

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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Why are nurses afraid of research?

James Meek

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Welcome to the spring edition of *HIV Nursing* with the theme being Research and Advanced Practice. This is my first edition as guest editor and I have thoroughly enjoyed the process; I hope that you enjoy this edition.

When you mention the word 'research' to nurses, you either see a positive glow or a negative expression. The worry of: How can I undertake research and undertake my role? And what happens if it all goes wrong? These are common thoughts as we contemplate commencing a piece of research. We need to not be afraid of research and instead embrace it within our profession. Do not get me wrong – I am aware that as nurses we have advanced so far with research practice, and this edition shows examples of this hard work. However, we need to maintain this progress.

As nurses we all should be working within our professional code of conduct [1] which highlights the importance of delivering care based on the best available evidence or best practice. We all know we need to do it but how can we ensure we do if we are afraid of the 'R' word? Most of us at some point, probably via an academic course, will have undertaken a literature review. This is the backbone of research and the starting point for most of us. Once a literature review has been completed I would recommend submitting it to an academic journal for consideration for publication. However, sadly what normally happens is we file it away, never to be seen again. Let's no longer be scared of the word 'research' and instead encompass it within our daily lives. Use that literature review to instead provide you with the confidence to contact your employer's research team and find out the process for putting your thoughts into practice.

Jane Bruton starts us off with an interview with an Advanced Nurse Practitioner (ANP) working at Chelsea and Westminster NHS Foundation Trust. This interesting interview gives us a snapshot of the role, and highlights the challenges and rewards that they face. It also outlines the career pathway progression from Clinical Nurse Specialist to ANP.

Michelle Croston is currently an HIV Nurse Specialist and is studying for a professional doctorate at Manchester Metropolitan University. She gives *HIV Nursing* an account of interpretative phenomenological analysis, and how this is a suitable research methodology in nursing practice.

Emma Macfarlane provides us with a qualitative piece of research she undertook as part of her MSc in Advanced Nursing Practice. She examined nurses' attitudes to caring for people who are HIV positive in non-specialist settings. Semi-structured, in-depth interviews were undertaken with nine nurses and she presents the results from her research.

Helen Reynolds and colleagues offer an article about the autonomous role of the research nurse. They discuss the role as a valid career pathway with the position involving promotion of clinical trials, recruitment of participants, education alongside clinical care and support.

Juliet Bennett and colleagues provide *HIV Nursing* with an article identifying HIV as a long-term manageable condition with patients self-managing care; however, there is some evidence to suggest resistance to change as some patients still require regular specialist advice and support. The focus groups within this research all highlight stigma and the lack of sympathy compared to other long-term conditions.

Next we have two articles from around the world on HIV and research. Wesley Too provides us with an account from Uganda on experiences, reflections and discussion in joint interviewing. Secondly, Denise Cummins and colleagues in Australia provide us with an interesting article on minor neurocognitive disorder in HIV and its documentation.

Claire McCausland and I finally close this edition with a book review on Doing a literature review in nursing, health and social care [2]. This book is useful for those planning on undertaking a literature review, which is a fundamental starting point with any research study.

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Interviewing an advanced nurse practitioner

Jane Bruton

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In the uncertain world of the changing NHS and commissioning structures, nurses need to continue to look for opportunities to demonstrate our key role in delivering patient-centred care at advanced levels. In the following interview with Breda Patterson, Advanced Nurse Practitioner at Chelsea and Westminster NHS Foundation Trust, she outlines the challenges and rewards of her role and the importance of team working.

JB: How did you become an Advanced Nurse Practitioner?

BP: Well, my route was probably not the usual one into such a role! I was working as a senior staff nurse at the time and my role had already considerably expanded to doing stable patient clinics, which we set up in our clinic in 2005. I knew I wanted to continue to work clinically rather than pursue a management career but wasn't really sure how feasible this was in HIV. The HIV clinical nurse specialist role at this time involved management of a complex caseload of patients who were poorly adherent; however, most of the outpatient nursing team had undergone intensive adherence support training with the CNS. Therefore, these patients were increasingly being taken on by the clinic nurses and as such, the need for such a specialist role was waning. Agenda for Change was being implemented in the Trust at the time the CNS had left the post; therefore I was invited with the Clinical Nurse Lead for HIV to present our outline for a new role to the AfC panel and it was they who decided that the job description merited the title of Advanced Nurse Practitioner! It has probably been in the 7 years since then that I have fully gotten to grips with what the title and the role entail.

JB: So can you tell me what your role entails?

BP: As I said, the role has evolved hugely in the past 7 years. Initially I felt like a fraud as I was in the very privileged but terrifying position of moulding the job as I saw fit. I was working with the same team – both medical and nursing – that I had worked with for several years, yet most people did not fully understand what this new role and title involved. So there were loads of challenges in the early days, and still sometimes now! Trying to ensure that my colleagues had some understanding of what I was doing. I remember clearly some of my earliest clinics: I had 25-minute appointments, similar to specialist registrars, and I often fretted about doing everything that was required in a clinical consultation, but also doing the things that are traditionally considered nursing

tasks such as venepuncture, vaccination, sexual health screens. I did not feel it was fair to ask my nursing colleagues to do these things when I – a nurse also – should be doing it, even though it was impossible to squeeze all of this into a 25-minute appointment! I have long since realised my limitations and the fact that *I can't* do everything, and provided I am honest with my colleagues, I am able to provide a comprehensive service with the support of the whole team.

I currently manage a caseload of approximately 350–400 patients who I see routinely in clinic. This includes patients who have been recently diagnosed through to patients who are taking antiretroviral therapy, both stable and more clinically complicated patients. Psychosocial support remains a significant element of my role. I think this should be an inherent facet within HIV advanced nursing practice. My specialist area is HIV and aging, and I co-manage a dedicated clinic for the over 50s which incorporates specialist clinical management, psychosocial and neurocognitive evaluation and drugs reconciliation. Our patient cohort is aging so this service is becoming hugely over-subscribed and we are considering more innovative ways of managing the service.

JB: Can you describe a typical day?

BP: A typical day starts at 8am or before – thank God for Blackberrys! Replying to emails and checking phone messages. We have a pre-clinic meeting, at 8.30, which involves all members of the multi-professional team in clinic for that session meeting to discuss the patients coming in. This meeting means that all clinicians have gone through their clinic list in advance, checked results and looked up the patient's electronic notes. Even if I am seeing a patient who I have never seen before, I have a good knowledge of their history and don't have to ask them questions which they feel they have answered a hundred times before. This meeting also facilitates a much more collaborative approach to management of more complex patients as it can be agreed within this meeting who might be the most appropriate person to see that patient on the day.

My remit as an advanced practitioner includes assessing, investigating, diagnosing and treating patients, and obviously patients may present to a routine outpatient appointment feeling unwell. If I feel confident to manage this problem within my scope of practice, I have the support of my

consultant to do so. However, if I feel this is beyond my scope of practice, I feel confident discussing this with my medical colleagues and asking for their input. We start seeing patients at 9am and usually I finish my clinic at approximately 1pm. The next couple of hours are spent doing administrative follow-up from clinic, whether that is clinic letters or referrals. I also attend the HIV virtual clinic where patients who need to switch their antiretroviral therapy are discussed. This clinic provides excellent education and I pick up referrals of patients who may be struggling with their treatment and require extra support. My role also encompasses local and national teaching, audit and service development. As well as catching up with patient correspondence before the end of the day, I have joint responsibility with my nurse practitioner colleague to check all results of patients who attend for blood tests without making a follow-up appointment, and follow up these patients accordingly.

JB: What do you think are the key skills you need as an ANP?

BP: Unlike in the US where a Masters degree is an essential requirement for nurse practitioners and advanced nurse practitioners, this is not the case in the UK at the moment. However, having completed my post-graduate diploma and currently doing my MSc dissertation, I believe it adds an invaluable set of skills to further enhance the scope of the ANP role.

The modules I studied included advanced physical assessment, non-medical prescribing, organisational change, evidence-based decision-making and principles of research methodology. As well as the clinical skills I have developed, I have a greater appreciation of the wider NHS political landscape and the challenges we face with the future of healthcare and HIV services.

I feel I am a conduit between strategic policy developers in my service and shop floor practice. I think a willingness to be flexible and adaptable with how we provide our services is essential as an ANP as we are likely to be a pivotal part of future HIV service provision. I feel very privileged to have the ability to practice independently and autonomously but with the support of a dynamic and skilled nursing team, and a supportive and encouraging medical team. I read a document recently about advanced practice and it beautifully summarised my thoughts on the whole "maxi nurse/mini doctor" debate surrounding advanced practice, and it states that the care we deliver is not medical care or nursing care but patient care and it is about ensuring patients receive the appropriate care and treatment that they require.

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Reflecting on research methodology choice

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When I began, great emphasis was placed on the methodology that I was going to use in order to carry out my doctoral study, exploring how HIV nurses elicit patient concerns. I was encouraged to spend lots of time reading a variety of different research theories in order to use them to guide my work.

After a while I started to feel overwhelmed by the complex terminology and very tricky philosophy that underpinned certain approaches to research. I was encouraged to find a methodology that gave me 'an inner smile' – one that was similar to my beliefs as a person and a practitioner. I wondered for a long time what all this very clever advice meant, and after much thinking I arrived at the following conclusion.

Essentially, as HIV nurses we are often required to provide care in a way that facilitates a patient's ability to make sense of what is happening to them,

what HIV means to them individually and within the context of their social world, in order for them to adjust to their HIV diagnosis. Whilst making sense of the patient's experience, the nurse is also detached, involved in secondary 'sense-making' of the HIV diagnosis, and drawing on our own mental faculties in order to help patients make sense of their experience.

Therefore, I turned to the literature in order to look for a research methodology that would be suitable in exploring my research phenomena of interest.

What is interpretative phenomenological analysis (IPA)?

This approach was developed by Smith in 1996 as an approach to qualitative enquiry which originated in psychology, and has been adopted widely across a range of different applied psychologies such as health, counselling and

occupational health. Interpretative phenomenological analysis is an approach to qualitative experimental research that has gained momentum and popularity over the past 10–15 years. The approach has its roots in psychology and recognises the central role of the analyst in understanding the experiences of the participants.

IPA's philosophy has been informed and underpinned by three key areas, phenomenology, hermeneutics and idiography.

A central assumption of IPA is that people have relatively stable ways of perceiving their experiences, which are influenced by language, thoughts, feelings and physical experiences [1,2].

IPA is committed to how people make sense of their major life experiences. A key principle of IPA is that humans are sense-making creatures; therefore the accounts that participants provide will reflect their attempts to make sense of their experience [3].

IPA has theoretical generalisability rather than empirical generalisability by linking to the research. In other words IPA studies look at participants' experiences that emerge through the data and then consult the wider literature, so the evidence is firmly rooted within the participant's words.

Characteristics of an IPA study

Research question

The aim of the research question in IPA tends to focus upon the person's experience of a particular phenomenon in a particular context. Examples of IPA research questions: *How does being HIV impact on personal relationships?* [4] *How do gay men think about sex and sexuality?* [5]

The IPA researcher

The focal points of IPA researchers are the perceptions and views of the participants. IPA works well if the participant cares or has an interest in the topic under investigation. IPA researchers acknowledge that the experts within the experience are the participants.

Sample size

Within IPA the sample size is purposeful, homogenous with an average size of 6–15. The sample homogenous characteristics are defined by the topic of interest. Participants represent a perspective, not a population. Therefore the results of an IPA study would offer insight into the phenomena and never claim generalisability.

IPA focuses on idiography

The individual account of the experience acknowledges the importance of individual narratives against the rest of the sample. Therefore data is analysed on a case-by-case basis. With high-quality IPA studies it is possible to pick out the

individual stories from the collective voices of the participants.

Development of superordinate themes

IPA is characterised by the development of superordinate themes within the data analysis. Emergent themes are grouped together and categorised under an overarching theme. So there would be one theme that contains a set of sub-themes.

IPA provides a stance and process for qualitative data analysis. It offers an established, systematic and phenomenological focused approach to the interpretation of first person accounts, which is committed to situating personal meaning in context. As a novice researcher this stance and process appealed to me as it gave clear structure and a logical process to follow, whilst interpreting data that had been generated as a result of carrying out in-depth interviews.

IPA can be characterised by a common set of processes moving from a descriptive participant's account to a more interpretative account. IPA is commitment to understanding the participant's point of view with a psychological focus on personal 'meaning-making' in that particular context. This is then applied flexibly according to the analytic task.

IPA examines cognitions and emotions which are underlying in descriptions of subjective experiences. Analysis is an iterative process of fluid description and engagement with the transcripts; it involves flexible thinking, processes of reduction, creativity and innovation. IPA has been described as an interactive and inductive cycle, which acknowledges that the analytical processes described are largely unremarkable when compared with other qualitative data analysis methods. Therefore, it might be more appropriate to view IPA as a stance when interpreting data analysis rather than a distinctive method.

The aim of IPA is to explore in detail individual and personal and lived experiences and to examine how participants make sense of their personal and social worlds. The main currency for an IPA study is the meanings that particular experiences, events and states hold for participants. As a novice researcher this tradition was very appealing, as it did not feel too dissimilar to techniques that were already being used within clinical practice. IPA appeared accessible, flexible and applicable. This approach to qualitative research also appealed as it acknowledges the uniqueness of individual sense-making involved in processing experiences, which then enables people to make sense and add meaning to the experience from their own unique position and context of their personal/social worlds – emphasising that no two persons' recollections of the same event will in fact be the same, but may share similar meanings.

What does 'Double Hermeneutics' mean?

IPA also emphasises that research is a dynamic process highlighting that there is an active role for the researcher within the process. The researcher is making sense of the participant, who is making sense of X. In one sense the researcher is like the participants, drawing on mental faculties they share, but at the same time the researcher is different to the participants, always engaging in secondary sense-making of someone else's experiences [3]. It recognises that it is not actually possible, even if it might be desirable, to remove ourselves, our thoughts and our meaning systems, in order to find out how things 'really are' in a definitive manner, which other methodologies advocate. Double hermeneutics is the acknowledgement that the researcher is part of the research process.

The role of reflexivity

Reflexivity allows the researcher to acknowledge their role in the creation of the analytical accounts [6]. I began to understand the importance of reflexivity in relation to my own work and I began to wonder how this would translate to my written work. How would I capture this for the reader? I turned to the literature for guidance to see how other researchers had presented this aspect to the reader. What steps had they taken in order to demonstrate to the reader this reflexive process? I came across the following two studies that helped shape my understanding.

1. An Interpretative Phenomenological Analysis of Therapists working with Clients who have Fibromyalgia [7].

Rowarth's work clearly outlines her position statement as a therapist who is also living with fibromyalgia. There is a clear, reflexive section, which explores the author's position and how this would be used to add a deeper layer to the analysis section.

2. Evolutionary Theory of Mate Selection and Partners of Transpeople: A Qualitative Study using Interpretative Phenomenological Analysis [8].

Within Forde's work reflexivity issues are clearly explored as she places herself within the research and states her rationale: being a partner of a transperson is her motivation for undertaking this research. There is a jargon-free statement about her feelings and position within the participant's information sheet. Ethical issues are also clearly explored in relation to her research approach.

After reading these pieces of work I gave a sigh of relief. I could defend decision-making and produce a high-quality piece of work that would stand up within the academic and research community. This

new-found awareness would also help mute my quantitative research colleagues' cries of bias.

An overview of Idiography in IPA

Idiography refers to the commitment of a single case in its own right, which then moves to a process where the single case is compared against the rest of the participants' cases, in order to explore more general claims. Single case accounts can also be the entire focus of the IPA study [1,3].

IPA situates participants in their particular contexts, exploring their personal perspectives and starting with a detailed examination of each case before moving to general claims. The following two publications provide examples of idiography from within IPA studies:

- 'I was like a Wild Wild Person': Understanding Feelings of Anger using Interpretative Phenomenological Analysis [9].
- The Experience of living with Parkinson's Disease: An Interpretative Phenomenological Analysis Case Study [10].

Data analysis

IPA is not a prescriptive approach; rather it provides a set of flexible guidelines, which can be adopted by individual researchers to help with their research aims. As a novice researcher these steps were very appealing as I was able to follow them until I began to develop my own IPA way of thinking.

The process I used to analyse my interview data was adapted from Smith and Osborn 2003 [3]:

- Several close and detailed readings of the data to obtain holistic perspective so that future interpretations remained grounded in the participant's accounts.
- Initial themes were identified and organised into clusters and checked against the data.
- Themes were then refined, condensed and examined for connections between them. Superordinate themes were then identified.
- A narrative account of the interplay between the interpretative activity of the researcher and the participant's account of their experiences in their own words was produced.

In order to reach this point and understand the 'textbook, off-the-shelf' version of how to analyse data, I looked within published research studies for examples of this process.

Examples from within the literature included:

- Knight, Wykes and Haywood's 2003 study ['People don't Understand': An Investigation of Stigma in Schizophrenia using Interpretative Phenomenological Analysis (IPA)] [11] is a good example of analysis where the wider literature is used to back up verbatim quotes from participants.

- Howes, Benton and Edwards' 2005 study (Women's Experience of Brain Injury: An Interpretative Phenomenological Analysis) [12] aimed to investigate the perspectives of women with acquired traumatic brain injury. Six women were interviewed and from this the major theme that emerged was awareness of change, the emotional reaction, struggling to make sense, and finally, adaptation and acceptance. Each theme is clearly represented with verbatim abstracts, with most of the participants' interviews being able to contribute to support each theme. This helped to demonstrate the concept of superordinate themes.
- Cassar and Shinebourne's study (What does Spirituality Mean to You? An Interpretative Phenomenological Analysis of the Experience of Spirituality) [13] is also a good example of how data analysis is presented, showing clear decision-making when establishing superordinate themes. Smaller themes are also presented under larger themes.
- Hadfield, Brown, Pembroke and Haywood's study (Analysis of Accident and Emergency Doctors' Responses to treating People who Self-harm) [14] is a good example that is clearly written using staff as the participants; the interview schedule is shown to the reader, the data is very well presented and justified, and the major themes are broken down into superordinate themes. These themes are then discussed in relation to the wider literature and implications for practice are discussed.

After reading these studies and a few other high-quality studies the 'off-the-shelf textbook' began to make sense and I would highly recommend this as being a valuable way of understanding any research methodology.

Concluding thoughts

IPA is a relatively new approach to research and therefore is open to interpretation. This has been my interpretation of what IPA means to me and I have suggested some key elements that I feel constitute a high-quality IPA study. For practitioners interested in considering IPA as a research methodology, I would highly recommend reading Smith, Flowers and Larkin (2012) [1] and also high-quality IPA studies to establish whether my understanding of this approach meets with your own.

IPA can offer an adaptable and accessible approach to phenomenological research that adheres to guidelines regarding rigour and validity. It is an approach that emphasises the importance of individual accounts so has much in common with the nursing ethos to provide holistic patient care.

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'It's nothing special ... but we are more careful': A study of nurses' attitudes to caring for HIV patients in non-specialist settings

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Background

Human Immunodeficiency Virus (HIV) is now a chronic illness and HIV-positive patients can expect to have a near-normal life expectancy [1] with a greater risk of death from age-related rather than HIV-related illnesses [2]. This, coupled with a reduction in HIV-specialist inpatient units, means that HIV patients are increasingly likely to be cared for in general hospital settings, by non-HIV specialist nurses. However, HIV remains a stigmatised condition [3] and there is anecdotal and research evidence to suggest that HIV patients have poor experiences of healthcare, which may or may not be related to their HIV status.

The Nursing and Midwifery Council (NMC) *Code: Standards of conduct, performance and ethics for nurses and midwives* [4] states that nurses should treat people as individuals, respect their dignity and not discriminate against those in their care. Yet there is evidence to suggest that within the nurse-patient relationship, the care provided may be influenced by particular characteristics of the patient, or qualities of the nurse [5]. The notion of the 'unpopular patient' considers how factors such as social class, race and age may affect patients' popularity, but other factors including type of illness, as well as attributes traditionally associated with stigma such as homosexuality and drug use, may also result in a patient being considered unpopular [5,6]. In addition, factors such as lack of knowledge and fear of contagion have been identified as significant in influencing nurses' attitudes towards caring for HIV patients [7, 8].

For my Master's Degree in Advanced Nursing Practice I chose to conduct a small qualitative case study, to explore factors affecting nurses' attitudes to caring for HIV-positive patients in non-specialist settings. Semi-structured, in-depth interviews were conducted with nine nurses working in general medical settings in a large teaching hospital in London, where the local HIV prevalence is above the London average [9]. Ethical approval for the study was granted by my university research ethics committee; NHS ethics approval was not required as the study did not involve patients.

Study aims and design

The aim of the study was to answer the following questions:

- What are the attitudes of nurses working in non-HIV specialist hospital settings to caring for HIV-positive patients?
- What factors influence these attitudes?
- How are these attitudes expressed?

In order to be eligible for the study participants had to be Registered Nurses who had been involved in direct patient care in the previous 12 months. No experience of looking after HIV patients was required as this was potentially a variable in influencing attitudes [10,11]. Nurses were recruited during a 1-month period in 2012. The study was advertised via the hospital intranet and I also visited many of the wards in an attempt to recruit nurses. Interviews were conducted on the wards in a private area and were digitally recorded and transcribed *verbatim*. Thematic analysis was used to organise and analyse the data.

Five main themes were identified from the data relating to knowledge, fear, comfort zone, stigma and being more careful.

Knowledge ... it would be nice to have more

All the nurses in the study, with the exception of one, said that their knowledge of HIV was limited.

'I haven't got hardly any knowledge really. I've probably got as much knowledge as the general public ... all I really know is the basics ... you can catch it from blood, sex ... I don't really know much else about it.'

Nicola

However, despite admitting to limited knowledge, all of the nurses knew that prognosis and life expectancy for HIV patients has improved greatly in recent years, as well as having a good knowledge of how HIV is transmitted. Most of the nurses had not done any HIV-specific training and had acquired most of their HIV knowledge on the job, through their own reading, or the media, and several of the nurses stated they would like to have more knowledge, including that provided by their employer as part of regular updates.

Fear: Nobody wants to use this room

Fear of contagion is a theme discussed in the literature [8] and was raised by several nurses in this study. A nurse, who had worked in a blood-borne virus setting, described occasions where administrative staff had put on gloves to enter clinical rooms and retrieve notes. Only one nurse expressly stated she was afraid of catching HIV in the work place; all other respondents felt that universal precautions were sufficient to protect them from occupational exposure. However, it was suggested that patients revealing their HIV status to nurses was something that was appreciated, and that people's 'universal' precautions might change in light of such a revelation.

'They make it their place to make us aware, which is lovely.'

Karen

'Sometimes, which is not a very good practice [we] go to the patient's bedside without a sharps bin. With patients that are HIV positive ... we just have to carry one ... which really we should be doing.'

Angela

Out of my comfort zone

Nurses expressed the view that in general, due to a lack of knowledge, they did not feel able to support patients with HIV emotionally or in regard to giving information, particularly for newly diagnosed patients. An experienced haematology nurse specialist described her feelings when dealing with a newly diagnosed HIV patient:

'The patient was really, really bad, and it took an hour and a half to calm him down ... it was really, really tricky ... I felt well out of my comfort zone at that stage and I thought, I've counselled people for years and years ... and even then I felt, I don't know what to do here.'

Beth

'Probably some things will be really emotional and you find it very difficult to explain everything...I might not have the right words.'

Phyllis

However, nurses also acknowledged the importance of communication, regardless of knowledge.

'I haven't necessarily got the knowledge but I'm there to listen, and that helps.'

Jade

Nothing special ... but we are more careful

All of the nurses in the study expressed the view that they do not consider HIV being different to any other disease, or something which is out of the ordinary, and that they would not take extra precautions when caring for HIV patients. However, when presented with scenario questions nurses did mention taking precautions, which they may have not felt necessary to mention if they really did believe HIV to be 'nothing special'.

'Their care's exactly the same as everyone else ... apart from taking the precautions.'

Sheila

'There's no difference really apart from knowing that she's HIV and just take precautions, wearing gloves where you need to wear gloves...but nothing much really. No difference to any other patients...just to be careful and take precautions.'

Phyllis

'[There is] nothing special ... just be mindful ... be careful of everything ... you see? Other than that...we are more careful ... with the sharps and everything, more careful with the spills ... it's in our minds but it's not special, if you know what I mean?'

Angela

'If you're cannulating or if you're taking bloods...you're very conscious of those sorts of things...washing your hands and making sure you don't needlestick.'

Beth

Stigma: Not a leper ... not an outcast

HIV is well documented as a stigmatising disease [3] and ideas relating to HIV-associated stigma were presented by several of the respondents.

'I think with a lot of people there's an awful lot of taboo there about HIV ... if someone says "I've got cancer" you say "oh I'm really sorry" and people are very sympathetic. I think people with HIV, from how they portray it ... feel there's still this stigma with it.'

Beth

Some of the nurses talked about the importance of touch as a way of communicating to patients that they are not stigmatising them:

'The touching element ... I gave him a hug ... the younger nurses, they're so good but as soon as he may have HIV its eeeugggh and you're like ... no!'

Jade

'I'd probably give her a big hug and reassure her ... she isn't a leper, isn't an outcast.'

Linda

However, some respondents talked about prejudicial attitudes from colleagues and others:

'I've only had one nurse pass comment ... that nobody with HIV should be allowed to get pregnant'

Sheila

'My experience ... with two student nurses ... they asked me who I notified about patients' status...because they could infect people!'

Marion

'We've got a consultant who'd ring me up and say "put her in the side room."'

Sheila

Two of the participants expressed the notion that some people with HIV are not to blame for their infection, raising the question as to whether they feel that others are to blame for theirs:

'We've got the lady who got it accidentally through a blood transfusion or something like that.'

Karen

'There's very innocent ways ... of getting it through blood products and stuff like that...so nine times out of ten these people can be very innocent people.'

Sheila

Discussion

None of the nurses in the study expressed overtly negative attitudes towards caring for people with HIV. However, as the quotes presented here demonstrate, there may be more subtle ways that nurses differentiate the care they give to HIV patients, such as being 'more careful' when knowing someone is HIV positive or by making a

judgement about whether someone has contracted HIV 'innocently' or not. As all of the nurses had a good knowledge of how HIV is transmitted, the fact they talked about taking more care when dealing with body fluids from HIV-positive patients suggests they may have some fear of becoming infected, although only one nurse admitted to this directly. This could be linked to the idea that fear of contagion [8] is more related to the consequences of infection rather than the likelihood, and particularly the social consequences of HIV as a stigmatising disease [12]. Although on a conscious level the nurses themselves may not be aware of these subtleties, the patients they are caring for may be able to perceive some differences in the way their care is delivered, and this is an area that is definitely worthy of more exploration.

Nurses in this study all expressed a desire to gain more knowledge around HIV and to improve their skills in delivering information to HIV patients, including in their ability to discuss HIV testing and to deliver test results. How we can best deliver such education to both pre- and post-registration nurses is an important consideration both at local and national level, and will be increasingly relevant as testing in non-traditional settings becomes more commonplace.

Conclusion

Although this was a small-scale study and there were limitations, the study demonstrated that in order to ensure provision of equitable, high-quality care for HIV patients in general hospital settings, it is important to consider nurses' attitudes towards HIV and how these attitudes are expressed during patient care episodes. Further work is now needed to look at how we can ensure nurses have the knowledge and skills to deliver effective care to HIV patients, particularly around HIV testing and information giving.

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The autonomous role of the research nurse

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Introduction

The prominence of the clinical research nurse has increased over recent years with the formation of the National Institute for Health Research (NIHR) Comprehensive Clinical Research Network (CCRN) in 2007, following the Government's new health strategy (Best Research for Best Health [1]). The aim of the NIHR CCRN is to widen participation in research and ensure that patients and healthcare professionals from all parts of the country are able to participate in, and benefit from, clinical research in all areas of disease and healthcare. The CCRN provides a research infrastructure for the NHS through 25 Comprehensive Local Research Networks (CLRN) that offers practical support to clinical researchers. Following a review, the CLRN have been simplified to 15 networks effective from April 2014. Benefits that have arisen from the CLRN include research delivery support, local and national networking opportunities, and access to funded training [2]. The NIHR has also developed a clinical academic training pathway for research nurses. Research nurses play a pivotal role in enabling clinical research to be delivered. The research nurse acts as an educator, informer and advocate as well as a direct care giver [3]. This article aims to explore the role of the research nurse.

The research nurse is involved throughout a clinical trial at various stages that include trial co-ordination, recruitment and study-specific procedures. A research nurse may also be involved in protocol development, ethical and regulatory submissions, and data analysis. Data from research have informed HIV treatment guidelines. Current British HIV Association guidelines recommend the

use of triple therapy [4]. The development of effective HIV medication has impacted on mortality rates due to AIDS-related causes [5]. Clinical trials provide the evidence that medication is effective, efficacious and well tolerated [6].

Advanced practice

The role of 'nursing' has developed over the years and it is a practice almost unrecognisable from the form it was a hundred years ago [7]. The recent introduction of the advanced nurse practitioner (ANP) allows the registered nurse to work at a level well beyond initial registration [8]. The Department of Health's position statement on advanced level nursing [8] identified benchmarks that were contained in four themes (Panel 1). The National Leadership and Innovation Agency for Healthcare states that advanced practice should be viewed as a 'level of practice' rather than a specific role and is not exclusively characterised by the clinical domain, including roles such as: research, education, managerial and leadership [9]. ANPs use their existing knowledge and skills to inform and further develop their practice by managing their own workload, and therefore work across professional, organisational, agency and system boundaries. ANPs also network at various levels (local, regional, national). Competencies associated

Panel 1: Advanced level nursing – four themes

- Clinical/direct care practice
- Leadership and collaborative practice
- Improving quality and developing practice
- Developing self and others

Panel 2: Key messages of the Declaration of Helsinki

- Patients' interests and welfare is the ultimate goal
- Privacy is essential
- Written informed consent obtained for all participants
- Refusal does NOT impact patient–doctor relationship
- Participant should be reassured of best care/treatment
- Participant is free to withdraw at any time

Panel 3: Key messages of the Declaration of Helsinki

- Written research protocol used
- Risk should not exceed benefits
- Independent approval of study prior to initiation
- Research conducted by medical/scientific-qualified persons
- Ensure accuracy of data

with this role include: direct clinical practice; expert coaching and guidance; consultation; research; clinical and professional leadership; collaboration; and ethical decision making [10]. The research nurse combines all of these competencies, often working independently to fulfil the criteria of the research project.

Research guidance and regulation

Experimenting on humans for research is historical. Unethical experiments carried out by The Nazis led to the development of The Nuremberg Code (1974) which was the leading code for all subsequent codes made to protect human rights in research [11]. The World Medical Association (WMA) later developed the Declaration of Helsinki (Panels 2 and 3), which is a set of ethical principles to protect the rights of humans in research including research on identifiable human material and data [12]. All those working in research on humans are duty bound to adhere to government standards [13] and those outlined in the Good Clinical Practice (GCP) requirements. Compliance with GCP assures that the rights, safety and well-being of participants in clinical trials are protected [14]. Nurses in research are expected to be trained in, follow and adhere to these guidelines within their practice.

Clinical trials are important and testing treatment effectiveness prior to its use is essential. Although extremely rare, volunteers can experience serious side effects such as those reported at Northwick Park Hospital in March 2006 [15]. The Medicines and Healthcare Products Regulatory Agency (MHRA) protect public health by regulating a wide range of materials including: medical devices, medicines, blood and therapeutic services that are derived from tissue engineering [16]. The MHRA has the power to prosecute a manufacturer or distributor if a

law has been broken; they can also withdraw a product from the market and suspend production [17], and therefore all trials involving a medicinal product require MHRA approval. Before any trial can go ahead ethical approval needs to be independently reviewed and approved. Ethical reviews are designed to ensure that the benefits of research do not come at the expense of exploiting the vulnerability of participants [18,19]. Within the UK any research involving human participants must be reviewed by independent ethics committees, and once an application has been submitted an ethical opinion must be given within 60 days [20]. Panel 4 outlines the responses that may be received [21]. Any research that is to be carried out within the NHS must receive permission from the local research and development department.

Confidentiality

One aspect of the research nurse's role, and fundamental to research requirements, is preservation of participant confidentiality. Preserving the confidentiality and rights of those

Panel 4: Possible outcomes of ethical approval**Approval**

The study can go ahead with no further amendments.

Conditional Approval

The ethics committee provides a list of minor amendments to be implemented by the applicants before the study begins. However, the amendments do not have to be re-reviewed by the committee.

Provisional Approval

The decision letter will detail the changes that are needed before approval can be granted. The 60-day clock is suspended until the researcher responds to the points made by the committee. The study cannot start until the committee has approved the changes.

Researchers should respond by sending a letter that explains what action has been taken on each point. Copies of all modified documents with changes tracked and version numbers updated should also be sent.

When the response is received, a subcommittee will review the changes. Ongoing problems related to the modifications can be raised, but the committee cannot raise new concerns at this time.

Rejection

The committee thinks that the study, as it stands, is not ethically sound. A list of reasons will be given for this decision. On receiving a rejection, researchers may appeal to another research ethics committee, who will receive the original paperwork.

When reviewing such an application, committee members are not bound by the preceding opinion, and it is not uncommon for opinions to be reversed.

If a rejection is upheld, advice may be given about how the project could be redesigned.

participating in research is important to the research process. Maintaining confidentiality is also said to be important in terms of demonstrating trustworthiness and maintaining integrity in the researcher–participant relationship [22]. Within the UK the Data Protection Act (1998) defines the criteria for handling all identifiable information including the obtaining, holding, use or disclosure of such information. The Research Governance Framework sets out the responsibilities that must be accepted when conducting research that involves the use of patient-identifiable information [13]. Further guidance on confidentiality and the use of medical data in research has been issued by bodies such as the British Medical Association, the General Medical Council and the Medical Research Council [23].

Trial conduct

Trial co-ordination

Research nurses tend to have the role of study co-ordinator with the principal investigator having ultimate responsibility for trial conduct. The co-ordinator is responsible for overall day-to-day running of the trial and requires a good understanding of the methodological, ethical and practical issues and the research process itself. The study co-ordinator provides a single point of contact for the trial. Trial duties include screening participants for the trial, completing data forms, obtaining trial samples, processing samples in the laboratory for transport to central laboratories, organising trial visits, providing counselling and information to participants and monitoring participants' adherence to the trial protocol. In summary the research nurse acts as an educator, informer and advocate as well as being a direct care giver [3].

Recruitment

Recruitment begins with the dialogue which takes place between a research nurse and a potential participant prior to the initiation of the consent process [24]. Providing the participant with all information prior to consent is crucial so that the participant is equipped with the knowledge to make an informed decision to take part in the trial. Gaining informed consent is central to research involving humans and obtaining informed consent helps ensure that people are not deceived or coerced into research [25]. Informed consent is ongoing and participants can decline to take part at any stage of the research process. Research studies can often become disrupted due to problems with recruitment [26] and there is a need to explore why protocol-eligible participants refuse to participate in clinical trials [27]. Despite the general public expecting, even demanding, innovative preventative strategies involving cutting-edge treatments, most individuals do not participate in research studies [27]. A previous analysis of more than 100 trials showed that less than

one-third of trials achieved their original recruitment target and half were awarded an extension [28]. It has been suggested that some demographic characteristics of participants, such as age, gender, income and education, are better predictors of enrolment and attrition [24,29,30]. Other factors identified as problems to recruitment and retention include contextual and environmental factors along with the design of the research trial [31]. Within our research team, barriers commonly experienced include: taking extra medication, timing of visits and taking time out of work to attend trial appointments.

Communication

Nurses working at an advanced level use complex reasoning, critical thinking, reflection and analysis to inform their assessments, clinical judgements and decisions and therefore require high-level communication skills [8]. Communication is an essential skill for a research nurse. Collaboration and communication between study participants, the principal investigator, MHRA, ethics committees, study sponsors, research team and the team providing the participant's routine health care is vital for the success of any clinical trial [32]. Patient safety and the provision of excellent care are important factors of contemporary healthcare delivery, and effective communication is a crucial element of these [33]. Patients and their relatives regard effective communication with health professionals as a vital component of their care [34].

One of the major causes for complaints is poor communication with the patient in person; they can be left feeling uninformed, uncertain, frustrated, unsatisfied and anxious [35]. To gain valid informed consent potential participants require a good understanding of the risks and benefits involved in trial participation. It is therefore essential that a research nurse is able to communicate effectively with the participant. This continues throughout the trial as a participant undergoes trial-specific procedures that are often additional to clinical care. In fact, it has been reported that retention of participants often depends on effective and ongoing communication [32].

Study-specific procedures

Every clinical trial has a protocol that requires adherence. The protocol sets out the number of trial visits and the requirements for each visit. Comprehensive management skills are required to ensure trial visits and procedures occur at the right time. It is also essential that study documentation is an accurate record of a participant's study visit. Attention to detail plays a major role in documentation and subsequent transfer of data to electronic study-specific databases. Quality assurance of trial data is normally provided by the trial sponsor in the form of monitoring. Queries will then be raised which require a response within a specific time frame. Clinical skills such as

phlebotomy, observations, clinical examination and reviewing participants for adverse events are used on a regular basis. Research nurses may also have responsibility for processing laboratory samples prior to shipping to external laboratories.

Clinical trials

Potential participants need to consider both the potential risks and benefits from participating in clinical trials. Potential benefits include accessing new treatment, regular and in-depth clinic appointments, new treatment may be more effective than the standard of care and the overall research may benefit others. Possible risks involved with clinical trials are that the new treatment may have unexpected or worse adverse events than compared to standard treatment, the new treatment may not always be more effective than current licenced treatment, more frequent and longer appointments, for randomised trials there is no treatment choice and if the trial is blinded, participants are unaware of what active treatment they are receiving. Recently HIV-positive patients have had access to the new integrase inhibitors, elvitegravir and dolutegravir. The Phase III data for both drugs showed non-inferiority to raltegravir [36,37].

Our unit over the past 6 years has developed a research nursing team to conduct commercial and academic trials in patients and healthy volunteers. The team have recently completed a multicentre clinical trial that aimed to investigate the feasibility and safety of treating HIV-positive patients with boosted protease inhibitor (PI) monotherapy. Participants were also invited to participate in two sub-studies. Of the 20 patients (7 female) recruited, 11 were randomised to receive PI monotherapy. Other trials have involved (HIV-negative) healthy volunteers and HIV-positive patients investigating the pharmacokinetics of HIV medications when co-administered with other medication to elucidate drug-drug interactions. Trials currently running for HIV-positive patients include interventional and observational multi-centre trials.

Conclusion

The research nurse role is an advanced practice role that is now recognised as a valid career pathway. Although the role can be very challenging at times, it provides an arena to develop clinical skills alongside research, laboratory and critical reasoning skills. The research nurse plays a pivotal role in the promotion of clinical trials, the recruitment of participants for clinical trial participation, education of participants and the clinical care and support of participants throughout their participation in clinical trials.

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As HIV moves towards a chronic disease, how involved are patients in their own care?

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Sussex and Surrey HIV Nurses' Network (SSHIVNN)

Introduction and background

This study explored the lived experience of people with HIV in relation to how study participants have adapted to changes in health-related service provision; their views on how they perceive services and how they would like to see such services provided in the future. The study was undertaken by members of the Sussex and Surrey HIV Nurses' Network (SSHIVNN).

In the UK, 60% of the total adult population report having at least one chronic health problem, and up to 45% of people have more than one chronic condition [1]. These numbers are expected to increase as people are living longer and this presents the NHS with a significant challenge. The 'biomedical model' [2] where health care professionals diagnose, prescribe and monitor patient's compliance, appeared to work well for acute conditions, but in recent decades has been seen to be less effective for chronic conditions. With increasingly stretched resources and a governmental drive to encourage people to take responsibility for their health, service provision within the NHS has changed.

Self-management has come to play an important additional role in the management of certain long-term conditions such as asthma, heart disease, HIV and diabetes. There is increasing acknowledgement amongst health care professionals (HCPs) that people with a chronic condition may have the most comprehensive expertise in dealing with that condition, and many now view self-management as an important component of holistic care.

The BHIVA Standards of Care for People Living with HIV state that individuals should be enabled to maximise self-management and should have opportunities to be actively involved in decisions about their health care [3]. The document emphasises that living a good quality of life with HIV calls for strong self-management skills, education and engagement with peer support (Standard 9); together with joint decision-making with HCPs (Standard 10). In the MEDFASH Recommended Standards for NHS HIV Services (2003) [4], Standard 3 is to facilitate the empowerment of people with HIV to have personal control and choice over the management of their HIV. Joint decision-making and recognising the

stigma and social exclusion unique to HIV disease are given priority.

A comprehensive literature review was undertaken prior to this study. This revealed a lack of evidence regarding how HCPs can best support the self-management efforts of those with chronic disease. Furthermore, the papers that were identified were derived mainly from theoretical and empirical work in the areas of prevention, addiction, and adherence to medical regimens for single diseases. There appeared to be a lack of research in the field of HIV, especially around patients' perceptions, perceived benefits and disadvantages of an empowerment model.

Aims of the study

The research aimed to explore the following issues, as described by patients and healthcare professionals.

- The experience of stigma and isolation in those affected by HIV
- The impact of antiretroviral therapy on life expectancy, quality of life and attitudes to living with HIV
- The move toward primary care and the use of GPs for all non-HIV-related conditions
- Patient variability – in skills, willingness, ability etc. to take on a self-management role

Methodology

A qualitative study was undertaken using focus groups to explore people's lived experiences. Ethical approval was obtained.

Inclusion criteria

People living with HIV, and aged 18 years or over, who were accessing services within the Sussex and Surrey area.

Participants diagnosed with HIV for more than one year were eligible in order to allow those taking part to have had time to come to terms with their diagnosis, and to ensure they had some experience of using HIV-related health services.

Recruitment



Posters and leaflets were displayed in community settings and at Royal Sussex County Hospital. Nurses from across the network could refer interested participants to the project manager to obtain further information about the study. Those who agreed to participate attended a focus group where informed consent was received.

Demographics

Six focus groups were conducted with a total of 25 participants, 7 female and 18 male.

Time since diagnosis varied from 1 year to in excess of 25 years and the age range varied from 27 to 75 years of age.

25 to 35 years	6 participants
36 to 45 years	8 participants
46 to 55 years	9 participants
55 and over	2 participants

Method of analysis

The focus group discussions were recorded and transcribed verbatim and analysed with key extracts coded using qualitative thematic analysis. Thematic analysis focuses on the human experience subjectively, emphasising the participants' perceptions, feelings and experiences.

Results

- Five main themes emerged:
1. Living with HIV and coping with daily life
 2. Empowerment and self-management
 3. Accessing support and information
 4. Stigma and isolation
 5. Experience of using services and changing/future service provision

Living with HIV and coping with daily life

The notion of HIV as a manageable disease was debated by many participants. Many expressed difficulties living on a day-to-day basis with HIV. Participants listed problems such as chronic fatigue, managing long-term adherence to medication, the need to attend multiple medical appointments, depression and low mood.

I'm just wiped out for the entire day so it's sort of, your whole life involves taking tablets.
Female, aged 55, diagnosed 5 years

Many participants had also experienced a lack of understanding and tolerance from others such as employers and had intermittent feelings of being unable to cope, physically and/or mentally. The period following new diagnosis was particularly highlighted as a time when intensive support is required. However, the majority appeared to have adjusted since diagnosis as these excerpts show.

Life goes on ... at first you're going to die and the pain you're going to go through, well you actually pass through that point and start thinking, actually I'm waking up every day and I'm still alive and then you get to this moment where you kind of think life's for living.
Female, aged 27, diagnosed 3 years

The uncertainty around disease progression impacted on day-to-day life. In addition, restrictions on lifestyle due to the number of medical appointments and medications arose as an issue for several participants. This was described as an 'ongoing struggle' on several occasions, especially when also trying to work.

I've lived the last 19 years, I've not seen it (CD4 cell count) go up. I've seen it as a threat to me getting a full time work that might have like quite a bit of stress involved in a full time job so you don't take all those kind of opportunities ... but you can't stand the fact that you're on benefits for so long.
Female, aged 48, diagnosed 20 years

Getting older with HIV was also a recurring theme, a challenge, often not of huge concern but certainly a complicating factor, often involving visits to several different outpatient departments for concurrent medical problems.

“ ... lots of appointments what with the arthritis, which is now becoming limiting, ... I have to take steroids and because I'm now diabetic too so I have to take insulin for that and it's all sort of the complex thing and it's also trying to work out how many of things would I have got with age had I not been HIV positive? ”

Female, aged 66, diagnosed 15 years

For some people mental health problems preceded diagnosis but had been exacerbated by it; for others mental health issues were part and parcel of an HIV diagnosis. Mental health issues had just as significant an impact on the lived experience of those with HIV as physical health issues and concerns.

Empowerment and self-management

The concepts and perceptions of self-management and empowerment were explored. Many found it difficult to articulate what they felt these terms to mean but a few were able to verbalise their understanding:

“ Self-management to me is something that's appealing. I mean I certainly want to access an HIV consultant if I felt the need to but you know ... obviously the day will come when I will be on treatment ... and the transition to treatment, I would think I'd need care there, but I think once I'm on the treatment regimen I think I'd be quite happy to self-manage my own. ”

Male, aged 44, diagnosed 3 years

A theme running throughout was that living and surviving longer with HIV was seen to impact on attitudes towards life. There was a sense that knowledge about HIV improved over time, and that this acquired knowledge better equipped individuals for dealing with new symptoms and managing their disease. However, approximately one-third of participants expressed views that suggested they felt decidedly disempowered.

“ We're not the medical people are we, we're just the people that take the pills, so it's like we have to put our trust in them (the health care professionals), that's all we can do ... ”

Male, aged 38, diagnosed 8 years

In every focus group, concerns were expressed about the vulnerability of some people living with HIV, as this quotation illustrates:

“ You're kind of being expected to manage yourself and I think there's a gap there that's not being met really. I think there's probably a lot of people that are positive that actually could really do with some help, and it might be just on the mental and psychological level ... just helping them find direction to move forward perhaps? ”

Female, aged 42, diagnosed 4 years

Accessing support and information

Experience of accessing services over time appeared to facilitate more effective use of, or access to, health care services. In addition, the majority of participants were keen to share their acquired knowledge with others living with HIV. Peer support was almost unanimously acknowledged as valuable. The value of receiving support from somebody who has lived with HIV was felt to be beneficial, along with a sense of belonging to a group.

“ Sometimes someone who's living, is living with the condition for a long time, is the best person to tell someone ... it's no use someone who is living a normal life in coming and telling me I'm going to be alright. Maybe after sometimes we'll come to accept it but it's really just someone doing their job. ”

Female, aged 27, diagnosed 3 years

There was considerable diversity in support structures, some having close-knit support networks of relations and friends whilst others felt isolated and estranged from relationships which predated their diagnosis; this sense of isolation appeared to arise in partnership with the experience of stigma.

With regard to accessing information about HIV disease: some was gleaned through peer networks, but this was not necessarily seen as a reliable source. Some participants were happy to read up on HIV disease, treatments and symptoms, but many expressed uncertainty about looking for sources of information themselves, especially in relation to use of the internet. The majority felt that it was still their clinic and health care professionals' role to pass on relevant evidence-based information.

The experience of stigma and isolation

Every focus group identified stigma as a common experience in society, the workplace and in health care settings. About half the participants had encountered a lack of knowledge from others about transmission risk. Social isolation, sometimes self-induced, was commonly identified too, as this quotation illustrates:

“ Since I’ve been diagnosed I’ve cut myself off from a lot of people. I’ve got five grandchildren ... one of my daughters worries that I pass it on to them, even though she understands it couldn’t ... and I get worried about if news ever got out and if my grandkids ... get picked on. ”

Female, aged 66, diagnosed 15 years

Overwhelmingly, HIV is still seen, by those taking part in these groups, as ‘different’ from other chronic long-term health conditions. A view that it “isn’t like any other disease” came across strongly. There was also the perception that the general public are not as sympathetic as they might be for a cancer diagnosis and people still feel a need for secrecy around their HIV diagnosis.

Experience of using services and changing/future service provision

Problems accessing and using primary care services were voiced repeatedly. Few reported positive experiences of using their GP Practice since their HIV diagnosis. Concerns included those about confidentiality, difficulties getting urgent appointments without divulging their status to reception staff, perceived lack of HIV knowledge on the part of the GP, lack of empathy on the part of staff, insufficient consultation time and poor channels of communication between their treatment centre and GP.

“ You go to the reception, and you get asked questions like, why do you want an emergency appointment? And I’m thinking, if I’ve said an emergency, I need to see the doctor, what do you want me to say, that I’ve got a sore bum, or what? ”

Male, aged 55, diagnosed 10 years

Some also felt that if they went directly to their treatment centre new problems were investigated more quickly than when they went to their GP. The general consensus of opinion was that while in theory it was probably more appropriate to use GPs for non-HIV-specific related concerns, in reality most people still rely on their clinic as the first ‘port of call’.

The importance of continuity of care was expressed as essential. Many participants gave examples of times when they benefitted from being seen by somebody who knew their history well, as opposed to several negative experiences where this wasn’t the case. People found it very frustrating to have to repeat their story to new HCPs at each clinic visit.

“ I’ve been quite lucky in that I’ve kept my same HIV doctor and liaises quite closely with all my other consultants which makes life an awful lot easier, I think if I personally was to be moved onto seeing different doctors each time certainly the level of care that I would get would definitely go downhill. ”

Male, aged 55

Accessibility, whether in or outside of standard clinic hours, is also important; and participants were appreciative of rapid access to medical advice when they needed it. A further difficulty, described by one of the participants as the ‘yo-yo effect’, is the going back and forth between different medical teams for different health complaints. Also arising consistently, were concerns about lack of access to mental health support and counselling, either through local lack of availability or not knowing how to access these services:

“ I want to go somewhere where I know I’m treated as a whole person, because what’s going on with you, it’s both physical and mental and even how you adhere to your medication, you’ll go through that kind of roller coaster thing and mental support is just as important. ”

Female, aged 27, diagnosed 3 years

There was considerable debate about how future services might look and the possible impact of any changes. What seems to be important is the sense that people want to be treated as individuals; with the complexities that an HIV diagnosis brings, not just in terms of physical problems but also social and mental health needs. Notions of centralising clinical services, reducing the overall number of clinics, as well as proposals for an increased role for primary and community care, were raised for discussion. Many thought that change needed to be managed carefully and the impact of any change on the patient’s experience of and access to care, particularly for the very vulnerable, should be minimised. An overwhelming assumption in every group was that changes were driven by an attempt to ‘normalise’ HIV care, which was felt to be unrealistic.

The majority of participants were suspicious that proposals for change were also driven by cost concerns rather than questions of quality or equity. Many felt they were currently in receipt of care of a very high standard and so suspect that this standard will be compromised in the name of efficiency or cost-saving in the current economic climate.

There was considerable anxiety in relation to losing, or the dilution of, existing services which are felt, on the whole, to be supportive and effective.

For people to actually say they're taking people on from that specialist care and handing them to people who are not specialists feels like a big danger. The reason that we adhere so well to our medication is because of the specialist support we have been given. For me to feel safe and disclose that I am HIV positive ... to have somewhere to turn to if I have a problem, I call my specialist nurse and she knows all about it.

Male, aged 55, diagnosed 10 years

Conclusions

These elements of care, highlighted as important by participants, appear to build confidence in service users and it could be argued, facilitate empowerment and subsequently self-management. However, it could also be argued that there is a resistance to change, particularly amongst patients who have accessed services for a long period of time. Despite HIV now being viewed as a manageable disease, many people feel strongly that they continue to need regular specialist support and advice on a readily accessible and flexible basis.

People with HIV want to see more done to tackle pervasive stigma within health care settings and more informed HCPs, especially in primary care. This study is useful to those responsible for commissioning and designing services, as well as for nurses in understanding their patients' anxieties and needs, providing an important opportunity to advance the debate about the role of primary care in supporting the health of people with HIV to better facilitate self-management.

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A practical guide to joint and individual interviewing of people living with HIV in Uganda: reflections from practice

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Background

Recent research carried out in Uganda on experiences of patients living with advanced AIDS (PLWA), and their caregivers' accounts, suggests that disclosure among PLWA is a sensitive issue [1]. Sensitivity around disclosure among PLWA has been linked to stress and apprehension in day-to-day living: with whom you associate, the extent of interactions and network of friends. The following picture shows the location where the research was carried out: Hospice Africa Uganda. The study was conducted between January and June 2009.

My experience of visiting patients who had not fully disclosed their HIV status to family members or friends was ambivalent: a visitor (researcher) would be free to converse in most areas without hesitation but attract a mixed reaction when the topic switched to experiences of living with HIV/AIDS. These emerging scenarios attracted my attention. The following photos show the two home visits which were made. In photo A, the patient preferred to be interviewed individually whilst in the second photo B, the patient preferred to be interviewed with her caregivers because the patient had disclosed and was getting support from family members as seen in the photo.

With the sensitivity around HIV disclosure among people living with HIV, it became apparent to me that I needed to be careful handling the interview process. The dynamic of communications in the context of patients living with HIV/AIDS needs to be explored further to establish support needs for disclosure. Every participant was unique and so I was cautious and aimed at handling the interview process in an ethically acceptable manner. For



Figure 1: Wesley Too stands outside Hospice Africa Uganda premises, which provides both care and training facilities.

instance, I always sought consent on 'what, whom to be with or not to be with, and where' to establish the most suitable situation for the participant(s). It is widely documented that HIV/AIDS has attracted a profound stigma that has equally influenced the level of disclosure to family members and friends. This perspective is shared among certain groups of infected and affected people in the society in general, who live with uncertainty about how other people may react to disclosure as well as disclosure's role in coping with HIV/AIDS. Presented with such dilemmas, some patients faced challenges on how to handle interviews in their homes, especially where family members did not know the diagnosis of the patient being interviewed. Thus, there were conscious acts of balancing secrecy in talks/interviews and the choice of approach to interviewing. I seek to explore my experience of joint and individual



Figure 2a,b: Two examples of home visits in Uganda from a Hospice Africa Uganda palliative care worker.

interviewing in the context of patients living with HIV/AIDS and their nominated family members, and in this reflection I try to capture the overall picture.

Interviews were conducted at home. On arrival I would explain the research study and answer any query the patient and family had, and thereafter informed consent was sought. The patient was requested to nominate a carer of his/her own choice. It is during this time that the patient's preference for joint interviews/single interviews was established. In the dyad, which is the patient and carer pair, the patient granted consent and 16 preferred joint interviews with their carers, four preferred to be interviewed alone, whilst a further two did not have a carer.

Interviews began with the opening questions which sought to encourage participants to narrate their account of living with HIV/AIDS whilst reflecting on coping strategies. The patient could be requested to tell a story from the time of when they acquired the disease to date. Follow-up questions were posed to enable patients to reflect on what was helpful or not in their experience of living with HIV/AIDS, as well as exploration of the support network established since contracting HIV/AIDS. Further questions in the interview established the experiences after palliative care interventions were started and what the patients would like to tell other patients in a similar situation.

Interviewing process: experiences, reflections and discussions

Joint interviewing has been rarely explored as a qualitative method; instead individual interviews have become the norm [2]. There is little documentation regarding interviewing two individuals concurrently [3]. It is proposed that in day-to-day living, realistic and socially salient features of some interviews often mean that there is a second individual contributing even if the interviewer planned to have individual interviews. This is true especially in interviewing patients with HIV/AIDS and their caregivers in the African context where it is difficult to exclude an individual in his or her own home. Most African communities view a patient's needs/experiences as communal, requiring the presence of another individual to signpost the relationship and responsibility of caring. With the advent of joint interviews in my study, methodological and ethical issues arose, and I had to navigate and accommodate special cases with flexibility in adopting joint interviews. Whilst I had earlier planned to have individual interviews, asking patients with advanced AIDS to recount their experiences of living with HIV/AIDS and getting care necessitated the presence of other individuals who in most cases happened to be the main caregiver and who were supporting the patient [4].

Some patients felt that there was no secrecy to necessitate individual interviews. This was particularly common with couple interviews – when one partner was suffering from HIV/AIDS and the other was the main caregiver. In the cultural context, separating an individual for an interview often could be perceived as increasing the patient's burden [5] and therefore many caregivers/family members would in most cases be present to help their patient complete the interviews and support them in giving an account of their experiences, especially if their patient was bedridden and unwell.

Whilst many caregivers or family members felt that they were giving a correct account of their patient during joint interviews, it was not true in all cases; a patient's experience could have been misrepresented by caregivers [6]. There have been documented experiences where the main carer's own needs are similar to or different from those of the patient [5]. This could raise an ethical dilemma on issues relating to intrusion, inclusion and confidentiality which was problematic to handle. It has been suggested that carrying out joint interviews can lead to antagonism, especially when it comes to level of disclosure which was a common phenomenon with some patients living with HIV/AIDS.

In cases where the caregiver has not been disclosed to, the patient was uncomfortable and it caused distress to share his/her living experiences in the presence of another individual. In such common cases during my study, the patient's choice was respected and he/she was encouraged to give the account of his/her experience in a suitable and private convenient location. Whilst giving the opportunity for patients to decide on joint/separate interviews as an approach of showing respect, and offering a degree of empowerment, unfortunately, with patients who opted to have separate interview, themes of exclusion and not feeling part of the society were echoed. Joint interviews may present the challenge of having one person dominating the discussion [3]. In my study, specific requests were made to allow an individual to expand on a particular situation or comment, a step that moderately controlled the effect of domineering.

The experience of collecting data in joint interviews has also presented to me an opportunity to realise how imperative this approach is, not only in providing rich data, but also in creating a platform to discover different areas to be explored/studied. Among the opportunities that joint interviews presented to me was the chance to observe the interaction of caregivers and patients (in their joint construct/validation process) as well as their experience of confronting the reality of living with HIV/AIDS, and how each of the dyad shared or differed in understanding and perceptions about lived experiences. One study supports the

encouragement of such approaches that spawn rich data and also adequately address objectives of the study [4] and to me, joint interviews were more acceptable in African culture and produced a lot of data for this study. I found joint interviews particularly informative in the sense that the majority of patients living with advanced AIDS were bedridden at home and in their villages, living in small or limited space, and in most cases sharing the same room with the carer, which limited living conditions and could make it difficult to ask someone to leave his/her own house (see photo B).

Whilst joint interview presented an ethical dilemma to me in the sense that the dyad could be observed echoing each other's words in areas that seemed important to them, sensitive issues raised during the research might not have been adequately addressed, as questions surrounding full disclosure and shared information still exist among patients living with HIV/AIDS. It is suggested that shared words can be taken to demonstrate public rehearsed accounts with the implication that their contribution is somehow less true than private accounts [2]. This is because a dyad's joint interview is characterised by a pre-existing relationship which makes it more likely to have some common shared understanding of events/experiences unlike focus group discussions.

It was generally observed in the study that during the process of conducting joint interviews, participants would be heard agreeing on certain explanations and therefore participate in the joint validation course through influencing or reinforcing what the other can recall. This observation, however, would also present the challenge of control (who is influencing who); of when someone should speak for someone else; or of influencing each other in validation [5].

Conclusion

In conclusion, joint interview approaches are still an unexplored field in health research, worthy of some attention. This is reflected in the difficulty searching for literature supporting the utilisation of this approach, yet it is commonly used whilst collecting data through interviews. Joint interviews present an opportunity for dyads to express joint construction of an experience and help in understanding the relationship between patient and caregiver.

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It's not in the notes!

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Abstract

Background

Minor neurocognitive disorder (MND) may be difficult to identify, as key symptoms can be due to other clinical conditions, such as depression. Using a client self assessment booklet, *HIV associated MND (mild neurocognitive disorder). How to recognise the signs and symptoms*, we recruited 123 participants from three clinical sites: an inner metropolitan hospital-based HIV clinic, an inner metropolitan sexual health clinic, and a suburban hospital-based HIV clinic in Sydney, Australia. A medical record audit was conducted to ascertain whether signs and symptoms (S&S) of MND, identified by the patient and/or their nominated caregiver, were discussed at their following medical consultation. Although the medical record may not reflect the medical consultation, a lack of documentation may indicate of the lack of importance the doctor may have placed on the issue at the time. We assumed, in the absence of documentation, that there had been no discussion of the issue with the patient regarding the symptoms reported, and that no follow-up would occur.

Methods

Using the booklet, patients and/or their nominated caregivers identified S&S of MND. A list was generated of their specific S&S and was placed in their medical record as a reminder for the doctor and to aid discussion at the patient's next medical consultation.

An audit of the clinical files was then conducted, focusing on the next three medical appointments to ascertain whether there was documentation regarding discussion with patients about their S&S and if follow-up or investigation was mentioned.

Results

One hundred and twenty-three patients and 43 caregivers were recruited across three sites. Of these, 92 patients and 30 caregivers (73%) selected four or more S&S.

Documentation of discussion regarding these results with the patient was as follows: at the inner metropolitan hospital-based HIV clinic, 26%; at the inner metropolitan sexual health clinic, 43%; and at the suburban hospital-based HIV clinic, where there was no documentation in any notes, 0%. This gave an average of 26% across the three sites.

Introduction

HIV enters the central nervous system (CNS) within days of the initial infection and is present in the CNS throughout the course of the disease, frequently leading to HIV-associated neurological disorders (HAND). The disorders that comprise HAND are: asymptomatic neurocognitive impairment (ANI), minor neurocognitive disorder (MND) (which is symptomatic), and HIV-associated dementia (HAD) [1].

The introduction of combination antiretroviral therapy (cART) for HIV has had a substantial impact on morbidity and mortality for people living with HIV (PLHIV). The aim of cART is to suppress viral replication and maintain and/or strengthen the immune system. Despite virologic suppression current rates of HAND approach 50% [2]. Risk for HAND increases with age, and older adults tend to have co-morbid medical conditions, which may

further increase the risk of HAND. This represents substantial personal, societal and economic burdens [3].

Often PLHIV may underestimate or ignore S&S of HAND. Chiao *et al.* [3] found that patients underestimated self-reporting of symptomatic impairment and Hinkin *et al.* [4] reported 26% of their study participants with memory impairment on neuropsychological testing denied deficits.

One aim of this study is to ascertain whether using the booklet *HIV associated MND (mild neurocognitive disorder). How to recognise the signs and symptoms*, a self-assessment tool, could be useful for early recognition of S&S of MND which could be discussed with the doctor during regular medical appointments.

Documentation in the medical records facilitates the diagnosis and treatment of patients. Few studies have assessed the quality of outpatient medical

record documentation [5]. In this audit it was expected that S&S identified by the patient and/or carer would be discussed in the medical consultation and documented in the patient medical record. In addition the outcome of the consultation would be recorded, for example: had investigations been ordered? Were there changes to cART? Was there continued monitoring for any future signs of MND?

Method

This is a sub-study of a prospective, observational multi-site study which aimed to validate the usefulness of a patient self-assessment tool [*HIV associated MND (mild neurocognitive disorder). How to recognise the signs and symptoms*]. This tool may lead to effective intervention through early identification of MND with the potential to halt progression or reverse S&S of MND in this population.

The study was conducted across three sites in Sydney, Australia: an inner metropolitan hospital-based HIV clinic, an inner metropolitan sexual health clinic and a suburban hospital-based HIV clinic.

Using the booklet patients and their nominated caregivers identified S&S of MND. S&S fell into four key areas: concentration (nine questions), memory (nine questions), coordination (six questions) and memory (nine questions). There were two additional questions about coping ('Are you putting off important tasks?' and 'Do you find at the end of the day you are more tired both mentally and physically?'). A total of four or more symptoms from the 33 was considered the threshold for further discussion with their doctor.

Initially, it was noted by the researchers that patients were forgetting to discuss their S&S with the doctor. As a solution to this the researchers transcribed a list of the S&S identified by the patient and/or carer. This list was put in a prominent place in the patient's medical record to act as a prompt for discussion to ensure that the information was easily accessible to the doctors reviewing the patients. Both the doctors and patients stated this was a useful reminder.

A clinical audit of the medical record was completed to ascertain the outcome of the consultation and notation of the discussion. Medical records were reviewed for three documented visits after the generated list of S&S had been placed in the clinical notes.

Ethics submission has been approved by Royal Prince Alfred Hospital Ethics Committee (X10-0354+HREC/10/RPAH/618) and Liverpool Hospital Ethics Committee (SSA/11/LPOOL/203).

Results

Across the three sites 166 participants were recruited to the study: 123 patients and 43 caregivers. Of these, a total of 122 (92 patients and 30 caregivers) selected four or more S&S. The percentages of documentation in the medical records are seen in Table 1.

Discussion

A clinical audit is used to improve the quality of health care services by systematically reviewing the care provided against set criteria. The clinical audit process is a cycle of activities, which can be repeated as required. A topic area which clinicians want to assess or improve is chosen. Objectives are established by the clinicians subject to available evidence. A set of clinical criteria is developed against which current practice is assessed [6].

Evidence of clinical information in the medical notes is essential as a legal record of what occurred in a medical appointment. Documentation of clinical assessment is useful as a historical record for future consultations, for baseline findings and ongoing assessment and treatment. Documentation in the medical record also validates the patient's discussion of their experience of S&S. Documentation as a mode of communication between health care providers in an outpatient setting is pivotal to providing a continuum of care for the patient.

The medical records were reviewed for three documented visits after the generated list had been placed in the clinical record. We anticipated that there would be written evidence of the discussion with the patient regarding the S&S noted from the list generated from the booklet. We also wanted to ascertain the outcome of the consultation: whether investigations had been ordered; if there was discussion about or change in antiretroviral medication; whether a plan was made to monitor for any increased signs of MND in the future.

It was assumed that if there was no documentation in the medical record there had been no discussion of the patient's S&S. At the inner metropolitan and suburban hospital HIV clinics, researchers were aware that there was clinical review regarding S&S

Table 1: Documentation of discussion with the patient in clinical notes.

Inner metropolitan hospital HIV clinic	Inner metropolitan sexual health clinic	Suburban hospital-based clinic	Total documentation across all sites
26 % (17/65)	43 % (7/16)	0 % (0/11)	26 % (24/92)

identified with some patients, as this was discussed in the post-clinic meeting. Yet this discussion was not documented in the medical record. At one site there was no documentation and at the others it was limited to about one-third of the medical records. This may result in poor outcomes on continuum of care. Lack of documentation of historical clinical data could impact negatively on the patient. Chiao *et al.* [3] noted that PLHIV may underestimate their S&S, thus if the doctor did not document discussion of these the patient may feel that their experiences have not been taken seriously and this may impact the patient's relationship with their doctor. In addition it may also impact future medical assessment, whereby there is no information written to prompt inquiry with the patient regarding any changes in their S&S.

Chiao *et al.* [3] noted that physicians may not have time to assess function accurately as they have to juggle competing priorities during medical consultations. Initially patients in this study were advised to discuss their S&S at their next medical appointment. On discussion with doctors after the first few consultations we discovered patients were not bringing up the issues with their doctor. We then asked the patients and they cited reasons such as: they forgot; they did not think it was worth mentioning to the doctor; or they thought the doctor was too busy. Subsequently a list of the S&S the patient and/or carer identified was generated and the list was placed in a prominent position in the patient's medical notes. Both doctors and patients said the list was a useful reminder to prompt discussion.

Nurses are well placed to assist in the process of communication between patient and doctor regarding discussion and documentation pertaining to S&S experienced by the patient. The nurse may have more time to explore the issues being experienced by the patient and then liaise between the patient and doctor. The nurse may also document clinical findings from their own consultation with the patient.

Conclusion

Documentation is essential as a verification of what happens in the consultation with the PLHIV. Documentation of S&S is essential as a baseline and for future clinical review. Utilising the permanent medical record is paramount for ongoing communication and for continuum of care of the

patient. Anecdotal evidence from some post-clinic meetings suggested that discussions did take place which were not documented in the medical record. Further research needs to be undertaken to ascertain if there are any specific reasons for this. In the case of further research, a formal process of documentation of discussions, independent of treating clinicians, should be made by researchers. Assessment of whether such documentation was used by treating clinicians would need to be incorporated in the process.

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Book Review

Doing a literature review in nursing, health and social care

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Undertaking a literature review (LR) is a fundamentally important part of the research process, especially within healthcare. Whether you choose to undertake an LR as part of a programme of academic study; for submission in a journal; or purely for your own curiosity, you will need to take a structured approach. The aim of undertaking an LR is to assist practitioners in understanding the vast amount of literature that is available on a specific topic. Alongside this, an LR will demonstrate an understanding of a multitude of individual research articles that have been analysed and critiqued in order to produce a piece of work that expresses the practitioner's interpretation of the findings.

Coughlan, Cronin and Ryan's book (2013), *Doing a Literature Review in Nursing, Health and Social Care*, is divided into ten key chapters. The first two chapters provide an overview of what an LR is and the various types that can be undertaken. It examines the term evidence-based practice and the importance of healthcare professionals (HCPs) utilising current evidence to ensure practice remains up to date; however, it also recognises that HCPs may struggle with the sheer volume of available research. Chapter Three centres on systematic reviews and the importance of utilising high-quality research papers to analyse and synthesise the information to produce an unprejudiced conclusion.

Chapters Four to Seven examine selecting a review topic, searching the literature, reading and organising the literature, and finally the process of critically analysing and synthesising the information. This elementary part of undertaking an LR is discussed in depth and provides the reader with the necessary knowledge in order to do this. Interestingly, it discusses 'grey literature' and the importance of searching for conference

presentations and unpublished works such as Masters and PhD studies. It identifies that this may be time consuming; however, this may be beneficial to the LR.

Chapters Eight and Nine discuss writing up the LR and the referencing process. They cover presenting an LR in a transparent and accurate way to inform the reader of the value of the evidence utilised. They consider tips to enhance the written work and factors to avoid. An outline of the three main types of referencing style commonly utilised within healthcare is presented, namely Harvard, American Psychological Association (APA) and the Vancouver system. They demonstrate that good referencing can reduce the likelihood of accidental plagiarism.

Finally, Chapter Ten explains what can be done with an LR; for example, submission to an academic journal for publication or utilising the LR at a conference presentation.

Overall this book provides the reader with a very detailed interpretation of undertaking an LR in nursing, health and social care. The book is well written and organised into distinctive chapters explaining to the reader the process step by step. Often terminology is a barrier to the reader; within this book the language is clear, with any jargon utilised being explained further. This practical book is highly recommended to undergraduate and postgraduate students studying health-related courses as well as HCPs planning to undertake an LR in practice.

Doing a literature review in nursing, health and social care by Michael Coughlan, Patricia Cronin and Frances Ryan is available from Sage Publications priced £18.99

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