**Context**: I have completed observations with staff at Positive Link which is a unit of the Bloomington hospital that provides holistic services to those affected by HIV. In order to further my research regarding social support exchange in the context of HIV, I conducted an interview with a young African-American gay man named Kory who is a client of Positive Link and has been living with HIV for over two years. Kory is a friend of mine and I have known him for a bout two years now. Since it was difficult to set up a time to meet face-to-face, he agreed to be interviewed via a video conference. The video conference took place in my office located in the School of Informatics at Indiana University using my personal laptop. The interviewee was in his apartment located in Bloomington, IN, and used his laptop (and Facebook) in order to connect to the online meeting. The entire interview was audio recorded. The transcript of the interview is presented below.

counter

fridge

Laptop / camera

**Fig 1**. Kory’s kitchen (place from where he connected to the video conference).

**Transcription key:**

Participants:

**K**: Kory, Positive Client, interviewee.

**F:** Fernando, interviewer.

Other:

**[RN]:** researcher note

**[OC]:** observer comments

( ): Behavior or action

[pause]: Pause taken during verbal interaction

... Incomplete sentence or thought

*Word in italics:* Verbatim speech content.

**- Transcript -**

**[Start time: 6:31pm]**

**[recorder timestamp: 00mm:00ss]**

[**RN** (Apr 13 2017): I am friends with Kory, and I have been in his apartment before, so I had a pretty good idea of the space he was having the video conference]

[**RN** (Apr 14 2017): During the entire interview, Kory looked straight into the camera showing his face and upper torso. There was a lot of light in the kitchen so I could see Kory’s face clearly. I was in my office and I switched the lights on before the video conference so Kory can see me clearly as well. I placed my computer on my desk and sat on a chair in front of it. I looked straight into the camera during the whole interview, except for brief moments when I had to look at my notepad when I wanted to take a quick note.]

[**OC**: Kory connects to the video conference from the kitchen in his apartment. He is wearing a light tank top that reveals the toned muscles of his arms]

**F***: Thank you very much for your time Kory. I will start with a question and then we will, you know, continue the interview and it will probably take about 40 minutes, okay? So could you talk about the last time you felt supported regarding HIV?*

**K***: Ah felt supported? It's a pretty broad aaa it's a pretty broad question but hm so okay so today.. my health insurance has* [sounds like left] *cuz I'm no longer employed* [name of employer omitted]*. And so not having health insurance and having HIV is problematic cuz of the cost of the medicine.*

**F***: Ahem*

**K***: I'm appointed a state-sponsored social worker and she and I have been working since about January trying to find a health insurance plan that will give me the coverage that I need and reduce the cost as much as possible and so mm because I've been traveling, aa I've sent a bunch of paperwork to her prior to my trip which is about a month-long trip and we have communicated a little bit by email, but when I got back I learned that some of the process of getting the health insurance wasn't going t.. she didn't start because I needed to be in town. Essentially, if a letter came in through the mail I would need to be home in order to pick it up and go through it and sign off and send it back, and so my actual amount of medication is dwindling and that has been pretty concerned and she is now working with a couple of doctors and nurses in town and then people within her like within her colleagues to try to find me some extra medication until my health insurance kicks back in. And so, in terms of the support, aa it's nice to have an ally in that capacity because I... of course I have friends that are sympathetic hmm and others that I know that are hiv positive that kind of understand the hurdle that you go through, but to have someone whose job it is to know how to navigate the system and support me in that respect has been very helpful.*

**F***: How is your relationship with a social worker in Positive Link?*

**K***: In fact, I felt bad. Because I'm not used to..* (Kory gets up and goes to the fridge to grabs something from the fridge) [**RN April 13th 2017**: Kory grabbed a cup of yogurt] *not used to having someone provide for me in that way. Like the things that, the.. I mean, have you met Katy?* (Kory gets back and sits down in front of his laptop)

**F***: No, I haven't.*

**K***: Katy I think is one of the new ones there. So, one of the things that she does is she just kind of like researches all the paperwork that I need to fill out and then she fills it out and I'm not used to having someone do that for me and so I feel... that's her job, like that's what she's there to do, but I feel bad that what she's doing. Like I feel I'm grown man, I'm capable, I could do that. Hmm but.. so she handles that. So, talking with her today and she was describing like the different resources that she was going to find for me and fill out. I felt hmm humbled. Next time I see her I want to like bring her a gift or something like bake her some cookies or something like that and taking it to her. Hmm because she is... I'm thinking about this.. she is helping me in a very personal.. in a way that you would almost only go to someone who is like your family to get that type of help. When you are sick, there's one thing to go to the doctor. He's going to prescribe medicine for you, but there's another to go to a friend who is going to make chicken soup for you. Hmm and Katy is really providing kind of chicken-soup style care hmm for me. She's not.. hmm I think I'm doing a bad job describing this.. hmm*

[pause]

(Kory looks away from the camera and stares away to something beyond the computer)

*Like if I'm going to Angie's List I can hire people to fix my sink or fix my car, fix my house or repair you know something, but she's helping to fix my body* (Kory looks straight to the camera again) *Hmm which is so much.. has such greater value in the long term. Hmm and so yeah I think that I want to.. my relationship with her is good. But I want to show her how much I do appreciate the work she's done.*

**F***: So, when you were talking about the characteristics of a good supporter, you were talking about a particular kind of supporter who may be a friend or a family member. But then you seem to describe a good supporter in a different way when it comes to a social worker or a doctor.. is that what you are saying?*

**K***: Yes*

**F***: Do you think that you need both types of support? You know the good supporter who is your friend as well as social workers who work in this area?*

**K***: I think the focus is wrong part. It's not that I need good supporters* (Kory pronounces slowly and gives emphasis in the accent to the last syllable (TERS) of supporters) *as a noun. I need good support as a verb and so the verb meaning that there will be a context in which I need support and it doesn't really matter who it's coming from. And it's just that it needs to come in a certain way. So when I need health insurance navigation advice, I need a good supporter, but I need good support and that support that I get from a healthcare worker is going to be more beneficial towards that type of support.*

**[time: 6:44pm]**

**[recorder timestamp: 13:00]**

**F***: Okay, and do you think when it comes to getting this help, this support, is it always in a face-to-face scenario with a person or do you also have other sources where you can get information that might be helpful or supportive to you? I don't know if you have any other examples of where you could get this support.*

**K***: Of course, you know there are online resources that I tap into, but the support is...* [pause] *the support is less direct. Like I'm not going to a forum in order to post what I am presently struggling with emotionally or umm* [unintelligible] *try and get a response from an actual person.*

[**OC**: Kory uses his hands a lot when he speaks]

*It's more.. for instance when I go online and I'm looking for a hookup, the person is a little informed about the risks of contraction of HIV um it's nice to be able to quickly point to umm an online or studies that have their research results published online or at least their latest updates and progress published online, and  I can grab that information and then pass it along to the person that I'm trying to get in bed with. And sometimes that is enough to umm help reduce the stigma associated with HIV. So information is proxy for a umm a person who can* [unintelligible]

**F***: Okay, mm apart for this incidence with the insurance that you were having right now, can you remember of any other difficult or distressing moment that you've had in the past?*

**K***: Oh yeah, this one happened pretty recently. Umm* (Kory reaches to food outside of the view of the camera and starts eating something) *Sorry, my.. I've kept this.. my diagnosis from my parents since I became positive about two and a half three years ago. And I just went through, or I'm going through a breakup umm and as I was telling my mom some of the reasons for the breakup I revealed how I contracted HIV and I got it through my partner via unsafe sex and he had lied me about this status.. well that's a longer story there.. but, in sharing that I was positive to my mom, she then told me that she had two brothers that died of AIDS which I didn't know.. I knew those uncles when I was younger, but I didn't know that they were HIV positive and that they had progressed to AIDS. One, she suspects got it through intravenous drug use and then the other, she thinks it was some type of extramarital gay hookup or something like that.. and so, it was really hard over the phone to kind of hear the pain that my mom was going through learning what I have, given the lost that she has had in her life. Um and* [pause] *it was umm part of the challenge for me was that because I've know that I've had this for, you know, 2 years now, it wasn't new to me anymore. Like. I didn't have anything to come to terms with. But for her, this was a major shock. Umm*

**F***: So what did you do then? Did you direct her to any specific source of information?*

**K***: No. no. It's all just been.. we've.. conversation, we've just been talking one on one.*

**F***: Okay, so you were the one who was providing the information, the supportive help. Do you think that you mom, at that point, needed to have that support from you? or do you think that she just wanted information, she just wanted to make sure that you were okay..*

**K***: I think that support comes through information umm and so I wouldn't necessarily split those two things. umm she of course wanted to know that I was okay. umm I think that I provided.. even though she works in the medical field. She's a nurse. Umm hearing from me that the medication is a lot better now. That your prognosis is extremely great provided that you maintain the treatment. That vitals, not my vitals, but my lab results have all been consistently in good ranges. you know that was reassuring more reassuring and more, I think  substantive, than having found that same information online or through like an external source, but hearing it from me meant more.*

**F***: have you been a source of support to other people living with HIV in the past? Has anyone come to you for help or advice at any point after you became HIV positive?*

**K***: Umm yeah, umm on a couple of occasions.*

**F***: Could you describe what happened?*

**[time: 6:48pm]**

**[recorder timestamp: 17:00]**

**K***: it depends on the knowledge level. When they umm I guess they contracted it. I'll give you two different examples: With one, a gentleman that I knew who was married and got HIV from having an extramarital affair umm had very little knowledge about HIV and STIs in general. And so a lot of his immediate fears were health related, but like extreme.. you know, am I going to die tomorrow? you know, am I going to.. eh how quickly does this metas.. umm become, you know, a very vey severe threat to my health. What are the chances of that I 've given this to my wife.. umm you know, can I transmit it by kissing her? Can I, you know, do I need to wash my hands?.. you know really really basic questions of how do I prevent this from becoming something that destroys my life or the life of someone that I know. But not having any real knowledge about how to protect himself and what the risks are. And so, the support that I brought was information of a.. what the disease is, and this is what, this the ways in which you can go about living your life in a healthy way. Umm here are some resources.. I'm pointing to different web sites or centers that he can find some help. And he was more than an acquaintance, but less than a friend. And so, we haven't had, you know, too much contact. But he did know that I was positive. umm now with another example, umm there is someone that I knew who was well.. he had many friends who were HIV positive umm and when he became positive his questions were so much of a how do I.. umm oh no this is the end of the world, what do I do now. His questions were more practical like how do I find a doctor, how do I get my insurance so that I can pay for my medication. umm are there alternative medications that I should be looking at? his were very medical specific and navigating the health insurance process, you know, kind of specific case. And so my support in that circumstance was just kind of describing the things that I've gone through in order to find doctors and health insurance and you know those cases, and then pointing him in a similar direction.*

**F***: Okay, in your experience, could you describe a person that would be a good supporter? versus a person that would be a bad supporter to people living with HIV?*

**[time: 6:51pm]**

**[recorder timestamp: 20:20]**

**K***: Hmm for me that question changes over time. When I first learned that I was positive, the best support that I received came from friends that would give a long deep hug.. They didn't really go and to try question the life choices that I've made and that have wound me up to that point. It was those that came that said, you know, I'm here for you. um that was the form of support that was in some cases the most helpful, the most useful help during that same time of first learning about it were the ones that told me about their experiences of finding doctors and finding, you know, navigating the health insurance process.. now, having had it for a while, the best support that I receive are from those that umm* [pause] *hmm the best support that I receive are*.. [pause] *I guess.. okay, so some of it has to do with when does it become an issue in my life. uhmm going to the grocery store, the fact that I'm HIV positive doesn't have an impact on me. Trying to find someone to sleep with HIV has an impact on me. And so, the best support that I get comes from those men that I'm attracted to that whether or not they are HIV positive, they are aware of the relative risks associated with having sex with someone who is positive. Umm and so, the support of community yeah is the person that is just informed.*

**F***: Speaking, probably changing from the topic of support, how would you describe a good day in your life?*

**K***: in the context of HIV or..*

**F***: No, in general.*

**K***: A good day in my life:* [pause] *not having an existential crisis.*

**F***: What do you mean?*

**K***: I'm constantly thinking that I'm under performing and that there are goals and tasks that I need to accomplish in order to be valuable as a person. And so, umm I was going to say that for me a good day is when I'm popping on all cylinders. Where everything is clicking. and it's just this idea that I have things that I set out to do during the day and all of those things are happening and they are happening with ease, umm with grace and I'm doing them well.*

**F***: Can you tell me about the last time you sought help or support for something not HIV related?*

**K***: hmm I mean I went to meet with my therapist this morning. And so the support that I was receiving from her was in trying to tackle that existential crisis sort of thing. How to live day to day and not worry so much about hmm future events.*

**F***: Do you think that your therapist is helping?*

**K***: I do. more or less, and some sessions are better than others. I'm extremely challenged and I leave as an emotional wreck, but feel transformed, but then other days, kind of like today,  it was more of a temperature check, keep on with what you are doing.*

**F***: Could you describe these sessions?*

**K***: Generally I come in, I describe my present state of affairs minus the past week or two weeks since we've last seen one another. She usually comments on inconsistencies with my narrative in that I will say or [sounds like expose] that my goals or values are one thing, but that my actions go in a different direction. And so, we flush that out as to why I'm thinking one thing, but behaving in a different way. Umm and there's kind of this back and forth when she will ask questions that challenge, the kind of probe.. primarily is to get me to think more deeply about the assumptions that I'm making on my present circumstances or of myself. And it's a dialog that happens between us for about 45 minutes.*

**F***: If someone you know was recently diagnosed with HIV, and this person came to you, how would you support that person?*

**K***: I would give him a big hug and hold on to them until they pretty much physically try to push me away from the hug. And I would let them know that I am there for them to.. for them when they need to vent, when they need to cry, when they need to talk, when they need to ask for advice umm but to reassure them that there's someone here that is willing to listen. Remind them that is not a death sentence um I would be very clear that it is a change um that there are things that they will have to do differently in their lives now but it's not [sounds like insurmountable]*

**F***: What would be those changes?*

**K***: One, behavioral change. Having to take medication daily, if it's something that you never had to do before um and to know that it's necessary to do this, it's not optional, that's a lifestyle change. Informing others about it um is a behavior change that you have make and you have to find ways to do that that you are comfortable with. You know, some guys will wait until right before sex is about to happen and it's like oh by the way,.. other guys won't tell at all. and then some guys would be very very upfront like Hey, my name is bla bla and I'm HIV positive. And so, finding the balance between when to disclose and then being able to handle the rejection that comes and does come. That's a challenge.*

**F***: Do you think there is a particular type of technology that you are grateful it exists that helps you with challenges?*

**[time: 7pm]**

**[recorder timestamp: 29:25]**

**K***: Indirectly. For me, it's the ability to get medicine. Umm so I was travelling abroad this past month and different countries that have different laws on um how easily prep the Truvada preventative HIV med is dispersed really changes the way that men approach sex there. I was trying to think.. I think in Paris, I think, is very difficult to get the medication, same with Barcelona. And so, what that has done, is simplifies having the disease even more because risk is greater for this men because they are not on something. Um and so, this knowledge of oh god you're positive okay well, in the conversation here, it's not going to happen. Whereas when you are in say Germany or Vienna, where it's easier to get the medication, um a lof of people are already on it um and so the communication is like "oh well, thanks for telling me, Im on prep." So, I'm thankful I guess for the technology such that it has provided for the medication and the ease of access to the medication.*

**F***: So you are saying that there are difficulties in people getting prep because of a lack of technology?*

**K***: Oh it's difficult because how broadly you define technology. Um I mean in some sense however their technological infrastructure setup is likely and price prohibitive for health insurance or the medical facilities to adopt using the medication. Uh it could say that technology has limited the spread to the communities necessary to understand that it isn't a gateway drug. Um what I'm getting here at is that you can't, if there is a social component to the reason that Paris doesn't have medication but Berlin has the medication, you can divorce that from the technological. Or the technological component can't be divorced from that social component. Um I don't know what the specific technology would be um, but I know that technology facilitates the dissemination of the drug.*

**F***: Do you think that stigma plays any role in that?*

**K***: Of course, yeah what I was saying before, access to medication helps reduce the stigma. Um the reduction of stigma increases support. Um*

**F***: Could you describe any moment of situation where stigma affected you?*

**K***: Yeah, it happens pretty regularly when I'm on any type of online platform trying to hook up. You know I reveal my status and it becomes this gamble of if the person is going to be willing to engage or if they are against it.*

**F***: Do you think that these hookup applications have somehow helped manage the consequences of stigma in any way?*

**[time: 7:04pm]**

**[recorder timestamp: 33:52]**

**K***: Some have done better than others. So, most of the apps have now migrated to a system where you can disclose your status and put it inside of your profile. Um I think that this has hurt more than it has helped. And more hurt because it.. for those who are opposed to engaging with someone that is HIV positive, the lack of putting your status is a signal that you are positive, or by putting your status it definitely or clearly signals that you are hiv positive. And so, that person can choose not to engage with you prior to having any form of conversation that could have mediated some of his objections. It's basically like you had this giant bulls eye in your head. If you don't want to talk to that person you can steer clear from them. But, by limiting the conversation, you've limited the access to changing an opinion. The, in some ways, disclosing the information inside your profile has helped because some sites will allow you to put positive, undetectable or on prep, and in both of those cases, it highlights that it's more nuanced, and it's not that you are just positive or negative. Um, it's.. you're negative and taking active steps to try and protect yourself from catching the virus, or you're positive and you have taken active steps to prevent the transmission of the virus. And so, both of those labels help to promote that nuance. Hmm the [unintelligible] also do pretty well in putting up little adverts for fund raising campaigns like an AIDS walk or an AIDS bike ride or an HIV, you know, awareness or something like that becomes a platform for delivering you know that message Hey this is a community that you should get involved in. And then I know that some of the HIV testing centers would put a profile on these sites with the hopes of engaging people... um it's like an information board like I have a question and then I can immediately talk to somebody to get an answer. So, in that ways, it is helpful.*

**F***: What would you like to tell everyone about people living with HIV?*

**K***: Um not a.. it's an illness that it's unpaired with diabetes in terms of its prognosis for living a long life. Uhm and it's a manageable condition that it's not a immediate death sentence.*

**F***: What would be mitigating circumstances for a good prognosis?*

**K***: Access to healthcare, access to information are the primary components of that. As far as I know, most states have initiated programs hm definitely with the federal health insurance that will allow you to get the medication that you need. but mm it does take extra effort hmm and sometimes that effort is difficult if not impossible to put in in order to get tested regularly, see your doctor regularly. Um have access to and afford the medication that you need to take regularly. Um so yeah there are mitigating circumstances. Particularly, since the populations.. particularly even more so because of the populations that are affected by the disease disproportionately have or are more likely to have those mitigating circumstances.*

**F***: Did you ever in the past try to look for help and support and it didn't work? Could you describe such situation?*

**K***: in the context of HIV?*

**F***: yes*

[pause]

**K***: No.. that hasn't really been my experience.*

**F***: Okay, outside the context of HIV?*

**K***: Yeah, definitely, but it touches on some things that I'd rather not get into.*

**F***: Okay, thank you very much for your time.*

**[End time: 7:10pm]**

**[recorder timestamp: 39:52]**