

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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Aims and Scope

HIV Nursing has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

HIV Nursing is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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HIV and behaviour change

Catrin Evans

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This issue of *HIV Nursing* focuses on behaviour change in relation to HIV/sexual health and specifically considers the nurse's role in supporting clients, families and communities to adopt safe/healthy behaviours. This issue therefore relates directly to the 'health promotion' category that NHIVNA has set out as one of the core areas of competency for nurses working in HIV [1]. According to the NHIVNA competency framework, all HIV nurses should be able to educate others about HIV/sexual health, assess health promotion needs and implement a range of behaviour change strategies. These may vary from having risk-reduction/health-promotion conversations directly with clients to making appropriate referrals in more complex situations. At more senior levels, HIV nurses need to ensure that health promotion is systematically addressed across a service or clinical network.

The limits of behaviour change

Any practising nurse will know, however, that supporting behaviour change is 'easier said than done'. The articles in this issue illustrate this point very clearly, alerting us to the challenges, but also setting out possible solutions. The challenges are, without doubt, considerable. Research has demonstrated again and again that individual behaviour is influenced by a dynamic and complex interplay of psychological, emotional, social, cultural, economic and political factors [2]. One of the main criticisms of individually orientated cognitive-behavioural models of change is that they presume an empowered 'rational-individual' as their target. In this issue, we can see from Garry Brough's, Paula Seery's and Flick Thorley's articles, that, in the face of social or emotional pressures, good intentions about health can all too easily go awry and that alcohol and drug use in particular can quickly override all considerations of risk. For this reason, the behaviour-change discourse has shifted internationally over the last decade from an emphasis on individually oriented risk-reduction interventions towards a 'combination prevention' approach [3]. This approach calls for intensive and simultaneous strategies that operate at multiple levels (e.g. combining individual risk-reduction strategies with community mobilisation and peer education to change social norms, and political advocacy to create supportive government policies and to provide accessible and equitable services). Building on this theme, Ian Hodgson's articles discuss the complexity of risk and the need to broaden out prevention strategies to include a focus on human rights.

The role of nurses

For many nurses, however, the bulk of health-promotion activities do take place during one-to-one interactions with clients. A key challenge, therefore, is how to make use of a very limited period of time to undertake health promotion (often on sensitive topics) in an effective way. Two articles in this edition focus on motivational interviewing as a promising way forward. Michelle Croston provides a useful overview of motivational interviewing and suggests ways in which it can be used to promote medication adherence. Heather Wilson's article focuses on the personal, professional and organisational challenges of implementing a motivational interviewing approach in practice. The research evidence on motivational interviewing shows that it has significantly better outcomes than 'usual care' [4,5]. The beneficial effect wears off over time, however, suggesting that nurses need to continue to offer support to clients on a regular basis. Heather Wilson's article indicates that there is still much to be learned about how best to integrate this kind of health-promotion approach into routine practice within busy clinic environments.

Learning from each other about what works

Coates *et al.* [3] make the point that there is often a wide gap between obtaining a significant behaviour-change result in a controlled experimental study and replicating this success in the real world of practice. If you have examples that you could write up as case studies of how motivational interviewing or other behaviour-change/health-promotion strategies have been implemented in your own clinical areas, please do send them in as case studies or audit reports. The *HIV Nursing* editorial team would love to hear from you.

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Behaviour change: a patient/professional perspective

Garry Brough

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KReceiving an HIV diagnosis is a defining moment. I have often likened it to being brought to a screeching halt at a red STOP light, whereupon a huge magnifying glass focuses on your life to show you exactly what's got you here. That was my experience in 1991, and as I had already started looking at my issues around low self-esteem and confidence, internalised homophobia and their link to excessive alcohol use, it was a watershed moment.

I was a scared and pessimistic 23-year-old who was told he wouldn't live to see 30, but was determined to have some kind of real life before that and ideally, not be drunk while it happened. I had been immersed in the London club scene for 5 years and the HIV diagnosis was yet more evidence (on top of a nearly ruined liver and a constant sense of insecurity) that things weren't working. Having already tried counselling and a year's abstinence from alcohol (followed by another year of drinking just as much as before), I finally acknowledged in 1992 that I was a mess and that if I wanted to live as long and healthily as possible I needed to change. I took the '12-step programme' route, as medication and counselling had not done the trick, and found that learning from others who had the same difficulties was a rewarding and humbling experience. Peer support was a revelation – I heard people express feelings I couldn't have put into words and was not only encouraged to speak and be heard, but was told to get involved and help others while working on my issues. Like many gay men I met, my lack of self-esteem had manifested itself in a desperate need to be wanted and desired, which meant that, when alcohol or drugs were added, I would pretty much do whatever someone wanted, just to keep them around, even if we ran

out of condoms. In short, good health and long life was not my priority – feeling wanted in the moment was more important to me.

'Peer support was a revelation'

Changing those destructive behaviour patterns was easier once I'd accepted there was a problem. Learning how to live and interact in an honest and sober way took a lot longer, but the lesson of living 'one day at a time' proved as useful in living with HIV as it was for recovery from alcoholism. HIV-related peer support, however, did not provide the same boost as recovery programmes or today's solution-based training, such as Newly Diagnosed Courses or Positive Self-Management Programmes. In that era 'support groups' were often more about helping people to die comfortably than live healthily, as there was so little hope. So I made my own way, using alternative therapies, more counselling, personal development courses and seminars, and some great self-help books.

Developing KS and receiving an AIDS diagnosis in 1995 was the hardest blow. I was angry that, despite having done all the 'right' and 'healthy' things, I still hadn't been able to beat AIDS. I was forced to accept a level of powerlessness that was previously unimaginable, but kept on track by focusing on the few good things I could do to improve the situation. Realistically though, the only thing I genuinely had any power over was my attitude to what was happening; I had changed from a 'glass half-empty' guy to a positive and enthusiastic person, and was able to see that even in the worst-case scenario I could have hope and humour. This proved to be a priceless asset during the chemotherapy, PCP, meningitis and septicæmia.

Starting HAART in 1997 turned my health around and the YMCA Positive Health Exercise Referral Programme literally got me back on my feet after all my ill health. Having already discovered how my behaviour and habits could adversely affect my health, I learned how exercise could reverse much of the damage done to my body by the virus and the opportunistic infections. I was surprised at both the massive boost in my self-esteem from having a 'buff' gym-trained body and the seismic shift in negotiating the 'dating' process caused by the arrival of internet dating sites. By the age of 34 I was emotionally and physically in the best shape of my life (having retrained as a Pilates Instructor and Personal Trainer); I was single and dating online for the first time and exploring my sexuality more openly than ever before. A large part of that was due to my willingness to disclose my status online. My fear of rejection because of my HIV status had been put into perspective by my experiences of AIDS. After being told by doctors that 'there's nothing more we can do', and 'it's just a matter of time', the issue of sexual rejection takes on a different and relatively insignificant perspective, and I was in no way going to go back into any 'closet' and hide my status. I had also learned over the years that sooner is better than later where disclosure is concerned, and being able to state this up-front online simplified things further. I started meeting other positive guys and for the first time in my life started having regular unprotected sex with them. There was a lot of discussion of superinfection at that time, which tended towards scare-mongering, but I was very well informed given my active participation within my clinic and felt that with an effective HAART regimen and some open and clear discussion, there was probably very little risk involved.

Human beings are capable of finding any evidence necessary to support or justify our behaviour (and especially our pleasure), and I do not lack this character flaw. My experience is that extremes of behaviour can be fairly easily sustained. Excess and abstinence seem to require much less work than healthy balance, and there were a couple of years where I veered towards sexual excess and away from the middle ground I'd worked to achieve, especially after a bereavement, which I avoided dealing with emotionally by having more sex. The result was more sexual partners, more unprotected sex, and a resultant increase in the number of STIs I contracted. Whilst working as a Patient Representative in the UK's second largest HIV clinic, providing peer support on a range of issues including good sexual health, I found myself in the embarrassing position of having the first registered case of LGV in the clinic. I discussed the matter with a health advisor who knew that I had as much knowledge on sexual health matters as he did, but needed to do his job and talk it through anyway. However, instead of simply regurgitating the facts about STIs, he spoke about his own

Tips for engaging patients in positive behaviour change.

- Take a motivational interviewing course to learn some basic techniques
- Draw out the person's own motivations and desires to balance the perceived losses – if the change isn't going to make them happier and it's not their idea, it's not going to happen
- Find out where/how they've achieved successes in the past to see if particular strategies might be reused successfully
- Lecturing and scaremongering generally don't work – open and honest discussions that examine pros and cons support self-advocacy
- Accentuate the positive. It's possible to discuss HAART without either dwelling on or minimising potential side effects
- Model good behaviour by using examples of how you've overcome difficulties when you feel a personal approach would help
- Signpost to peer-led training such as PSMPs and Newly Diagnosed Courses
- Stress that change is not necessarily about 'giving up' things - moderating or limiting behaviours can be enough. If someone wants their life to change, they'll have to make changes – 'if you always do what you've always done, you'll always get what you always got'.
- Maintaining change can be tough to start with but gets easier the longer you do it – create new 'healthy' habits as you phase out the unwanted ones
- Get patients to identify 'triggers' for particular behaviours and to create their own strategies for dealing with prospective problem areas in advance, always remembering that 'if at first you don't succeed, try, try again', without beating yourself up.

experiences as a positive gay man and described the changes and choices he had made to try and improve his health and sexual behaviour. It was an excellent example of modelling good behaviour rather than lecturing. I was already used to doing this in my work with clients, but hadn't experienced it from the receiving end for some time.

Working again on my issues and behaviour, I looked at what I really wanted and recognised once again that my sexual desires were for the most part borne out of loneliness and a desire for intimacy. I have met many gay men who are looking for intimacy, but end up with just sex because of a lack of genuine communication and/or fear of rejection. So I upped my openness another notch both online and in person, sharing honestly not only about my status but also my thoughts and feelings. I discovered that the clearer I was about what I was looking for, the more I attracted people who wanted the same thing. By 2007, I was having better sex with fewer and more regular playmates and had moved away from group sex. The emergence of sexually transmitted hepatitis C in the HIV-positive gay community and

amongst various friends and playmates further contributed to this shift.

Despite this progress, I had one further night of excess at a party during Sao Paulo Gay Pride in June 2008 with a group of HIV-positive men, using the 'one last time can't hurt' chestnut as justification. I had a great party and holiday and came back to London to change jobs to become a HIV Health Trainer. The training was fascinating because there was an even greater focus on motivational interviewing techniques than when I had trained as an exercise professional. Once again, I was forced to re-examine my own behaviours, past and present, and consider further changes and modifications. Then, within a month of starting the job I was diagnosed with hepatitis C, contracted during my trip to Brazil.

'Excess and abstinence seem to require much less work than a healthy balance'

The frustration of having locked the stable door after the horse had bolted was particularly keen, but I resolved that I would find the positive in this situation. Having felt the anxiety of disclosure in relation to both my sexuality and HIV and knowing from experience that the thought is more frightening than the act, I decided to write about contracting hepatitis C for NAM and to discuss it openly wherever possible. At the 2008 BHIVA Autumn Conference, three colleagues (also peer educators and advocates) told me that they had also been diagnosed within the last few months. The phrase 'don't do as I do, do as I say' has always interested me when applied to the health service, given the high levels of cigarette smoking and alcohol (ab)use amongst healthcare professionals. There seems little doubt that a person can have all the facts, figures and knowledge relating to the negative health outcomes of certain behaviours and still be almost entirely resistant to making changes to improve their own health.

Knowledge may very well be power, but in truth it only really becomes powerful when first applied

directly to the minutiae of one's life situation via some kind of stock-taking exercise and then followed up with action. My experience as both service user and provider has been that neither lectures nor scaremongering result in sustainable behaviour change. Far higher levels of success can be achieved by working with a person's hopes and desires, helping them to understand personal and communal responsibility and weighing up the pros and cons in a way that puts them at the centre of the decision-making process.

My personal experience has been that the more comfortable and happier within myself I become, the easier it is to make better health choices and reduce potentially harmful behaviour. Of course, this equation is entirely reversible – making supportive health choices makes for greater self-respect – and is the exact opposite of a downwards-spiralling vicious circle. Having some idea of what I want in life, having goals and dreams and then recognising where my actions and behaviours may limit those possibilities has been more useful in helping me make changes than knowing or even experiencing the negative health impact of those lifestyle choices. I have modified and changed much of my behaviour for the better, but the process never really stops. Now that I don't work daily in a gym I rarely exercise, despite knowing that almost all the age-related co-morbidities that will be exacerbated by both age and HIV can be reduced if not removed by regular exercise. Which brings me back to an axiom that has held me in good stead since my 12-step programme days – it's about 'progress, not perfection'. This is a saying I continually aspire to and recommend as a productive and positive way of living – consider your options, recognise the things that are 'wrong' for you, then keep doing the next 'right' thing.

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Crystal methamphetamine: an intractable problem

Flick Thorley

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Introduction

Five years ago, little was known about N-methyl-1-phenyl-propan-2-amine in the UK; however, more commonly known as crystal methamphetamine, it is now a widely used recreational drug and an increasing problem on the gay scene and in HIV and sexual health services. It is also known by a variety of names including crystal meth, Tina, ice, crystal, tik, speed, chalk, meth, crank, yabba, P and Christine.

Crystal meth is a stimulant that was allegedly first synthesised from ephedrine in 1919 in Japan [1]. It has since been used for medicinal purposes, particularly for treating attention deficit hyperactivity disorder (ADHD) in the US [2], and in the 1950s it was prescribed to treat disorders such as narcolepsy, alcoholism, depression and obesity in the UK [3]. During World War II it was used widely by troops (Allies and Axis) as a stimulant – in Germany its tradename was Pervitin – and allegedly administered daily to Hitler from 1942 [4]. In the US during the 1960s, it started being made and sold for illicit recreational use and during the 1980s there was a massive rise in its recreational use with the emergence of the rave/dance scene. In 1989, the *Economist* reported that 'San Diego is the methamphetamine capital of North America'. Recreational use has reached epidemic proportions throughout parts of America, Australia and Asia and it is now being used by gay men in the UK.

Until the early 1990s, most crystal meth was made in laboratories run by traffickers, and the US market was supplied from Mexico and California. However, over a short space of time, an increasing number of small-scale labs started to be found in rural, suburban and low-income areas in the US [5]. To demonstrate the massive increase in demand, the Indiana state police found six labs in 1995 compared with 1260 in 2003. The first crystal meth factory was found in the UK in 2005, and many more have been found since. Globally, users are said to outnumber those of heroin and cocaine combined, but its prevalence in the UK is still a matter of some debate. It is manufactured using a number of easily accessible household products and pseudoephedrine products bought over the counter. It was reclassified in 2007 as a Class A Drug in the UK.

In 2009, the television producer and broadcaster Louis Theroux presented a programme which focused on crystal meth as a drug problem in the Californian city of Fresno where it was associated with heterosexuals, poverty and crime; in the UK, the epidemic is mainly associated with gay men. America and Australia have been dealing with the problem of crystal meth in their gay populations for a number of years but there has been little awareness of the problem in the UK, and subsequently scant resources available to address it.

Physical and psychological effects

Crystal meth is addictive [6] and associated with unsafe, uninhibited, marathon sex with multiple partners, and unsurprisingly it is becoming a problem for sexual health services. Crystal meth can be snorted, ingested, injected, smoked or taken anally (booty bumped). Depending on how it is taken will impact on how quickly it takes effect and how long the effects last, which can be anything up to 24–36 hours. Aside from the risks of contracting HIV, hepatitis C and other STIs, common physical problems include not eating or sleeping for days or weeks, weight loss and facial wasting, hypertension, twitching, sores, impaired thermoregulation, 'crystal dick' (similar to 'brewer's droop' and often counteracted by the addition of Viagra), palpitations, arrhythmias, tremors, gastrointestinal problems and skin rashes. Rotting teeth and receding gums are also a problem (Google 'meth mouth' to see pictures of this condition). The psychological effects of crystal meth include euphoria, aggression, anxiety, paranoia, repetitive and obsessive behaviours, suicidal ideation and psychosis. Mood disorders associated with crystal meth withdrawal are more severe and last longer than many other drugs [7].

Addiction

Chelsea and Westminster NHS Foundation Trust provides the largest HIV service in Western Europe and an increasing number of HIV-positive men, many also with hepatitis C, and many presenting with new-onset acute mental health problems, are being seen who talk about their crystal meth use.

In my job as the Clinical Nurse Specialist in HIV and Mental Health, I frequently see gay men with no previous history of mental health problems presenting with acute psychiatric symptoms.

Common presentations involve patients believing they are being monitored via the internet, being spied on by CCTV, believing the police or some other authority is after them and believing that they are in immediate danger. This has resulted in some moving house frequently, changing their phone numbers numerous times, moving about using different computers, not opening their post for fear of being 'found', believing their friends and family have turned against them etc. The common denominator is crystal meth. When someone presents in this way, this type of psychosis is very hard to treat. Once developed, it seems so real to the patient: why would they want psychiatric services when they need the police?

Many users with no history of dependency can start exhibiting addictive behaviour very quickly. Even when users want to extricate themselves from the drug, they can not because of the sexual and social networks they are involved with. The most successful way of beating the problem appears to be not to start.

The first major casualty of crystal meth who I met was a well-educated, bright, 31-year-old gay man with no psychiatric history. He presented as acutely psychotic and distressed and following lengthy assessment was diagnosed with drug-related psychosis; specifically, crystal meth-related psychosis. This was in 2005. He was paranoid, delusional, had developed an obsessional habit and in the process was destroying his relationship, job and friendships. He also had absolutely no insight into this and did not accept his drug use had anything to do with his terrifying reality. Over time, he was treated with antipsychotics, antidepressants, hypnotics, psychiatrists, psychologists, the Mental Health Act and substance misuse services. Throughout this, he had periods of time when he almost felt safe and that his life was back to how it had been before. Three years after I first met him, he was found dead in suspicious and bizarre circumstances and his post mortem toxicology screen showed he had taken crystal meth prior to his death.

Neurotoxicity

Owing to the increased number of patients presenting to our department with complex crystal meth-related psychological, psychiatric and physical issues, we have had to learn about the drug quickly, and what we have learnt is horrifying.

Methamphetamine releases high levels of the neurotransmitter dopamine, which stimulates brain cells, enhancing mood and body movement [8]. This is why people feel confident, fabulous and take more risks as normal inhibitions have been bypassed. It also appears to have a neurotoxic effect, damaging brain cells that contain dopamine and serotonin. Over time, methamphetamine

appears to cause reduced levels of dopamine, which can result in symptoms like those of Parkinson's disease, and also to long-term low mood. MRI studies on crystal meth users in the US show very clear damage to the brain, specifically to the parts that involve memory (the hippocampus), emotion and reward (the limbic system). Dr Paul Thompson, an expert on brain mapping at UCLA, described what was seen as 'a forest fire of brain damage' [9].

Treatment and support

In liaising with local NHS and voluntary sector drug treatment services, it became clear that although these agencies are more than happy and willing to get involved in supporting and treating people, they are not seeing people who use crystal meth. We are, however, and our patients do not want to go to those services because the issues around this particular drug problem are commonly very specific to sex, sexuality, sexual behaviours, sex sites on the internet, and general internet behaviour. Although this is how this dependency starts, we are seeing an increasing number of men whose active sexual and social lives are disintegrating into isolated crystal meth use at home, and who have psychotic and delusional ideas and dependency on other drugs such as GBL (γ -butyrolactone) and heroin to help with the comedowns. When these men do come looking for help, they are currently presenting to the HIV and GUM clinics as these seem to be the places gay men can speak freely about issues, and get the help and support they are seeking. In some centres, it may be possible to set up appropriate help via local substance misuse services, but in larger centres, substance misuse services are borough and postcode specific, which makes them inaccessible to many people who attend our clinics. Cognitive behavioural therapy, motivational interviewing, gay-specific harm reduction interventions, which target physical health concerns, and psycho-educational groups and programmes, all have the potential to help but research in the US shows poor long-term outcomes. In London, we are lucky to have access to Antidote (www.thehungerford.org/-antidote.asp), an easily accessible, non-postcode-specific substance misuse service for the lesbian, gay, bisexual and transgender community.

In our experience, many gay men do not want to access generic mental health or drug services as they do not see themselves as having generalised mental health problems or experiencing the same issues as other problem substance users. This is even though the detrimental effects on their lives can be similar. Traditional harm-minimisation and risk-reduction strategies for recreational drug use also appear to have poor success in supporting people taking crystal meth.

Conclusion

Club or party drugs have long been associated with the gay scene and many people have used them, and keep using them, while living productive and healthy (ish) lives. Crystal meth is changing this.

For us to understand what people are actually doing, it is important that health professionals ask the right questions, whether they are in HIV or sexual health clinics, GP surgeries, drug services or elsewhere. As the incidence of crystal meth use increases, which is likely because it has done everywhere else, awareness about the use of the drug in the UK will increase too and appropriate services will, hopefully, be developed.

In the meantime, we are trying to understand the extent of the problem. While we are aware of the individuals who admit to meth use and who ask for help at the Chelsea and Westminster Hospital, we also investigated the prevalence of meth use among general HIV clinic attendees who have not yet identified it as a problem. In October 2010, we left anonymous questionnaires in the Kobler Clinic, Chelsea and Westminster Hospital, the Nkosi Johnson Unit at Charing Cross and at 56 Dean Street, that asked HIV-positive people about crystal meth use.

We received 418 returned questionnaires and the answers gave the results shown in Panel 1.

Further reading

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Panel 1

- 332/418 (80%) respondents were MSM
- 85 (20%) in total had used crystal meth in the past 12 months (all MSM)
- Only 35/85 had told a health professional
- Use ranged between daily and yearly
- Most common route for taking crystal was smoking, followed by snorting and then injecting 1% (4)
- 12% (48) reported unprotected penetrative sex while using crystal meth, 1% (5) were not sure whether this had happened or not.
- When asked about antiretroviral use, 11% (45) stated they had not missed any doses because of crystal meth in the past year, one person reported missing more than 50 doses, 3% (13) reported missing between 1 and 10 times.
- Of those who reported crystal use, 13/85 (15.3%) reported missing at least one HIV clinic appointment in the past year.
- Of those who missed at least one HIV clinic appointment, 9/13 (69%) were using crystal either monthly or more frequently.

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The sexual health of young people in the UK who acquired HIV at birth

Paula Seery

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Young people with perinatally acquired HIV (PHIV) are a small, emerging group in the UK. While antiretroviral therapy has dramatically improved life expectancy for children who acquire HIV perinatally [1], the impact of HIV on young people's sexual behaviour and relationships is also becoming more apparent. Young people, those aged between 16 and 24, make up only 12% of the population yet account for nearly half of all the sexually transmitted infections (STI) diagnosed in the UK [2]. The greater number of infections in this age group suggests there is more chance of young people acquiring an STI through unprotected sex.

For young people with perinatally acquired HIV, sexual risk behaviours may not only compromise their well-being, but also present a public health concern about increased HIV transmission, including transmission of ART-resistant strains to partners and offspring. It is therefore vital that young people receive essential education about sex and sexual health, and skills around negotiating sexual relationships, for them to have a satisfying and safe sexual life.

However, it is important that we understand what issues young people with perinatally acquired HIV are dealing with in their lives, and reflect this in our sexual health promotion in order for it to be both meaningful and of use. This involves giving consideration to how being born with HIV shapes the sexual experiences of young people in the UK today and what factors might prevent them from adopting healthier sexual behaviours. It is also important to understand the significance of their social contexts and the ways in which individual environmental, physical and psychological factors influence sexual behaviours.

Sociocultural factors

Of children with HIV in the UK, 97% have been infected through mother-to-child transmission [3]. Over 75% are of black African ethnicity, with 50% being born overseas [3]. Many young people with HIV are therefore living with parents who are struggling to cope with illness and immigration issues as well as the demands of family life, without support from significant family members. Some of these parents will be experiencing mental health problems, which will have significant implications for family functioning and adjustment [4].

Experiences of illness and loss may also leave

many young people with increased responsibility for their relatives' well-being and domestic duties in the home [5]. Social deprivation, financial difficulties and hardship can compound these problems [6] and further affect the structure and cohesiveness of families. These are all factors that have been associated in the generic sexual health literature with adolescents engaging in more risky sexual behaviours [7].

While there is growing evidence that frequent, good communication within families with young people about sex is likely to lead to improved sexual health in adolescence [7,8], young people need to be able to talk about their HIV in order for these important discussions to be open and of benefit. The isolation and instability parents experience going through immigration procedures and illness [9] can make these discussions feel potentially overly complicated and not a priority. Furthermore, health beliefs and attitudes to children's inclusion in decision-making processes are also culturally specific [10] and can affect the possibility of open conversations between parents and children.

Adult behaviour of various sorts has also been found to influence teenage sexual behaviour [11]. Clearly, parents' own sexual relationships have the potential to affect young people's sexual behaviour in both positive and negative ways. Weatherburn *et al.* [12] highlighted that anxieties about passing HIV onto partners, fear of disclosure, rejection, and criminal prosecution [13] were reasons given by adults with HIV for not pursuing sexual relationships. For young people this can reinforce the view that having HIV stops you from having intimate sexual relationships.

If parents are not having a sexual relationship then adolescents will need to find sexual role models outside their family. Interaction and support from neighbours and family friends has been associated with lower rates of teenage pregnancy [7]. However, the social isolation of families can reduce a young person's exposure to significant adults outside the family unit who could become role models and influence their attitudes to sexual behaviour and risk.

Many studies suggest that consistent parental supervision can delay sexual initiation and reduce teenage pregnancy [14,15]. The social problems experienced by parents living with HIV can sometimes impact on their ability to adequately supervise and support their children. However, it is

also true that parents' own fear of stigma can lead to even closer monitoring and control as 'normal' adolescent social experiences such as having friends in the house, sleep-overs and school trips raise parents' concerns about the possible discovery of HIV [5]. Many young people are keen to meet others with HIV; to be able to talk openly about HIV, share experiences and develop friendships. This offers important opportunities for formal and informal peer education and support. However, some parents fear open discussion will lead to information passing back into their community and deny young people such opportunities.

Stigma can also emphasise 'difference' as young people try to fit in with peer-group norms [5,16,17]. Some are able to talk about their HIV with friends or even significant adults. For those who are not, keeping HIV a secret is one way of being seen to be 'normal' and therefore being treated the same as everybody else [17]. However, this can clearly be very stressful for a young person to maintain.

For young people growing up with HIV, every sexual experience carries a 'risk'. The negative discourses of transmission and criminalisation surrounding the sexual behaviour of people with HIV [18] are bound to have an effect on their sense of sexual identity. The extra responsibility that young people with perinatally acquired HIV feel for negotiating safe sex at a time of sexual inexperience and therefore vulnerability can sometimes be overwhelming and distort the view that sex is a normal and pleasurable experience.

During adolescence, as influence shifts from the family to peer groups, so peers begin to exert an important influence on young people's sexual behaviour. They discuss sexual health issues with their friends to establish values and rehearse adult sexuality [11]. Many studies have identified peer norms regarding acceptability of sexual behaviour, and the number of peers who are sexually active, to be associated with early sexual activity onset and risk behaviours in adolescents [14]. For some, accelerating sexual behaviour is one way of increasing their social standing within their peer groups [19,20]. However, it is important to remember that peer norms can have a positive as well as a negative effect on sexual behaviour [7,21].

There are very few studies that have looked at the sexual behaviour of young people with perinatally acquired HIV. The results from the few US studies that have looked at this seem somewhat contradictory. While some suggest that young people do not engage in high-risk sexual activity because of fears of disclosing their HIV status to a partner or as a strategy to avoid infecting their partners [22,23], others suggest that the life-limiting potential of HIV might make them rush into sexual risk behaviour at an early age [22]. Studies have also found significant levels of unplanned pregnancies, suggesting that young women with

perinatally acquired HIV are practising safe sex no more than their HIV-negative peers [24,25].

In an ideal world, knowledge of HIV would lead to a reduction in sexual risk-taking behaviours; however, in reality, young people's behaviours are affected by many other powerful influences. It is important to avoid the assumption that health behaviours are rational as there are many other 'rationalities' that influence their lives and actions [26]. A young person might intend to use condoms but this involves negotiation within structurally unequal and gendered social relationships [27]; and thus, there can be many reasons why they do not. Marston and King [28] suggest that male discourses emphasise the social importance of sex, and may lead to a young man prioritising the experience over any risks, whereas young women might not suggest condoms to avoid appearing too experienced or to comply with their partner's desires. If sex happens without planning or discussion (perhaps to avoid potential awkwardness), young people are more likely to have unprotected sex [28]. Embarrassment has also been found to put inexperienced males off using condoms in case they did not 'do it right' [29]. Furthermore, embarrassment can inhibit young people from accessing condoms, particularly in more rural areas [29].

Physical and psychological factors

In addition to sociocultural factors, there are physical and psychological factors that can influence the sexual behaviours of young people with perinatally acquired HIV. When HIV is acquired in infancy, underlying systems are still developing and there can be long-term consequences. Growth and neurocognitive development can be affected, particularly where there have been severe clinical symptoms early in life. Neurodevelopmental problems can cause a diverse range of mobility difficulties from those that bring about wheelchair use to those that cause abnormal gait [30]. These physical impairments may increase stigma, placing limitations on a young person's social and sexual opportunities and behaviours.

HIV also affects hormonal systems involved in the control of growth and pubertal development as a direct result of immunosuppression. Buchacz *et al.* [31] found that young people who acquired HIV perinatally go through puberty at older ages than uninfected young people. In addition, Foster *et al.* [1] found that 5% of these young people (≥ 13 yrs) were found to have severe growth retardation. Delays in puberty and growth can mean that not only the physical but also the social and sexual development of these young people often falls behind that of their peers [32].

Although many young people with perinatally acquired HIV are asymptomatic, numerous studies

document the occurrence of at least some cognitive and language delays as a result of HIV [4]. Furthermore, their academic achievements may show poor attainment, which may have implications for the person's ability to understand the illness, and can complicate understanding of sexual health messages and negative peer influences [22]. Poor school performance resulting from cognitive deficits may also lead to low self-esteem. For many young people, the impact of developmental delay and cognitive deficits may affect friendships, complicate decisions around HIV disclosure and impact on their sexuality [23].

For those affected by lipodystrophy, the visibility of the symptoms can lead to feelings of unattractiveness and low self-esteem. Schooler *et al.* [33] found that boys with low body satisfaction were unclear about their sexual choices and consequently resisted talking about sex with partners, making them less likely to have safe sex.

As many psychiatric disorders emerge in adolescence, studies have looked at the impact of HIV during this time. Results from these have shown higher rates of serious behavioural and emotional difficulties, with emotional difficulties the most frequently reported by parents and young people [34]; these results were consistent with other life-limiting conditions, suggesting a correlation between psychological distress and having HIV [34,35]. These findings, however, were not related to current disease severity but rather its social sequelae [36].

The highly contextual nature of the physical and psychological factors surrounding HIV impact on young people's psychological adjustment and can lead to anxiety and depression. Low mood can make young people susceptible to self-medicating with alcohol and recreational drugs, which can in turn initiate or compound mental health symptoms [6]. Young people who use drugs and alcohol because of low mood are particularly vulnerable; for some alcohol is consumed in order to engage in behaviours not normally contemplated and can lead to more unsafe sex [37,38].

Health promotion

The WHO defines sexual health as a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence [39].

With this aim in mind, effective health promotion with young people should involve interventions of different kinds that run in parallel and are complementary to one another [40]. At an

individual level there is a place for school-based approaches, workshop-based methods with other young people with HIV, as well as opportunistic health promotion with individuals, all ideally supported by the family.

Young people have been very critical of sex and relationships education (SRE) taught in schools in the UK [41]. The narrow focus on the biological aspects of sex education fails to engage with the real dilemmas experienced and ignores the need for discussion around more emotional aspects and the skills needed for coping with relationships [41]. A recent review of SRE in schools emphasises the need for partnership between schools and families and improved training for teachers [42]. The development of comprehensive sex education policies can improve the opportunities for young people to understand sexual health issues and has the potential to reduce teenage pregnancy and STI rates.

Young people attending a sexual health workshop for European youth living with perinatally acquired HIV in 2008 [18] expressed how having HIV had not had a negative impact on how they felt about themselves; they felt attractive and confident that their sexual partners would accept their HIV. However, even these young people who were arguably coping well with their HIV, did not feel confident in talking about it with their sexual partners [18], suggesting that more opportunities for young people to talk about their HIV are needed. Where family members are not 'available' to talk to and it is not possible to talk openly with peers, there can be few opportunities to explore and learn about sexual health. The role of the health services is clearly vital as we are in a position to address these issues openly and sensitively.

The focus for this work needs to be led by young people themselves and will depend on individual factors such as maturity, cognitive abilities and other physical and psychological factors. While there is much work to be done around teaching techniques for condom use, this should take account of how young people might deal with specific situations they may encounter. This could involve considering negotiation strategies whether initiating sex, using condoms or simply saying 'no'. However, there is an argument for beginning this work early before a young person considers becoming sexually active [43]; it is also important to bear in mind that more than a quarter of young people are sexually active before the age of 16 [43].

Conclusion

Sexual health promotion that emphasises the pleasurable potential of sex, while also acknowledging that young people may not always be able to resist real-world pressures towards unsafe sex, can help to address the emotional dilemmas faced by them, and build confidence. Talking

openly about what HIV means to them is clearly important in addressing disclosure issues with sexual partners and can help to enhance understanding. As young people with perinatally acquired HIV are an emerging group, there is an urgent need for further studies and audits. These could help elucidate the ways in which health promotion strategies for young people could ameliorate the sociocultural factors that would otherwise compromise their own or their partners' sexual health.

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HIV risk: danger, what danger?

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Why do people put themselves at risk of catching incurable diseases? This question lies at the heart of most public health initiatives. On evidence just from the UK, where chlamydia continues to infect large numbers of sexually active people [1], unprotected sex is still, for many, an acceptable option. This article considers aspects of risk and risk assessment in the context of sexual health, focusing on human immunodeficiency virus (HIV), and recommends stigma reduction and the notion of universal risk as key tools in the battle against HIV infection.

Theories of risk

Risk assessment is an individual decision people make about the severity of a particular risk. Many theories address why people make certain decisions in particular contexts. In psychology, there are heuristics – shortcuts we use for working out how to proceed in a situation, based on factors such as how representative what we see is believed to be true (representativeness), or what is already known about a subject (anchoring) [2]. In social anthropology, decisions can be influenced by how free people feel to actually make them, or how constrained they are by the social environment [3].

In medical anthropology, illness and disease are distinct: disease is defined by experts, but illness by culture [4]. People therefore make sense of bodily dysfunctions using models of understanding based on cultural and personal factors [5]. Notions of

causation, treatment, prognosis and affect are malleable, and one of the most important lessons for public health specialists is to acknowledge the many contrasting beliefs in peoples' worlds – and their bodies. Indeed, for one scientist seeking an explanation of beliefs about zombies (yes, they 'exist') in 1980s Haiti:

'As a Western scientist seeking a folk preparation [for resurrecting 'zombies' in Haiti] I had found myself swept into a complex worldview entirely different from my own, and one that left me demonstrating less the chemical basis of a popular belief than the psychological and cultural foundations of a chemical event.[6, p. 265]

Davis, as a botanist steeped in empiricism, discovered powers of belief that, in this case, underpin a robust and lingering system shaping the worldview of thousands about seemingly unlikely events.

In the HIV context

In the context of risk and HIV, this reminds us never to underestimate individual and cultural perceptions. More importantly, we should not assume people are behaving 'blindly' when they seem to place themselves in situations where vulnerability to STIs and HIV is increased. It is easy for those of us working in public health to be sanctimonious about these apparently unwise life decisions, but non-adherence to sexual health

advice is not generated in a vacuum, and is certainly not 'ignorance' (perhaps the most overused pejorative in sex education), but is simply compliance with social and cultural norms [7]. Successful public health initiatives, for example that in Uganda during the 1990s, are able to bridge the gap between what the person thinks they know and what they *should* know. The urgency of this is illustrated by a recent report suggesting women in the UK are increasingly in denial about the possibility of being infected with HIV [8].

This writer has for a long time been a contributor, answering questions on HIV, to the website AllExperts (www.allexperts.com). Many queries come from people who did something they think was risky, but is actually rarely so – for example mutual masturbation with a person who they think may have HIV, or 'deep' kissing. This indicates that after the event, people tend to overestimate risk when in reality it is low. Sadly, on the evidence of epidemiology, many people also underestimate risk when it is high.

Another recent concern is risk compensation [9]. Here, the prevalence of antiretroviral treatment (ART) has led to an increased rather than decreased risk – people simply believe that the 'peril' of (in this case) HIV is reduced. Indeed, for those receiving ART, beliefs about apparent protection can lead to engaging in risky sex [10], and Bourne [11] illustrates this further in the context of superinfection. This is a concern not just in the UK but also Uganda [12], and denotes double infection, when a person already living with HIV is infected with a second strain following unsafe sex. Threats to treatment efficacy make this a serious hazard, and Bourne [11], undertaking research into perceptions of risk of superinfection on gay men living in the UK, found that men's perceptions of, and responses to HIV superinfection were diverse and depended on their information sources, individual context of risk behaviour, and how they regarded superinfection relative to other concerns. They do not lack knowledge of risk, but simply construct what is sometimes a flawed narrative.

A key element woven into the warp and weft of risk assessment, especially in the context of HIV, is stigma. HIV remains a heavily stigmatised pathology [13]. Labelling and social marginalisation of people living with HIV (PLHIV) results in members of the community unwilling to identify themselves as at risk, hence engaging in unsafe behaviour simply because they believe 'we' aren't like 'them'. A study in Zambia [14] suggests significant underestimation of HIV risk amongst young people, who cannot accept they may be part of a stigmatised group.

In addition, in heterosexual relationships, gender seems to have an impact on perceived risk severity. Kibombo [15], in a large longitudinal study in Uganda, found strong correlation between

perceived risk and risky sexual behaviour in adolescent males, but not females, who generally, regardless of sexual behaviour, feel at great risk of HIV, accepting a position closer to universal risk.

Implications: the requirement of a belief in universal risk

Many factors affect a person's ability to maintain risk-reducing behaviours [16], and we have seen that risk assessment is individual, constructed and founded on factors often having little relation to actual risk. How do we apply this to HIV prevention? Perhaps the most effective strategy is to encourage the position that the Ugandan women above take: belief in universal risk.

The notion of universal risk underpins universal precautions, the mantra drummed into generations of nurses to maximise infection control and prevent use of heuristics such as 'that person is too nice to have HIV' or 'that person is dirty so must have HIV' (a not uncommon assumption, and consistent with psychology's trait theory). Nurses working on HIV units and employing universal precautions do feel safe because they know they will not catch HIV. In one study [17] the ability to maintain notions of universal risk alongside universal precautions was predicated on two important factors: engaging with patients ('they are not different to me') and adopting a moral position that accepts all people are potentially at risk of HIV. No 'us' and 'them', just 'we'.

Educating communities about safer sex means promoting the notion of universal risk, and reducing dependence on heuristics and labelling as tools for decision-making. An impossible task? Perhaps so, sexuality is fraught with constructions, beliefs, fear, anxiety and passion. Sanctimonious-sounding education about universal risk is a real drag.

Recommendations

A recent news report [18], describing the outcome of a court case concerning Nadja Benaisa, a German singer accused of infecting previous partners with HIV, illustrates many of the issues in this article.

According to reports, her doctor told her the chances of spreading the virus were low. This is true of course. The average transmission rate of HIV in a single 'coital event' is relatively low, although this is dependent on factors such as the index patient's viral load [19]. This is no excuse for not using condoms of course, but similar cases (in the UK, the best known is of Sarah Porter from 2006, [20]), confirm the issue of stigma cannot be underplayed. In addition, Benaisa's partners must take some responsibility: what was their perception of risk? Even though she may not have told them she was infected (there is no evidence that she deliberately misled her partners, just that she didn't tell them she had HIV), how could they be certain that she was aware of her status anyway – many people are not?

This article has considered factors impacting on a person's perception of individual risk. For the public health practitioner however, individual behaviour is but one of a constellation of factors increasing or decreasing a person's *actual* risk. This consideration of 'risk context' is vital [21], and varies according to circumstances: for men who have sex with men (MSM), for heterosexual transmission and injection drug users (IDU). For each group there many factors shaping HIV risk, and key recommendations for action draw upon the Ugandan experience [9], where, at least in the early days of the epidemic, the country was highly successful at reducing new infections:

- Foster a personalisation of risk
- Use clear, consistent messages
- Combat stigma
- Seek out and support indigenous approaches and solutions
- Use multiple communication channels
- Secure the participation of individuals and organisations throughout society
- Reach out to male populations

Initiatives embracing these key points are more likely to bring perceived and actual risk closer together, and coupled with the notion of universal risk, could be more successful in ensuring those who are sexually active are able to reduce their vulnerability to what is, in reality, a difficult virus to catch.

Conclusion

HIV and chlamydia (from the Greek for 'cloaked') are both symptomless – the worst nightmare for public health (no visible sign means for many people no risk). However, risk reduction is for everyone [16] and maintaining the tension of universal risk coupled with universal precautions is a challenge (it seems paranoid), but is protective [22]. Its successful adoption is predicated on a societal shift in attitude towards PLHIV, acknowledging that people infected with HIV are no different. Bold measures to combat HIV stigma are now seen as a key element of HIV prevention and risk reduction [23], and once this position becomes the norm, then risk assessment will inevitably become more adept.

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Motivational interviewing: an overview

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Those who do not adhere to a therapeutic regime can represent a costly and troublesome problem for treatment providers. When patients attend inconsistently or participate half-heartedly in therapy, clinicians can become frustrated and even demoralised. Patients have poor disease control, a reduced quality of life, often presenting for care when they become ill and then face the risk of long-term disability. For antiretroviral medicines to exhibit optimal long-term benefits, people must maintain a high level of adherence over an indefinite period of time. Adherence includes not only taking medications but often making changes to lifestyles to accommodate medication-taking schedules and other requirements.

Traditional adherence strategies involve telling, instructing or showing clients what to expect from treatment and what they will need to do to make it successful. The underlying assumption is that clients are more likely to be engaged if they are provided with the correct information about the respective roles and functions of clinician and client.

Motivational interviewing (MI) is one patient-centred approach employed to improve antiretroviral adherence. Its empowering counselling style is thought to help patients resolve their ambivalence about starting and then continuing treatment by assisting a patient to identify their goals. MI works at facilitating patients to find their own reasons for change and helping them with their agenda. MI does not work for everyone, but it is one way of engaging patients and increasing their adherence.

This article looks at what motivational interviewing is and how it can be used, alongside the change process, to move patients around the 'change cycle'. It also focuses on the importance of ambivalence as an obstacle for change and highlights some motivational interviewing techniques that can be used to improve patient consultations. An example of dialogue from a patient consultation illustrates how the techniques have been used in clinical practice during the discussion on starting treatment.

Motivational interviewing is a patient-centred model that can be used along with existing practices but can also be used as a brief intervention. It is not meant to be prescriptive or replace current therapeutic interventions used in formal counselling sessions. The approach a practitioner will take will depend on individual training and experience.

What is motivational interviewing?

Motivational interviewing will be a relatively new concept for some. As with many academic theories, the language used is not everyday terminology and certain terms may require further explanation in order to gain a deeper understanding

The founding fathers of MI, Rollnick and Miller offer this definition:

Motivational interviewing is a client-centered, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence.

They go on to suggest that MI is a method of communication rather than a set of techniques, it is not a bag of tricks for getting people to do what they do not want to do [1,2]. It can be applied as a preparation for treatment, a free-standing brief intervention, an enduring clinical style or a fall-back approach when motivational obstacles are encountered [2].

MI uses many therapeutic methods such as reflective listening and accurate empathy, which are taken from the client-centred approaches of Carl Rogers [3]. MI takes a collaborative approach relying upon clients to be the experts on themselves. It also shares with humanistic psychotherapies and, more recently, positive psychology the underlying confidence that, given the proper supportive atmosphere, people will naturally change in a positive direction [4,5]. MI is a conscious, intentional process eliciting and strengthening a client's motivations for change. Rather than installing new beliefs, the therapist strengthens existing aspects of the client's own personal constructs and motivations. MI is never meant to provide a comprehensive model of change or to exclude other treatment methods. MI may be integrated with other approaches and systems of care. It is quite focused on the person's present interests and concerns. Whatever discrepancies are explored and developed have to do with incongruities amongst aspects of the person's own values and experience.

MI and behaviour change

A model that complements MI very well is Prochaska and DeClimente's transtheoretical model, which is currently the most popular stages of change model in health psychology [6]. The model

has worked with a variety of simple and complex health behaviours from encouraging people to use sunscreen to enabling them to quit cocaine. Prochaska and DiClemente developed their model after many years of observing patients who had successfully changed their behaviour and patients who hadn't. They believed that to adopt healthy behaviours and discontinue not-so healthy behaviours, people go through a series of five steps: pre-contemplation; contemplation; preparation; action; and maintenance [6].

The cycle of change

Pre-contemplation is the stage in which an individual has no intention to change a particular behaviour. Pre-contemplators are often characterised as resistant or unmotivated and tend to avoid information and discussions about the targeted health behaviour. It is useful for healthcare professionals to be aware that patients may sit in this part of the change process, as this knowledge can save time and strategies can be better implemented.

Example

- Healthcare provider (HCP): Have you thought about starting treatment?
- Patient: Not even thought about it.
- HCP: Would you like some more information?
- Patient: No, not really.
- HCP: OK, if that changes let me know

Individuals in the contemplation stage openly state their intent to change within the next 6 months. They are more aware of the benefits of changing, but remain keenly aware of the costs. Contemplators are often seen as ambivalent to change, or procrastinators. Practitioners meet a lot of people in this phase and it is probably the stage where MI can be most useful.

Example

- HCP: Have you thought about starting treatment?
- Patient: I have given it some thought and I do want to start treatment, but there again I'm not sure.
- HCP: What do you think the advantages and disadvantages are to starting treatment?

Preparation is the stage in which individuals intend to take steps to change, usually within the next month. Preparation is viewed as a transition rather than a stable stage. Support from healthcare professionals is vital in this stage and techniques can be implemented to strengthen patients' confidence and commitment to change.

The action stage is one in which an individual has made overt, lifestyle modifications for fewer than 6

Example 3

- HCP: Have you thought about starting treatment?
- Patient: I have thought a lot about starting treatment, I'm on septrin at the minute so have started setting my alarm every day, to practice taking my treatment at the same time.
- HCP: On a scale of 1 to 10, how important is starting treatment?
- Patient: I'd say it was very important ... so 8.

months. This is followed by the maintenance phase in which people work on maintaining a certain behaviour. For anyone who has tried to modify their own lifestyle, the action and maintenance phases are the most challenging and require lots of positive support [7].

These stages do not always form a linear progression and it is common for patients to relapse and also move from one stage to another within varying time frames. MI can be used to help people move around the cycle of change by facilitating behaviour change. This process requires patience and understanding from the practitioner as each person's change process is unique and occurs at the person's own pace. Ongoing support, acceptance and encouragement is vital. Very few behaviour changes occur as a result of eureka moments.

Resolving ambivalence

Ambivalence is a key obstacle to change, and a central focus of MI. People feel two ways about change, they want it and they don't. That is, arguments for both change and no change reside within the same person. Most people presenting to healthcare professionals have their reservations (resistance) about change, and being ambivalent (having conflicting ideas) is a common point at which people remain stuck for long periods of time. Ambivalence is a common human experience and a stage in the normal process of change. Resolving ambivalence has been a key to change, and indeed, once ambivalence has been resolved, little else may be required for change to occur. MI is a method designed to evoke and explore ambivalence, and to help the person resolve it in the direction of positive change. However, attempts to resolve ambivalence in a particular direction can lead to a paradoxical response; even strengthen the very behaviour that was intended to change [8]. It is also important to understand the balance between a person's motivation and ambivalence within that individual's social context of family, friends and community [8].

Techniques in MI

Asking good open questions can serve multiple purposes. The following are a few examples of brief questions that if accompanied by skilful listening

can serve the practitioner's purposes more efficiently than asking a string of closed questions.

What's worrying you today about your illness?

This is a useful question for locating the patient at the centre of the consultation. Responding respectfully to this concern will improve your rapport and provide a good platform for dealing with topics on your agenda.

What concerns you most about these medicines?

If this person is not taking their medication properly and seems unhappy with it, a question like this will reveal a lot about their attitude, behaviour and where the problem lies.

What exactly happens when you get this pain?

Here, the door is open for the patient to tell the story. The use of the word 'exactly' signals an intention to get to the bottom of the patient's concerns. If you listen for a while to the account, the answers to all sorts of factual and other questions may emerge.

What did you first notice about your condition?

The word 'notice' can be very useful. People usually respond well, because it invites the client to be the expert commentator about their own experience of events and behaviour. Information often comes flooding out, and the person feels heard.

Assessing the importance of change to your patients, and their confidence in their ability to change, allows you to use time spent with them more effectively. For example, if the major obstacle to change is the low importance placed on it, using certain questions can help to address this issue.

Example

- HCP: On a scale of 1 to 10, how confident are you about making the changes needed to start treatment?
- Patient: ... erm ... erm, I'd say about a 5.
- HCP: 5, that's an interesting score ... Is there something you could do to make that score higher?

Asking about the pros and cons for change can provide a set of key guiding questions that are particularly useful if someone seems uncertain about change, and can also give an opportunity to explore ambivalence. The patient then has time to come face-to-face with uncertainty in an accepting atmosphere in which his or her motivations are free to surface. At the heart of MI is the conviction that patients themselves have most of the answers.

Errors occur all the time when communicating with patients, MI highlights these potential errors and offers some alternative solutions. A few of these terms and explanations are given below in order to help improve patient consultations.

'Informing' is probably the most commonly used tool in healthcare communication. However, things can and do go wrong with the informing process. You may give what seems to be perfectly clear instructions, yet the patient does not collect a prescription or follow through with the next appointment.

'Elicit provide elicit' is a form of information-giving in MI. It places considerable value on drawing from the patient what they need and want to know, and critically, what new information means to them. This again emphasises a patient's active involvement in his or her own healthcare and is intended to enhance motivation for behaviour change. 'Elicit provide elicit' is not meant to be a linear sequence of steps but rather a cyclical process of guiding through information exchange. Although it revolves around 'informing' it also requires both asking and listening. The aim is to establish what patients already know, clarify and give any information required, and then establish whether the patient would like any more information [10].

Example

- HCP: What do you know about the treatment that you have been prescribed?
- Patient: I know that it will treat my virus, improve my immune system. I might get a rash, feel sick and have some loose stools.
- HCP: It sounds like you already know quite a bit about the treatment. Your treatment may also ... It is important that you contact ... if this happens. Would you like me to give you any more information?
- Patient: I think I know as much as I want to know about the tablets at the minute, thanks. You could tell me ...

As caring professionals we want to make things 'right' but try to avoid the 'righting reflex' by talking about how the information has affected other patients and avoid suggesting what patients should do. Instead, elicit from the patient how this has affected him or her and how they think they may be able to deal with it, drawing on similar previous experiences the patient may have experienced. This leaves the healthcare provider in a position of neutrality. In other words, information is provided and the patient interprets. The healthcare provider may have considerable expertise in what was good for other patients in similar circumstances and on some occasions it may be appropriate to share this with the patient. Patients, on the other hand, are usually experts about what works best for them.

Listening is one of the hardest tools in the healthcare setting. It is not the same as waiting to speak. A practitioner who is listening, even if it is just for a minute, has no other agenda than to understand the other person's perspective and experience. When practitioners take the time to listen, patients feel as though have spent longer with the

Example

- Your patient's blood results come back and under current guidelines his CD4 count has reached a level that treatment would be considered.
- HCP: Have you thought about starting treatment?
- Patient: I always hoped I would have more time to think about it. I know I need to start treatment. Just not sure what to do for the best (Ambivalent, contemplating)
- HCP: What do you think the advantages and disadvantages of starting treatment are? (Exploratory gauging question)
- Patient: I wouldn't feel so rough all the time, my viral load would come down, I'd have more energy. I would have to take medication every day, I'd have to alter my lifestyle. I'd be tied down to things.
- HCP: You have mentioned a lot of different pros and cons to starting treatment, mainly the biggest advantage to you would be feeling better. You also mentioned that there would be a certain amount of change involved. Have you thought what those changes might be?
- Patient: Not really ... Just know that I would have to take pills ... that's all.
- HCP: Would you like me to give you some more information about the medication, so we could discuss what changes you think you might need to make? (Elicit)
- Patient: Please. (Provide)
- HCP: What do you know about HIV treatment already? (Elicit)
- The patient then goes on to explain how the treatment works and some of the medication that he has heard about and the potential side-effects. By ascertaining what the patient already knows, the HCP can tailor advice to the patient, filling in any knowledge gaps and moving quickly on to issues that are pertinent to the patient.
- HCP: We have spent a little time discussing the treatment and some of the changes involved with the regimen. On a scale of 1 to 10, how confident are you that you could make the changes to your lifestyle? (Summary and gauging question)
- Patient: I dunno ... I guess I'm pretty confident that I could make the changes I needed to so, 8.
- HCP: 8 is a very high score ... Have you thought about when you would like to start treatment?
- The patient then goes on to discuss when they feel or think that they would like to start treatment. Further interactions can then be guided by this and it is also a good way to evaluate where the patient is in the change process.

practitioner than they actually have. Listening can also save time, because practitioners develop the ability to quite quickly grasp the essence of a patient's concerns, allowing them to move on to other topics more easily [11,12].

When listening, a practitioner will periodically summarise what the patient has said. Thus, what is chosen to be reflected back to a patient can make a difference. Patients who feel ambivalent have both sides of the argument within them, and will often back away from their own resistance when it is reflected [10].

Conclusions

Motivational interviewing, as a technique, does require training. However, there are practical techniques that can be added in to help consultations with patients. It is perhaps more about approaching communications slightly differently, adding more techniques into existing toolkits, in order to gain more from consultations. Motivational interviewing requires a certain detachment from outcomes, not an absence of caring, but rather an acceptance that people can and do make choices about the course of their own lives. Healthcare professionals are merely companions on the journey that is the patient's to make and, given the proper supportive atmosphere, people will change in a positive direction.

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Implementing motivational interviewing in practice: issues and challenges

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'Ironically it is acknowledging the other's right and freedom not to change that sometimes makes change possible' [1].

Introduction

In 2007, NICE guidelines were introduced that promoted the use of one-to-one risk-reduction interventions in sexual health/HIV settings [2]. The recommendations were very stringent, and have required sexual health and HIV services to look at the training of their staff, and try to implement more structured interventions. This article looks at the use of motivational interviewing (MI) in a sexual health setting, and the challenges to services and individuals wanting to implement an MI approach.

When should MI be used?

In a recent television documentary a teenage girl with HIV was talking to her doctor about starting her treatment [3]. The girl was reluctant and adherence to medication was clearly a problem. When she was interviewed on her own away from the hospital, she said 'I hate being told what to do'. As do we all. If we tell people what to do, the natural psychological response is for them to argue with us. Even if they say nothing, the argument carries on internally. If the dietitian instructs me 'Don't eat cake' my internal dialogue will form the opposing argument, 'well, I am just going to go and have a nice almond croissant to spite her'.

Motivational interviewing is a person-centred style of working that elicits and strengthens a patient's motivation for change; it avoids setting up an adversarial dynamic in the first place. We know that the words we say ourselves are much more effective than those other people say to us. Therefore the aim is to elicit 'change talk' from our patients. If we find ourselves doing all the arguing for change, then we have stolen the lines, we have been badly miscast. Worse still, we can end up in a battle with the patient, we argue for the change, give reasons, perhaps even tell them what to do, whilst they give us the reasons why they can't make the change: 'Yes, but I hate taking any tablets, I never do, it's unnatural'. We also risk the patient telling us what they think we want to hear; either because they want to 'be good' or they want us to stop bothering them so that they can get out of the room. The amount of 'change talk' that the patient uses is predictive of the success of the

intervention. If the practitioner moves into confrontation, the effectiveness diminishes.

MI is not suitable for all patients. Sometimes simple straightforward advice giving is all that is needed. MI has been developed for those whose behaviours are having an adverse effect on their health, such as those with addictions, diabetes or who need to lose weight. MI uses the person's own insights, and explores their resources and abilities to make their own changes. It therefore requires a level of self-awareness, and is not suitable for some patients who may lack insight due to a mental illness, or personality disorder.

Consider those patients who never seem to be able to take their medication consistently. They seem perfectly reasonable and listen politely to your explanations of how the drugs work and why they are important. They seem to understand but there is clearly some ambivalence. A directive approach may not elicit any helpful answers as to why these patients are not adhering to treatment. However, we do not always know exactly why we do things and it may be that there are deeper psychological problems for which the person needs support. An MI approach can really open up the conversation to help uncover what is actually going on as it focuses on recognising the dilemma, and exploring and resolving ambivalence is one of its basic tasks. In this situation, it is very likely that the patient will require psychological referral to deal with the underlying problems.

Another article in this issue of *HIV Nursing* talks about the process and techniques of MI, and describes how it is a very well researched method of facilitating change. MI has been found to be much more effective than giving advice, even in interventions as short as 20 minutes. The effect increases with follow-up, preferably with less than a 3-month gap. After 12 months control groups start to 'catch up' with those who have had MI [4].

How much training is needed to introduce MI into a service?

Implementing an MI approach in a sexual health or HIV clinic requires staff training and commitment. It has been shown that neither a short lecture nor self-directed training is effective enough [5]. Training needs to take at least one-and-a-half days, and contain practical exercises, where MI responses can be checked and corrected if necessary. Ideally

there should be ongoing supervision. The profession of the trainee has not been shown to make a difference to efficacy; it is the approach of the practitioner, especially when demonstrating consistency with MI responses that is the key [6]. Doctors, nurses and health advisors in clinic do not require separate training. Staff with prior counselling or psychology training will be familiar with the humanistic style of MI. Some of the techniques, such as OARS (Open questions, Affirmations, Reflective Listening and Summarising) are the bread and butter of humanistic psychology.

To expect all members of staff to have such intensive training and supervision is impractical and may be too expensive. In addition, some practitioners will not be interested in the approach. Clinical supervision can be threatening to some staff, and clinics with voluntary schemes for supervision have found that the uptake can often be very low.

Some clinics have had in-house training for all staff, led by a psychologist or health advisor. If key members of staff have had external training in MI, they can take the lead for their service. This takes the form of regular talks and case discussions in weekly staff meetings. Ongoing supervision can be led by the psychology team, and offered either one-to-one, or through group supervision. This model works well in bigger clinics, but is more difficult to implement in smaller services that may not have a psychologist, or only have access to one session a week, making training and supervision difficult to organise. The use of telephone supervision is a possible option, as is a monthly visit to an external supervisor.

Challenges in implementing MI within sexual health/HIV services

Personal challenges

'Resisting the righting reflex' is one of the basic conditions of practising MI. The 'righting reflex' is our desire to fix things, to make everything OK. Often this desire is very strong in those of us who have chosen to work in healthcare. Not only is it strong, it becomes stronger with experience, and the behavioural effect of being rewarded for our good work. This can be a very powerful drive. While in the consultation with our patient, we have certain goals, which can make things right. Those of us who work in sexual health are not only making things right with the patient, we are helping protect the world at large. So we may have the goal of our patients taking their medication. This will make them feel better and keep them healthy for (hopefully) many years. A patient presenting as healthy also makes us feel better. Our other goal may be for them to practise safer sex and not spread an infection to anyone else. This goal helps us to feel that we are protecting the public, as well as protecting the patient from the distress of passing their infection on.

MI is a very goal-orientated approach; therefore, it would be entirely consistent to keep these goals in mind whilst working with the patient. However, we need to remain detached from the outcomes whilst in the room with the patient. For example, if we believe that it is important to use condoms, and our patient does not, it is their beliefs and narrative that is important at that moment. This can feel at odds with our public health agenda.

My own experience, both as a practitioner and trainer in MI, has shown that this is one of the most difficult barriers to overcome. Training in MI can feel very de-skilling. We lose our old comforts of telling people what to do, giving them condoms, emphasising the importance of taking the medication. For example, a patient who has presented with repeated infections responds to your open questions by admitting that he simply will not use condoms. He has not said it before, as he felt you might 'tell him off'. Through listening and being curious about his situation, you foster his admission to himself that he is not ready to change. This is a patient who is pre-contemplative. MI is the most effective method of moving a pre-contemplative patient to contemplation. In this situation, a simple acknowledgement and summary of where your patient is, may well be the most effective thing you can do. In my experience these sessions often end with the patient beginning some change talk. 'I'm not ready to change, I don't enjoy sex with condoms. Mmm, perhaps I should start thinking about it as this is my third chlamydia infection.' These are words we need from the patient, not from ourselves. An open question such as 'Do you have any ideas as to how you might protect yourself from another infection?' could well help the person go away with some food for thought, and maybe start to contemplate change. One of the principles of MI is that it is always better to ask rather than to tell.

As a trainer, I have found that it makes us very nervous to think we may not be able to fall back on our usual scripts. In the example above, it is difficult to resist the urge of telling the patient he really must use condoms, demonstrating their use, and then handing him some condoms before he goes. It is also tempting to point out that these repeated infections are proof that he needs to change his behaviour. In training sessions, some members of staff have felt very worried that if they do not tell the patient what to do, then they are not doing their job properly. This has even come down to anxieties that they will be in trouble if they have not written in the patient's notes that they have told the person that they must use condoms, for example.

Fear as a motivating force is often used as a short cut, so the practitioner feels that if they make a quick statement such as: 'You need to learn from this, it's a wake-up call. If you don't use condoms you will be re-infected, or next time it could be worse', they have done their bit for health

promotion, and to motivate the patient to change their behaviour. They can also document that they have said this to the patient, which gives them satisfaction. This approach may well feel very familiar and may in fact be the most common. Unfortunately, for such a popular method, there is no evidence to show that fear works as a motivating force [1].

Organisational challenges

Time is another factor that makes implementing MI feel daunting. In fact, using an MI approach takes no longer than any other method. The results from one meta-analysis showed that using MI to take a patient history took no longer than asking a series of questions, and elicited a richer history [7]. However, the fear of opening a 'Pandora's box' is a very real one. This applies to all of us. In a busy clinic it may feel easier and more controlled to ask closed questions and not invite an open discussion. Also the constraints of service delivery, with the pressure to see as many patients as possible, can make us apprehensive about seeing patients for repeated consultations, especially if we think they may be time consuming.

Despite the challenges that trying to implement this approach could bring, it is the 'spirit of MI' that can change the culture of a service, and can be used in all areas of a patient consultation. For Rollnick and Miller [8], getting to grips with this is the most important thing. One or two trained staff in a clinic can have a great impact, even through simply encouraging colleagues to sit in with them and promoting this way of working with patients. It is best for trained practitioners to provide ongoing risk-reduction counselling, but all healthcare workers can benefit from taking a more collaborative approach with their patients.

While the NICE guidelines recommend two 20-minute risk-reduction counselling sessions for all patients having tests for STIs, clinics have been unable to offer such a resource-heavy service. Therefore, specific risk-reduction work tends to be targeted at those identified as 'high risk' by the clinician, and may well be opportunistic at the first visit, with arranged follow-up. Patients who need to re-attend, for example for hepatitis B vaccine, syphilis treatment or HIV management, can have risk-reduction counselling along with their regular follow-up appointment. Risk assessment should not just be about the patient's behaviour. Patients who are vulnerable in other ways, such as the very young or those who have been subjected to sexual abuse or domestic violence, will often be more likely to be at risk due to lack of agency in their sexual encounters. Risk reduction cannot just exist

in a vacuum, and support should be available for these patients.

One clinic in London has laminated posters of the 'stages of change' in every consulting room. This is an excellent idea as the message is there for every patient, and it encourages the patient to make their own assessment of how ready they are to change. It is also patient friendly, a visual confirmation that we do not expect people to be perfect, that relapse is normal and we do not judge them for it.

Conclusion

It seems fitting to end this article with a quote from Rollnick and Miller [1]:

'It is within this spirit of motivational interviewing that the three styles of communication come together. To guide rather than badger, to encourage rather than shame, to negotiate rather than dictate. The guiding style is considerably more effective than lecturing when behaviour change is needed, and it is also a lot more interesting and enjoyable for the clinician.'

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What is this thing about human rights?

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Human rights, and specifically, a rights-based approach, are now embedded in the lexicon of the HIV sector. Indeed, the XVIII International AIDS Conference (July 2010) had as its theme: 'Rights here, right now'.

What are human rights? Do we really understand what they mean, and how they fit with our work in the HIV sector? This article discusses issues around the application of human rights in the context of HIV, and considers methods for evaluating their application within organisations and systems providing treatment, care and support for people living with HIV (PLHIV).

What are human rights?

'Human rights' are essentially divided into two categories: economic, social and cultural; and civil and political [1]. Ensuring that people have a right to health for example, encompasses both categories, and seeking health in its broadest sense involves a range of endeavours that includes 'political, social, economic, scientific, and cultural actions that we can take for advancing the cause of good health for all' [2].

The rights-based approach, successor to the United Nations' (UN) 'needs-based approach' (prior to 1997), constitutes activities that further human rights; are guided by human rights standards and principles found in international human rights law; and builds the capacity of 'duty bearers' to meet obligations and/or 'rights holders' [3]. Pursuing a rights-based approach is now a core principle underpinning much civil society and health system work.

Who is affected by lack of access to a rights-based approach?

People in a range of contexts face significant threats to a range of rights as defined by the Universal Declaration of Human Rights [4]. Injection drug users (IDU) for example, in many countries are affected by overly punitive legislative systems, and approaches to policing that focus on command and control, rather than simply law and order.

HIV stigma is another example of a phenomenon that continues to impact on the lives of all those who do not 'fit' with community rules of inclusion. Much has been written about HIV-related stigma [e.g. 5–7] and similar mechanisms impact on the lives of people with mental illness, disabilities and physical deformity. Stigma in healthcare, a supposed 'safe haven' for those requiring nursing and medical care, is as strong as elsewhere [e.g. 8–

10]. Many people affected by HIV dread being admitted to non-specialist areas (general wards), and become desperate to be transferred to units where personnel are more used to caring for PLHIV [11]. For Sontag [12], all societies require an illness perceived as 'evil' and HIV has for a number of years served this purpose.

Adopting a rights-based approach to health certainly has a positive impact. In Peru, for example [13], increasing participation, ensuring equality of access and setting standards for policy making and social surveillance, ensured that the poor and those with difficulty accessing the health system received care. But what can be done to address this matrix of problems?

As members of civil society we should be certain of our position

Those of us working in the HIV sector often readily invoke vague notions of 'rights' and 'abuse' in our conversations, but are frequently less clear about the specific principles underpinning our activity. We should be in no doubt that our work is not simply a vague, über-liberal response, but is instead founded on established moral principles. Advocating for access to health services (and by implication, the same civil rights) is a moral obligation, rather than mere political posturing.

The value of adopting a view founded on morality, and rights-based legislation is that it supports the values we advocate in civil society and healthcare – autonomy, confidentiality, non-disclosure, health, consented treatment – all are sound ethical principles, enshrined in the Universal Declaration of Human Rights [4], codifying rights for all to physical and mental health. That some groups are denied this is simply flawed, and by using a rights-based approach, this exclusion can be challenged rigorously and robustly. Drawing on a narrative that includes key ethical principles adds a level of sophistication, and prevents glib reiteration of tired responses to the ongoing threat to human rights and appropriate levels of care.

We must use a workable framework for self-assessment

Advocating for human rights is predicated on the notion that these rights are being jeopardised, otherwise there would be no need for advocacy. As with many of the issues for which civil society advocates, societal responses are constantly regressing towards the mean of intolerance: an

entropic process pulling social systems away from providing equitable access to services, towards a situation where prejudice against outliers is the norm [14].

In addressing this, perhaps a useful place to begin is at home, and the *Code of Good Practice for NGOs Responding to HIV* [15] is a constructive framework for evaluating HIV systems' delivery, including as it does self-assessment, specifically addressing human rights [16]. This model can be applied easily to any context, and asks questions such as:

- Do your organisation's programmes contribute to the capacity and ability of human rights duty bearers (for example, HIV policy makers, government workers, employers and healthcare workers) to ensure that the rights of HIV and affected communities are protected, respected and promoted?
- Do your organisation's programmes and activities seek to inform communities about the forms, causes and effects of HIV-related stigma and discrimination and HIV-related human rights?

Monitoring organisations could have a huge impact on their effectiveness advocating for the rights of PLHIV. A key role of NGOs, for example, is to monitor for indirect or latent discrimination with regard to government allocation of resources, which, if inappropriate, can result in discrimination [17]. Indeed, for Heywood [18], 'ultimately, individual human rights must be something that ordinary people are themselves capable of protecting' (p. 30), and ensuring that internal systems are not prejudiced, and are inclusive, is a vital component in the HIV sector's external responses, exemplified in the MIPA principle (the meaningful involvement of people living with HIV and AIDS), and the introduction of support groups within organisations, for example within the UN (UN+) and IPPF (IPPF+).

The *Code* can be used in a variety of contexts to track quality of services in a context where, for perhaps too long, there is an assumption that because an NGO or HIV agency is involved in HIV care, it can do no wrong. This writer recently used self-assessment components of the code to evaluate a large capacity-building NGO working in Africa, providing HIV training and community support programmes. Commissioned by the organisation, the project aimed to track four key topics: rights; stigma; gender; and MIPA. Results from the project confirmed, as suggested by the *Code*, that although human rights are implicitly addressed, the topic is nested in other topics (stigma, gender, legal issues) rather than addressed as a discrete subject. A number of areas of good practice were identified, and lessons learned from this particular project include:

- Challenges in meshing transcendent human rights guidelines with local beliefs and mores

- Scaling up the understanding of human rights as an essential component of work in the HIV sector; valuing the person and the obligations of local services to address these rights
- The need to mirror care for individuals within an organisation, with the nature of care and support received by beneficiaries

How to make it all work: the problem of application

In the context of human rights, a key question must be: can a framework protecting the rights of the individual, such as the universal declaration, be applied outside a European and North American enclave, where it is taken for granted that individual agency can transcend that of the community?

A cursory look at events in different parts of the world suggests that, although the majority of countries sign up to the universal declaration, in practice there are variations that reflect extant cultural and social architectures. The rights of gay men in Uganda and Malawi; those wishing to have an abortion in Ireland; female genital mutilation in Sudan; or those placed at increased risk of poor healthcare because of the 'brain drain' (as discussed by [19]), are all human rights issues, and whilst 'difference' should be acknowledged, it is vital to avoid relativism. However, for Airhihenbuwa [20] 'any attempt to provide a health solution for a given community or society must take into serious consideration cultural factors' (p. 193).

In seeking a rights-based approach to health, there are many generic and individual needs that transcend nations and cultures. Fay [21] suggests that 'people recognizably living in different cultures cannot be living in a different world, but they may well be living differently in the same world' (p. 90). Sustaining a careful balance between cultural sensitivity and an overarching framework for individual human rights is difficult, but necessary. Structural violence must never be mistaken for cultural difference [22], and local interventions should always be critiqued on the basis of their health impact rather than heritage.

Concluding comments

Sadly, moral blindness leading to lack of access to essential services and human rights-based programming remains a risk to all agencies in the HIV sector, and constant vigilance and a willingness to adapt are required. Using tools such as the *NGO Code* can assist in identifying weaknesses within care and community systems. Adopting a dynamic approach, protecting human rights, and encouraging those with obligations to act, especially in the context of marginalised groups such as IDU or PLHIV, is vital if we are to avoid Robert Burns' caution of 'man's inhumanity to man makes countless thousands mourn'.

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