“The people that I think are not going to react good, I am not going to tell”: Onward disclosure to friends by young adults with behaviorally-acquired HIV

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**Abstract**

Sharing one’s HIV status with friends may help young people diagnosed with behaviorally-acquired HIV (BAHIV) access social support. Our qualitative study used Constructivist Grounded Theory to explore onward HIV disclosure decisions within friendships of young adults living with BAHIV. Semi-structured interviews were conducted with 10 participants (ages 22-26 years). Three themes were identified: (a) personal factors influencing disclosure decisions; (b) social factors influencing disclosure decisions; and (c) disclosure decision outcomes. The relational context appeared to be particularly important in deciding whether or not to disclose. Participants who had shared their status reported no negative and some positive consequences. Anticipated stigma was influential in situations where participants chose not to disclose; however, friendships were not adversely affected by non-disclosure. Key clinical implications are discussed.

**Keywords**. behaviorally acquired, disclosure, friends, HIV, young adults

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Since the introduction of effective antiretroviral therapy (ART) in the mid-1990s in high-income contexts, HIV has been seen as a chronic manageable health condition rather than a terminal illness. Nonetheless, many aspects of living with HIV are potentially challenging. One stressor facing people living with HIV (PLWH) after being diagnosed is deciding whether or not to disclose their HIV status to others (and if so, to whom, when, and how). There is often considerable anxiety about onward HIV disclosure ([Evangeli & Wroe, 2017](#_ENREF_12)) across HIV populations, largely due to fears of rejection and discrimination from others. Rates of HIV disclosure vary by the gender and sexuality of PLWH, as well as with whom they are sharing their status ([Daskalopoulou et al., 2017](#_ENREF_10)), perhaps due to within- and between-person variations in HIV disclosure anxiety.

It is relatively rare in high income countries, such as the United Kingdom, for people to be diagnosed with behaviorally-acquired HIV in their teens or early twenties ([Public Health England [PHE], 2016](#_ENREF_33)), which may be partly due to undiagnosed HIV in this population (Wong, Murray, Phelps, Vermund, & McCarraher, 2017). There is evidence that youth with behaviorally-acquired HIV (BAHIV) have more extensive experience of negative life events than youth with perinatally-acquired HIV (PAHIV; [Lewis, Abramowitz, Koenig, Chandwani, & Orban, 2015](#_ENREF_23)), including depressive symptoms ([Abramowitz et al., 2009](#_ENREF_1)) and virologic failure ([Wood, Lowenthal, Lee, Ratcliffe, & Dowshen, 2017](#_ENREF_41)). The recognition of challenges associated with being diagnosed with HIV at a young age (including low rates of treatment and viral suppression; Wong et al., 2017) has led to the development of specific psychosocial interventions for this population ([Brown et al., 2016](#_ENREF_5); [Hosek, Lemos, Harper, & Telander, 2011](#_ENREF_16)).

Arnett ([2013](#_ENREF_3)) argued that it was during the late teens and twenties that individuals established their identities, through making choices in areas such as love, work, and ideology. Other authors have highlighted the number of developmental changes and challenges during these ages ([Zarrett & Eccles, 2006](#_ENREF_42)). The way that adolescents and young adults adjust to living with a new or recent HIV diagnosis in the context of other developmental issues is likely influenced by social support ([Moss-Morris, 2013](#_ENREF_26)), both instrumental (physical or tangible) and emotional. Friendships are central to young adult lives ([Arnett, 2015](#_ENREF_2)) and support from friends may be particularly important for young adults with HIV to help them live and feel normal ([Smith, Dawson-Rose, Blanchard, Kools, & Butler, 2016](#_ENREF_38)). There is evidence that young adults feel closer to, engage in more activities with, and discuss more subjects with their friends than with their siblings ([Pulakos, 2001](#_ENREF_34)). Young adults also talk to friends about things they might withhold from their parents, such as dating and sexual behaviors ([Lefkowitz, Boone, & Shearer, 2004](#_ENREF_21)). A sense of belonging in relation to peers has been associated with fewer problematic behaviors directed toward self and others in adolescents ([Newman, Lohman, & Newman, 2007](#_ENREF_29)). In addition, negative relationships with friends have been associated with poorer health in young people with other chronic conditions ([Helgeson, Reynolds, Escobar, Siminerio, & Becker, 2007](#_ENREF_15)). The availability of social support from friends for young adult PLWH, at least in part, relies on the friend knowing their HIV status.

The Disclosure Process Model ([Chaudoir & Fisher, 2010](#_ENREF_7)) is one well-established model of onward HIV disclosure. The model proposes that HIV disclosure involves decision-making and outcome processes that differ by recipient, as PLWH engage in different disclosure events throughout their lives. The Disclosure Process Model suggests that approach goals (aimed at pursuing a positive outcome) and avoidance goals (aimed at preventing a negative outcome) influence disclosure behavior. A feedback loop is identified, where PLWH who have positive disclosure events become increasingly open about their HIV status and people who have negative disclosure events become increasingly concealed.

Abramowitz et al. ([2009](#_ENREF_1)) investigated the nature and type of support available to adolescents and young adults living with HIV (ages 13-21) and identified significant differences in perceived social support between those living with BAHIV and PAHIV. In particular, people living with BAHIV had lower levels of instrumental support, fewer friends overall, and fewer friends with HIV, despite disclosing their status to more friends than those with PAHIV.

Given the potential importance of friendships to young adults living with BAHIV, we explored their experiences of HIV disclosure to friends, as part of a larger project that aimed to develop a theoretical model of friendships and HIV disclosure decisions in this population (McKenzie, 2016). Our aim was to develop a grounded theory of HIV disclosure within friendships of young adults (ages 18-29) living with BAHIV.

**Methods**

**Design**

We adopted a qualitative cross-sectional design using Constructivist Grounded Theory (Charmaz, 2014). This approach was best suited to the study aims and was in line with the authors’ ontological, epistemological, and methodological orientations (Jeon, 2004).

**Sample**

Participants were recruited from three multidisciplinary London National Health Service clinics across two research sites. Two of the clinics were specifically for young adults (ages ≥ 18 with no strict upper age limit) either newly diagnosed or transitioning from pediatric services. The third was a general adult HIV clinic. Compared to other parts of the United Kingdom, the prevalence of HIV was high in both London boroughs of the research sites. In 2014 the prevalence of HIV diagnoses per 1,000 people (ages 15-59) was 15.08 and 5.29 for the primary and secondary research sites, respectively ([PHE, 2015a](#_ENREF_31)).

Inclusion criteria were that individuals were living with BAHIV, aware of their HIV status for at least 1 year, ages 18 to 29 years, and fluent enough in speaking and understanding English to allow an interview to be completed without an interpreter. This was to avoid the validity of the study being compromised if accurate or direct translation was not possible. All individuals meeting study criteria and who attended their routine clinic appointments were approached. The sample size was determined by theoretical saturation (Charmaz, 2014), that is, when gathering new data no longer revealed new properties of theoretical codes.

Potential participants were initially informed about the research by clinic staff during their appointments. Only those who expressed interest were offered a meeting with the first author to discuss the information sheet, which detailed the aims and purpose of the study. All participants were offered a £15 gift voucher for their time. Three people declined participation after speaking directly to the researcher; two did not give a reason and one identified concerns regarding confidentiality.

The sample was comprised of 10 young adults (8 male, 2 female) ages 22 to 26 years. Table 1 provides a summary of participant demographic details

**Ethics**

Ethical approval was obtained from Royal Holloway, University of London, and National Health Service research committees.

**Data Collection**

Written consent was gained from all participants after the information sheet was discussed. Participants completed a demographic questionnaire before each interview. With participant consent, relevant health-related data were also collected from clinic staff after each interview. All interviews were audio recorded and transcribed by the first author, who, at the time of data collection, was a Trainee Clinical Psychologist. The first author completed all interviews on site. Interviews were semi-structured and questions were generally open-ended and non-judgmental to encourage statements and stories to emerge (Charmaz, 2014). The interview schedule was used as a guide. General topics were covered across all interviews while specific additional or prompt questions were shaped by participant responses. Questions were occasionally repeated or paraphrased to confirm participant understanding. Questions that were included in the interviews are shown in Table 2. All interviews lasted between 30 and 60 minutes. Throughout the interviews the first author summarized participant narratives to ensure that they had been understood and interpreted correctly ([Forrester, 2010](#_ENREF_13)). The interview schedule was piloted with two young adults living with BAHIV who were not eligible for the study, due to their ages and length of time since HIV diagnosis. These were completed on two occasions, one prior to data collection and the other between the fourth and fifth interviews.

**Analytical Approach**

Data were analyzed according to the principles of Constructivist Grounded Theory ([Charmaz, 2014](#_ENREF_6)). Each transcript underwent three stages of coding: initial coding, focused coding, and theoretical coding. Codes were developed by the first author and verified by the second author. In line with Charmaz’s ([2014](#_ENREF_6)) Constructivist Grounded Theory, theoretical sampling was used in the form of adapting the interview schedule to ask about experiences not covered in earlier interviews, for example asking about times when participants may have come close to disclosing their status. Participants were offered the opportunity to give feedback on the results to (a) ensure the findings were coherent, (b) offer potential deeper insights about their lived experiences ([Charmaz, 2014](#_ENREF_6)), and (c) provide triangulation for the data. While three participants opted to give feedback, only one responded after data collection. Feedback was discussed via telephone.

**Quality**

Published guidelines on good practice and quality in qualitative research have been discussed ([Elliott, Fischer, & Rennie, 1999](#_ENREF_11)), including (a) owning one’s perspective (the first author kept a diary to reflect on the influence of personal thoughts and values on the collection and interpretation of data), (b) situating the sample (using demographic and HIV-related clinical data), (c) grounding the analysis in examples (using direct quotes from participant transcripts), and (d) providing credibility checks of the first author’s coding (by the second author). We achieved coherence by naming the theoretical codes appropriately and providing a clear and integrated summary of analysis. This was achieved by mapping out the emergent theory using a diagram, as well as providing a narrative account to understand the categories and the relationships between them. The first author also discussed codes and emerging theory in a peer supervision group, consisting of other grounded theory researchers. In line with Constructivist Grounded Theory (Charmaz, 2014), the first author wrote memos to explore reflections, ideas, and concepts arising from the data. The memos allowed for data comparisons and were vital in linking each stage of coding to the final development of conceptual categories.

**Results**

Upon interview, the time since HIV diagnosis ranged from 1 to 10 years. Five of the 10 participants had disclosed their HIV status to friends, all of whom had disclosed to more than one friend. The five who had not disclosed to any friends had disclosed to others, including parents, siblings, and intimate partners. Participants who had disclosed to friends tended to disclose selectively, which allowed them to reflect on factors facilitating and hindering disclosure in different friendships.

Both female participants and one male participant described themselves as heterosexual. English was a second language for three participants and four participants received an HIV diagnosis outside of the United Kingdom. Nine participants were taking antiretroviral therapy (ART). CD4+ T cell counts had been completed within 12 months of interview and viral loads had been tested within 6 months. One participant (Tyron) had recently undergone a course of chemotherapy for lymphoma, which can dramatically lower CD4+ T cell counts.

Three overarching theoretical codes were identified (see Table 3): (a) personal factors influencing disclosure decisions in friendships, (b) social factors influencing disclosure decisions in friendships, and (c) disclosure decision outcomes in friendships. Figure 1 demonstrates the interrelationships between the three theoretical codes and the nine focus codes comprising them.

**Personal Factors Influencing Disclosure Decisions in Friendships**

All participants identified personal factors that influenced HIV disclosure decision-making with friends. These included individual beliefs about HIV and about their friendships, as well as beliefs about the consequences of disclosure within friendships.

*Identifying pre-diagnosis knowledge and beliefs about HIV.* Participants varied in their knowledge about HIV before they were diagnosed, which appeared related to whether or not they had friends who were also living with HIV. Five participants who identified as men who have sex with men (MSM) described being friends with PLWH at the time of diagnosis. Jay described feeling reassured by seeing a friend living well with HIV, which helped him realize that HIV could have little impact on his daily life. All participants identified learning more about HIV after being diagnosed, mostly through interactions with health professionals, seeking information independently online, or meeting other PLWH through charity support groups. Overall, participants described a shift in their perspectives about HIV over time in the context of their experiences of living with the virus.

Five participants identified being uneducated about HIV before diagnosis. For some this meant having inaccurate beliefs about HIV transmission, whereas others identified knowing little about the virus or how it was treated. While participants described a shift in their own perspectives about HIV, some thought that their friends held knowledge and beliefs similar to their own ideas before diagnosis. Oludamola identified thoughts of wanting to avoid PLWH before he was diagnosed and described feeling certain that his friends would share this view.

*Identifying personal beliefs about friendships.* Participants reflected on HIV disclosure decisions in the context of more general beliefs about friendships. Some participants chose not to disclose to friends due to beliefs about the limited extent to which personal information should be shared between friends. Some participants made links to their own personal traits or qualities, such as being an “open person,” when detailing disclosure decisions. For these participants decisions to disclose or conceal their HIV status were consistent with how they perceived their identities within friendships. Participant personal beliefs about friendships were likely to have predated HIV diagnosis and to have continued to evolve over time (see Figure 1).

*Thinking about the consequences of disclosing to friends.* Eight participants spoke about the perceived consequences of friends knowing their HIV status as a factor in their disclosure decisions, which was related to the extent to which they believed disclosure could aid them personally. Kirsten and Jay described disclosing their status as a way of receiving social support in the form of talking to friends about HIV. In contrast, five participants described withholding their status from friends because they anticipated little personal gain from disclosing. Aaron and Tyron contemplated their disclosure decisions changing over time. Aaron specified wanting practical support from friends, such as “going to hospital with him” or “giving him company,” if his health deteriorated. Paul identified HIV as having little impact on his life, therefore, he felt no specific reason to disclose to friends.

**Social Factors Influencing Disclosure Decisions in Friendships**

All participants described social factors that influenced their decisions about whether to disclose to friends, although the majority came from the five participants who had not disclosed to friends. These factors were characterized by participant perceptions of individual friends, friendship groups, and the nature of friendships in general.

*Considering the nature of friendships.* Four of the five participants who had disclosed to friends identified specific characteristics of both individual friends and friendship groups that helped initiate disclosure conversations. Paul and Diego, who identified as MSM, described disclosing to friends with whom they shared a “party” lifestyle (involving recreational drugs) and to friends who either knew other PLWH or were living with HIV themselves. Both participants thought that HIV would be considered more acceptable to these friends compared to other friends, who had less experience with the virus. Overall, participants described disclosing only to friends who they felt sure would respond favorably, either because of positive personal qualities (e.g., being a “kind hearted” person) or because of the longevity of their friendships. All participants except Rita identified having close friendships, which they had maintained for many years. No participants described losing friends as a result of HIV.

*Difficulty trusting friends.* All participants who had not disclosed to friends described feeling scared or worried about friends sharing their HIV status with other people, either intentionally or unintentionally. Oludamola and Tyron described feelings of uncertainty about the consequences of disclosing to friends. While they did not know for sure that friends would share their HIV status, the perceived consequences were bad enough for them not to risk it. In this sense, withholding their status was a way of dealing with uncertainty.

*Not wanting to burden friends with HIV.* Four of the five participants who had not disclosed to friends described withholding their status as a way of protecting friends from the burdens of having a friend with HIV. Most participants described an accepting attitude toward their diagnosis, yet seemed to feel that friends might think differently of them. Sam and Mateo identified being able to manage HIV independently, although both had disclosed to their partners. Mateo described living well with HIV in terms of emotional wellbeing, whereas Sam emphasized physical wellbeing. Some participants described withholding their status to avoid distressing their friends.

*Identifying pre-existing negative beliefs about HIV held by friends.* Seven participants described concealing their HIV status due to anticipating that friends would either think or act differently toward them if they knew. All participants identified their friendships being unchanged by HIV largely due to friends not knowing their status. In other words, for some, if not all friendships, participants chose to conceal their HIV status as a way of avoiding potentially negative outcomes with friends. Four participants recalled situations when friends reacted negatively toward other PLWH, for example labeling them “dirty,” and described feeling certain that their friends would react similarly toward them. Three MSM participants predicted being judged by friends if they disclosed. In particular, they anticipated that friends would make judgments about how they acquired HIV, in terms of past behavior and lifestyle choices. Paul and Rita predicted they would lose friendships if they disclosed their status.

**Disclosure Decision Outcomes in Friendships**

Seven participants spoke about the impact of disclosure decisions on their experiences in friendships. These related to positive outcomes for participants who had disclosed to friends, as well as complications associated with hiding HIV for participants who had not disclosed to friends. Participant experiences of disclosure decision outcomes were likely to influence future disclosure decisions with friends (represented by feedback loops in Figure 1).

*Positive outcomes following HIV disclosure to friends.* Participants described positive changes in their friendships as a result of sharing their HIV status, which included feeling more valued by friends or valuing friends more, and feeling supported by friends to live well with HIV. Paul and Jay described feeling reassured by friends who were also PLWH, in offering a positive outlook toward their health.

*Complications associated with non-disclosure to friends.* Six participants identified complications as a result of concealing their HIV status from friends, largely in the context of medication and health care. For most participants these complications seemed to be relatively minor with few significant consequences. Rita and Tyron compared HIV to other physical and mental health conditions, including depression and cancer, and appeared to believe living with HIV as significantly worse. Paul and Tyron described feeling certain they would not disclose their HIV status to friends, which appeared to be due to experiences of internalized stigma.

**Discussion**

We examined HIV disclosure to friends in young adults living with BAHIV. There was considerable variation in the occurrence of onward HIV disclosure between participants (5 having disclosed to at least 1 friend, 5 to none) and within participants (5 disclosing to some friends but not others). No negative and a number of positive consequences were reported from those who had shared their status with friends. None of the participants reported friendships that had been negatively affected since HIV diagnosis, regardless of whether the friend knew about the participant’s HIV status (despite there being some minor complications associated with maintaining the secret) or not. This finding was in contrast to a study involving adolescents and young adults living with PAHIV (De Santis, Garcia, Chaparro, & Beltran, 2014), which found that HIV disrupted social relationships in the context of not disclosing to peers. This discrepancy could be explained at least in part by potential differences in disclosure experiences between the two populations; for example, young people living with BAHIV face the additional challenge of deciding whether to disclose to parents, whereas those with PAHIV have to navigate potential difficulties related to disclosing parental HIV status as well as their own. Young adults living with PAHIV were also likely to have been diagnosed at a younger age, which may impact beliefs about the meaning of HIV to self and others. De Santis et al. (2014) found that during diagnosis all participants were told not to share their HIV status with anyone, which resulted in understandable feelings of confusion and distress.

Our findings revealed that most of the factors influencing HIV disclosure to friends were related to the specific disclosure recipient, that is, participant thoughts and feelings about friends as individuals or members of friendship groups. This was in contrast to existing models of HIV disclosure ([Gaskins et al., 2012](#_ENREF_14); [Semple, Patterson, Shaw, Pedlow, & Grant, 1999](#_ENREF_36)), which mainly have focused on individual cognitive factors (e.g., risks and benefits, disclosure self-efficacy, HIV knowledge) assessed over a range of contexts. Participants tended to disclose to friends who they anticipated would react positively (and not to those where there were no anticipated benefits to sharing), based on their perceptions of a friend’s personal qualities and/or knowledge of HIV. This was consistent with the importance of disclosure approach goals ([Chaudoir & Fisher, 2010](#_ENREF_7)). There was no evidence of avoidance goals motivating disclosure, however. Similar findings have been identified in studies involving young adults living with other chronic health conditions ([Kaushansky et al., 2017](#_ENREF_20)), with disclosure to friends and peers who engendered a sense of trust, to those living with a chronic condition themselves, or who had a family member with a chronic disease or disability. Overall, the findings emphasized the importance of the relational context in HIV disclosure decisions. Perhaps social factors were particularly salient for HIV disclosure in friendships, given that typically there was no danger of onward transmission to negotiate when disclosing to friends (none of our participants reported having sexual relationships with their friends).

Participants who identified as MSM appeared to categorize their friends as belonging to distinct groups depending on whether they knew other PLWH. The participants tended to disclose to the former, the “in group,” and withhold their status from the latter, the “out group.” In this sense, they demonstrated a positive bias toward the in-group in terms of HIV disclosure. Consistent with Social Identity Theory ([Tajfel, 1978](#_ENREF_39)), this suggests that these individuals developed a collective, depersonalized identity based on positive perceptions of group membership ([Islam, 2014](#_ENREF_18)). Positive perceptions in this context were associated with greater exposure to HIV and, therefore, less likelihood of HIV stigma and discrimination.

All participants who had not disclosed to any friends identified fears that friends would share their status with others. Some participants perceived pre-existing negative beliefs about HIV by friends, which meant they anticipated that friends would think or act differently if they knew. This led them to withhold their HIV status to avoid potentially negative outcomes within friendships, such as being judged or rejected. Similar barriers to HIV disclosure have been reported in other studies involving adolescents and young adults living with HIV ([Bakeera-Kitaka, Nabukeera-Barungi, Nostlinger, Addy, & Colebunders, 2008](#_ENREF_4);  [De Santis et al., 2014; Hosek, Harper, & Domanico, 2000](#_ENREF_17); [Martinez, Lemos, & Hosek, 2012](#_ENREF_24); [Nostlinger, Bakeera-Kitaka, Buyze, Loos, & Buve, 2015](#_ENREF_30)). Our study also revealed other, less commonly reported negative disclosure outcome expectancies, namely concerns about burdening friends and being treated differently by them. There was no evidence of the negative feedback loop cited in the Disclosure Process Model ([Chaudoir & Fisher, 2010](#_ENREF_7)), that is, avoidance of disclosure was not preceded by negative disclosure experiences.

Most participants reported feeling uneducated about HIV or having inaccurate beliefs about transmission or HIV-related life expectancy before they were diagnosed. Two participants who knew friends with HIV described having a better understanding of the virus, however. Conceivably, one of the main ways for youth to acquire knowledge about HIV is through the education system. One participant described learning little about HIV as part of school sex education, and recent media publications in the United Kingdom suggest that additional training for teachers may be required ([Moorhead, 2015](#_ENREF_25)). The Children’s HIV Association (2015) has published guidelines to promote HIV friendly schools in the United Kingdom. Such guidelines have the potential not only to promote HIV prevention but also raise awareness of HIV for staff and pupils.

**Limitations and Strengths**

Qualitative research can be assessed on representational generalization, relating to two main issues: the quality of the research and the degree to which the sample is representative of the wider population *(*Lewis & Ritchie, 2013). In line with Constructivist Grounded Theory, our study involved co-construction between participants and researchers at all stages of analysis (Nagel, Burns, Tilley, & Aubin, 2015). The response rate (1/10) for participant verification after data collection was low, however. The quality of the research could have been further strengthened by the authors independently coding rather than the second author verifying the first author’s codes.

There may have been differences between those who attended clinic appointments (where recruitment happened) and those who did not, particularly in terms of adherence behavior and HIV viral load, compromising the representativeness of the sample. The response rate (10/13) was good; however, three people declined participation after speaking directly to the researcher. The inclusion and exclusion criteria were deliberately broad to aid recruitment, given the small available population of young adults living with BAHIV. Recruitment resulted in a diverse sample of participants, particularly in terms of ethnicity and length of time since HIV diagnosis. While White MSM are the group most likely to acquire HIV between the ages of 15 and 24 in the United Kingdom ([National AIDS Trust, 2015](#_ENREF_28); [PHE, 2015b](#_ENREF_32)), the study contained only one White British MSM. These features of the sample raise questions about whether the sample was representative of young people living with BAHIV in the United Kingdom and further limits generalizability. Another potential limitation of the study was that CD4+ T cell count data at the time of diagnosis were not collected for participants. People who test late for HIV have lower CD4+ T cell counts and are, therefore, more likely to be physically unwell ([Corkery, 2016](#_ENREF_27)). The stage of disease progression at diagnosis might have influenced participant friendship experiences and disclosure decisions.

Despite a heterogeneous sample, similar experiences were identified between participants, especially in terms of barriers to HIV disclosure. This suggests a degree of transferability of the research to other young adults living with BAHIV in the United Kingdom (Lewis & Ritchie, 2013) and strengthens the validity of the grounded theory (Charmaz, 2014). The study sample was also likely to be representative of young adults living with BAHIV in the United Kingdom on ART. In 2014, 95% of all PLWH in the United Kingdom on ART achieved viral suppression ([PHE, 2015a](#_ENREF_31)). All of the nine participants in the study on ART had undetectable HIV viral loads, which was in line with published international guidelines ([Joint United Nations Programme on HIV and AIDS, 2014](#_ENREF_40)).

In terms of the quality of the research, the concept of theoretical saturation has been interpreted and viewed differently by researchers. Charmaz (2014) argued that saturation was reached when gathering new data no longer revealed new properties of theoretical codes. Saturation appeared to be reached for the majority of codes as the latter participants resulted in significantly fewer new codes. Dey (1999) put forward the term “theoretical sufficiency” as an alternative to saturation. He argued that researchers were at risk of undermining the value and legitimacy of their analyses by adopting a directive and prescriptive approach as suggested by traditional Grounded Theory (Glaser & Strauss, 1967).

**Practice Implications**

Our findings provide important implications for nurses and other health professionals working with young adults living with BAHIV. In line with a stepped care model (British Psychological Society, 2011), nursing staff play a key role in providing frontline psychological support for young adults living with HIV, including issues related to HIV disclosure. Our findings suggest that health professionals should be guided not only on how to support young adults living with HIV to disclose their HIV status, but also on supporting their rights not to disclose, particularly given that non-disclosure did not have a detrimental impact on friendships in our sample. Despite the fact that HIV disclosure has often been viewed as adjustment behavior, our findings could help reassure health professionals that non-disclosure does not necessarily indicate poor adjustment to HIV.

While HIV disclosure interventions exist to support mothers living with HIV to disclose to their children ([Rochat, Mkwanazi, & Bland, 2013](#_ENREF_35)), women living with HIV to disclose to others ([Kaaya et al., 2013](#_ENREF_19)), and MSM living with HIV to disclose to family ([Serovich, Reed, Grafsky, Hartwell, & Andrist, 2011](#_ENREF_37)) and sexual partners ([Chiasson, Shaw, Humberstone, Hirshfield, & Hartel, 2009](#_ENREF_8)), no disclosure interventions have been identified to support young adults living with HIV to share their status with friends. Our study found positive benefits and no negative effects as a result of onward disclosure to friends and, therefore, an intervention focused on enhancing satisfaction with disclosure decision-making (which may result in decisions to share) could be warranted.

Our findings demonstrated evidence of on-going HIV-related stigma in young adults living with BAHIV. In particular, participants spoke about the anticipated negative consequences of sharing their HIV status with friends. Some of the MSM participants discussed internalized stigma, which has been identified as a risk factor for depression in this population (Dowshen, Binns, & Garofalo, 2009). Other studies have identified an association between internalized stigma and increased levels of illicit drug use, which may be used as a way of coping (Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2009). Based on these findings, it is important that nurses and other health professionals conduct regular mental health screenings with young people living with BAHIV.

Reducing HIV-related stigma should not only involve individual approaches (i.e., working directly with young adults with HIV), but should also target peer beliefs and other social and systemic factors. Campaigns that promote HIV-education in schools, such as the HIV friendly schools campaign (Children’s HIV Association[, 2015](#_ENREF_9)), could help reduce HIV-related stigma by raising young peoples’ knowledge about and awareness of the virus.

**Conclusion**

Our study was unique in allowing an in-depth exploration of the processes involved in disclosure decisions specifically to friends, and provided important information for nurses and other health professionals working with young adults with HIV, which may help guide conversations related to HIV adjustment and disclosure processes. We highlighted significant within-participant factors that influenced HIV disclosure to friends, including perceptions of individual friends or friendship groups. One option for future research could be to investigate the cognitive and affective determinants of HIV disclosure to individual friends and friendship networks prospectively. More research is also needed with young adults living with HIV to help develop appropriate HIV disclosure interventions within this population.

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**Key Considerations**

* Social factors (i.e., thoughts and feelings about friends as either individuals or as members of friendship groups) may be the most influential determinants of disclosure decision-making.
* Health professionals should help young adults living with HIV share their status if they wish, but should also support the right to not share their status.
* Experiences of HIV-related stigma (e.g., fear of being rejected because of HIV) play a key role in non-disclosure.
* Regular mental health screening in this population is an important intervention.

Table 1

*Demographic Details of Participants (*N *= 10)*

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Pseudonym** | **Age** | **Gender** | **Time since**  **diagnosis** | **Disclosed**  **to friends** | **Country or region of birth** | **Ethnicity** | **Sexual**  **orientation** | **Relationship stats** | **CD4+ T cell**  **counta** | **Viral load** |
| Mateo | 22 | Male | 2 years | Yes | South America | White Other (Latino) | MSM | Co-habiting | 375 | Und.b |
| Oludamola | 25 | Male | 1 year | No | West Africa | Black African | Heterosexual | Regular partner | 492 | Und. |
| Paul | 25 | Male | 4 years | Yes | United Kingdom | White British | MSM | Single | 585 | Und. |
| Kirsten | 23 | Female | 7 years | Yes | United Kingdom | White British | Heterosexual | Single | 500 | Und. |
| Rita | 26 | Female | 10 years | No | United Kingdom | Black British | Heterosexual | Single | 261 | Und. |
| Aaron | 25 | Male | 10 years | No | Northeast Africa | Black African | MSM | Single | 358 | Und. |
| Tyron | 23 | Male | 2 years | No | United Kingdom | Black Caribbean | MSM | Co-habiting | 45 | Und. |
| Sam | 25 | Male | 3 years | No | Caribbean | Black Caribbean | Bisexual | Regular partner | 629 | Und. |
| Diego | 23 | Male | 1 year | Yes | Europe | White Other (Spanish) | MSM | Single | 444 | 64865 |
| Jay | 25 | Male | 1 year | Yes | United Kingdom | Black Caribbean | MSM | Regular partner | 183 | 740 |

*Note.* MSM = men who have sex with men; Und. = undetectable.

1. Reported as cells/mm3
2. Undetectable viral load: < 50 copies HIV RNA/ml

Table 2

*Interview Questions*

|  |  |
| --- | --- |
| 1 | Tell me about your experiences of living with HIV.  In what ways has your life changed since your diagnosis? In what ways is your life the same? What were your thoughts or beliefs about HIV before your diagnosis? |
| 2 | Tell me about the important friends in your life.  How did you meet? How long have you been friends? Who are you closest to? What do you like about your friends? |
| 3 | Tell me about your friends that know your HIV status.  What were your thoughts and feelings about telling them? What made you feel more comfortable telling them? Was your decision to tell them planned or spontaneous? How does telling your friends affect your relationships with them? Have there been any times that friends have found out your HIV status without you telling them? |
| 4 | Tell me about your friends that do not know your HIV status.  What were you thoughts and feelings about not telling them? How does not telling your friends affect your relationships with them? In what ways do your relationships with friends you have told compare to those you haven’t? Are there any friends you haven’t told who you might tell in the future? What thoughts or images go through your mind when you think about telling them? Have there been any times that you have come close to telling them? |

Table 3

*Factors Influencing Disclosure of HIV Status to Friends: Theoretical Codes; Focused Codes; and Example Quotes*

|  |  |  |
| --- | --- | --- |
| **Theoretical codes** | **Focused codes** | **Example quotes** |
| 1. Personal factors influencing disclosure decisions in friendships | Identifying pre-diagnosis knowledge and beliefs about HIV | * *I never really heard about it. I never, like – because even in school when we done sex education class we were never told much on STDs or STIs, it was more about how to use a condom. And like, falling pregnant.* (Kirsten) * *So the kind of picture every African has in mind of HIV is like, once you get it, you are dead.* (Oludamola) * *Well… ‘Cause – my friend was – I seen him living his life and he was alright, I always knew that there was always things about HIV, especially in London, and how you can still live well and healthy.* (Jay) * *So that is like the picture they have, so I wouldn’t blame them. It has happened to me also, when I heard that someone had HIV I was like “Wow! That man! I’m not going near.”* (Oludamola) |
| Identifying personal beliefs about friendships | * *I don’t mind they know it because they’re my friends but friends shouldn’t know everything about you, there are some things – boundaries – with friends as well.* (Aaron) * *Yeah… so, yeah I think I’m generally a very, very private person. And my friends, they know that and they’re just like, “OK that’s just who he is.”* (Sam) |
| Thinking about the consequences of disclosing to friends | * *‘Cause I know I need someone to talk to and I know she was a great person to speak to […] so I just know that she is going to be there to support me.* (Jay) * *Don’t feel the need to tell them. Because, like, it’s always in the back of my mind but I’m never really thinking about it [HIV]. It’s not really a problem for me. I forget I have it sometimes.* (Paul) |
| 2. Social factors influencing disclosure decisions in friendships | Considering the nature of friendships | * *I think she’s more accepting, that’s why. Like she don’t have a problem at all …. Because she already had friends that had it. So it was, like, what’s one [more] going to be a problem?* (Paul) * *Well it’s not possible because the people that I think are not going to react good, I am not going to tell. I know my friends since 5 years and the other one since 17… so I knew they would react OK.* (Diego) |
| Difficulty trusting friends | * *I worry about that because I … if I explain [disclose] they, they maybe explain to other people.* (Mateo) * *He’d probably be a bit like me and one day he’ll accidentally let it slip.* (Tyron) |
| Not wanting to burden friends with HIV | * *I have this problem and it’s my problem… it’s not my friend’s problem, no. It’s my problem. I don’t worry about it but all of the people around me they don’t need it.* (Mateo) * *It’s actually just about me and my personal life, and it’s about me keeping myself healthy. So I don’t see the reason to burden them with that.* (Sam) * *They wouldn’t be like “oh, go away!” but I feel like they would be sad for me.* (Aaron) |
| Identifying pre-existing negative beliefs about HIV held by friends | * *So if I use a cup everyone might not want to use that cup, so they will just be like sceptical of everything I do.* (Oludamola) * *I heard someone actually sayin’, “If I knew someone with it [HIV], I wouldn’t talk to them.” Like, you’re just gonna drop your friendship because of the person’s sickness, it’s not like the person intend to have it.* (Rita) * *I know the mentality, even though time has gone on, it’s still the stigma behind gays and homosexuality, and HIV … they’ll look at me different – and everything would just be different.* (Jay) * *I really wanted to tell him, it’s like I had to slap myself like … “If I tell you, you would run a mile.” So… I just thought, “There’s nothing to say.”* (Rita) |
| 3. Disclosure decision outcomes in friendships | Positive outcomes following HIV disclosure to friends | * *When you go through something like that you know who your true friends are!* (Kirsten) * *I think the ones that had it – have HIV – like, I told them and they were like. “It’s fine, it’s just normal. Just carry on.”* (Paul) |
| Complications associated with non-disclosure to friends | * *I’m crafty, I’ve got it in a little box, so they just think it’s multi-vitamins.* (Paul) * *Cancer is awkward but I can manage it. HIV is just a no-go. I think it’s…[pause]… I think it just kind of makes you feel a bit dirty.* (Tyron) * *Sometimes I have to go to the hospital and he’s like. “Why? You are not sick. What are you going there for?” So, I tell him that the jaundice I had when I was in Nigeria … I need to go for some antibiotics.* (Oludamola) |

*Note.* STD = sexually transmitted disease; STI = sexually transmitted infection.