your later years of being alone—"Who will take care of me?" and "Where do I go when I can't live in a house or apartment by myself?" Such as assisted living or nursing homes, which I know my bank account can't afford. (54-year-old White male caregiver)</p>
Resiliencies	<p>I think as we age, we need to make sure that we have that—um, at least a base of community. And if we don't, as we get older, I think it may be harder to find. (66-year-old White male living with HIV)</p> <p>I just recently got a cat and it has really put me on a schedule. And a positive, more positive feeling. I'm not as depressed as I was. She makes me laugh. (54-year-old White male living with HIV)</p> <p>Animals. I have a little dog. And I, you know, I never thought I'd like a dog that much but it's amazing how it does give you some sort of support. You know it also puts you on a routine which I think is important because of memory issues and you know—so it's a good thing. (76-year-old White male living with HIV)</p>

So here, um, so there's like different [inaudible] people who are isolated and separated and lonely and don't feel community support, and then there are people who are not like that having another experience who benefit from the Desert AIDS Project, the uh, LGBT center, having many peers who have survived with or without HIV, so those social networks are absolutely resiliencies. They rely on each other understand each other, they understand each other, they find support with each other, they've had, uh, common experiences that they've gotten to share. Um, we have a lot of spiritual types of—spiritual organizations here in The Valley that people find support. There's support groups that people get connected in. Those are all forms of resiliencies that exist in the community.

*(58-year-old White male CBO representative)*

I think part of the success is when you're able to be stable and there is a certain amount of instability when you grow older. Some of it's financial and some of it's aging. And looking at how all of the community can come together and build a real network of services, volunteer or otherwise, seems to be very important because it would be great to have access to your doctors but if you don't also have access to other services, you may not take your meds or you may say, "Why bother?"

*(62-year-old White male CBO representative)*

You know another issue that this conversation reminds me of, is uh, specifically in this population, uh the majority of gay men with HIV who are aging don't have children. They don't have extended families, which is an absolute major form of support for aging populations in the country that are heterosexual, um and so that becomes another challenge. This is why community resources become so important because they don't have family resources—many of them.

*(58-year-old White male CBO representative)*

Well I was just—what you were talking about, about applicability, um—and we were talking about resiliencies that just brought it back to mind, just that, um, tendency to take charge of our health. I have a lot of straight friends with health issues who are, you know, they don't ask their doctors questions, they don't look anything up on the Internet; they take whatever's given to them. And um, the fact that we've been sort of trained to ask questions of our doctors even though they don't want them and um, that we have been—we show up for studies and we're interested in studies—that's one of those resiliencies; is that we've learned to be in charge of our health.

*(55-year-old White male caregiver)*

Well a lot of our subjects are very well read when it comes down to HIV, so they actually do know that they tend to age like 10 years faster than a person that's HIV-negative. So going to his point, a lot of them are also wondering, 'At what point should I do a bone density test?' since we know that osteoporosis is one of the problems that, um, HIV-positive men face a lot.

*(39-year-old Hispanic male HIV provider)*

Um, with that in mind too, the fact that there are so many services, I have yet to meet a person—I'm a therapist, so see psych-minded people who are probably proactive about a lot of their wellbeing. But I haven't met a person who is not

	<p>connected to care and insurance and who isn't regularly seeing a doctor. But that's not something I have to encourage, which is very different in Orange County, um, amongst the same population. And then, um, the de-stigmatization—I mean, people will be talking at Starbucks about their HIV status, meds, T cell count, in a way that they don't in a lot of other areas. Um, and I think in the age of PrEP, too, there's an awareness that, um, diagnosis does not limit you to a subset of people for any number [of] reasons now, you know, especially romantic dating and sexual—  <i>(46-year-old White male HIV provider and academic researcher)</i></p> <p>I'd agree with that. What I notice with clients—stable, stable long-term inoculated from, um, depression—that normally they are attending, uh, social groups at DAP or Mizell really consistently. Clients who aren't, don't, for a number of reasons.  <i>(46-year-old White male HIV provider and academic researcher)</i></p>
Involving community in research	<p>[unintelligible], otherwise we should choose or decide. You know, we're the ones that are here. Uh, we're here to give our opinion. And, you know, as best as it is, you know, what we think is important to us as a group should be—should be studied  <i>(69-year-old Hispanic male living with HIV)</i></p> <p>I think, um, a lot of studies, because they have to be so specific in certain—in what they're looking after—excludes a lot of us in that process. But we can't really be part of that because they're doing specific age groups or something. But, uh, like, I don't qualify for a lot of them. Um, so that's kind of a hindrance. I have to come up with my own, I guess.  <i>(76-year-old White male living with HIV)</i></p> <p>I've been—you know—I've been HIV-positive for 30—more than 30—almost 40 years, and I was in every study, and we haven't learned anything. You know, I mean, that's my—I mean, maybe I [unintelligible] the last comment—we haven't learned anything. But, um, it's a burnout thing. You know, it's over and over and over.  <i>(62-year-old White male living with HIV)</i></p> <p>But, if they're gonna research people who've been on drugs and have HIV for a very long time, we're all here, not over there.  <i>(72-year-old White male living with HIV)</i></p> <p>There is one thing I just thought of too. Sometimes when you're in a study then you can't—means you can't be in the future in any other studies. On the other hand, some of them do permit you to be in other studies. I mean, that was consideration for me, to be in—I didn't want to be in a study that would prevent me from participating in another study and/or going back to my old medicines if it would be necessary. And in the case of the CYDY-uh Pro140, they do let you—all of those options are good for me so I—that's one reason I jumped on that one.  <i>(76-year-old White male living with HIV)</i></p> <p>I'm gonna add again, that 75 year cap—how can they be studying something for people that are aging when they have a cap at 75? I mean, if I was 40, I might feel differently about it, but I'm not.</p>

*(76-year-old White male living with HIV)*

So interesting this community in particular there's sort of a have and have-nots. There's a lot of people HIV-positive/aging that have a lot of wealth and very few issues because they can get the support they need in multiple ways in the different—um, and then the ones who don't, who aren't in that situation, face much more—much greater difficulties. Um, so, however, if we were doing population surveys, definitely there's demographic information—I think there's demographic differences between single and coupled um, people because this creates a different dynamic also. And I'll just throw in gender and race.

*(58-year-old White male CBO representative)*

Well I was just gonna kind of add to that. Like maybe they need to have um, for an HIV-positive person, um, points in their aging—kind of like at, they say women at their age, well, around 50 get breast exams. Um, um, all those tests and like now a big thing with a lot of HIV males is anal cancer and a lot of doctors don't know much about it and don't have the equipment to check. But if they had like benchmarks of like, "Okay now you're 50, we need to do a colonoscopy."

*(54-year-old White male caregiver)*

The time it takes. Um, my partner participates in the San Diego study and, uh, it's like a whole day of riding back and forth in the car. Uh, he's dead tired when he comes back and it's, uh—and yet he wants to do this study. But these studies are so far away and so far in-between that, uh, it's hard for someone. I mean, if studies were a little closer to the Valley, I think a lot more people would volunteer to be in the studies, but these long distance drives and things are just too much.

*(76-year-old White male caregiver)*

One of the issues that I see and it's more global than what we've been talking about here, is the fact that there is a huge population overall of HIV-positive people in this valley and in this state, and yet the population that ends up involved in a study tends to be relatively small. They tend to be patients of a particular doctor, a particular clinic, a particular—services rendered from a particular resource like DAP, and that sort of thing. So, um, the thing for me is I would participate in studies—I don't know about them. Nobody tells me and there's no place I can go to find out about them unless I actively go from here, to here, to here, to here to look for them. So, there's no overall resource to let me know what's available out there that I might be able to help with—'cause whatever unique characteristics my body has that somebody else's might not.

*(63-year-old multiracial male caregiver)*

I think that's a really good point. The thing about—what I—I don't need to know more about the researcher's methodology because that's the stuff for scientists. What I need to know is the applicability of that data to my daily life. How does that data apply to me as a human being, apply to my community; what does it inform in terms of what I need to watch out for, things I need to think about? That's the interpretation. Having a study in a book is great—knowing that. But if I don't have any way to access that data in a way that's meaningful for me, then—other than the

fact that the doctor may be able to do something with what's going on with me a little earlier—I can't proactively manage my own health.

*(63-year-old multiracial male caregiver)*

It's absolutely, uh, that—I believe it's the approach, but even that approach is very slow. Like I said, you know, I know, uh, several guys who are east valley, Hispanic, HIV-positive, and no matter how many times they're saying that they're activists for it, it's a really strong bias against talking about it, against admitting it. Um, and you know it's tough to work against a massive cultural belief like that. Even when you do have great examples of advocates who we need more of, and that's super wonderful and I do think that's the way to go, it's just slow.

*(31-year-old White female academic researcher)*

Research organizations that have, uh, a, uh, commitment to the community. Um, staying in the community. Um, rather than coming in, poaching research subjects, and leaving. Um, so that people get their, uh, journal articles, um, published, but, um, but without any sort of sustained, uh, work in the community. So I think that those research organizations—and we have a few, um, and hopefully eventually someday some more, um—that have some sort of long-standing commitment, um, to staying in the community.

*(48-year-old White male academic researcher)*