

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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Juliet Bennett

Independent HIV Specialist Nurse Advisor

Welcome to the autumn edition of *HIV Nursing*. I hope you have all had a lovely summer and that those of you who were able to attend the annual conference in Cardiff came away inspired and energised? Please do take some time to consider any topics that you may have researched, any services you have audited, or policies or guidelines that you have helped to write as well as care-related initiatives that may make interesting reading. The Editorial Board are happy to take enquiries in relation to such ideas, even if they are still at a conceptual stage!

This edition carries no specific theme and as such has provided authors with an opportunity to publish on a variety of topics. Jackie Morton's thought-provoking article shows clearly that HIV is still largely viewed as 'different' from other chronic diseases. She identifies many significant challenges that are unique to HIV disease. The old challenges of fear and stigma remain but new ones are also arising: in the form of an ageing HIV population for example; or the complexity of managing co-morbidities; plus changing sexual practices; and the challenge of coping with the long-term side-effects of indefinite drug treatment.

Jackie stresses that in order for HIV to be viewed as 'another chronic disease' nurses, amongst others working in the field, need to continue to educate and share with those less knowledgeable and, critically, to engage those living with HIV in service design. This article raises an interesting question as to whether we are even close to being in a position to consider HIV disease as equivalent to any other long-term condition. And indeed, if we are, whether this is a view that will be helpful to PLWHIV in addition to the service providers and commissioners?

The authors of 'Breaking Bad News', Mark Roche and Michelle Croston (winners of the prestigious Krattinger Rennison prize in Cardiff!), provide us with an in-depth write-up of their research. Their small-scale study gives insight into this aspect of communication from an HIV perspective. Notably, from both the authors' research and from the wider literature, the differences within the context of HIV care, in this case in terms of the impact on nurses, is again evident. Breaking bad news is a complex process requiring a number of skills. Done badly the detrimental effects to a patient and their future relationships with health care services can be considerable. Michelle and Mark recommend some useful guidelines to support this aspect of your role.

From a theoretical perspective, the book review submitted by James Meek and Claire McCausland

covers *Communication Skills for Nursing Practice* (McCabe and Timmins, 2013), which is recommended reading for nurses in all fields; but in light of the previous article's focus on the complexity of communication within our specialty, perhaps it is especially relevant for us?

The book emphasises that nurses will learn professional behaviours as they continue to gain experience of working within their specialism. Therefore, the value of reflection, even for experienced practitioners, is evident. All of us, I'm sure, if we are honest and reflective practitioners, can see scope for improvement in our own communications. This pie chart is a good reminder, I think, of the complexity of communication and of the need for a high degree of self-awareness in this aspect of our interpersonal relationships. The verbal content of what we say plays a very minor part in what meanings are conveyed to the recipient during communication. The tone and pitch of our voice, and the conviction with which our words are delivered, for example, play a much more significant role in communication. Our body language, for example our facial expressions, eye contact and our physical position in relation to the recipient, are highly influential in how our messages are received and interpreted.

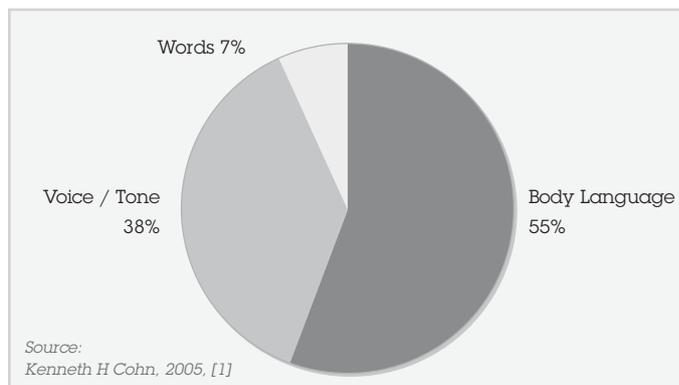


Figure 1: Components of conversation and their importance to meaning.

A growing body of evidence suggests that the quality of patients' relationships with their HIV care providers plays an important role in appointment adherence and therefore clinical outcomes [2]. To me it follows that higher-quality communication, inherent in all effective relationships, will maximise the likelihood of patient engagement.

Shaun Watson's piece on safeguarding raises awareness of an often challenging and complex issue, that of protecting vulnerable adults. The case study described clarifies the role of the community specialist nurse in co-ordinating efforts to respond to such a need. Again, what is clear to me is the

essential role of effective communication, in this instance in bringing a potential risk situation to the attention of the team, co-ordinating case discussions and effectively communicating action plans across a network of relevant practitioners, whilst actively involving and respecting the individuality of the patient. As Shaun emphasises, we are all responsible and should be continually vigilant in identifying those at risk and taking appropriate action with immediate effect.

Catrin Evans and Sylvia Nalubega write on the importance and value of applying evidence generated from qualitative studies to our work. Qualitative studies can be extremely useful in exploring the complexity and diversity inherent within HIV-related issues such as stigma and discrimination, adherence to treatment, or health-related behaviour choices such as sexual practice and risk-taking. The authors emphasise the particular value of reading systematic reviews as a time-efficient way of keeping up to date with new

developments in our field of practice, and thereby enhancing patient care.

I hope you find this edition, as always, a stimulating and relevant read. Please do circulate your copy amongst colleagues. The sharing of ideas and experience motivates and drives innovation in nursing which can only benefit our patients, so may I also take this opportunity to encourage you all to highlight such benefits of NHIVNA membership and to encourage others to join us.

References

1. Kenneth H Cohn. *Better Communication for Better Care: Mastering Physician-Administrator Collaboration*. Chicago, IL, Health Administration Press, 2005.
2. Flickinger TE, Saha S, Moore RD, Beach MC. Higher quality communication and relationships are associated with improved patient engagement in HIV care. *J Acquir Immune Defic Syndr*, 2013, **63**, 362–366.

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Breaking bad news: the HIV experience

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Background

The expression 'breaking bad news' is mostly associated with the moment when negative medical information has been shared with a patient or relative [1,2]. However, it can also be seen as a process of interactions that take place before, during and after bad news has been broken. The vast majority of the research undertaken in this area has been within oncology and palliative care, with much of what we know and use within our own practices originating within other disease areas. Little research has been conducted within HIV care to explore the process of breaking bad news (BBN) within this disease area.

What can we learn from the existing literature?

The needs of patients and the difficulties healthcare professionals (HCPs) face when breaking bad news, the knowledge, perception and skills in BBN as well as the effects of training sessions on communication skills, have been areas of interest for over 20 years. Empirical studies show that patients want to be informed about serious life-threatening illness [3,4]. HCPs acknowledge the rights of patients to be informed in these situations [5]; however, most of them have never received formal training to

support this task [1]. Key skills important in the context of BBN have been identified [1–6], and there is increasing evidence that the skills necessary to break bad news in a patient-centred manner can be acquired in courses using experiential teaching methods [7,8]. In addition, data from clinical studies indicate that good communication skills can contribute significantly to health and to satisfaction of both patients and HCPs [9,10].

Giving patients accurate information about their health can help them make informed decisions about their treatment and take responsibility for their care [11], increasing their understanding of the situation and helping them make appropriate plans for their future [2,12].

Traditionally, the breakers of bad news have been doctors, who take on this role because they have the responsibility for medical decisions [13,14]. However, within the literature the breaking of bad news is viewed as a multidisciplinary activity, with active involvement of a wider range of professionals working to support patients through the impact of the news [2,15].

The literature also views BBN as a process, one that includes the interactions that take place before, during and after the moment bad news is broken [16]. Within this framework, preparing the

patient for bad news, clarifying and explaining the information they have been given, and helping them come to terms with the situation is also viewed as part of the process [16,17].

There are a number of guidelines for best practice that have been developed in relation to this aspect of patient care in other disease areas [1,18]. Many of these offer step-by-step guidance for each of the processes of BBN. These guidelines tend to be based on an interaction where there is an opportunity to prepare for the confusion and give information in a relatively ordered manner and in a controlled environment.

BBN is a complex process and a highly skilled activity that needs to be done well to prevent detrimental effects to a patient and their future relationships with HCPs [1,19]. If bad news is communicated badly it can cause 'long-lasting distress, confusion and resentment' [20].

Study aims and objectives

- To evaluate self-perceived knowledge, perceptions and skills of HCPs who work in the field of HIV in relation to BBN
- To inform the development of educational material and resources to support HCPs in their role in relation to this aspect of care

Method

An online survey was sent to NHIVNA, BHIVA and BASHH members via their membership mailing lists. Permission was sought from the respective chairs of the organisations to access the membership. Ethical approval was not required. The project was registered with North Manchester General Hospital's R&D department (13recna29). Participants were asked to answer 15 questions designed to explore their knowledge, skills and perceptions in relation to BBN.

Findings

Participants' demographics

The overall response was 178 participants. Table 1 shows a breakdown of the participants. Table 2 indicates where participants stated they worked.

The majority of the respondents had over 10 years' experience of working within HIV care (74%; n=132).

What is BBN in HIV care?

Participants were asked to state, for a series of situations, whether or not this was breaking bad news to the patients. From the list, participants identified the following four as being considered BBN:

Table 1: Breakdown of participants

Occupation	Number of participants
Doctor	103
Nurse	58
Sexual health advisor	8
Allied HCPs including pharmacists and psychologists	9

Table 2: Participants' work settings

Setting	Number of participants
Genitourinary medicine	63% (n=109)
Specialist HIV outpatients department	53% (n=95)
Specialist HIV inpatient care	25% (n=44)
Community	12% (n=21)
Infectious diseases unit	10% (n=17)
Midwifery/obstetrics	2% (n=3)
Paediatric	1% (n=2)
Other, including palliative care, university, pharmacy and research	1% (n=2)

1. Giving an HIV diagnosis (90%; n=161)
2. Diagnosing a co-morbidity (80%; n=143)
3. Diagnosis of an opportunistic infection (79%; n=141)
4. Telling a patient they have a detectable viral load (52%; n=93).

The need to practice safer sex was not considered to be BBN by participants (59%; n=105); nor was the need to trace partners (71%; n=127). HCPs' perceptions about these two aspects of care are interesting and further work is needed to explore the patients' perspective. Then gaps in perceptions can be investigated to improve patient care.

What skills are helpful when breaking bad news?

The following skills were considered important when delivering bad news and are ranked in order of overall importance as indicated by the HCPs:

1. Having time to spend with a patient (99%; n=177)
2. Using simple language (92%; n=164)
3. The environment where bad news is delivered (87%; n=155)
4. Having a clear plan of action (84%; n=150)
5. Avoiding medical terminology (76%; n=136)

A high proportion of respondents (97%; n=173) felt that listening to their patient's concerns helped the patient to cope with bad news. Being empathetic was also viewed as another essential quality when delivering bad news (92%; n=163).

There was a range of answers that participants suggested in relation to knowing when they had delivered bad news to patients. These are ranked in order of the pre-identified responses offered (only 164 respondents answered this question):

1. Patient upset (97%; n=159)
2. Patient becomes silent (85%; n=139)
3. No response from patient (71%; n=117)
4. Patient keeps asking you the same question (66%; n=108)
5. Patient does not hear advice (63%; n=103)
6. Patient looks confused (60%; n=99).

What knowledge do HCPs have in relation to this area of care?

Overall the vast majority of respondents felt confident giving bad news (85%; n=152).

When asked to consider what enables HCPs to deliver bad news effectively the top three answers were: experience (95%; n=169); seeing other people do it (65%; n=115); and having to do it (62%; n=110). Interestingly, training was considered by 60% (n=106) of respondents to be effective in enabling them to deliver bad news.

Despite 62% (n=110) of participants stating that they had received training in relation to BBN, 80% of overall respondents could not name the training model used. Sixty-five percent (n=115) were not aware of any specific training in relation to BBN, and where participants did identify training it appeared to be for medics and held within oncology and palliative care settings.

If further training was made available the following methods have been ranked in order of preference:

1. Short educational session run in my workplace 71% (n=126)
2. Study days 47% (n=83)
3. Interactive lectures at conference 44% (n=78)
4. E-learning 30% (n=53)
5. Conference lectures 28% (n=49)
6. Reading materials online 22% (n=39)
7. Hard copy reading materials 12% (n=22)

Further comment was made by a respondent in relation to the availability of training in this area of care:

'Role play is really helpful, because it allows practice in a safe space. I think it would be good if BASHH and SSHA ran training sessions or study days on breaking bad news.'

What further comments do people have in relation to this area of care?

The real surprise in the data came in the results that participants left in the 'any other comments' section, which indicated the general feelings of respondents

in relation to this topic area. These comments were analysed and grouped into themes:

- (1) Personal characteristics and BBN
- (2) Impact of giving bad news on HCPs: ongoing support
- (3) Being patient centred: empathic professional
- (4) Role modelling: experiences of BBN

(1) Personal characteristics and BBN

Within the following extract, Participant A suggests that they do not feel that BBN skills can be taught *per se*, that experience, confidence and responding to patients' needs is how they believe BBN is better taught. Within the abstract they do not dismiss the idea of training as they feel it may act as a basis offering an understanding from which experience can then grow.

'I think this is not something that can be taught *per se*, but is thing you learn with experience, getting more experience and confident – you learn different reactions from patients and how to deal. But it's good to have a basis and understanding of what to do in certain situations.' (Participant A)

Personal characteristics and the impact these have on BBN is articulated by Participant B.

'Anything can be perceived as bad news by a patient and it important for clinicians to be sensitive. I have spent considerable time (over two years) training in psychosexual medicine and interpreting the doctor-patient interaction. I have gained much from this training. I think this should be available to all doctors – not a role-play fun and games brief learning but in-depth learning that makes one pause and reflect, perhaps in a group.' (Participant B)

Within this extract there is a clear sense from Participant B that the current training is not enough, suggesting that role plays and brief learning need to be replaced with a more intensive form of training for professionals. The suggestion of a higher level of training within this area of care may indicate how important Participant B feels this is to patient care.

This would conflict with what Participant C suggests as they believe a list of tips would be enough to help HCPs. There is an element of surprise that some psychiatrists have not been taught how to break bad news effectively. Within the extract, the idea of having tips to inform practice is also re-explored when Participant C suggests they learn an effective way to break bad news from the psychologist they work with. As Participant B implies, observation of the patient appears to be important, with the concept of needing time to do this process conceptualised within the extract.

'Even a list of tips would be useful. Even some psychiatrists have not necessarily been taught to give bad news at the start of a consultation, thus allowing the patient time to assimilate it; you need time to acknowledge the impact upon the patient and time to cover any burning issues they raise. I learnt that from a psychologist recently.' (*Participant C*)

Participant D acknowledges the difficulties of BBN and places importance on the therapeutic relationship, implying it can be a buffer to help patients respond to the news they are receiving.

'Delivering bad news is never easy, but if you have a good relationship with the person and they trust you this can make a difference to how they take the news delivered.'
(*Participant D*)

The importance of effective training in this area of care is indicated in the following extract.

'Giving bad news is a basic skill that we all need to be excellent at as very little in the NHS involves giving good news to patients unfortunately (nature of the beast). It should not be optional.'
(*Participant E*)

Within this extract, Participant E acknowledges the nature of the work we undertake and suggests that we should all excel in this area of care, as we are continually asked to deliver bad news.

(2) Impact of giving bad news on HCPs: ongoing support

The impact BBN has on the HCP emerged as a theme within the additional comments section.

Participant F offers the following comment in relation to how they managed their experience of BBN.

'Sharing of personal experiences from colleagues and also listening to patient accounts of their experiences both good and bad.'
(*Participant F*)

Participant G shares their approach to managing the impact BBN can have on patients.

'I personally try to follow up with a patient in a couple weeks after giving bad news, usually on a phone call. This can be time consuming, but I don't like the feeling of telling them something upsetting, then they never hear from me again. I think a follow-up phone call just to say hello, check to see how they are doing and see if any further questions have arisen is invaluable – and a way you can ensure patients stay engaged with the service.'
(*Participant G*)

Within this extract there is a clear process that Participant G uses to minimise the impact receiving bad news has on the patient. There is a clear patient-centred focus within the extract to try and

enable patients to remain in care.

'I think continuity of care is the most important. A doctor who knows their patient is best placed to modify their approach appropriately for that patient. It is much easier for the patient if they already know the clinician. They will feel more comfortable to ask questions as well.'
(*Participant H*)

Participant H highlights continuity of care as being important, suggesting a pre-existing therapeutic relationship would be ideal when breaking bad news. This would enable the HCP to proactively respond to the patient, with the benefit being that patients would feel more comfortable to ask questions.

Participant I highlights their thoughts in relation to BBN.

'We are expected to break bad news to patients and family members, most experiences come from watching others. Often feel unprepared and trip over words. I just try and put myself in their shoes. More training is definitely needed.'
(*Participant I*)

Within this extract, Participant I is very open in relation to their experiences when breaking bad news, and the idea that they 'trip over words' because they feel unprepared to deliver bad news. There is a suggestion within this that more training would help with this aspect of their role, which they are expected to carry out.

'Breaking bad news is an important part of working with people in a health setting. The way it is managed can significantly impact upon an individual's experiences of illness and their ongoing relationship with HCPs and service providers.'
(*Participant J*)

(3) Being patient centred: empathic professional

Within the additional comments there was a strong sense of participants wanting to demonstrate their empathic approach to this area of care.

'Giving some warning signs that some difficult news is about to be given helps to allow patient to think that things are not all OK. Expect some denial and that not everything you have said has been heard. It may need to be repeated and need to include time for patient to ask for this. Or it may need to be repeated at another visit.'
(*Participant K*)

Participant L follows on from this by offering the following cautionary advice.

'Always remember that every person is different and no two people will react the same way to the same piece of bad news.'
(*Participant L*)

The significance of BBN is also reflected in the following extract.

I think sometimes that all the good news around effectiveness of HIV treatment can make us less sensitive to what a devastating diagnosis HIV can be. We can be a bit quick to move the conversation on to positive and reassuring aspects of care/prognosis without exploring what the diagnosis means to that individual.' (*Participant M*)

Participant M also adds a cautionary note with respect to how we approach bad news within HIV care, suggesting that despite the advances in HIV care we also need to realise the impact that this news will have on the patients and allow them time to process what this may mean for them.

(4) Role modelling: experiences of BBN

Alongside training in BBN, a common theme that emerged was that of watching someone else deliver bad news.

'Seeing other people giving bad news – many do it all well, but often done badly and have tried to learn what works well, and avoid what doesn't work.' (*Participant N*)

Also personal experiences were suggested as a way to learn.

'Personal experience of being the recipient of bad news. Also observing good practice of someone delivering. Thinking now – also I learned a great deal from seeing it been done in a dreadful way! So lessons from both.' (*Participant O*)

Participant P suggests the role of bad experiences in shaping how they now break bad news more effectively.

'Learned from seeing other people do it badly!' (*Participant P*)

Implications for practice

The Psychological Standards 2011 [21] state that advanced communication skills training should be available for those who frequently have to break significant news, including HIV test results, explain complex formulations or discuss distressing issues.

Psychological support should be an integral part of the role of every health and social care practitioner working with PLWHIV. Many will require training in communication skills, BBN, and recognising or screening for psychological distress.

With this in mind, and alongside the findings of this small-scale study, it would appear clear that there is a need to develop more robust educational resources in relation to this area of care in order to improve patient care.

Discussion

Key themes pertinent to BBN have been

highlighted that are reflected in the wider BBN discourse. The qualitative statements from participants in this study have highlighted that there are certain elements within HIV care that make BBN unique within HIV care, which is not reflected in the current body of evidence. Further research is suggested to explore this further, as is the development of study days and e-learning resources which specifically explore BBN in the context of HIV care.

Conclusion

This small-scale study gives insight into BBN from an HIV perspective; themes that have emerged within the wider literature are also present, yet it would appear that there are some unique aspects of HIV care that remain different. Courses that are developed in relation to this area of care need to be responsive to the challenges that HCPs face within HIV care.

References

1. Baile WF, Buckman R, Lenzi R, Glober, G, Beale EA, Kudelka AP. SPIKES – A six step protocol for delivering bad news: application to the patient with cancer. *Oncologist*, 2000, **5**, 302–311.
2. Fallowfield L. Giving sad and bad news. *Lancet*, 1993, **341**(8843), 476–478.
3. Meredith C, Symonds, P Webster L *et al*. Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. *BMJ*, 1996, **313**, 724–726.
4. Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med*, 1980, **92**, 832–836.
5. Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physicians' attitudes towards telling the cancer patient. *JAMA*, 1979, **241**, 897–900.
6. Maguire P, Pitceathly C. Key communication skills and how to acquire them. *BMJ*, 2002, **325**, 679–700.
7. Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a Cancer Research UK communications skills training model for oncologists: a randomised control trial. *Lancet*, 2002, **23**(359), 650–656.
8. Charlton R, Smith G. Perceived skills in palliative medicine of newly qualified doctors in the UK. *J Palliat Care*, 2000, **16**, 27–32.
9. Ong LM, de Haes JC, Hoos AM, Lammes FB. Doctor-patient communication: a review of the literature. *Soc Sci Med*, 1995, **40**, 903–918.
10. Ramirez AJ, Graham J, Richards MA, Cull A, Gregory WM. Mental health of hospital consultants: the effects of stress and satisfaction at work. *Lancet*, 1996, **347**(9003), 724–728.
11. Tuckett AG. Truth-telling in clinical practice and the arguments for and against: a review of the literature. *Nurs Ethics*, 2004, **11**, 500–513.
12. Vivian R. Truth telling in palliative care nursing: the dilemmas of collusion. *Int J Palliat Nurs*, 2006, **12**, 341–348.
13. Morrissey MV. Extending the theory of awareness contexts by examining the ethical issues faced by nurses in terminal care. *Nurs Ethics*, 1997, **4**, 370–379.
14. Verhaeghe S, Defloor T, Van Furren F, Duijnste M, Grypdonck M. The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. *J Clin Nurs*, 2005, **14**, 501–509.
15. Mcsteen K, Peden-McAlpine C. The role of the nurse as advocate in ethically difficult care situations with dying patients. *J Hosp Palliat Nurs*, 2006, **8**, 259–269.

16. Tobin G, Begley C. Receiving bad news: a phenomenological exploration of the lived experience of receiving a cancer diagnosis. *Cancer Nurs*, 2008, **31**, E31-E39.
17. Dewar A. Nurses' experiences in giving bad news to patients with spinal cord injuries. *J Neurosci Nurs*, 2000, **32**, 324-330.
18. VandeKieft GK. Breaking bad news. *Am Fam Physician*, 2001, **64**, 1975-1978.
19. Rassin M, Levy O, Schwartz T, Silner D. Caregivers' role in breaking bad news: patients, doctors, and nurses' points of view. *Cancer Nurs*, 2006, **29**, 302-308.
20. Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet*, 2004, **363**(9405), 312-319.
21. British Psychological Society (BPS), British HIV Association (BHIVA) and Medical Foundation for AIDS & Sexual Health (MedFASH). Standards for psychological support for adults living with HIV, 2011. Available at: www.bhiva.org/StandardsForPsychologicalSupport.aspx (accessed June 2014).

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HIV as a chronic disease and co-morbidities

Jackie Morton

Chair HIV Scotland and HIV Activist

HIV, as a chronic disease, is explored alongside its counterparts, considering the similarities and differences of co-morbidities, the ageing factor, societal expectations and its impact on people living with HIV.

After 30 years, HIV is now ranked alongside other chronic diseases, heralding a near-normal life expectancy for those infected by the virus [1]. But can HIV really be viewed alongside the many well-known conditions such as arthritis, asthma, cancer, diabetes and chronic obstructive pulmonary disease (COPD) [2]? What defines HIV as a chronic condition? It certainly is a human health condition that is persistent or long lasting once adherence to daily treatment drug regimens is achieved [3]. In 2012, an estimated 98,400 people were living with HIV in the UK, with 490 deaths recorded. Whereas, at the peak of people being diagnosed by the end of 1995, the overall total of reported HIV infections in the UK was 25,689, with 1723 deaths recorded [4]. Across the world, death from AIDS is on the decline where there is equitable access to antiretroviral medication (ARVs), and resistance is decreasing due to improved regimens [5]. The World Health Organization (WHO) reports chronic non-communicable conditions to be by far the leading cause of mortality in the world, representing 35 million deaths in 2005 and over 60% of all deaths [2].

But this is where HIV differs from other chronic diseases. It is a communicable disease. It is preventable and, once infected, the positive person has to adhere stringently to their drug regimen, to sustain HIV suppression, reduce the risk of drug resistance, to improve overall health, quality of life and survival. Isn't that the same as anyone with a chronic disease? So how else does HIV differ from other chronic diseases?

Various co-infections, co-morbidities and other health conditions are common among people living

with HIV [6]. For example, hepatitis B or C linked to liver cancers, human papilloma virus (HPV) linked to cancers of the anus and genitals, and other sexually transmitted diseases leading to cancers of the cervix, bowel or kidneys and of the lymphatic system [7-11]. Approximately 9% of HIV-positive people in the UK are co-infected with hepatitis C [12].

There is a plethora of literature on the impact of ARVs' actions on a person's already damaged health system, suggesting people living with HIV are more prone to heart disease, certain cancers, osteoporosis and premature ageing [13]. Alternatively, highly active antiretroviral therapies (HAART) have significantly lowered HIV-associated neurocognitive disorders (HAND). This form of treatment not only reduces HIV viral levels in the body; it reduces the effect of HIV on the brain. HAART also reduces incidences of opportunistic infections, such as toxoplasmosis and cryptococcal meningitis, both of which negatively affect the brain [14]. Equally sinister AIDS-defining cancers, Kaposi sarcoma (KS) and non-Hodgkin's lymphoma, are diminishing due to improved ARVs [15]. Prior to the availability of effective ARVs, 90% of patients with pulmonary KS progressed and died of their disease. In contrast, where effective antiretroviral therapy (ART) is available, the proportion of patients with pulmonary KS experiencing fatal disease progression has been reduced to 47%. Restoration of the immune system as a consequence of ART may contribute to the latency of the human herpes virus, which causes KS, a connective tissue cancer. In addition to the indirect effect of ART on KS growth, at least some of the protease inhibitors have specific antineoplastic effects [16].

HIV thrives on human behaviour, bringing a range of different risk factors that substantially differentiates it from other chronic diseases. For instance, sexual behaviour and injecting drug use are the most common routes for HIV infection [17].

In 2012, in the UK, there were 6360 new HIV infections diagnosed. Of these, 51% (3250) were among men who have sex with men (MSM); 45% (2880) amongst heterosexuals; 120 infections through drug use and 110 infected through vertical transmission (mother to child) or through exposure to blood products abroad/accidental injury [4]. It is arguable that many other chronic conditions are as a result of human behaviour; for instance, excessive obesity can lead to heart disease or smoking can lead to respiratory disease. HIV is transmitted from person to person, making it preventable [18].

As people grow older, mortality and morbidity due to a range of conditions associated with HIV may not be obvious to those who specialise in care of the elderly and HIV [19]. HIV is not a unique chronic disease linked to early decline through ageing. Other chronic diseases such as rheumatoid arthritis and diabetes show earlier age functional decline, that is organ system injury, repeated hospitalisation and death. People living with HIV and on ARVs can respond to interventions systematically used to address multiple contributing factors to age decline alongside other chronic diseases, for instance, changing behavioural patterns such as stopping smoking, reducing alcohol consumption, avoiding obesity and exercising regularly [20]. Menopause in women accelerates the risk of osteoporosis, cardiac disease and neurological conditions [21]. Studies in the US, for example, found the prevalence of osteoporosis more than three times greater among HIV-positive individuals compared with HIV-negative study participants. Another study found that, among patients receiving continuous antiretroviral therapy, bone mass density (BMD) steadily declined compared to the patients receiving intermittent CD4 cell count-guided antiretroviral therapy, whose BMD remained stable or increased [22].

Older HIV-infected adults face unique health challenges stemming from age-related changes to the body accelerated by HIV infection, the side effects of long-term treatment for HIV, the infection itself and often, treatments for age-associated illnesses [23]. In 2006, an estimated 25% of people living with HIV in the US were aged 50 years and older. A study of these individuals found that extended exposure of these adults to both HIV and antiretroviral drugs appeared to increase their risk of illness and death from cardiovascular, bone, kidney, liver and lung disease, as well as many cancers not associated directly with HIV infection [24]. In 2012, some 990 (15%) of all new HIV diagnoses in the UK occurred in people aged 50 years and older [4]. Health care providers may not consider individuals aged 50 years and over to be at risk of HIV infection, and consequently may not discuss or act on HIV prevention measures. To complicate matters, the signs and symptoms of HIV/AIDS in older adults can easily be mistaken for conditions associated with ageing, delaying the

diagnosis of HIV infection and the start of appropriate therapy [23].

Prior to 1960 there were only two significant sexually transmitted diseases, syphilis and gonorrhoea [25]. HIV did not exist in the UK before the 1980s. The 'Swinging Sixties' and 'Glam Rock' in the 70s influenced teenagers of the era. Life became liberated, drugs accessible, promiscuity prevailed. Yet, many stoic values survived, influenced by Victorian grandparents and Second World War veteran parents. Many maintained a tradition of marrying young, adhering to their wedding vows, keeping their sexual preferences secret even though many yearned for relationships with members of the same sex. Practices viewed as unsavoury by society, sex and drugs, moved underground. It was a time when children born out of wedlock were removed for adoption, never to be known by their birth parents unless the individual chose to search some 20 or so years later.

Therefore is it not understandable that the use of condoms may not be a consideration with people over 50 as they move into new relationships after a long-term partner? Condoms were the forms of contraception used to prevent pregnancy in the 60s/70s, with very few thinking of using them to prevent sexually transmitted diseases [26]. Early in the US HIV epidemic, the National AIDS Behaviour Survey found that in respondents 50 years and older who reported at least one HIV risk behaviour there was a very low rate of condom use; over 85% of respondents reported never using or had inconsistent use of condoms during sexual activity. In addition, more than 90% of respondents over 50 years old had never had an HIV test performed [27]. Reviews of older adults found that they engage in a variety of sexual activities, although older men reportedly were more sexually active than older women. A large majority of older women lacked knowledge of personal risk and/or had not engaged in protection behaviours [28].

Polypharmacy in the older HIV patient is particularly concerning. Medications prescribed for more common chronic medical conditions and ARVs can have interactions. Fluctuations in body weight with age, for example, may reduce the total body water leading to more concentrated drug levels in blood and tissues and increased toxicity. Alternatively, increases in body fat, which acts as a depot for lipid-soluble drugs, can result in decreased serum drug concentrations and may initially lower drug effects. With repeated dosing and time, accumulation of lipid-soluble drugs in body fat can lead to toxicity. Slower gastrointestinal absorption rate may lead to delayed onset of drug effects. Drugs that are highly protein bound may produce enhanced effects as a person ages and protein concentrations decline [29]. Are caregivers, clinicians and specialists in HIV, geriatrics and primary care equipped to understand the interaction of HIV medication on an ageing body?

The penultimate difference of HIV versus other chronic diseases is the ability of an infected person to disclose their status to others. Feelings of shame and fear can bring abandonment and isolation. This may limit access to care and treatment and caregivers or family members may be more concerned about the infectious nature of caring for an HIV-infected person, particularly one who may be dying, and limit their contact as a consequence. Welfare reforms may not recognise the chronic nature of HIV, with some HIV-positive 'disabled' people neglecting health and nutrition for financial reasons and fear of disclosure [30].

Finally, in London and across Europe gay men continue to throw caution to the wind, engaging in highly risky 'chemsex' parties [31]. Older women changing sexual partners, perhaps due to divorce or death, are more sexually active. Coupled with menopausal changes in vaginal mucosa this increases the likelihood for trauma, STDs and HIV [32]. Drugs can now be used to treat erectile dysfunction in older men to enable a more fulfilling, lasting sex life. Same-sex partnerships are now part of society. Immigration, sex workers, injecting drug users, bisexuality, transgender people and MSM are all associated with HIV. All are already powerful sources of stigma and discrimination and people who have acquired their HIV in any of these classifications face a double stigma. This leads to marginalisation of people living with HIV, who are shunned by many in society. Very few chronic diseases are so abhorrently received as HIV [33].

How do we as clinicians reduce the ignorance that still surrounds this chronic disease that sits in the shadows of its counterparts? Break down 'the icebergs' that instilled fear in a whole generation of adults and show society that HIV should be an equal partner with other chronic diseases. Educate and share knowledge with those less knowledgeable on the condition. Most of all engage those living with HIV in service design. HIV is a virus waiting for a human behavioural failing. There is no cure for this chronic disease and its 'positive' host.

References

- Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. *Lancet*, 2013, **382**(9903), 1525–1533.
- World Health Organization. *Noncommunicable diseases*. Available at: www.who.int/topics/noncommunicable_diseases/en (accessed July 2014).
- The Department of Health (Australia). *Chronic disease. Definition*. Available at: www.health.gov.au/internet/main/publishing.nsf/content/chronic#def (accessed July 2014).
- Public Health England. *HIV in the United Kingdom: 2013 Report*. Key findings: pp9–11,20. Available at: www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317140300680 (accessed July 2014).
- UNAIDS. *Global Report: UNAIDS report on the global AIDS epidemic*. Available at: www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/unciaids_global_report_2013_en.pdf (accessed July 2014).
- World Health Organization. *Clinical guidance across the continuum of care: managing common coinfections and comorbidities*. Chapter 8. Available at: www.who.int/hiv/pub/guidelines/arv2013/coinfection/arv2013_chapter08.pdf (accessed July 2014).
- National AIDS Trust. *Hepatitis C and HIV co-infection. Report: January 2012*. Available at: www.nat.org.uk/media/Files/Publications/Jan-2012-Hepatitis-C-and-HIV-co-infection.pdf (accessed July 2014).
- Cancer Research UK. *HPV vaccines*. Available at: www.cancerresearchuk.org/cancer-help/about-cancer/cancer-questions/cervical-cancer-vaccine (accessed July 2014).
- WebMD. *Information about the Human Papillomavirus (HPV), 2014. Facts about HPV*. Available at: www.webmd.com/sexual-conditions/hpv-genital-warts/hpv-virus-information-about-human-papillomavirus (accessed July 2014).
- Macmillan. *HIV-related lymphoma*. Available at: www.cancerresearchuk.org/cancer-help/about-cancer/cancer-questions/cervical-cancer-vaccine (accessed July 2014).
- Chu C, Selwyn P. Complications of HIV infection; a systems-based approach. *Am Fam Physician*, 2011, **83**, 395–406.
- Health Protection Agency. *Hepatitis C in the UK – 2011 Report*. Available at: www.hpa.org.uk/webc/hpawebfile/hpaweb_c/1309969906418 (accessed July 2014).
- Avert. *HIV, Growing Older and Ageing with HIV. What it means to grow old with HIV*. Available at: www.avert.org/growing-older-and-ageing-hiv.htm (accessed July 2014).
- Avert. *HIV, Ageing and Comorbidities. Health Conditions among adults growing older with HIV. The Brain*. Available at: www.avert.org/hiv-ageing-and-comorbidities.htm (accessed July 2014).
- Gulich AE, Li Y, McDonald AM, Correll PK, Law MG, Kaldor JM. Decreasing rates of Kaposi's sarcoma and non-Hodgkin's lymphoma in the era of potent combination and anti-retroviral therapy. *AIDS*, 2001, **15**, 629–633.
- Von Roenn, J. Treatment of HIV-associated Kaposi sarcoma, 2003. HIV InSite Knowledge Base Chapter, Jamie H. Von Roenn MD, Northwestern University. Available at: <http://hivinsite.ucsf.edu/InSite?page=kb-00&doc=kb-06-02-04> (accessed July 2014).
- Koblin BA, Husnik MJ, Colfax G *et al*. Risk Factors for HIV infection among men who have sex with men. *AIDS*, 2006, **20**, 731–739.
- National Institute of Allergy and Infectious Diseases. *HIV/AIDS. Quick Facts about HIV Transmission*. Available at: www.niaid.nih.gov/topics/hivaids/understanding/pages/riskfactors.aspx (accessed July 2014).
- Fauci AS, Hodes RJ, Whitescarver J. *NIH Statement on National HIV/AIDS and Ageing Awareness Day. Sept 18, 2009*. Available at: www.nih.gov/news/health/sep2009/niaid-17.htm (accessed July 2014).
- Justice AC. *Ageing with Complex Chronic Disease: The Wrinkled Face of AIDS*, 2010. Available at: www.thebodypro.com/content/art58052.html (accessed July 2014).
- Alcaide M. Ageing and HIV Co-morbidities: A Challenge for Engagement in Care. *8th International Conference on HIV Treatment and Prevention Adherence*. June 2–4, 2012, University of Miami, School of Medicine. Available at: www.iapac.org/AdherenceConference/presentations/ADH8_Invited_Alcaide.pdf (accessed July 2014).
- Grund B, Peng G, Gibert CL *et al*. Continuous antiretroviral therapy decreases bone density. *AIDS*, 2009, **23**, 1519–1529.
- Fauci AS, Hodes RJ, Whitescarver J. *NIH Statement on National HIV/AIDS and Ageing Awareness Day. Sept 18, 2010*. Available at: www.nih.gov/news/health/sep2010/niaid-09.htm (accessed July 2014).
- Centers for Disease Control and Prevention (CDC). HIV Prevalence estimates – United States. *MMWR*, 2008, **57**, 1073–1076.

25. Bohlin R. *The Epidemic of Sexually Transmitted Diseases – A Christian Solution: An STD Epidemic*. Available at: www.probe.org/site/c.fdKEIMNsEoG/b.4218347/k.46BD/The_Epidemic_of_Sexually_Transmitted_Diseases.htm (accessed July 2014).
26. Styles R. Happy condom week! From linen cloths, to sausage skins and rubber dipped in sulphur ... the curious history of the condom revealed. Published Mail Online: 15:23, 7 February 2013/updated 17:03. Available at: www.dailymail.co.uk/femail/article-2275040/happy-condom-week-from-linen-cloths-suasage-skins-rubber-dipped-sulphur--curious-historycondom-revealed.html (accessed July 2014).
27. Stall R, Catania J. AIDS risk behaviors among late middle-aged and elderly Americans. The National AIDS Behavioral Surveys. *Arch Intern Med*, 1994, **154**, 57–63.
28. Nguyen N, Holodniy M. HIV infection in the elderly. *Clin Interv Aging*, 2008, **3**, 453–472.
29. Ramsey LE, Tucker GT. Clinical pharmacology: Drugs and the elderly. *Br Med J (Clin Res Ed)*, 1981, **282**(6258), 125–127.
30. Radcliffe S. NAT Parliamentary Briefing: The Welfare Reform Bill and people living with HIV, 2012. Available at: www.nat.org.uk/media/Files/Policy/2012/WRB_NATBriefing_2ndreading.pdf (accessed July 2014).
31. Travis A. Drug experts issue warnings over chem-sex parties. Home Editor Reporter, *The Guardian*, 27 May 2014.
32. Shah SS, McGowan JP, Smith C, Blum S, Klein RS. Comorbid conditions, treatment, and health maintenance in older persons with human immunodeficiency virus infection in New York City. *Clin. Infect Dis*, 2002, **35**, 1238–1245.
33. Oshakati Mwandangi CH. Abhorrent AIDS programme. *The Namibian*, Economic News, 24 March 2006.

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Qualitative systematic reviews and their role in evidence-based HIV nursing

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Introduction

Decisions for healthcare delivery and health policies should be based on the highest level of existing research evidence [1]. Achieving this can be challenging given the large body of existing literature generated by empirical studies [2], which may have biases, methodological flaws or may be time and/or context specific. Additionally, individual studies can reach conflicting conclusions making it hard to decide which results should inform policy or practice decisions [1]. Systematic reviews, which bring together the results of primary studies, offer a solution to such concerns.

Systematic reviews are described as explicit, reliable, reproducible scientific methods which limit bias by identifying, selecting, critically appraising and synthesising all literature on a given topic from all relevant individual studies. As such, they provide the most accurate and trustworthy results, which are more acceptable and accessible to decision-makers [3–6], enabling health care professionals to offer focused and individualised care, in which up-to-date evidence is integrated with patients' own values and needs [7].

There are many different types of systematic reviews. The most common are those based on quantitative evidence which may or may not include meta-analysis, and those based on qualitative evidence. This paper aims to describe the method and process of qualitative systematic reviews and their importance in informing evidence-based HIV nursing practice.

What is qualitative research?

Qualitative research is an approach that is concerned with exploring and understanding the meaning of phenomena in society, often through techniques such as interview or observation [8,9]. Qualitative approaches particularly seek to uncover the thoughts, perceptions and feelings experienced by individuals under real-life (naturalistic) contexts [9]. These approaches usually involve small numbers of research participants, which allows for an in-depth investigation and eventually a rich understanding of a particular phenomenon [10].

What are qualitative systematic reviews?

Qualitative systematic reviews present conclusions derived from combining and integrating all the findings from original (primary) qualitative studies. As such, they provide a comprehensive and detailed picture of the phenomenon studied and enable new insights to emerge [11,12].

Different types of qualitative reviews

There are several different approaches to undertaking qualitative systematic reviews. The two main approaches are *integration* or *meta-aggregation* and *interpretation* or *meta-ethnography* [11]. Integration/aggregation, which includes the Joanna Briggs Institute (JBI) meta-aggregation approach, involves the assembling of findings from empirical studies and pooling (or aggregating) them based on similarities in meaning [2,13]. Using a process similar to thematic qualitative data analysis, the findings are further aggregated into categories and then into over-arching 'synthesised findings'. This approach explicitly aligns itself with the philosophy of pragmatism, and enables delivery of readily applicable directive 'synthesised findings' which can be used to inform policy or professional practice [12]. By contrast, interpretive synthesis, such as meta-ethnography, aims to re-interpret (not just to summarise) original research findings in order to generate new knowledge or theory [13]. Meta-ethnography therefore tends to yield results where implications for practice can be inferred but may not be explicit [13,14].

Why are qualitative reviews important?

There are two reasons why qualitative systematic reviews are important for HIV health care. Firstly, they serve to guide new research by generating and refining research questions and by demonstrating gaps in the existing evidence base [15]. Secondly, they guide HIV nursing practice by producing generalisable and trustworthy evidence, for example about the experiences of HIV patients/clients, which is essential in supporting decisions in the provision of HIV care [2]. Such reviews provide an opportunity to

incorporate the patient's viewpoint into evidence-based HIV practice.

Evidence generated through reviews of qualitative HIV studies can address issues such as how HIV interventions and other care services are perceived by users, or what factors facilitate/deter adherence to treatment or the choice of health promoting lifestyles [2]. For example, Musheke *et al.* [16] undertook a review which sought to establish the factors that enabled or deterred patient acceptance of taking an HIV test in sub-Saharan Africa. Findings from this review of patients' experiences indicated that the perception of not being at risk of contracting HIV, HIV-related stigma and financial constraints were major contributing factors to the low testing uptake. The reviewers recommended that efforts to scale up HIV testing in this region should aim at addressing these identified barriers. In another example, a qualitative review by Sandelowski *et al.* [17], which synthesised qualitative findings about stigma in HIV-positive women, found that HIV stigma was a key problem facing HIV-positive women. The conclusion drawn from this review was that 'other people' in the lives of the HIV-positive women were also significantly affected by the stigma and therefore should be targeted in the implementation of stigma-reduction interventions. According to the reviewers, this meta-synthesis was able to confirm the recurrent themes identified in individual primary studies of HIV-positive people and stigmatising conditions (both qualitative and quantitative), which would otherwise not have been concluded based only on one primary study.

How are they done?

Although there are different approaches to systematic reviews of qualitative studies [2], the steps involved are similar in all of them. Below, we describe the JBI meta-aggregative approach to the process of meta-synthesis.

The research question

The first step in conducting a systematic review is to formulate a review question. This needs to be precise and must indicate the population (participants), phenomenon of interest and the context. This is relevant in order to guide the users of the review to ascertain whether the findings can be transferable to other contexts or whether they are only focused on a particular situation [2,11].

The review protocol

A review protocol serves as the map for the review [1], and it should follow a standard format to keep track and ensure that the process is rigorous and in keeping with the standards of scientific research [2]. The review protocol clearly outlines the specific steps to follow [11], which include: the

background information of the review topic; the review question; the aim and objectives; the criteria for including or rejecting studies; how studies will be identified; assessment of the quality of identified studies; how the data will be extracted from the included studies; and the synthesis of the data to generate conclusions [2,11]. These steps are explained in more detail below.

Types of studies to include

According to JBI [11], qualitative systematic reviews can synthesise findings from studies that have used a variety of qualitative methodologies. Therefore, all qualitative methods that follow an interpretive paradigm, aiming at understanding the human condition, are considered (e.g., phenomenology, ethnography, grounded theory and action research). Usually, a systematic review will try to include all studies that meet the inclusion criteria in any language, and will seek to translate articles where appropriate. However, due to time and financial constraints, this can be difficult to achieve for some reviews.

Search strategy for identification of studies

The literature search is aimed at identifying *all* studies that fit the inclusion criteria [2]; therefore, it is recommended that prior to commencement of a systematic search for literature, a *systematic search strategy* is established to ensure that the search will be thorough, rigorous, comprehensive and unbiased [18]. It is advisable to seek the help of a librarian for this stage. Many databases do not have detailed thesaurus terms for identifying qualitative studies [11], therefore reviewers should avoid limiting the search, for example to a methodology or research design. It is also advisable that the search is not limited to only well-known databases since qualitative studies may be spread within a wide range of bibliographic databases [19,20]; reference tracking is also very useful for identifying relevant papers for the review [21].

Assessment of methodological quality

The meta-aggregation approach places a strong emphasis on the assessment of the quality of methods used by the included studies, to rule out methodological flaws which may increase the risk of biased results [13]. There are several critical appraisal tools that can be used [14,22]. The JBI tool focuses on assessing the following domains:

- The congruity between the philosophical position adopted by the study and the study methodology
- The congruity between the methodology and the research questions and objectives, the representation of data, and the interpretation of the results

- The disclosure of the researcher's background, and/or any influences of the researcher(s) on the results
- The representation of participants' views in the conclusions drawn from the analysed data [14]

Qualitative papers selected for retrieval should normally be assessed by at least two independent reviewers who afterwards meet to discuss the assessment outcomes. Any disagreements between the two should be resolved with a third reviewer [14]. The critical appraisal process determines whether or not a study is judged to be of sufficiently high quality to include in the systematic review.

Data extraction

In this stage, the included papers are read and re-read and relevant data are extracted using a standardised data extraction tool. The data extracted includes: (i) background information about the study (e.g., details about the methodology, method, phenomena of interest, setting, geographical and cultural contexts, participants, method of data analysis, author's conclusion, and reviewer's comments); and (ii) the key findings accompanied by illustrative quotes [11,14]. JBI [14] defines a finding as 'a conclusion reached by the researcher(s) and often presented as themes or metaphors' (p 40).

Data synthesis

The extracted findings are pooled using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI QARI) approach (see Figure 1). This is done through assembling the findings from the papers rated according to their quality, and categorising these on the basis of similarity in meaning. The categories are then subjected to a further meta-aggregation in order to produce a comprehensive set of 'synthesised findings' [11,14]. These synthesised findings indicate readily accessible recommendations that can be used as a basis for evidence-based practice.

Where do we find qualitative systematic reviews?

Qualitative review reports can be found in the JBI database of systematic reviews, the Cochrane Library and other research journals.

Conclusion: using qualitative reviews to improve HIV nursing

With the current emphasis on evidence-based practice (EBP), HIV nurses are required to base their practice on the best available research evidence [23–25]. Reading systematic reviews is an important and time-efficient way of keeping up to date with new developments in HIV nursing care,

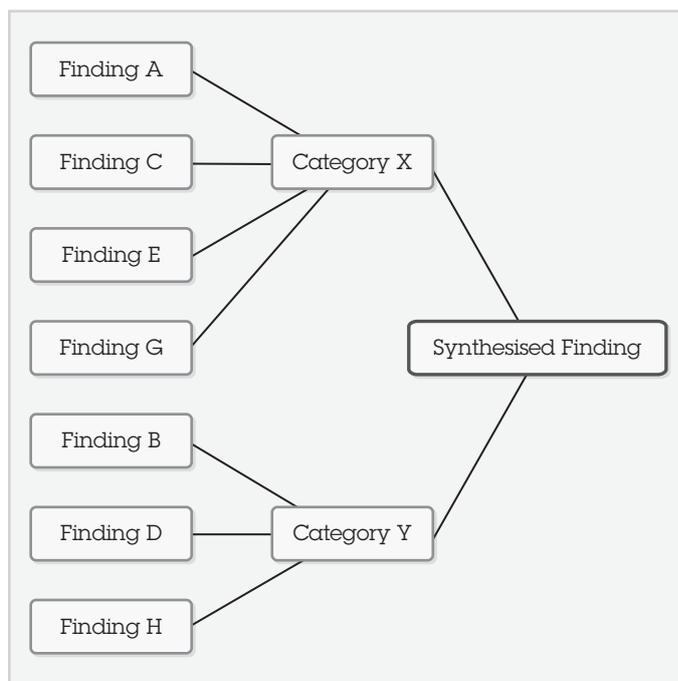


Figure 1: Summary of the JBI approach to meta-synthesis

which will result in better patient care and improved service delivery processes [26].

References

1. Centre for Reviews and Dissemination. *Systematic Reviews: CRD's guidance for undertaking reviews in health care*. Centre for Reviews and Dissemination (CRD), University of York, 2009.
2. Korhonen A, Hakulinen-Vitanen T, Jylha V, Holopainen A. Meta-synthesis and evidence-based health care—a method for systematic review. *Scand J Caring Sci*, 2013, **27**, 1027–1034.
3. Gough D, Thomas J, Oliver S. Clarifying differences between review designs and methods. *Syst Rev*, 2012, **1**, 28.
4. Manchikanti L, Datta S, Smith HS, Hirsch JA. Evidence-based medicine, systematic reviews, and guidelines in interventional pain management: part 6. Systematic reviews and meta-analyses of observational studies. *Pain Physician*, 2009, **12**, 819–850.
5. Manchikanti L. Evidence-based medicine, systematic reviews, and guidelines in interventional pain management, part I: introduction and general considerations. *Pain Physician*, 2008, **11**, 161–186.
6. Dixon-Woods M, Booth A, Sutton AJ. Synthesizing qualitative research: a review of published reports. *Qualitative Research*, 2007, **7**, 375–422.
7. Jadad AR, Cook DJ, Jones A *et al*. Methodology and reports of systematic reviews and meta-analyses: a comparison of Cochrane reviews with articles in paper-based journals. *JAMA*, 1998, **280**, 278–280.
8. Creswell JW. *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. 3rd ed. Sage Publications, London, 2009.
9. Gribich C. *Qualitative Research in Health: An Introduction*. Sage Publications, London, 1999.
10. Mack L. The philosophical underpinnings of educational research. *Polyglossia*, 2010, **19**, 5–11.
11. Joanna Briggs Institute. *Reviewers' Manual: 2011 edition*. The Joanna Briggs Institute, University of Adelaide, South Australia, 2011.
12. LoBiondo-Wood G, Haber J. *Nursing Research: Methods and Critical Appraisal for Evidence-based Practice*. Mosby Elsevier, St Louis, US, 2006.

13. Hannes K, Lockwood C. Pragmatism as the philosophical foundation for the Joanna Briggs meta-aggregative approach to qualitative evidence synthesis. *J Adv Nurs*, 2011, **67**, 1632–1642.
14. Joanna Briggs Institute. *Reviewers' Manual: 2014 Edition*. The Joanna Briggs Institute, University of Adelaide, South Australia, 2014.
15. Petticrew M, Roberts H. *Systematic Reviews in the Social Sciences: A Practical Guide*. Blackwell Publishing, Oxford, 2006.
16. Musheke M, Ntalasha H, Gari S *et al*. A systematic review of qualitative findings on factors enabling and deterring uptake of HIV testing in Sub-Saharan Africa. *BMC Public Health*, 2013, **13**, 220.
17. Sandelowski M, Lambe C, Barroso J. Stigma in HIV-positive women. *J Nurs Scholarsh*, 2004, **36**, 122–128.
18. Wilczynski NL, Marks S, Haynes RB. Search strategies for identifying qualitative studies in CINAHL. *Qual Health Res*, 2007, **17**, 705–710.
19. Noyes J, Popay J, Pearson A *et al*. *Qualitative Research and Cochrane Reviews. Cochrane Handbook for Systematic Reviews of Interventions. The Cochrane Collaboration*. John Wiley and Sons, Chichester, UK, 2008.
20. Stansfield C, Kavanagh J, Rees R, Gomersall A, Thomas J. The selection of search sources influences the findings of a systematic review of people's views: a case study in public health. *BMC Medical Research Methodology*, 2012, **12**, 55.
21. Papaioannou D, Sutton A, Carroll C, Booth A, Wong R. Literature searching for social science systematic reviews: consideration of a range of search techniques. *Health Info Libr J*, 2010, **27**, 114–122.
22. Hannes K, Lockwood C, Pearson A. A comparative analysis of three online appraisal instruments' ability to assess validity in qualitative research. *Qual Health Res*, 2010, **20**, 1736–1743.
23. Fitzpatrick J. Finding the research for evidence-based practice. *Nursing Times*, 2007, **103**(17), 32–33.
24. Polit DF, Beck CT. *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. 7th ed. Lippincott Williams & Wilkins, 2010.
25. Burns N, Grove SK. *Understanding Nursing Research: Building an Evidence-Based Practice*. 4th ed. Saunders: Elsevier, 2007.
26. Youngblut JM, Brooten D. Evidence-based nursing practice: why is it important? *AACN Clin Issues*, 2001, **12**, 468–476.

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The views and experiences of HIV research participants in sub-Saharan Africa: a worked example of a qualitative systematic review

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Background

HIV clinical trials are increasingly being conducted in sub-Saharan Africa [1–3]. There is a tension between the pressure to increase levels of research participation whilst at the same time ensuring informed consent and the protection of participants' rights [4,5]. Researchers need to be aware of the particular ethical issues that underpin HIV research conducted in low-income settings. This necessitates hearing from those who have agreed to participate in research and who have experienced the research process.

This qualitative systematic review aims to synthesise existing qualitative literature to answer the question: What are the views and experiences of HIV research participants in sub-Saharan Africa? The review aims to highlight key issues that need to be addressed to ensure high-quality ethical HIV research practice in sub-Saharan Africa.

Methods

This meta-synthesis employs the meta-aggregation approach developed by the Joanna Briggs Institute (JBI) [6]. This approach involves assembling the findings from primary studies and categorising them based on similarity in meaning to reach overarching conclusions [7]. Studies that focus on qualitative data, including but not limited to designs such as phenomenology, ethnography, grounded theory and action research, are considered. The review includes studies whose

participants are current or former adult HIV research participants from sub-Saharan African countries.

Nine databases (CINAHL, MEDLINE, ASSIA, PsycINFO, Web of Science, Embase, The Cochrane Library, Joanna Briggs Institute Library and African Index Medicus) were searched in June 2013, followed by hand searching of reference lists. Studies published between 1995 to present were considered. The grey literature included reports from the World Health Organization and UNAIDS, while hand searching was carried out from Google web and the Google Scholar database. Table 1 shows the search strategy used.

Results

The systematic search yielded 8334 articles, while another four papers were identified from hand searching. Out of these, only 12 studies met the inclusion criteria and were critically assessed using the JBI's Qualitative Assessment and Review Instrument (QARI). Following quality appraisal, one study [8] was excluded on the basis of poor quality. This left 11 studies to be included in the review. Figure 1 presents the details of the search results.

Main characteristics of included studies

All 11 included studies were published within the past decade, between 2004 and 2012; and of these,

Table 1: Search strategy

Key concept	Synonyms/related terms/alternative forms for key words
<i>Views and experiences</i>	view*, experience*, understand*, comprehen*, concern*, opinion*, attitude*, perspective*, belie*, knowledge, perception*
<i>Research participants</i>	research participant*, research subject*, study participant*, study subject*, healthy volunteer*, trial participant*, trial subject*, lay people, community member*, public, opinion leader*, stake holder*, client*, patient*, family member*
<i>HIV research</i>	HIV, HIV? AIDS, AIDS, malaria, TB, tuberculosis, vaccine trial*, health? related research, health research, health service* research, biomedical research, research, clinical research, medical research, clinical trial*, social science research, health survey*, experimental stud*
<i>Sub-Saharan Africa</i>	sub? Saharan Africa, Africa, African countries, low income countr*, resource limited countr*, resource limited setting*, developing countr*, non? Western countr*, developing world, under? developed countr*, poor countr*, low resource setting*, third world nation*
<i>Informed consent</i>	Informed consent, consent*, ethic*, bioethics*, participation
? and *, wild-card characters used in the searches	

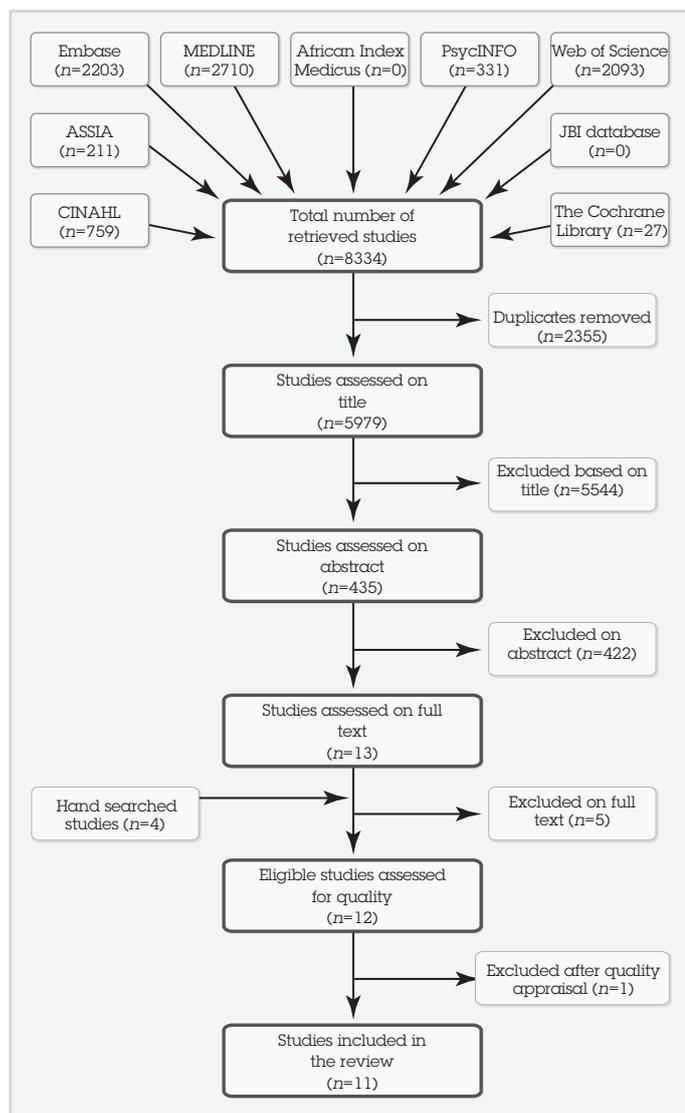


Figure 1: The process of identifying studies for inclusion in the review.

eight studies [9–16] were recently published (2011 or 2012). The included studies represented only five sub-Saharan African countries; four from South Africa [11,12,17,18], one from Kenya [10], three from Tanzania [9,15,16], one from both South Africa and Zimbabwe [13], and one from both Zimbabwe and Malawi [14]. In addition, one study [19], was carried out in three countries, one Caribbean and two African, but did not provide details of the specific countries.

Findings

The 11 studies reported findings from a total of 461 participants. A total of 58 findings were extracted from the included studies and were included in the synthesis. The findings were grouped into eight categories based on similarity of meaning, and were further synthesised in a meta-synthesis which yielded four synthesised and directive findings to be used as the basis for evidence-based practice and evidence-based recommendations. These were:

(i) Participation in HIV research is related to perceived personal benefits and benefits for wider society.

- (ii) Research participation is influenced by fear of social or physical harm.
- (iii) Poor understanding of research processes and concepts is common.
- (iv) Social relationships and domestic contexts have a significant impact on HIV research participation and adherence.

Table 2 presents the categories and synthesised findings from the review. The latter will be discussed in turn below.

Participation in HIV research is related to perceived personal benefits and benefits for wider society

This review indicates that individuals were motivated to participate in HIV research due to a range of perceived benefits. These include personal gains such as lifestyle change [15]; accessing prompt and adequate medical care and treatment [15,16,18,19]; receiving information about their health status [14,17]; and protection from infections and rape [13,14]. These benefits were motivations for research participation as cited by one participant:

'I have not been sick since I knew that I am HIV-positive but I know that if you are HIV-positive you must always check your CD4 count, you must not wait until your CD4 count goes down. I think that is the thing that made me decide to come and join the study even though they told me that they are doing research but I wanted to see if they were going to help me' [12].

Interestingly, the review showed that financial benefits were rarely cited as primary motivations for research participation. For those who mentioned money as a motivation, it was as an added benefit rather than a primary motivation as illustrated by one participant:

'I would say money also helped me in addition to the other things that I was getting here' [12].

The review also indicates that participants were motivated to take part in research for altruistic reasons [11–13,15]. Participants who mentioned altruism as a motivating factor believed that their participation could make a positive contribution to society, as illustrated in the statement:

'I have decided to sacrifice myself; I have already sacrificed to rescue this world. If it is a vaccine, then it will help other people ... Jesus died on the cross to save others. So, I sacrifice myself too ...' [15].

This review has shown that perceived benefits are vital for motivating participation in HIV research. Previous studies have had similar findings [20–23]. Researchers should endeavour to disclose fully all

Table 2: Categories and synthesised findings from the review

	Categories	Synthesised findings
1	Perceived personal benefits	Participation in HIV research is related to perceived personal benefits and benefits for wider society
2	Motivating factors for research participation	
3	Fears related to HIV stigma	Research participation is influenced by fear of social or physical harm
4	Fears related to potential harm associated with the HIV vaccine	
5	Misconceptions about HIV research	Poor understanding of research processes and concepts is common
6	Mixed understanding of the research	
7	Influence from social relationships	Social relationships and domestic contexts have a significant impact on HIV research participation and adherence
8	Economic and domestic factors	

the likely benefits, including individual benefits and those for wider society.

Research participation is influenced by fear of social or physical harm

Participation in HIV research can be associated with considerable fear and uncertainty, mainly due to HIV stigma and worry about potential harm from research interventions. For example, the fear of finding out one's HIV sero-status was a common barrier to research participation [10,11,15], as illustrated by this quote:

'I think people can come [to participate in an HIV vaccine trial] but they fear knowing their HIV status and stigma from people when they know your status ... There is no problem in joining the protocol; the fear is knowing their HIV status. What will be done to me once they know my HIV status?'

This fear of stigmatisation cuts across both HIV-positive and HIV-negative research participants [10].

Other findings illustrate fears related to uncertainties about HIV research interventions, such as the possibility of acquiring HIV through the vaccine, possible harmful effects related to the vaccine [9,16], and the efficacy of the research interventions [13]. Related to this finding, it was obvious that some participants did not trust the researchers as they mentioned being unsure of what their intentions were [9]. Participants also expressed fears related to specific trial interventions such as blood draws, which were perceived to be harmful to health [16].

Previous literature has also shown that HIV research evokes significant fears [24–26]. Since the majority of HIV research studies will require a confirmation of one's HIV sero-status, it is crucial that fears related to HIV testing are addressed early in the research. HIV stigmatisation can have other negative effects such

as discrimination, which can result in stress or problems within the family or community. HIV research participants require continuous assessment to identify potential negative effects, and counselling and support facilities should be available if required. Research nurses can be helpful in this role since they possess counselling skills and interact more with research participants compared to the rest of the research team.

Poor understanding of research processes and concepts is common

This review indicates that misconceptions about HIV and related research processes are still common among HIV research participants. For example, some participants thought that participation in HIV research meant that someone was HIV positive [11]. This resulted in some of them becoming reluctant to participate as reflected in this illustration:

'If I were positive I would join all these programmes but because I am HIV negative I just don't care. I feel this way after testing; before testing I just had faith that I was negative' [11].

Furthermore, the review reveals mixed understandings of the research process and of some key concepts in HIV research. Some concepts of the research would be understood while others would not. For example, some studies revealed that participants had understood well the study purpose and did not feel forced to participate in the research, while at the same time it was difficult for some participants to fully understand concepts such as randomisation [16,19]. This can be confirmed from the two illustrations below which were from one study:

'This research was about the product ... like the gel that you put into the vagina if it can prevent STDs.'

'She said they decided to give her AZT because she had had a miscarriage' [19].

In relation to this finding, the review shows that repeated explanations are necessary to improve understanding of key concepts among some participants [18].

Another misconception was related to misunderstanding the overall goal of HIV research referred to by some authors as 'therapeutic misconception' [8]. This is when some participants attribute the study intervention as being intended for their treatment (rather than for research).

When such misconceptions occur, there may be a lack of voluntary participation and informed consent [27]. Some studies suggest that misconceptions arise out of problems with language and the use of translators has been recommended as a strategy to enhance understanding of the research among lay populations who may not speak English [28]. However, this may present some challenges such as the misinterpretation of research concepts, especially when lay translators with no knowledge of scientific terms are used. In addition, some scientific terms do not exist in local languages and therefore cannot be translated directly. Therefore, employing qualified and knowledgeable research staff to undertake informed consent, or providing in-depth training for lay persons involved in eliciting informed consent, is essential.

Social relationships and domestic contexts have a significant impact on HIV research participation and adherence

This review reveals that social, economic and domestic factors are critical in determining HIV research participation and adherence to study requirements among participants in sub-Saharan Africa. Findings indicate that participants encountered a number of discouragements from family, friends or even non-research medical personnel which had a negative influence on their decisions to participate [9,15].

In some cases, individuals were willing to participate in principle, but could not due to the strong pressure exerted on them by close relatives or intimate partners as illustrated by this quote:

'My fiancé did not accept it completely! And he warned if I enrol in the trial our relationship would end; even though he had already paid a dowry, he would cancel our marriage plans ... I felt bad because I had already committed myself with that relationship and I saw there is no need to force him' [9].

The findings show that failure to adhere to trial interventions was often attributed to the influence of intimate partners, especially where study interventions affected their sexual life such as using condoms, diaphragms or microbicide gel [12,13]. This was illustrated by one participant:

'Yes I did have a problem with my partner – he did not want to use condoms. When I asked him to use condoms, he said it means I do not trust him, you see' [12].

These barriers appear to be more common among female participants. This review also identifies a range of other barriers that affected HIV research participation, for example, financial and domestic commitments [11], and the requirement to travel long distances [12].

Despite the challenges and barriers affecting HIV research participation in sub-Saharan Africa, findings from this review show that there are some factors that motivated research participation. For example, participants noted that the kind and caring treatment they received from the study team was a strong motivation to stay enrolled:

'I think it [staff attitude] helped me because when I thought about coming to the clinic I knew that I am going to be laughing and talking to people who care about me and I loved to come to the clinic' [12].

Encouragement from close family members also motivated participants to participate [12].

Although some of the social influences were facilitators to research participation, the majority acted as barriers and seemed to be highly associated with a lack of understanding of HIV research by the general population. Sensitisation about HIV research programs therefore should be given a priority in sub-Saharan Africa, and such activities should target the entire community. Economic and domestic factors seemed to affect women more than men, and could be attributed to gender inequalities identified in African settings [29]. These factors can be addressed by strategies such as reimbursements (for time spent on the research study) and transport refunds [27].

Conclusion

The results of this review show a willingness by participants to participate in HIV research. However, their understanding of the process can be limited and the experience may cause anxiety or have negative consequences. Furthermore, sustained participation may become problematic due to social pressure or social commitments. The review findings suggest that there is an ongoing need to develop better ways to explain research processes and to support the participants when/if they encounter problems. Research nurses have a key role to play here. Interestingly, there were no studies that explored reasons for drop-out after enrolment or that explored the post-trial experience. This is an important gap in our current understanding of the experience of HIV research participation.

References

1. Lairumbi GM, Parker M, Fitzpatrick R, English MC. Forms of benefit sharing in global health research undertaken in resource poor settings: a qualitative study of stakeholders' views in Kenya. *Philos Ethics Humanit Med*, 2012, **7**, 7.
2. Silverio A. HIV Research in Africa. *Stanford Journal of International Relations*, 2006.
3. London L, Kagee A, Moodley K, Swartz L. Ethics, human rights and HIV vaccine trials in low-income settings. *J Med Ethics*, 2012, **38**, 286–293.
4. Mbuagbaw L, Thabane L, Ongolo-Zogo P, Lang T. The challenges and opportunities of conducting a clinical trial in a low resource setting: the case of the Cameroon mobile phone SMS (CAMPS) trial, an investigator initiated trial. *Trials*, 2011, **12**, 145.
5. Fitchett JR. Ethical considerations of clinical trials in the developing world. *Trans R Soc Trop Med Hyg*, 2009, **103**, 756–760.
6. Joanna Briggs Institute. *Reviewers' Manual: 2014 Edition*. The Joanna Briggs Institute, University of Adelaide, South Australia, 2014.
7. Korhonen A, Hakulinen-Vitamen T, Jylha V, Holopainen A. Meta-synthesis and evidence-based health care—a method for systematic review. *Scand J Caring Sci*, 2013, **27**, 1027–1034.
8. Stewart K, Sewankambo N. Okukkera Ng'omuzungu (lost in translation): understanding the social value of global health research for HIV/AIDS research participants in Uganda. *Glob Public Health*, 2010, **5**, 164–180.
9. Tarimo EA, Thorson A, Kohi TW, Bakari M, Mhalu F, Kulane A. Reasons for declining to enroll in a phase I and II HIV vaccine trial after randomization among eligible volunteers in Dar es Salaam, Tanzania. *PLoS One*, 2011, **6**, e14619.
10. Nyblade L, Singh S, Ashburn K, Brady L, Olenja J. "Once I begin to participate, people will run away from me": understanding stigma as a barrier to HIV vaccine research participation in Kenya. *Vaccine*, 2011, **29**, 8924–8928.
11. Onoya D, Reddy P, Sifunda S, Wingood GM, van den Borne B, Ruitter RAC. Barriers to recruitment and retention of HIV-negative Black South African women into behavioral HIV prevention programs. *Journal of HIV/AIDS & Social Services*, 2011, **10**, 248–264.
12. MacPhail C, Delany-Moretlwe S, Mayaud P. 'It's not about money, it's about my health': determinants of participation and adherence among women in an HIV-HSV2 prevention trial in Johannesburg, South Africa. *Patient Prefer Adherence*, 2012, **6**, 579–588.
13. Kacanek D, Dennis A, Schin-Hodoglugil NN *et al*. A qualitative study of obstacles to diaphragm and condom use in an HIV prevention trial in sub-Saharan Africa. *AIDS Educ Prev*, 2012, **24**, 54–67.
14. Woodsong C, Alleman P, Musara P *et al*. Preventive misconception as a motivation for participation and adherence in microbicide trials: evidence from female participants and male partners in Malawi and Zimbabwe. *AIDS Behav*, 2012, **16**, 785–790.
15. Tarimo EA, Thorson A, Kohi TW *et al*. A qualitative evaluation of volunteers' experiences in a phase I/II HIV vaccine trial in Tanzania. *BMC Infect Dis*, 2011, **11**, 283.
16. Reynolds J, Mangesho P, Vestergaard LS, Chandler C. Exploring meaning of participation in a clinical trial in a developing country setting: Implications for recruitment. *Trials*, 2011, **12**, A114.
17. Stadler JJ, Delany S, Mntambo M. Women's perceptions and experiences of HIV prevention trials in Soweto, South Africa. *Soc Sci Med*, 2008, **66**, 189–200.
18. Pistorius AG, van de Wijgert JH, Sebola M *et al*. Microbicide trials for preventing HIV/AIDS in South Africa: phase II trial participants' experiences and psychological needs. *Sahara J*, 2004, **1**, 78–86.
19. Kass NE, Maman S, Atkinson J. Motivations, understanding, and voluntariness in international randomized trials. *IRB*, 2005, **27**, 1–8.
20. Kiawi E, McClellan-Lemal E, Mosoko J, Chillaq K, Raghunathan PL. "Research participants want to feel they are better off than they were before research was introduced to them": Engaging Cameroonian rural plantation populations in HIV research. *BMC Int Health Hum Rights*, 2012, **12**, 8.
21. Jewkes R, Sikweyiya Y, Nduna M, Shai NJ, Dunkle K. Motivations for, and perceptions and experiences of participating in, a cluster randomised controlled trial of a HIV-behavioural intervention in rural South Africa. *Cult Health Sex*, 2012, **14**, 1167–1182.
22. Burgess LJ, Sulzer NU, Hoosain F, Leverton N, Bliganut S, Emanuel S. Patients' motivations for participating in cardiovascular clinical trials: a local perspective. *Cardiovasc J Afr*, 2009, **20**, 220–223.
23. Mfutso-Bengo J, Ndebele P, Jumbo V *et al*. Why do individuals agree to enrol in clinical trials? A qualitative study of health research participation in Blantyre, Malawi. *Malawi Med J*, 2008, **20**, 37–41.
24. Mugusi F, Josiah R, Mushi A *et al*. Dropouts in a long-term follow-up study involving voluntary counseling and HIV testing: experience from a cohort of police officers in Dar es Salaam, Tanzania. *J Acquir Immune Defic Syndr*, 2002, **30**, 119–123.
25. Dhalia S, Poole G. Barriers of enrolment in HIV vaccine trials: a review of HIV vaccine preparedness studies. *Vaccine*, 2011, **29**, 5850–5859.
26. Olin J, Kokolamimi J, Lepira FB *et al*. Community preparedness for HIV vaccine trials in the Democratic Republic of Congo. *Cult Health Sex*, 2006, **8**, 529–544.
27. Essack Z, Koen J, Slack C, Lindegger G, Newman PA. Civil society perspectives on negative biomedical HIV prevention trial results and implications for future trials. *AIDS Care*, 2012, **24**, 1249–1254.
28. Henderson GE, Corneli AL, Mahoney DB, Nelson DK, Mwansambo C. Applying research ethics guidelines: the view from a sub-Saharan research ethics committee. *J Emp Res Hum Res Ethics*, 2007, **2**, 41–48.
29. Gitanjali B, Raveendran R, Pandian DG, Sujindra S. Recruitment of subjects for clinical trials after informed consent: Does gender and educational status make a difference? *J Postgrad Med*, 2003, **49**, 109–113.

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HIV and the adult at risk: a safeguarding issue

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Defining the 'adult at risk'

The Department of Health's 'No Secrets' document [1] defines the adult at risk as one who is aged 18 years or over who may be unable to take care of themselves or protect themselves from harm or exploitation. The term 'vulnerable adult' was once used; however, it was felt that 'vulnerable' may imply that some fault for the abuse lay with the abused adult [2]. An adult at risk may be elderly, have a long-term illness/condition, a mental health problem or a disability, may have difficulty in seeing or hearing, misuse substances and alcohol, or may be frail or ill (the list is not exhaustive). HIV is classified as a long-term condition and is therefore viewed as an area in which adults may be at risk. Throw into this mix stigma and discrimination, secrecy and embarrassment, drug, alcohol and mental health issues, social isolation, cognitive impairment and ageing and it is easy to see the 'vulnerabilities' with which some of our client group present. The broad definition of an 'adult at risk', referred to in the 1997 Consultation Paper 'Who decides?' issued by the Lord Chancellor's Department [3], describes a person: "who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care

of him or herself, or unable to protect him or herself against significant harm or exploitation". Caring for an adult at risk is complicated and can be made more so by issues around their capacity to make decisions. There is a wealth of documentation and policy to support those being abused, and covering other areas such as child protection, domestic violence, human trafficking, forced marriage, honour-based violence, abuse by children etc.

An adult at risk's vulnerability is determined by a range of interconnected factors, some of which are summarised in Table 1 [3].

Defining Abuse

Abuse can be described as a violation of an individual's human and civil rights by any other person or persons. Abuse may consist of a single act or repeated acts. It may be physical, verbal or psychological; it may be an act of neglect or an omission to act, or it may occur when an adult at risk is persuaded to enter into a financial or sexual transaction to which he or she has not consented, or cannot consent. Abuse can occur in any relationship and may result in significant harm to, or exploitation of, the person subjected to it. It can happen to anyone, anywhere. In the context of safeguarding, abuse is defined as the following:

Table 1: Factors determining vulnerability

Personal characteristics of the adult at risk that increase vulnerability may include:

- Not having mental capacity to make decisions about their own safety, including fluctuating mental capacity associated with mental illness
- Communication difficulties
- Physical dependency – being dependent on others for personal care and activities of daily life
- Low self-esteem
- Experience of abuse
- Childhood experience of abuse

Social/situational factors that increase the risk of abuse may include:

- Being cared for in a care setting, that is, more or less dependent on others
- Not getting the right amount or the right kind of care that they need
- Isolation or social exclusion
- Stigma and discrimination
- Lack of access to information and support
- Being the focus of anti-social behaviour

Personal characteristics of the adult at risk that decrease vulnerability may include:

- Having mental capacity to make decisions about their safety
- Good physical and mental health
- Having no communication difficulties or if so, having the right equipment/support
- No physical dependency or if needing help, able to self-direct care
- Positive former life experiences
- Self-confidence and high self-esteem

Social/situational factors that decrease the risk of abuse may include:

- Good family relationships
- Active social life and a circle of friends
- Able to participate in the wider community
- No stigma or discrimination
- Good knowledge and access to the range of community facilities
- Remaining independent and active
- Access to sources of relevant information

- (a) *Physical abuse* – including hitting, slapping, pushing, kicking, misuse of medication, restraint, or inappropriate sanctions
- (b) *Sexual abuse* – including rape and sexual assault or sexual acts to which the vulnerable adult has not consented, or could not consent, or was pressured into consenting
- (c) *Psychological abuse* – including emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from services or supportive networks
- (d) *Financial or material abuse* – including theft, fraud, exploitation, pressure in connection with wills, property or inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits
- (e) *Neglect and acts of omission* – including ignoring medical or physical care needs, failure to provide access to appropriate health, social care or educational services, the withholding of the necessities of life, such as medication, adequate nutrition and heating
- (f) *Discriminatory abuse* – including racist, sexist, abuse based on a person's disability, and other forms of harassment, slurs or similar treatment
- (g) *Institutional abuse* – mistreatment by poor or inadequate care practices where more than one adult is at risk

Safeguarding

Safeguarding is everybody's business. Each borough throughout the UK will have their own safeguarding policy and guidance [2], but all should follow national guidelines and any issues that relate directly to law. Staff training should be mandatory for anyone who works with adults at risk (paid and voluntary staff). Everyone working with patients has a duty of care to an adult at risk and should:

- Act to protect the adult at risk
- Deal with immediate needs and ensure the person is, as far as possible, central to the decision-making process
- Report any abuse to an appropriate person or service (e.g., the line manager)
- If a crime has or may have been committed, contact the police to discuss or report it
- Record the events

The Department of Health has developed principles that form the basis of responsibilities to safeguard adults at risk:

- Empowerment – involvement of the person at risk with proper consideration of mental capacity
- Partnership – working together with agencies
- Proportionality – with respect to assessed risk and harm

- Transparency – sharing information with consent and full participation in investigations

Table 2 summarises the seven key stages of the safeguarding process. The local safeguarding area manager (SAM) will lead and arrange meetings coordinating all the documentation and people involved.

Case study: David, an adult at risk?

David was 57 years old and had lived with HIV for the past 18 years. He had been in and out of hospital several times over the past few years with falls, neglect and chest infections. His engagement with HIV services had been poor (he last had bloods taken 18 months ago and he said he was 'crossing his fingers that his CD4 was still OK'). During his last admission the ward nurses noted some neglect and referred him to the HIV clinical nurse specialist (HIV CNS) for community management of his health and services. He had been on and off antiretroviral medication (ARVs) since his diagnosis (presently not taking anything as he 'ran out months ago'). He drank and smoked heavily.

On initial assessment he was unkempt (wearing the hospital gown he was discharged home in the week before); he was emaciated but said that he didn't eat much and was happy with his alcohol intake, feeling that this was not an issue as he only drank in the late afternoon/early evening. He admitted to drinking three bottles of wine and four cans of Guinness a day; however, he had been drinking when he was assessed at 10.30 am. His family were aware of his diagnosis, and very supportive, but lived far away; he spoke to his sister on the phone at least once a week. Despite feeling 'chesty' he felt that smoking helped him relax and didn't want to cut down: "It's my only pleasure." He was advised to continue taking Septrin, which he had been prescribed for some time. Although happy to have support he refused to talk about his HIV and had disengaged from his clinic. He explained that he felt embarrassed about his HIV status. He was aware that he should go back to his HIV clinic and restart medications and was planning to 'sort this out'. He lived alone with two cats which he loved and cared for well. His flat was dirty, nicotine stained and needed some repairs. He tended to live in the kitchen, at the back of the property, where he sat and smoked and watched TV most of the day. There was some food around but mainly takeaways, some stale bread and tinned food. He was generally very talkative about his life and the cats, and seemed to be happy with his life. The HIV CNS agreed to see him every two weeks and to try to re-engage him with the local HIV service. However, at the end of the assessment he mentioned that on the way home from hospital he was approached at a bus stop by a man he didn't know who then came back and moved in with him

Table 2: Seven key stages of the safeguarding process

Stage	Activity	Responsibility	Timescale
1: Raising an alert	Act to protect adult at risk Deal with immediate needs Report to line manager Consider reporting to the police, if a crime Record	Everyone with a duty of care	Immediately if emergency, or within same working day (this should be within four hours)
<i>Decision:</i>	Take any immediate management action to identify and address the risk Decide if a referral is needed If NHS, consider reporting as serious incident (SI)	Alerting manager Safeguarding adults lead Member of staff, if appropriate	Immediately or within 24 hours
2: Making a referral	Refer to safeguarding adults referral point Report to the police, if a crime If NHS, make a report under SI procedures Notify CQC if necessary Gather initial information Clarify facts	Adult at risk (carer, friend, relative) Manager Safeguarding adults lead Other professional Any staff in emergency	Immediately or within 24 hours
<i>Decision:</i>	Evaluate risk Decide if safeguarding adults procedures apply Agree interim protection plan (police investigation may have begun) Decide if a strategy meeting or discussion is necessary	SAM and relevant partner organisations	Within 24 hours of referral
3: Strategy discussion or meeting	Evaluate risk	SAM and relevant partner organisations Adult at risk as appropriate	The same day or within five working days from receipt of the safeguarding adults referral
<i>Decision:</i>	Decide if investigation necessary Agree investigation plan If not safeguarding adults agree appropriate action If not safeguarding adults close process at this point	SAM and relevant partner organisations Adult at risk as appropriate	
4: Investigation	Conduct investigation Re-evaluate risk Collate evidence and share with involved organisations Produce and distribute report	Coordinated by SAM with relevant partner organisations	Within 20 days from receipt of referral
5: Case conference and protection plan	Receive investigation evidence Evaluate risk Formulate protection plan Close safeguarding adults process Keep under review	Coordinated by SAM with relevant partner organisations Adult at risk / family / advocate	Within 20 working days from receipt of report (or as agreed at strategy discussion or meeting)
<i>Decision:</i>	Agree outcome Agree review		
6: Review of the protection plan	Review the protection plan Evaluate risk	Coordinated by SAM with relevant partner organisations Adult at risk / family / advocate	Within three months of case conference or as agreed at case conference
7: Closing the safeguarding adults process	Complete safeguarding adults process Sign off safeguarding adults process Review process continues Decide if a referral to a serious case review is required Dissemination of lessons learnt Process may also be closed pending outcome of prosecution	Signed off by SAM	On agreement with other organisations and adult at risk

for a few days, stealing his credit card and some valuables and cash. David refused to call the police; he felt embarrassed, saying it was 'his own fault for allowing him to stay'. However, the police had been alerted via David's GP (who lived next door) who raised a concern as David had been burgled recently and there had been a previous incident when someone he befriended had taken his bank and credit cards and taken money from his account. A safeguarding incident was raised by the GP and reported to the local team.

A meeting was called between the local safeguarding area manager (SAM), drug and alcohol agency psychologist and support worker (who had supported David for a number of years), the local police liaison officer, HIV specialist nurse, social services and David's GP. Communication and access to David had been difficult as he stated he had lost his phone (a cordless landline was somewhere in his flat and his mobile had been stolen). It was felt at this time that David was an adult at risk; he was, perhaps, too trusting of strangers and in need of company. He had suffered some financial abuse but refused to discuss whether there had been any psychological/physical abuse. It was felt that as he was discharged from hospital in hospital pyjamas, carrying an NHS property bag on public transport, this may have made him an obvious 'target', but it was felt that he had capacity to make the decision to allow the stranger to stay with him. He was more vulnerable later in the day when he had been drinking. The action plan at this meeting was to provide him with a new phone, offer some home support, such as a housing support worker, and try to re-engage him with the drug and alcohol support service. However, over the next few months David failed to answer the phone or the door; he could be seen in the kitchen but refused to open the door when called. The police visited on several occasions but again he failed to respond. All of which he denied when challenged, stating that his TV was loud and he didn't hear.

Two weeks later David was hospitalised after another fall (he had stumbled in the dark and blamed the cats but he managed to call the ambulance). This time he was assessed over a few days and recommenced on ARVs. A discharge-planning meeting was held and the community matron arranged for district nurses to supervise his ARVs on a daily basis. David agreed for a 'key safe' to be placed outside his flat to enable access for the nurses. The HIV CNS arranged a weekly visit to monitor his health, walk him into the HIV clinic for bloods and a check-up, and refill the dosette boxes. The housing support worker helped David with his bills and arranged for his door/windows to be repaired and other general maintenance of his flat such as a new washing machine and clearing the drains.

Over the next few months David responded well to the new care package. He managed to take his ARVs daily and his flat was cleaned and doors repaired. David's family came to see him and were shocked at his appearance and his property, stating that he was always immaculate and took pride in his environment. He continued to drink but stated that he had reduced his intake to two bottles of wine and two cans of Guinness. However, another safeguarding incident was raised by the community matron after David let two men into his flat whilst the district nurse was there. The district nurse believed they were friends and she did not challenge the visitors who David stated he knew from the pub. After a brief conversation David gave them his bank card and access code to get him some food and drink...they failed to return and over £1000 was taken from his account. A capacity assessment was requested, and this was undertaken by the SAM and community matron. David was found to have short-term memory loss, and confusion attributed to his alcohol use, but didn't lack capacity. Issues of mental capacity, and the ability to give informed consent, are central to decisions and actions in safeguarding adults. Interventions need to take into account the ability of adults to make informed choices about the way they want to live and the risks they want to take. This includes their ability:

- to understand the implications of their situation
- to take action themselves to prevent abuse
- to participate to the fullest extent possible in decision-making about interventions

The Mental Capacity Act 2005 [4] provides a framework to empower and protect people who may lack capacity to make decisions for themselves, and establishes a framework for making decisions that may be life-changing events or everyday matters on their behalf. All decisions taken in the safeguarding adults process must comply with the Act which states that 'a person lacks capacity in relation to a matter if at the time they are unable to make a decision for themselves in relation to the matter because of an impairment of, or disturbance in, the functioning of the mind or brain.' A person is not able to make a decision if they are unable to:

- understand the information relevant to the decision
- retain that information long enough for them to make the decision
- use or weigh that information as part of the process of making the decision
- communicate their decision (whether by talking, using sign language or by any other means)

Mental capacity is time and decision specific, meaning that a person may be able to make some decisions but not others at a particular time, making it very difficult to assess. A patient's ability to make

a decision may also fluctuate over time, and all of this adds to the complexities involved in deciding upon a person's capacity. In David's case his decision to allow a stranger to stay with him may have been sound and not questioned if the stranger had stayed and left without any problems, and likewise with the men who took his bank card to go shopping, if they had been friends and had returned. Where his capacity was in question was his inability to suspect ill will or bad intent in others, thus leading to the financial or psychological abuse he suffered. From a safeguarding point of view there was obvious financial abuse but perhaps some psychological abuse (fear for his own safety was discussed) and this could be linked to his general embarrassment about his HIV, although it could also be linked to his obvious frailty and general ill health. He was perhaps too trusting and also stated that he didn't want to upset the men who he felt would come back with his shopping. The police believed they knew who the men were and investigated the theft. David's carers were reminded not to let anyone in the property. David's mood was very low after the second theft and he fell into a depression, leading to more alcohol use. Unfortunately he was readmitted to hospital with breathing difficulties, and an MRI scan showed he had developed small cell carcinoma in both lungs, which had spread, and he was given a prognosis of less than six months. David seemed to take the news well and was very philosophical about the diagnosis and prognosis: "We all have to go sometime." After a period of symptom control in hospital, he was transferred to a nursing home under the care of the local Macmillan team and died peacefully in his sleep three months later.

Conclusion

Safeguarding is everybody's business, and the consequences of ignoring abuse or leaving it unchallenged could be detrimental to health, sometimes fatal. Vigilance, particularly when visiting someone at home, is important; however, in David's case issues only came to light when he felt comfortable to talk to someone about them. In many cases, embarrassment or a perceived lack of interest may mean that some feel unable to talk about what has happened or is happening to them. An awareness of the issues around safeguarding and a solid working knowledge of the policies and guidance that support it are vital.

References

1. Department of Health. *No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*, 2000. Available at: www.elderabuse.org.uk/Documents/Other Orgs/No Secrets.pdf (accessed July 2014).
2. Social Care Institute for Excellence with the Pan London Adult Safeguarding Editorial Board. *SCIE Report 39: Protecting adults at risk: London multi-agency policy and procedures to safeguard adults from abuse*, 2011. Available at: www.scie.org.uk/publications/reports/report39.asp (accessed July 2014).
3. Lord Chancellor's Department. *Who decides? Making decisions on behalf of mentally incapacitated adults*. Available at: <http://webarchive.nationalarchives.gov.uk/+http://www.dca.gov.uk/menincap/meninftr.htm> (out of date but cited for historical purposes).
4. HM Government. *Mental Capacity Act (2005)*. Available at: www.legislation.gov.uk/ukpga/2005/9/contents (accessed July 2014).

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Book review

Communication skills for nursing practice

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In the second edition of their book, McCabe & Timmins comprehensively outline essential communication skills for nursing practice. Whether you are a student nurse or an experienced practitioner this book provides the theory to support reflection upon practice by discussing approaches to effective communication. Communication in human existence is both voluntary and involuntary; even when we do not want to communicate with words we often do so with our actions or body language. It is vital that HIV care providers are aware of their communication skills to enhance patient experience and support ongoing engagement within services. This is particularly important when dealing with individuals with comorbidities as HIV moves into a chronic long-term health condition.

The book has 11 chapters, and is presented in three parts. The first part, which is divided into three chapters, provides an overview of communication theory, nursing theory and effective communication. A range of communication models are presented and critiqued to support identification of the multidimensional nature of communication specifically related to nursing practice. Although the terms 'patient focused' and 'patient centred' are used interchangeably throughout this section, the concept of individualised care has for some years been considered a key component in the delivery of high-quality nursing care. It is also considered that nurses will learn professional behaviours as they continue to gain experience of working within their specialism. Therefore, the value of reflection for experienced practitioners is not only in enhancing their nurse-patient relationship but also in setting an example of excellence in care to junior colleagues.

The second part is presented in five chapters centred on communication skills, barriers to effective communication, conflict, collaborative communication and communicating in different situations. Modes of communication are examined to outline the importance of self-awareness; this helps to gain a deeper understanding of subconscious communication and the potential impact this can have on the nurse-patient relationship. Approaches to overcome communication barriers are considered and allow for identification of personal factors and barriers the nurse or patient may present. Conflict does occur in

the workplace; this is not exclusive to the nurse-patient relationship as it can also arise amongst colleagues or services with which the nurse collaborates. Different types of responses to dealing with conflict are examined. Awareness of these is required for self-assessment and understanding of the fine line between assertiveness and aggression. Breaking bad news, grief and bereavement are often considered difficult situations by nurses, which require enhanced communication skills; this is often due to a lack of experience.

The final part is presented in three chapters. Personal and professional values, advocacy, ethics, accountability, and professionalism are explored to examine how these influence nursing practice. The value of self-awareness on the development of therapeutic relationships is explored to identify how essential this is to practice. It is suggested nurses may see themselves how they would like to be seen rather than how they really are. By gaining a greater depth of self-awareness the nurse is better placed to develop into the practitioner they want to be. This allows the nurse to make the transition from unconscious communication, by bringing their thoughts, feelings, actions, values, attitudes and beliefs into consciousness. The final chapter outlines the value of experiential learning in closing the gap between theory and practice. The use of a model of reflection in examining everyday occurrences is thought to be an influential and significant aspect of learning, although journals, diaries and clinical practice models are advocated also.

The book presents exercises and case studies within each chapter that afford the reader an opportunity to gain a better understanding of themselves and their interpretation of communication within nursing practice. This book is logically presented in distinct chapters that outline the essential communication skills required for quality nursing practice. Although it is focused on communication in nursing, all practitioners working within health and social care could apply the content to their field of practice. We would recommend this book for students studying health-related courses and other healthcare practitioners who wish to enhance their ability to develop positive therapeutic relations.

McCabe C, Timmins, F. *Communication Skills for Nursing Practice* (2nd Edition), 2013 is available from Palgrave MacMillan, priced £22.99. ISBN 978-0-230-36920-7

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