CASE REPORT

Stigma kills! The psychological effects of emotional abuse and discrimination towards a patient with HIV in Uganda

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Accepted 16 June 2017

SUMMARY

Our patient is a 58-year-old Ugandan woman. After her husband's death in 1994, the patient was forced to leave her home by her late husband's family and arrangements were made for her mother to provide care until her inevitable death. The patient suffered from multiple mental health disturbances as a result of discrimination. Socially isolated after years of self-neglect, she prepared to overdose. In 2007, she became open regarding her status after receiving psychosocial support from various sources. She opened her home as an HIV clinic with the help of a local doctor, and subsequently the majority of her psychological symptoms were resolved. This case illustrates the negative impact that stigma and discrimination can have on mental and consequently physical health, both acutely and chronically. It also highlights the importance of social and psychological support in maintaining the well-being of patients with HIV globally.

CASE PRESENTATION

Our patient is a 58-year-old Ugandan woman born and raised in a small village north of Kampala in the Wakiso District. Her first husband became sick in early 1990. She took her spouse to a hospital in the city where both were diagnosed with HIV. At the time, in Uganda, antiretroviral treatment (ART) was largely not available to the general public and, without the medication he required, the patient's husband died 4 years later.

After the death of her husband, the patient was forced to leave their family home. With her HIV status now more widely known among the villagers, the reputation of her former husband's family was at risk. Friends who had borrowed possessions from her publicly burnt them to minimise the chance of transmission, adding to the external stigma. Care of the patient was entrusted to her mother by her late husband's family until her anticipated death from untreated HIV.

In 1995, the patient developed a severe rash, however, the extremity of her paranoia at that time meant that she remained at home for fear that others may recognise this as a symptom of 'the slim' (local slang for HIV). She became progressively more paranoid, believing people in the street were singing about her. Her sleep was regularly disrupted by continued internal stigmatisation and night terrors, reliving emotional abuse that she had

received as well as experiencing recurrent dreams of drowning. She stated that she had only been able to sleep for 1 hour at a time from the date of her diagnosis in 1990. In addition, she also experienced panic attacks on attempting to leave the house; racing heart, shortness of breath, tremulous body, chest tightness, sweating and nausea. These experiences were enough to convince her to remain inside. Not only did this socially isolate the patient, it prevented her from leaving the house to obtain necessary medical advice.

After experiencing both internal and external stigmatisation, the patient suffered from a number of symptoms of depression, although she had not yet received a diagnosis. These symptoms included anxiety, insomnia, panic attacks, poor concentration, low mood and feelings of hopelessness and worthlessness. Following a number of years suffering from this low mood and anxiety as well as flashbacks of emotional abuse, she prepared to end her life by overdose, and penned a suicide note to her mother. This was following a visit to a neighbour who was known to be suffering from HIV. She found her friend emaciated, paralysed and confused, with significant discharge and deformation of her vagina. This was the first of many of the patient's friends to die from the condition. Frightened to discuss the situation she returned to her home, determined she would not succumb to such a fate. The patient's mother stopped her from taking the large quantity of chlorpromazine—used locally as an over-the-counter medication for sedation—and encouraged her to attend counselling. Her mood improved after attending these sessions at her local church.

In 1998, the patient married her current husband. When the two had first met 2 years previously, the patient explained why it was impossible for her to have a partner. This invited his disclosure: he, too, was HIV positive. They attended hospital together to receive treatment but as they were unable to afford ART, co-trimoxazole (Septrin) was administered alongside basic lifestyle training; the simple instructions to eat well, practise safe sex, use a mosquito net and avoid stress.

Fortunately, the patient did eventually start ARTs in November 2004 with the support of her current husband, funded by The AIDS Support Organization. Although there was a successful medical treatment in place, her psychological symptoms

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To cite: Ruffell S. *BMJ Case Rep* Published Online First: [please include Day Month Year]. doi:10.1136/bcr-2016-218024

remained. In 2007, the patient became open about her HIV status in the hope of combating these symptoms. Although the taunts and negative stigma continued, the chorus of villagers proclaiming she was positive now became a beacon informing people where to turn. As a result, she opened up her home as an HIV clinic with the help and support of a local doctor. Following this, the majority of her psychological symptoms ended. She is now 58 and has an undetectable viral load. The patient understands only too well the psychological effects of HIV and she now conducts regular home visits to counsel patients.

GLOBAL HEALTH PROBLEM LIST

- ▶ A diagnosis of HIV has a significant, often overlooked effect on mental health.
- ▶ Discrimination from the community prevents patients from receiving the treatment they require and has a significant effect on mental and physical health.
- ▶ Social support can have an extremely positive effect on mental and consequently physical health.
- ▶ Social support is often lacking in developing countries.
- ▶ Psychological support in HIV-positive patients needs improvements in developing countries.

GLOBAL HEALTH PROBLEM ANALYSIS

HIV is a heavily stigmatised chronic condition with the potential to affect all areas of a patient's life, including their mental health. It is worth noting that when referring to mental health in this paper, the terms 'condition' and 'disorder' will be used interchangeably, equally referring to the medical condition and the lived experience.

Those with HIV have been found to be more likely to develop mental health disorders, often due to the stigma, shame and discrimination associated with the condition. Interestingly those with mental health disorders have also been found to be more likely to contract HIV.¹ The Ugandan National Policy Guidelines describes HIV Counselling and Testing (HCT) as 'the most important service in HIV/AIDS prevention and care strategies'.² Despite this, two and a half decades after HCT was introduced, there is still an absence of utilisation of the treatment that is deemed to be 'the most important'.

The effects HIV has on mental health in a global context

Although mental health disorders are extremely common in those suffering from HIV, a large proportion of such cases goes undiagnosed and unrecognised.³ It is vital we increase the diagnosis and management of such conditions to successfully reduce morbidity and mortality as a result of HIV, both in regards to physical and mental health.

Those suffering from HIV have been found to be twice as likely to suffer from a major depressive disorder than those without a diagnosis.⁴ Depression has been found to be the most common mental health condition experienced by those diagnosed with HIV.⁴ In a population of HIV-positive individuals in South Africa, a country that is similarly affected by HIV, 5%–10% were found to have major depressive disorder, while 15%–20% were diagnosed with minor depression.³ HIV-positive patients are at an increased risk of actual and attempted suicide when compared with those with other chronic diseases or members of the wider population. Interestingly, with regard to HIV, this does not appear to be related to the stage of the disease.⁵ In a sample of HIV-positive patients from Kampala, Uganda, 51.2% of participants were found to be suffering from significant psychological distress, 17.1% having attempted suicide within

the last year. 40.8% were found to be depressed, 45.6% anxious and 1.2% manic.⁶

Post-traumatic stress disorder (PTSD) has also been identified as being prominent in populations suffering from HIV/AIDS. Those meeting the criteria for PTSD (14.8% of a sample in South Africa) have also been shown to have increased rates of major depressive disorder, suicide ideation and social anxiety disorder.⁷ Although our patient was never formally diagnosed with PTSD, her clinical profile has been suggestive of an individual suffering from the condition; with symptoms such as flashbacks associated with anxiety. PTSD most commonly develops secondary to a diagnosis of HIV, although 36% of patients in the above study were thought to have developed PTSD as a result of the HIV diagnosis.⁷ It is unclear as to what specifically led to the development of such symptoms in our patient, although the HIV diagnosis and the subsequent social isolation no doubt both played a significant role.

It should also be noted that those with mental health disorders are at an increased risk of acquiring HIV. This is thought to be due to social vulnerability, drug and alcohol misuse and consequently unprotected sexual relationships often associated with mental health problems.⁸ This undoubtedly has potentially serious consequences to public health in regards to the spread of HIV.

The aetiology of such psychological difficulties must also be considered. These may occur as a direct result of neuropsychiatric complications of HIV that are developed as the disease progresses. The neuropsychiatric effects of HIV are more prevalent in developing countries where patients refrain from visiting the hospital due to poor education, social stigma and fear. ART, which is often used at detection, can also have psychiatric side effects. Long-term use of efavirenz is specifically associated with depression, anxiety and paranoia,⁹ though there may well be other predisposing factors that contribute to the development of these symptoms. The psychosocial complications arising from stigma and discrimination must also be considered within the patient population with HIV.¹⁰ It should also be noted that the increasing age of patients with HIV has been thought to expose individuals to more common diseases, such as cancer, stroke or indeed depression.¹¹

The psychological effects of stigma and discrimination

Stigma and discrimination have been suggested as the main causative factors in regards to the development of the psychological symptoms described above, as well as having a significant association with poor treatment adherence.¹² It has also been evidenced that stigmatisation increases HIV-related symptoms—both physical and cognitive.¹² Stigma can be internal—felt stigma, or external—response from others. Both have different effects on the psychological state of the patient.¹³

Internal stigma

Internal stigmatisation (or self-stigmatisation) has been found to be associated with paranoia and delusions in those suffering from HIV.¹⁴ Our patient openly admitted to such experiences regarding people shouting at her and discussing her condition in the street, as well as night terrors. Our patient suffered from internal stigmatisation in a variety of forms; primarily through shame at having survived when her husband had not, as well as the negative connotations associated with HIV; such as sex work. She also admitted feeling guilty for acquiring the condition—as she concluded she must have committed a serious mistake to have contracted such a disease. In the years leading

up to her diagnosis, stigma associated with HIV had been much more extreme, often resulting in sufferers of the condition being banished from their homes and disowned by their families. Although this was largely no longer the case, our patient's expectation of discrimination prevented her from seeking the support and treatment she required. Stigma and discrimination are long-term stressors that can result in avoidance of treatment, poor adherence, poor self-care, social isolation, depression, suicide and death.^{15 16} Unsurprisingly, a significant association has emerged between internalised stigma and the development of depression and anxiety.¹⁷

Fortunately, the patient was tested for HIV, although there was a delay in starting treatment. Many avoid the test for fear of discrimination if the results are positive.¹⁸ It is vital that we combat such issues to avoid that which is listed above and to reduce rates of HIV transmission. Anxiety regarding discrimination and fear of emotional and even physical abuse may prevent patients from disclosing their status to partners or adopting safe sex practices, resulting in higher rates of HIV transmission and ultimately, higher death rates.^{15 16}

External stigma

The discrimination associated with a diagnosis of HIV is often as a result of misinformation. Despite improvements in education and understanding, stigma surrounding HIV remains. This is especially true in sub-Saharan Africa, where HIV is associated with infidelity and sex work.¹⁹ WHO 2015 guidelines help combat barriers to HIV treatment, such as stigma and discrimination, in a wide variety of means; varying from educational programmes to the positive promotion of treatment and prophylaxis.²⁰ Despite this, a study in the USA revealed 40% of the adult population perceived a risk of transmitting HIV through coughing, sharing a glass or sneezing. The same population of adults were also found to be more likely to state that 'the patient got what they deserved'.²¹

Stigma has been shown to have a negative impact on mental health through discrimination; inaccurate stereotypes are often formed resulting in prejudice.²² Employers, friends and even family regularly reject those suffering from HIV.¹⁷ This can have a negative impact on one's mental health when social identity is threatened. In sub-Saharan Africa, social identity of the self and the family are equally at risk of prejudice.²² Studies have shown that a significant proportion of those diagnosed with HIV experience abuse, avoidance and isolation within their communities. Our patient experienced external stigma and discrimination due to community ignorance and misleading education in regards to HIV. The external stigma she experienced included being forced to leave her late husband's family home, as well as having possessions she had lent to friends and family members burnt in the street in front of her. This stemmed her feelings of worthlessness, social isolation and lack of self-care; our patient felt excluded from the community with almost no social support and no one to turn to. This resulted in depression, anxiety and suicidality and prevented her from seeking treatment. Lack of education and resultant discrimination had disastrous consequences for our patient, and it almost ended her life, as it did her late husband's.

The AIDS integrated programme in Zambia has echoed the success our patient saw; that disclosure of HIV status can have a positive effect on those suffering from the condition in the surrounding community. Those living with HIV have acted as role models encouraging others to come forward for testing or treatment.²³ Case reports conducted by the AIDS integrated

programme in Zambia have clearly shown the success of this role modelling care in reducing stigma, both internal and external. This initiative dispels myths regarding HIV such as that regular daily contact can result in transmission of the virus and educates friends and relatives of patients to provide the care and support required.²⁴

Suicidality is prevalent in those with HIV,²⁵ especially in Uganda. Of those suffering from HIV, 7.8% were found to have a 'moderate to high risk for suicidality' in Entebbe. The main method of suicide is overdose, often from HIV medications due to accessibility. Multiple studies have been conducted throughout the West to assess the risk factors of suicidality in patients with HIV. The results of the studies suggest specific categorical effecting factors, which are sociodemographic, psychiatric, psychosocial and clinical. Within psychosocial factors, social support was highlighted as an important factor in determining suicide rates.²⁶ The effect of social support should not to be underestimated, as it has the potential to decrease suicidality in patients with HIV globally.

The importance of social support

Social support is undeniably vital in all areas of life, especially when combating a condition such as HIV. The WHO defines psychosocial support in those suffering from HIV as 'support that addresses the ongoing psychological and social problems of HIV-infected individuals, their partners, families and caregivers'.²⁷ This support can focus on the acute stress reaction that often follows a diagnosis of HIV or can address the long-term stress associated with the complications of a chronic condition.²⁸ Social support has been categorised into two different domains; structural social support (the support network) and functional social support (specific functions of those within the network). Both have been shown to be of vital importance to the improvement of well-being of those with HIV.²⁹ Many studies have illustrated the importance of social support to decrease levels of depressive symptoms, as well as anxiety, both in the short and long term.³⁰⁻³² Interestingly, it is the perceived social care that has been found to positively impact the patient's mental health, as well as regular attendance to an HIV clinic.³¹

Despite the benefits of social support being widely recognised, there are still many cases where those suffering from HIV do not receive the social support that could help them. As previously discussed, a diagnosis of HIV has been associated with developing mental health conditions which social support helps to tackle. It has also been found that disclosure of HIV status to friends and family, as well as regular contact with services, can, in itself, help to improve symptoms of mental health conditions, with a predicated 32% variance.³⁰ In our case, disclosure and social support had a much greater impact on the patient's mental health.

Those living with HIV can potentially experience a wide variety of stressors from the point of their diagnosis. Social support groups have been found to improve quality of life³³ and reduce morbidity and mortality as well as improving retention in care.³⁴ Attending support groups has been shown to increase confidence, reduce perceived stigma as well as build coping skills and self-esteem.³³ A cohort of 268 patients with HIV in South Africa showed that involvement in a support group could predict whether treatment was likely to be successful throughout the first 24 months.³⁵

Those with HIV utilising such groups have been found to experience less emotional distress, whereas those who have not engaged are more likely to adopt avoidant coping styles.³⁶

Communication between members of a support group has been found to act as an emotional outlet, with feedback from the group described as being an essential element of their support.³⁷ The WHO has promoted peer support groups for those suffering from HIV to reduce stigma and discrimination and to encourage disclosure and help patients adhere to treatment and remain in care.^{38–40} Attending support groups has even been correlated positively with an increase in condom use and reduced HIV transmission rate.⁴¹ A study conducted in Mozambique found a significant increase in the proportion of patients who continued to actively remain in medical care receiving ART.⁴² After 1 year, the retention rate was 97.5%, dropping to 91.8% after 4 years. This showed a significant increase in retention when compared with those not receiving group support where only 85% in Mozambique and 74% in South Africa had remained in medical care after a year.⁴³

Social support groups for those suffering from HIV have become common throughout Uganda.^{44–46} They have been shown to reduce stigma—both internal and external⁴⁴—and increase the percentage of those disclosing their HIV status and also increase referrals to HIV health facilities.⁴⁵ Peer support groups in Ugandan schools have also been found to reduce the degree of psychological distress experienced by those living with HIV, specifically in regards to anxiety, anger and depression.⁴⁶ Unfortunately our patient was not aware of any such groups locally. She did, however, begin to receive group support as she set up her own clinic. Peer support groups have specifically been found to improve the psychosocial functioning of patients living with HIV.³⁸ In our patient's case, after she publicly disclosed her status and opened her home as an HIV clinic, her psychological symptoms began to resolve. As our patient was in the planning stages, she was in regular conversations with her new colleagues; this acted as an informal peer support group. This provided an important adjunct to her clinical care allowing her to cope with her diagnosis. Many of those who were involved in helping her set up the clinic chose to do so as either they or their family members were affected by HIV. These planning sessions provided a forum to discuss how to best proceed with the clinic and became an opportunity to support each other in regards to their own or loved one's health. She specifically described the importance of 'no longer feeling alone'; accepted finally for who she was. She described the overwhelming joy on finding acceptance within this group and the intense relief when she was not rejected. She was able to discuss concerns and fears as well as share how it had felt to receive such abuse and isolation for so many years. In turn, she learnt how others had experienced similar pain and was able to empathise with and support them. Providing this role was beneficial to her new colleagues and allowed our patient to prove to herself that she was not worthless and had no need to be ashamed of her HIV status. This resulted in an increase in self-worth, self-efficacy and self-value as well as a substantial decrease in her anxiety and depressive symptoms. It was not long before separate meetings were organised regularly to allow people to discuss their personal issues related to living with HIV; and the first community volunteer support group was thus formed. Since this time, the clinic has encouraged the formation of support groups for peers, community members, volunteers, those living with HIV and even the carers and support networks of those living with the condition. This is an example of the wide variety of forms social support groups can take.

These support groups are by nature open and non-judgemental, and sharing personal experiences with peers therefore allowed our patient's self-esteem to improve. She was also

continually motivated by these sharing forums to maintain adherence to ART. Her psychosocial functioning improved to the point that she was no longer afraid to leave the house. She was able to take back control of her health and therefore life. Our patient specifically used the social support provided by these groups to transform her social functioning and psychological well-being. The taunting that once trapped our patient inside her house became a beacon informing people where to go to for support and treatment of HIV. Our patient was able to discuss the stigma—both internal and external—she had received and recognised that psychological complications could arise from HIV as well as physical ones. The group support she received from peers, the community and others living with HIV facilitated her improvement in general health and well-being by acting as an essential adjunct to her clinical care. Even now she regularly attends groups sessions with peers at the clinic—a routine she describes as vital in maintaining her psychological well-being and adherence to medication. Our patient also takes an active role in leading group sessions for patients and family members. She understands only too well the importance of such support in encouraging people to disclose their status, adhere to treatment and accept the diagnosis.

Although support groups are often formed from community based programmes, these do not necessarily have to be based within health facilities. Many are solely based in the community or are as a result of non-governmental organisations. In addition to the studies cited above based in Africa, group support for those with HIV has been found to be successful throughout the world.^{47–51} In China, family sessions have been implemented with great success.⁴⁷ Those who underwent the group sessions were found to have a significant improvement in family functioning and support and decrease in the symptoms of depression at both 3-month and 6-month follow-up. This is thought to be as a result of family support in a variety of domains including; financial support, psychological support, support with HIV status disclosure and physical assistance. Family members were found to have a greater understanding of the condition and empathise with the patient. Although in some cases, this was found to result in psychological distress for the family members involved, it also directly enhanced the support family members provided.⁴⁷ Our patient clearly described the importance of having an understanding family with her current husband and mother preventing her suicide and facilitating her decision to start ART. Her case also illustrates the danger of not having a supportive family network. The depression and isolation that followed dismissal from her late husband's family also almost lead to her death.

In Haiti, support groups run from medical centres have developed strategies to deal with distress in youth affected by HIV.⁴⁹ Young people involved were found to have improved psychological functioning as well as less psychological symptoms and a greater degree of perceived social support. Their carers were also found to have lower levels of depression, perceived stigma and a greater degree of perceived social support.⁴⁹ In Peru, peer support groups have been found to significantly improve patients' adherence to ART as well as reducing mortality at 24 months.⁵¹

The benefit of social support groups for those with HIV has been illustrated in different countries and in different communities.^{52–53} Group sessions were conducted with gay and bisexual men in the USA where they received 10 sessions comprised of coping effectiveness training. After these sessions, their levels of anxiety, stress and burn out had significantly reduced and they experienced an increase in coping self-efficacy. These sessions

took place over a 3-month period; however, benefit was still seen at up to 12 months.⁵² Attendance of group sessions for HIV-seropositive drug users was found to significantly correlate with 'healthier drug behaviour' at 6-month follow-up in Georgia, USA.⁵³ Such support groups are thought to be effective as a result of their information provision. Participants have a greater understanding as to which behaviours are likely to result in negative outcomes such as transmission, and are therefore able to reduce their risk. Attending such groups, although designed to modify behaviour associated with risk, is also thought to provide emotional support. As discussed above, such forums allow participants to feel acceptance rather than isolation, as well as providing a safe space for the discussion of issues relating to their condition and lifestyle. This support increases confidence, reduces perceived stigma as well as building coping skills and self-esteem.³³

In more recent times, online support groups have become popular for those with HIV—these groups transcend countries and even continents. They have been found to be highly effective in the areas of information provision and emotional support.⁵⁴ Online support groups have been found to be particularly successful for stigmatised conditions such as HIV due to anonymity. This allows potentially embarrassing issues to be discussed without fear of one's identity being known. The vast number of people with internet access allows for individuals to specifically search for others with similar experiences or perspectives to themselves. Time and location barriers are minimised with online groups, although internet access may in itself be a barrier for some. The amount of information available with online support groups, as well as the diversity of members is also undoubtedly an attractive feature of such support groups. In fact, 54% of the population of North America are thought to have visited an online support group for a health-related illness.⁵⁵ Some of the benefits of online support groups include lack of stigmatisation, large quantities of available information, an increase in openness due to anonymity and ease of access, for most. The importance of feeling accepted as part of a group cannot be underestimated. Group interactions help to prevent the feelings of isolation, guilt and shame and therefore can improve psychological well-being dramatically. They also help to improve the participants' understanding of the condition; dispelling myths and reducing stigma and discrimination. These features make online support groups extremely successful at improving psychological well-being. However, obvious drawbacks of online groups include a lack of specialist advice and potentially misleading or incorrect information, as well as the potential for 'trolling'.

A joint home care programme initiated by the Ministry of Health and non-governmental organisations in Cambodia demonstrated the positive effect of home care.⁵⁶ Counselling, welfare support, education and basic treatments are provided during home visits for those with HIV/AIDS. An improved quality of life has been reported, specifically due to increased confidence and reduced suffering. Evaluation found 92% stated that without the home care plan they would have felt significantly more isolated, with less support, loss of confidence and feelings of hopelessness⁵⁷; much as our patient experienced. Sixty-three per cent of participants also admitted the home care had helped to positively change their outlook on the situation.⁵⁸ In addition, 33% of patients and 42% of family members reported a decrease in stigma and discrimination from the community as a result of the home care programme. Importantly, 45% of patients admitted increased comfort in disclosing their HIV status after the initiative.⁵⁸ Seventy-nine per cent of family members felt they

could better cope with an individual with HIV at home, with 31% of those with HIV stating the initiative improved how they were treated by family members.⁵⁸ Leaders in the community observed a decrease in stigma, fear, anger and discrimination as well as an increase in compassion, support and understanding. This was echoed by an increase in the levels of referrals made to the joint home care programme by neighbours and friends of those living with HIV in the community.⁵⁸

Psychosocial support has also been shown to be vital in maintaining patients adherence to treatment.⁵⁹ This has been found to be especially true in the first 6 months of diagnosis,⁶⁰ with mental health disorders having a direct, negative impact on treatment adherence.⁶¹ As patients are often unaware, the consequences of deviating from the treatment regime are severe, with many returning for treatment with advanced disease or even perishing without receiving appropriate long-term care.⁶² The positive effects of perceived social support are not to be underestimated, with patients reporting lower levels of depression, resulting in improved adherence to treatment regimens and consequently an improved CD4 count, as well as a greater quality of life.⁶¹ Community health workers have been utilised in a number of studies and have been shown to increase treatment adherence by directly focusing on psychosocial support.⁶³ In fact, the WHO now suggests that psychosocial support should be included in all regional guidelines at every stage of care of those with HIV.²⁸

A dynamic interaction has been illustrated between stigma and social support. As previously discussed, stigma and lack of social support has a negative effect on treatment adherence. Lack of social support has been found to directly correlate with decreased improvements immunologically and worsened physical recovery from HIV,⁶¹ potentially influenced by poor management of the condition as a result of psychological distress.⁶⁴ When levels of stigma increase, social support has been shown to directly suffer.⁶⁵ It could be considered that improved emotional support in turn has a positive effect on decreasing stigma and thus improving patient's overall health.⁶⁵

In our patient's case, lack of social support resulted in our patient suffering from severe depression and anxiety. She described refusing to seek medical help on developing a widespread rash, due to fear others would suspect she was HIV positive and her inability to obtain the emotional strength to leave her home. It was in 1996 when the patient met her current husband; also suffering from HIV, he attended hospital with her to receive treatment. Her husband provided the support, both emotionally and socially that allowed our patient to eventually attend the hospital to obtain the ART required. The patient's husband and family recognised her suicidal ideation, which acted as a red flag. They encouraged her to attend counselling sessions where her well-being significantly improved. The patient's case is in keeping with research that suggests the support from one significant person within a patient's close social network may indeed play a major role in improving mental health symptoms, separate from that of the general social support network.²⁸

Our patient received psychosocial support in a number of domains. She has since said, "everyone wants to be my friend; there isn't a family in this village unaffected by HIV". Although it is impossible to know for sure, it seems reasonable to assume that if she had received the social support she required from the time of her diagnosis, her psychiatric well-being would be more speedily improved. In addition, according to the suggested evidence above, local discrimination against the patient may well have been much less severe. This may then stand for other members of the community who are likewise affected by the disease.

One source of psychosocial support within Uganda is the traditional healers. Although our patient did not receive support from them, they are the first point of call for an estimated 80% of those seeking healthcare in Africa.⁶⁶ The term traditional healer can be used for people using a variety of practices, from herbalism to spiritualism. In Uganda two non-governmental organisations (NGOs) formed a collaboration between modern and traditional medicine—Traditional and Modern Health Practitioners Together against AIDS. This aimed to provide support concerning the prevention of the spreading of the virus, as well as the treatment, care and support of those with HIV and AIDS.⁶⁷ Further projects have provided traditional healers with training in counselling those with HIV, as well as general education regarding AIDS and sexually transmitted diseases.⁶⁸

What is the solution?

Mental health problems have been shown to have a negative impact on patients' adherence to treatment, as well as overall disease outcome.⁶⁹ Uganda was previously recognised globally for its success in reducing the prevalence of HIV early in the epidemic, with rates reduced from 18% in 1990 to 6.4% in 2005. Unfortunately, the prevalence of HIV rose to 7.3% in 2011 and the epidemic continues to be a significant global health issue.⁷⁰

Community-based HCT has been recognised as one of the most effective ways to reach men and children who do not attend formal facilities.⁷⁰ Despite the success of community-based HCT (95% uptake in 2011),⁷⁰ there is minimal funding in this area in Uganda. It should also be noted that the quality of counselling has come under scrutiny by the Ugandan Ministry of Health. Measures following the Social Protection Life Cycle Approach have been put in place in the National HIV and AIDS Strategic Plan 2015/2016—2019/2020 to attempt to improve the social support—including counselling—provided.⁷⁰ The above research suggests that by simply addressing issues regarding depression in those with HIV, management and subsequent transmission rates may be significantly improved.⁷¹ If the counselling provided is indeed as important as it is thought to be, the US\$7.56 per session, it costs seems to be a fair price when compared with the US\$420 it costs to provide a year's ART.⁷⁰

Research conducted in 2005 in Uganda showed that in a sample of 46 patients with HIV, 38 (82.6%) were suffering from a psychiatric condition, as determined by the Mini International Psychiatric Interview carried out in The AIDS Support Organisation. Out of the 15 counsellors interviewed, only one had received training in regards to mental health issues and two felt confident they could manage such problems. Most of the counsellors believed they should be further trained to provide the necessary care.⁷² Although counselling is no doubt of vital importance, other psychiatric and psychological interventions would be of unprecedented value. Techniques such as cognitive behavioural therapy and interpersonal therapy have been suggested to help patients suffering from HIV,⁷³ though cost of treatment is a significant barrier, especially in developing countries. It is of vital importance that support continues in all domains throughout the duration of the chronic condition. Psychological distress is prominent at the early and late stages of the disease, as discussed above, and can feature whenever a new symptom arises, such as a friend or family member passes away, social stigma increases or a coinfection develops.⁷⁴

As previously mentioned, contact with services is only one aspect of social support. The importance of the support provided by one's social network cannot be underestimated. To fully use

such support, those within the network must have a solid understanding of HIV; therefore, stigma and discrimination should be minimised through education. It has been evidenced worldwide that through education HIV stigma can be reduced, improving both the psychological and physical health of those with the disease.⁷⁵

A global review of literature pertaining to the reduction of stigma through education identified four categories of intervention; counselling, information provision, skills building and contact with those effected.⁷⁶ The importance of counselling and its implementation has been discussed throughout this report. In regards to the provision of information, both peer education⁷⁷ and school-based interventions⁷⁸ have been found to be particularly successful in the developing world. It is essential that the provision of education reaches wider demographics to successfully improve outcomes for those with HIV globally. It should be noted that it is not only the patient who requires such education. It is of absolute importance that the patient's support network has an accurate understanding of the condition to achieve the substantial benefits to physical and mental health.

Patient's perspective

- ▶ My pain and hurt improved much when the other villagers supported me. But I am still haunted by the past and the way I was treated. Even now I wake at night, thinking of the bad things that were done to me.
- ▶ Now everybody wants to be my friend; there isn't a family in this village unaffected by HIV!

Learning points

- ▶ Stigma, discrimination and misleading education can often result in depleting psychological well-being, increasing suicide and death rates.
- ▶ The consequences of the above include increased rates of transmission and poorer physical health outcomes due to reduced treatment adherence.
- ▶ Psychological and psychosocial support is vital in improving mental and therefore physical health outcomes.
- ▶ Psychological support can take the form of counselling, specific therapies such as cognitive behavioural therapy as well as general social support.
- ▶ Education is vital to reduce stigma and discrimination within effected communities and globally as well.
- ▶ Better education will improve social support and consequently psychological and physical health outcomes of the patients.

Acknowledgements Special thanks to the patient and her clinic for opening their doors to allow this case report to be written.

Competing interests None declared.

Patient consent Obtained.

Provenance and peer review Not commissioned; externally peer reviewed.

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