

HIV complex care and care coordination: the nurse's role

Shaun Watson

Clinical Nurse Specialist (HIV Community)

Abstract

Over the past 30 years treatment for HIV has developed to a point where today, people living with HIV now have a near normal lifespan. However, living and ageing with HIV, just like the general ageing population, means that healthcare professionals are now managing, supporting and caring for a group of people who are at risk of developing increasing numbers of comorbidities and complexities. The management of HIV and complex care is now a priority for all healthcare professionals. This article will define the complexities experienced by people living and ageing with HIV; describe the types of complex issues seen and discuss how we can best support and manage those who are faced with HIV and complexity; and also define and consider the nurse's role in care coordination and complex case management.

Key words: HIV, complexity, complex care, case management, care coordination, integrated care

A. Revalidation

This article has been prepared with continuing professional development (CPD) in mind and can be used to support your revalidation. It is estimated that 2.5 hours of CPD activity will be required for completion of the reading, 'time out' activities, the quiz and writing a brief reflective account in relation to your learning and its applicability to your practice. There is a self-assessment quiz at the end of this article for you to assess what you have learnt.

B. Aims and intended learning outcomes

The article aims to increase your knowledge and confidence in assessing and caring for people living with HIV who have complex care needs.

After reading this article, undertaking the activities and completing the self-assessment quiz you should be able to:

- Understand and define the concepts of HIV and complex care;
- List and discuss at least three components of HIV and complex care;
- Show awareness of the nurse's role within complex care;
- Describe care coordination and explain the importance of this within complex care;
- Outline the list of complex care within HIV and AIDS reporting system (HARS) data collection and discuss why this category may need to change to reflect HIV today; and
- Review your current practice and guidelines around care coordination and case management for people living with HIV and complex care needs.

C. Introduction

Living with HIV has changed as the epidemic has developed over the past 30 years from a life limiting

illness with complicated drug regimens along with health and social care services designed to holistically manage and support the individual. Today, thanks to the successful use of antiretroviral therapy (ART), HIV has been redefined as a long-term condition, but also an illness that has and will incorporate issues of ageing, comorbidities and other long-term conditions in a time when management and support is fragmented across primary, secondary and tertiary care services [1]. People living with multiple health and social care needs often experience a highly fragmented service, leading to suboptimal care experiences, outcomes and costs [2]. For many HIV will remain a manageable illness peppered with annual clinic appointments, email and telephone appointments and home delivery of medications. For others the complexities of living with HIV may also mean living with other chronic conditions or comorbidities affecting their work or home life; families and friends may add to this complicated, complex picture.

D. Defining complexity

Defining complexity can be elusive; several have tried, for example, Loeb *et al.* [3], and Safford and colleagues [4], see Figure 1.

Within HIV, defining complexity can take many forms from national indicators such as Payment by Results and HARS data (Box 1) [5,6], with Kirwan *et al.* mapping the complexity noted in clinics against the HARS data [7], stating that one in eight people living with HIV have complex needs. Halman *et al.* looked at three variables: medical, psychiatric and housing instability to define their complex but small cohort of individuals with late-stage HIV [8]. Social issues, such as housing, finances and poor, unsupported mental health may adversely affect adherence and engagement in care with some lifestyle factors such as diet, exercise, smoking, alcohol and recreational drug use affecting the development and progression of issues such as respiratory and cardiovascular disease. However, there

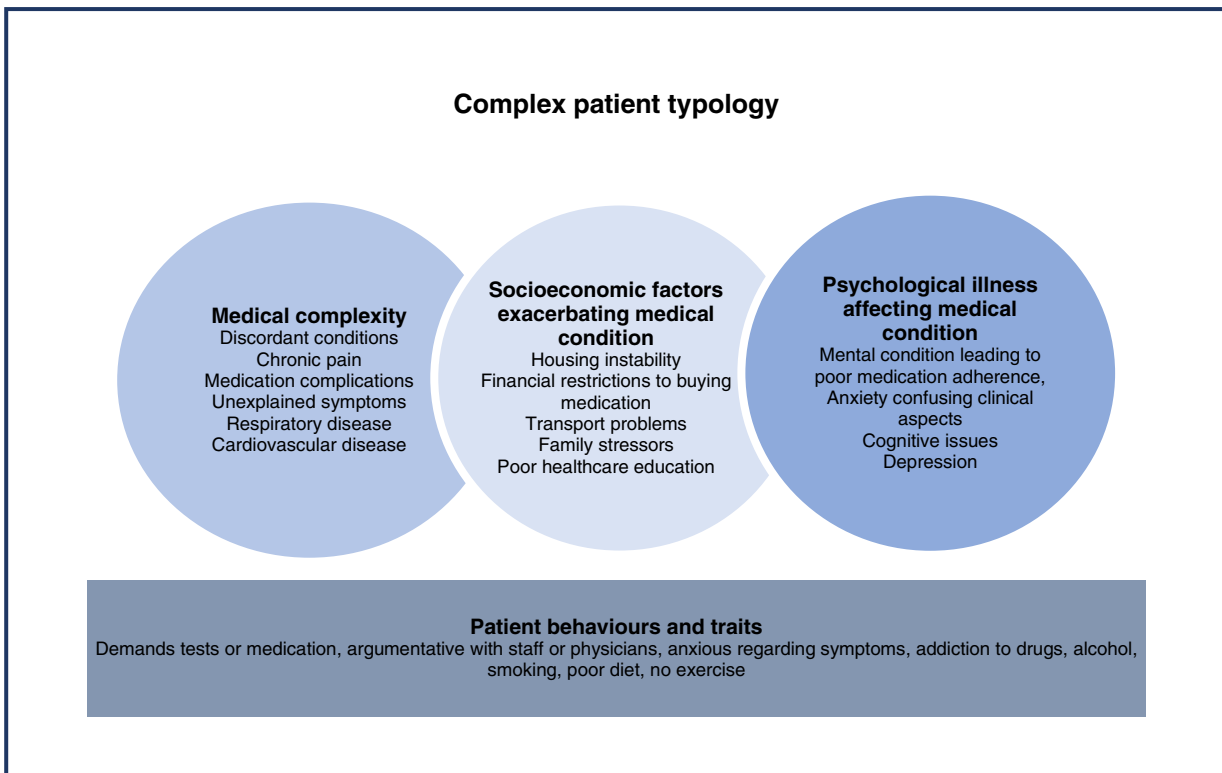


Figure 1: Defining typology of complex patients. Adapted from Loeb et al [3].

appears to be very little else published despite complex care being the most part of an HIV healthcare professional’s day, but perhaps we are entering a new era of HIV care in which we need to focus upon, not only the effects of HIV, but all the associated issues that can, and will, impact upon future care and engagement with HIV services.

E. Thinking about complexity

When you assess a patient for the first time what do you ask? Do you refer to care models like the nursing process, such as Roper, Tierney, and Logan, or Orem’s self-care? Do you have set pro forma to complete? How robust is your assessment and how much time do you realistically have to do this? For a person living with HIV and complex care issues, a thorough holistic assessment looks not only at the medical issues that they are living with but also their psychological, socioeconomic status and other issues that add to the complex nature of their lives. Figure 2 lists some of the issues that you could encounter when thinking about living with HIV and complexity.

Box 1. Payment by results: the HIV outpatient currency

- Category 1** New Patients (7%) – are those that have been newly diagnosed in the UK or have newly started ART.
- Category 2** Stable Patients (80%) – are patients not on ART or stable and started ART more than 1 year ago.
- Category 3** Complex Patients (13%) – patients who fall into **Category 3** have a complexity that identifies them as a special patient group, needing high levels of maintenance, or being highly dependent patients. Complexities include:
 - Current TB co-infection on anti-tuberculosis treatment
 - On treatment for chronic viral liver disease
 - Receiving oncological treatment
 - Active AIDS diagnosis requiring active management in addition to ARV (not inpatient care)
 - HIV-related advanced end-organ disease
 - Persistent viraemia on treatment (>6 months on ARV)
 - Mental illness under the care of a psychiatrist
 - HIV during current pregnancy

Source: Department of Health, UK [5,6].

Time out activity 1

Complexities

Look at the list of complexities as mentioned in HARS in Box 1 and write down what is missing, it may help to think about the complex patients you see in your work place. How would you categorise these complexities?

There are many factors at play that affect the general population as a whole as well as those living with HIV. The population is living longer and as people age they are experiencing increasing disability. In the UK, life expectancy has increased by more than 10 years for men and women; in these later years, people often experience chronic pain, physical disability and cognitive impairments [10]. For people living with HIV, along with the general population, we are looking at an ageing population who have an increasingly sedentary lifestyle alongside dietary and addiction

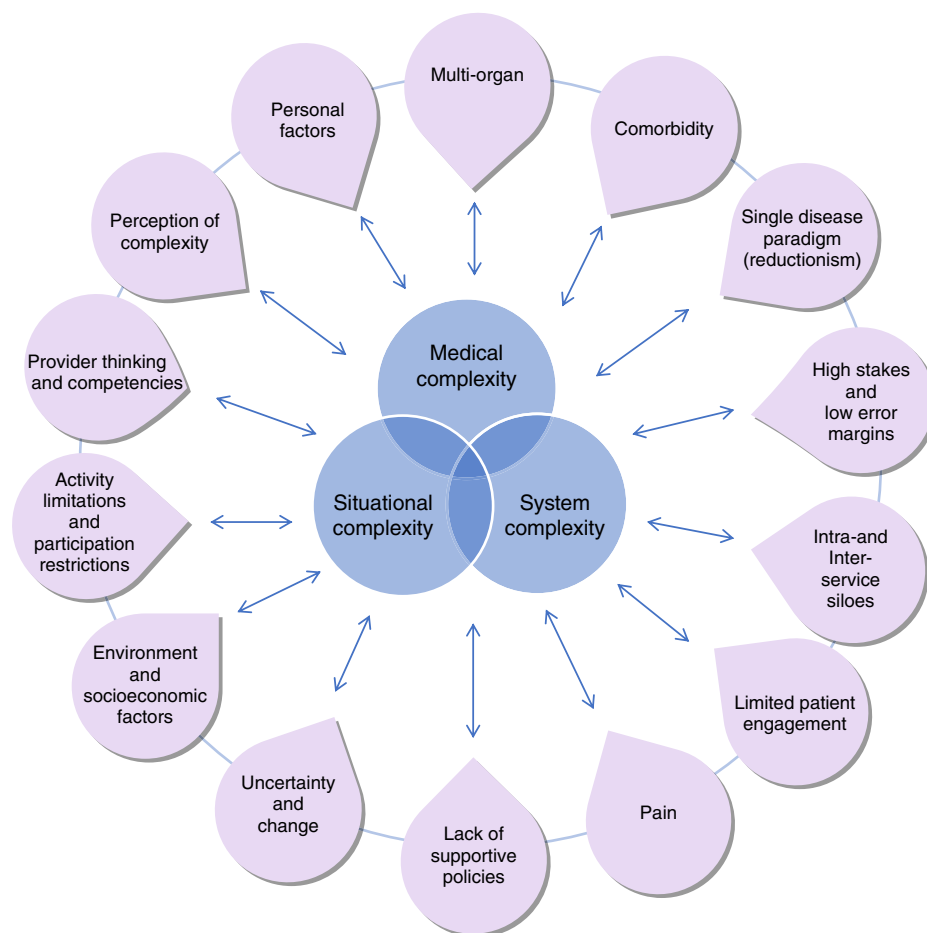


Figure 2: Factors associated with health care complexity. Adapted from Kuipers et al [9].

issues; such as an increase in consumption of sugary, high-salt processed food, for example, ready meals and takeaways; reduced consumption of fresh fruit and vegetables; and continuing high rates of recreational drug use, smoking and alcohol consumption [11–15].

F. How do we assess and manage complex patients?

Think about patients in your workplace who you think of as complex, challenging and complicated. What makes them complex? Do your colleagues think the same as you or do they view them differently? Is the patient challenging and, if so, is it the situation or the patient who presents the challenge (or both)? Challenging patients can be those described as having 'any non-verbal, verbal or physical behaviours exhibited by a person which makes it difficult to deliver good care safely' [16]. But what are these 'behaviours'? It could be aggression, violence, depression, apathy, excitedness, mania or silence, the list is endless and what may be challenging for one person may be everyday challenges and management issues for another. Verbal challenges could come in the form of stigma, racism, homophobia, transphobia, threats, intimidation or offensive language. We all will have our own thoughts and feelings around what we can, can't or won't find acceptable. How many times has a patient said something that you haven't challenged because 'it wasn't the right time or place'? Hallett states that an understanding of the causes and

prevention of challenging behaviour and conflict are important for all healthcare staff because related incidents can occur in any setting [17]. Is this something that is part of your mandatory training? Managing complexity can easily lead to conflict with competing priorities and general frustration.

Time out activity 2

Complex needs

Think about a patient who you think of as complex or having complex needs.

List the medical factors that make up this complexity.

Are they related to HIV and are some of these issues long-standing concerns preceding their HIV diagnosis?

G. Breaking down HIV complexity

For this section HIV complexity will be broken down into four categories, see Figure 3. In general, it helps to focus on the negatives of complexity and think about how we can support and manage this, but this section will also endeavour to look at some positive aspects and good practice. Initially there are a few important issues to be considered: assessment, experience and beliefs.

Assessment and experience: getting to know the person sitting in front of you is vital and this needs to

<p style="text-align: center;">Medical</p> <p>HIV (not controlled by ART) Issues of ageing (frailty, coordination) Polypharmacy and resulting side-effects, adherence issues Comorbidities Co-infections (TB, HCV, HBV) Cancer Pregnancy Recreational drug use Alcohol misuse Disability (access, understanding)</p>	<p style="text-align: center;">Psychological</p> <p>Ongoing mental health diagnoses Issues of ageing (cognitive changes, memory) Stigma (discrimination) Anxiety and depression Agoraphobia (other issues that may preclude engagement) Denial Fear and (or) embarrassment Challenging behaviour (anger, apathy) Intimate partner violence, vulnerabilities and safeguarding issues</p>
<p style="text-align: center;">Socioeconomic</p> <p>Isolation Poverty (benefits, loss of work) Housing issues (homelessness, hostel, temporary housing) Social care issues Third sector support Family issues (care demands, childcare, pet responsibilities) Travel (distance, cost) Time (juggling work/study/family with appointments)</p>	<p style="text-align: center;">Other</p> <p>Culture (upbringing) Faith and belief systems Past experiences or expectations of health and social care Motivation and engagement Language and understanding Educational level Competing priorities Multiple hospital appointments (different sites, communication systems) GP involvement (access to notes, disclosure)</p>

Figure 3: Four categories of HIV complexity. ART = Antiretroviral therapy.

be holistic (encompassing all aspects of their lives). As a community specialist nurse, I have the luxury of not only seeing the person in their homes, and all the information that gives, but also the time for a full assessment. One of the first questions to ask is: 'What is your experience of ill health and healthcare before your HIV diagnosis?' which will give you a good understanding of how someone will/has managed their, potentially, new situation. What are their experiences of ill health and hospital care as a patient, or as a carer or family member? For those nurses who have less time to assess someone's experience of care, it is something that could be readily dropped into general conversation, think of your hairdresser casually asking, 'Are you going on holiday this year?' This initial conversation can then set the scene for the ongoing assessment. Discover what their priorities are and how HIV fits into this.

Beliefs: explore the patient's beliefs around not only HIV but also treatment or medication. Do they take prescribed or over-the-counter medication, vitamin pills or supplements etc. presently or in the past? How do they manage them and why do they take them? Again a simple, 'So I see you take a multivitamin, what made you start taking it?' It's an easy ask, but will show you how they feel about their general health, did they seek advice, if so, from whom? Explore their beliefs around HIV and the effect it has on their health.

Medical complexity

HIV in itself may not be complex (barring issues of stigma, discrimination and ongoing health issues). If ART works well and overall general health is good then it may only necessitate annual or twice-yearly appointments for blood tests and medication, but if ART isn't successful and side effects worsen or cause treatment cessation then complexity may ensue. As the

person living with HIV ages they may experience other health concerns, some of these may be dealt with by the GP or within other hospital departments (such as cardiology, rheumatology, oncology etc.) Complexity may arise in situations where communication between the HIV clinic, other health departments and the GP have not been allowed by the person living with HIV for confidentiality, discrimination or stigma issues, and where electronic or written note systems are not readily accessed or communication, in general, is poor. Some of these health issues could be pre-empted in the initial assessment, especially in identifying family health issues that could raise a flag for future health. Annual review and supporting lifestyle changes can be a proactive way of preventing issues that may add to complex health as well as working with the patient around disclosure issues to other healthcare professionals. Some people living with HIV (and other long-term health issues) can be skilled self-managers and may easily navigate their way around numerous health issues, appointments and different healthcare settings, others may feel completely overwhelmed. Having spoken to many new or recently diagnosed people living with HIV, the general opinion is that the NHS is *the NHS*, and as such, one in which we all communicate freely between different hospitals, primary and secondary care. Of course, this could be highlighted in the initial assessment when discussing disclosure and open communication between the HIV clinic and general primary, secondary and associated care settings, although desirable, is not the case at all and communication, or lack of it, can be the main issue in why healthcare becomes complex. Just think about times when you have had to call another department or healthcare professional, what makes this easy or difficult? For some, writing down the issue in a confidential encrypted email is the best course of action, or speaking directly to the healthcare department or professional, but we are still in a world

of postal letters, faxes and automated telephone systems, all or none of which take time and add to communication problems.

Psychological complexity

Anxiety and depression about living with HIV is common [18–20] as are ongoing or unsupported mental health issues unrelated to HIV [21–23], and these can add a different dimension to complex care. If unsupported you may be managing and supporting someone who is emotionally labile, chaotic, disengaged or unmotivated by healthcare and society in general. Those who are supported by mental health services may or may not want their HIV to be disclosed, which could further complicate communication. Furthermore, there is general confusion about whether or not mental health is additionally complicated by organic HIV issues, such as HIV-associated neurocognitive diseases or recreational drug or alcohol misuse.

Denial of HIV itself or confusion about treatment, such as thinking undetectable means HIV free, particularly when the person may have strong faith or beliefs around religion and healthcare, can be difficult to manage and this could involve joint working with faith leaders, challenging long-held beliefs and risking the patient isolating themselves further from care. Here the role of peer support may be a valuable tool, providing them with support from similar faiths or cultural heritages [24].

Socioeconomic complexity

For community nurses this is the largest area of complexity and one which has no quick fix. Housing, homelessness, poverty, closure of support agencies and changes to the benefit system may well add additional issues to a person's life. For example, a person living with HIV may not be able to afford to travel to the clinic(s), may be losing weight owing to poor nutrition, or suffer from hypothermia in winter owing to increasing heating costs, with the embarrassment stopping them discussing this with the healthcare professional until they miss appointments, are noticeably underweight or are admitted to hospital with pneumonia. Some of these issues can be easily remedied by ready access to welfare support, citizens advice or voluntary HIV/mental health/welfare agencies, who can signpost or offer practical help. This may be noticeable in those who are seen as complex, older and not working; but complications and socioeconomic issues may still arise for patients who are in employment, in education and housed but suddenly find themselves redundant, having lost work due to excessive time off, or increasing recreational drug (particularly chemsex whose effects may not be initially recognised until problems arise) or alcohol use. Knowing who is around, such as partners, children, friends and family is important. Should someone become ill, who will support them? Family, especially children, can add extra issues such as disclosure; Who knows about the patient's HIV status? How supportive are they and who to contact?

Other complexity

All of the complex issues raised in the medical, psychological and socioeconomic sections can be further complicated by other 'life' issues, for example, stigma, language, culture or level of education and understanding. HIV stigma and other factors such as fear, shame, embarrassment and lack of self-confidence can have a devastating effect and raise complexity to higher levels as we manage and support people living with HIV who just don't want to be in the clinic or to be associated with HIV care. In the early days of the HIV story people were, on the whole, too sick to work or study but today we have had to tailor our services to manage a cohort of working people so we offer 'out of hours' and weekend clinics. However, if a person living with HIV has other ongoing issues with increasing appointments, treatment may interfere with work and necessitate more time off or disclosure to their employer. We are now becoming aware of other issues that can add 'hidden' complexity, such as intimate partner violence, vulnerability and safeguarding.

As nurses who work predominantly within specialist HIV services, perceived issues around HIV may be uppermost in our minds, but for some of our patients living with HIV are also living with diabetes, a sick child, a chronic cardiac problem, a terminal cancer diagnosis; are at risk of losing their home or haven't disclosed to their parents and need to borrow money to pay the rent: HIV may be the last thing they want to think and talk about. The issue of competing priorities is something that needs to be discussed, especially if you see the person as someone with unmanaged complex needs and questions, such as, 'What are the top five issues you want to discuss?' are useful in setting the patient agenda, working with them to ensure that they stay engaged with their HIV service and enabling them to effectively manage their other areas of complexity or concern.

Time out activity 3

Complexity categories

Think about the patient you considered in Time out activity 2.

Can you identify the systematic and situational factors that add to the complexity of their situation?

Are they cared for in different settings? How many other teams are involved in their care? Is this communicated to the HIV team or do you communicate with these other teams or healthcare professionals?

H. Communication is key

Brownie, Scott and Rossiter state that 'Caring for a patient whose recurring symptoms and repeated presentations to healthcare services are characterised by chronicity and complexity could be challenging for healthcare professionals, regardless of their level of skills and experience' [25]. Their work looked at the communication skills needed by nurses to effectively

care for those with complex needs breaking down those skills to:

Mindfulness: focusing attention and awareness to enable the nurse to cast aside bias and assumptions, creating an opportunity to be 'therapeutically present' allowing the nurse to hear and validate the patient's experience, fostering a feeling of trust and understanding [26].

Recognition of the invisibility of some chronic illnesses: patients, especially at hospital appointments, prepare themselves, they shower, dress well and may outwardly portray themselves as 'well'. Copen stated the damage that statements such as 'You look so good.' can do, conveying the message that they can't be that sick and invalidating their experiences of ill health [27].

I. How do we manage complexity

Remember, we are nurses and have specific roles within our work. Complexity can be overwhelming and when confronted by a patient who is not coping with their life it is tempting to try to solve all these issues for them. The more complex HIV and its treatment is to manage the greater the need for patient support to improve adherence, engagement, self-care and manage symptoms. By looking holistically, care can be tailored to each patient. Some will need more support; some will be more than capable self-managers. There may be some degree of shared decision-making where a decision is taken as to which areas of complexity need to be addressed and a list of priorities may be compiled, this could incorporate [28]:

- **Medication optimisation:** addresses issues and challenges around adherence. This may be something as simple as referring to speak to the pharmacist, access to community HIV support, peer support or the use of technology, such as the Liverpool interactions app [29].
- **Care optimisation:** looks at where care is carried out. This can involve onward referral or signposting to support agencies including social workers, peer support and voluntary agencies for assistance when needed. It could involve, if possible, shifting care to one site so that medical records and appointments can be better coordinated.
- **Management of symptoms:** symptoms/side effects that are troublesome and need to be better managed, for example, referral to pain or sleep clinics, dieticians or physiotherapy.
- **Self-care education:** supports the person to identify risk behaviours, nutrition, exercise and to encourage smoking cessation with programmes such as 'expert patient' or 'positive self-management' [30].
- **Comorbidity management:** includes screening for other sexually transmitted diseases, cancer, osteoporosis, diabetes, viral hepatitis, as well as depression and anxiety, which can hinder care [31].
- **Continuity of care:** nurse collaboration with other providers and supports consistent healthy patient-provider relationships.
- **Emotional and social support:** includes helping patients navigate concerns around stigma, support groups etc.

J. Case management, integrated care and care coordination

The latest BHIVA Standards of care (2018) discusses the role of the care coordinator recognising the complex nature of HIV, ageing and long-term health. The standards state that 'a care coordinator role has been successfully used in other conditions such as mental health and is widely advocated for people with complex needs' [32]. This isn't a new concept within HIV. Halman *et al.* in their study highlighted the need 'for improved coordination of medical and psychiatric care, as well as an integration of psychosocial, recovery oriented addictions and harm reduction services to enable all patients to benefit from the advances in HIV/AIDS medicine' [8], and among vulnerable populations with HIV, comprehensive care coordination may substantially improve short-term outcomes for previously diagnosed clients, especially those returning to care after a gap of >6 months [33]. However, the role highlighted by the new BHIVA standards is not well defined. Questions on who the care coordinator is, their role, and whether this is an integral part of patient care or a separate role within HIV care remain unanswered. Care coordination has been described as:

... a person-centered, assessment-based, interdisciplinary approach to integrating health care and social support services in a cost-effective manner in which an individual's needs and preferences are assessed, comprehensive care plan is developed, and services are managed and monitored by an evidence-based process which typically involves a designated lead care coordinator [34].

BHIVA standards state that a 'care coordinator should be utilised for people living with HIV with higher levels of need and while not present in all localities, a specialist HIV nurse working in the community may be particularly suitable' (see Box 2 for the full list of complex care quality statements). This, of course, may work well in areas of high HIV prevalence that have access to an HIV community nurse but in smaller HIV clinics the role of care coordinator may well be taken on by a specialist nurse; in larger clinics the role maybe too time consuming and complex care coordination may then necessitate team coordination. Case management comprises a subset of care coordination models. Successful care coordination models demonstrate accountability for the organisation of patient care, build respectful relationships and agreements among care partners, support patients regardless of where they access health care and establish good communications among care partners [14].

McDonald, Sundaram and Bravata researched care coordination in the general population defining it as:

... the deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care [35].

The researchers discussed care coordination as having the following components:

Box 2. Supporting people with higher levels of need quality statements

- People newly diagnosed with HIV should have a comprehensive assessment of their physical and mental health, past medical history, as well as wider determinants of health such as drug and alcohol use, housing, finances, employment, and social support. This should be repeated annually and used to identify those who may have higher levels of need.
- Where increased need is identified, a 'personalised care plan' should be developed to highlight priorities for that individual and targeting of resources. This should act as a framework for management plans and referrals to other agencies.
- Where social care needs, financial difficulties, housing or other insecurities, are identified, clinics should have as a minimum, signposting to, or information, about sources of advice and support to address these difficulties.
- HIV services should actively prioritise care planning for people with increased needs where there is a clear deleterious interaction with patterns of engagement in care and/or adherence to treatment.
- Enquiry about current or past intimate partner violence (IPV) should be made at baseline in all people newly diagnosed with HIV and this should be periodically reviewed, for example as part of an annual assessment. HIV services should have robust, agreed pathways for referral to support services for people reporting IPV, be able to conduct risk assessments and have staff trained in safeguarding issues of children affected.
- Adherence to ART is likely to be more challenging for people with higher levels of need and thus the choice of treatment is particularly important. Consideration should be given to drug choice that might facilitate adherence for that individual. For example, homeless people may find storage of a large number of boxes of different medications more difficult, so a lower tablet number may be beneficial.
- Interventions should be planned with the person according to needs as well as clearly agreed priorities and aims. Peer support should be offered to all patients, but in this group, there may be particular benefits in providing support in negotiating the health and social care system and reducing isolation.
- A care coordinator should be utilised for people living with HIV with higher levels of need and while not present in all localities, a specialist HIV nurse working in the community may be particularly suitable.
- HIV support services, often provided by the third sector, are of great value in supporting people with higher levels of need. Support provided by clinical and other support services must be as coordinated as possible with strong referral and communication links.
- HIV services should actively identify problems with alcohol and/or drug use in people living with HIV and have robust referral pathways to the relevant support services. Clinics should have as a minimum, signposting to, or information, about sources of advice and support to address these difficulties.

Source: BHIVA Standards of care, 2018 [32].

- Numerous participants, typically involved in care coordination; as care becomes complex there is an increase in number of health and social care participants and the complex relationships between them.
- Coordination, essential when participants are dependent upon each other to carry out disparate

activities in a patient's care with those involved contributing specialised knowledge, services and skills to provide a comprehensive, coherent and continuous response to a patient's unique care needs.

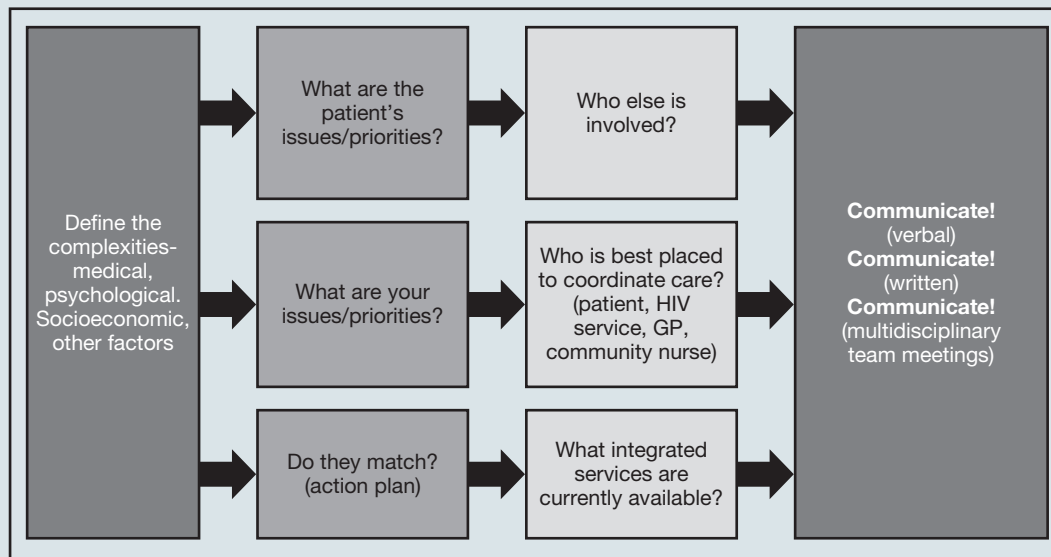
- Each participant requiring adequate knowledge about their own and others' roles, and available resources, such as local support services. Effective coordination depends on knowledge of individual roles and working relationships but some involved in a patient's care may also have differing opinions about the roles they and others should assume [36], these differing views about roles may lead to ineffective communication and a blurring of boundaries such as a nurse taking on a social work(care) role.
- Participants relying on exchange of information, but this may be infrequent and in ways that may affect patient care adversely [1]. Integration of care activities that have the goal of facilitating appropriate delivery of health care services is required.

The *NHS five year forward view* makes the case for the integration of health and social care, primary and specialist care, and physical and mental health care [37], with integrated care occurring when organisations work together to meet the needs of their local population, for example, peer support from a voluntary agency working within HIV clinics or local working with mental health services, in some ways HIV services have led the way in collaborative, integrated care. Goodwin *et al.* stated that:

Integrated care means different things to different people. It can be defined as an approach that seeks to improve the quality of care for individual patients, service users and carers by ensuring that services are well co-ordinated around their needs [38].

Integrated care is necessary for any individual for whom a lack of care coordination leads to an adverse impact on care experiences and outcomes, often with a single point of entry – designating a case manager who helps with assessing needs, sharing information, and coordinating care delivery by multiple formal and informal caregivers will help provide integrated care [38]. However, the lack of joined-up care has caused much frustration and the case for care and support to cross health and social boundaries and become 'integrated' is needed. Therefore, with an ageing HIV population living with increased complexity we perhaps need to look towards individual services and organisations that manage and support education, prevent comorbidities, encourage self-care, support primary care (to prevent people being sent back to HIV services for general ill health or rebounded between the two services) and develop pathways of care that are well coordinated, collaborative and integrated.

People living with HIV and complex needs may consume the highest proportion of resources, thus, an integrated, coordinated health and social care system that provides a streamlined service, prevents duplication and has a rapid response to emergencies is desired.

Box 3. Complex Care: tips for success**Time out activity 4****Care coordination**

If you were the care coordinator for the patient you described earlier, how would you manage and support them through their healthcare journey, think about 'ideal world' versus 'reality'?

What, if anything, needs to change? Is this realistic or something that you could develop within your sphere of work, locality or nationally?

K. Conclusion

We are now entering a new era of life-long HIV care and, for some, this will be a complicated, complex journey. As nurses working in HIV we need to enable our patients to manage this journey with ease, but systems may not be available; breaking down the complexities, case management and skilled support will be our tools. Knowing your role within the management and support of patients living with HIV and complexity is vital towards working with the patient to smooth their journey through the care system, whether as care coordinator or as a part of the multidisciplinary team. Knowing your role will allow you to be an effective partner in the complex care pathway as well as an understanding of your limitations, triggers and frustrations that could complicate this journey.

L. Acknowledgements**Funding**

This article has been supported by an educational grant from MAC AIDS. The company has had no editorial input in the article.

Conflicts of interest

Shaun Watson is current Chair of NHIVNA, a member of the clinical reference group and has undertaken

none-promotional and advisory work with several pharmaceutical companies (Gilead, ViiV and MSD).

M. References

1. Baylis A *et al.* *The future of HIV services in England: shaping the response to changing needs.* King's Fund. 2017. Available at: www.kingsfund.org.uk/publications/future-hiv-services-england (accessed May 2018).
2. Goodwin N, Sonola L, Thiel V, Kodner D. *Co-ordinated care for people with complex chronic conditions: key lessons and markers for success.* King's Fund. 2013. Available at: www.kingsfund.org.uk/publications/co-ordinated-care-people-complex-chronic-conditions (accessed April 2018).
3. Loeb DF, Binswanger IA, Candrian C *et al.* Primary care physician insights into a typology of the complex patient in primary care. *Ann Fam Med* 2015; **13**: 451–455.
4. Safford MM, Allison JJ, Kiefe CI. Patient complexity: more than comorbidity. the vector model of complexity. *J Gen Intern Med* 2007; **22**(Suppl 3): 382–390.
5. Department of Health. *HIV outpatients and payment by results currency: a simple guide.* Available at: assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/214924/HIV-Outpatients-A-Simple-Guide.pdf (accessed May 2018).
6. Department of Health. *HIV adult outpatient pathway.* 2013. Available at: www.gov.uk/government/publications/payment-by-results-hiv-outpatients-currencies (accessed May 2018).
7. Kirwan P, Chau C, Yin Z *et al.* Assessing the clinical complexity of a national cohort of adults accessing HIV outpatient care. *23rd Annual Conference of BHIVA*, 4–7 April 2017, Liverpool, UK. Abstract O30.
8. Halman M, Carusone SC, Stranks S *et al.* Complex care needs of patients with late-stage HIV disease: a retrospective study. *AIDS Care* 2014; **26**: 320–325.
9. Kuipers *et al.* *Complexity and health care: health practitioner workforce services, roles, skills and training, to respond to patients with complex needs.* ClinEdQ. 2011. Available at: www.health.qld.gov.au/__data/assets/pdf_file/0027/150768/complexcarefull1.pdf (accessed May 2018).
10. Nolte E, McKee M. Integration and chronic care: a review. In: *Caring for people with chronic conditions: a health system perspective.* Maidenhead: McGraw Hill; OUP; 2008.

11. Alharbi M, Gallagher R, Kirkness A et al. Long-term outcomes from Healthy Eating and Exercise Lifestyle Program for overweight people with heart disease and diabetes. *Eur J Cardiovasc Nurs* 2016; **15**: 91–99.
12. Baumann S, Toft U, Aadahl M et al. The long-term effect of a population-based life-style intervention on smoking and alcohol consumption. The Inter99 Study—a randomized controlled trial. *Addiction* 2015; **110**: 1853–1860.
13. Braithwaite RS, Fang Y, Tate J et al. Do alcohol misuse, smoking, and depression vary concordantly or sequentially? A longitudinal study of HIV-infected and matched uninfected veterans in care. *AIDS Behav* 2016; **20**: 566–572.
14. Brennan-Ing M, Seidel L, Rodgers L et al. The impact of comprehensive case management on HIV client outcomes. *PLoS One* 2016; **11**: e0148865.
15. Helleberg M, May MT, Ingle SM et al. Smoking and life expectancy among HIV-infected individuals on antiretroviral therapy in Europe and North America. *AIDS* 2015; **29**: 221–229.
16. NHS Protect. *Meeting the needs and reducing distress: guidance on the prevention and management of clinically related challenging behaviour in NHS settings*. Available at: www.maybo.co.uk/file/2135/meeting_needs_and_reducing_distress.pdf (accessed May 2018).
17. Hallett N. Preventing and managing challenging behaviour. *Nurs Stand* 2018; **32**: 51–63.
18. Garey L, Bakhshaei J, Sharp C et al. Anxiety, depression, and HIV symptoms among persons living with HIV/AIDS: the role of hazardous drinking. *AIDS Care* 2015; **27**: 80–85.
19. Kagee A, Saal W, Bantjes J. Distress, depression and anxiety among persons seeking HIV testing. *AIDS Care* 2017; **29**: 280–284.
20. Murphy PJ, Garrido-Hernansaiz H, Mulcahy F et al. HIV-related stigma and optimism as predictors of anxiety and depression among HIV-positive men who have sex with men in the United Kingdom and Ireland. *AIDS Care* 2018: 1–7 (Epub ahead of print).
21. Rueda S, Law S, Rourke SB. Psychosocial, mental health, and behavioral issues of aging with HIV. *Curr Opin HIV AIDS* 2014; **9**: 325–331.
22. Sherr L, Clucas C, Harding R et al. HIV and depression—a systematic review of interventions. *Psychol Health Med* 2011; **16**: 493–527.
23. White JM, Gordon JR, Mimiaga MJ. The role of substance use and mental health problems in medication adherence among HIV-infected MSM. *LGBT Health* 2014; **1**: 319–322.
24. Positively UK. *National Standards of Peer Support*. 2017. Available at: hivpeersupport.com/ (accessed May 2018).
25. Brownie S, Scott R, Rossiter R. Therapeutic communication and relationships in chronic and complex care. *Nurs Stand* 2016; **31**: 54–63.
26. Rossiter R, Walton C, Scott R. Key attributes of therapeutic communication. In: *Critical conversations for patient safety*. Tracey Levett-Jones (ed.). Australia: Pearson; 2014. pp. 102–112.
27. Copen L. Talking to someone with a chronic illness. *CNN*. Available at: edition.cnn.com/2012/09/11/health/invisible-chronic-illness/index.html (accessed April 2018).
28. Croston M, McLuskey J, Evans C. How do nurses facilitate shared decision making in HIV care?: an exploratory study of UK nurses knowledge, perspective and experience of facilitating shared decision making in clinical practice. *EJPCH* 2016; **4**: 693–704.
29. University of Liverpool. HIV Drug Interactions. Available at: www.hiv-druginteractions.org (accessed May 2018).
30. living well. Available at: www.livingwellcic.com (accessed May 2018).
31. National HIV Nurses Association. *Annual health review for people living with HIV: a good practice guide*. Available at: www.nhivna.org/annual-health-review-for-people-living-with-HIV (accessed May 2018).
32. British HIV Association British HIV Association. *Standards of Care for People Living with HIV*, 2018. BHIVA. Available at: www.bhiva.org/standards-of-care-2018.aspx (accessed April 2018).
33. Irvine MK, Chamberlin SA, Robbins RS et al. Improvements in HIV care engagement and viral load suppression following enrollment in a comprehensive HIV care coordination program. *Clin Infect Dis* 2015; **60**: 298–310.
34. National Coalition on Care Coordination. *Policy Brief: Implementing care coordination in the patient protection and affordable care act*. 2011. Available at: www.rush.edu/national-coalition-care-coordination#actionsresources (accessed May 2018).
35. McDonald KM, Sundaram V, Bravata DM et al. Closing the quality gap: a critical analysis of quality improvement strategies (Vol 7: Care Coordination). Rockville, MD: Agency for Healthcare Research and Quality, 2007.
36. Swartztrauber K, Vickrey BG. Do neurologists and primary care physicians agree on the extent of specialty involvement of patients referred to neurologists? *J Gen Intern Med* 2004; **19**: 654–661.
37. Stevens S. Simon Stevens on the NHS five year forward view. King's Fund. 2015. Available at: www.kingsfund.org.uk/audio-video/simon-stevens-nhs-five-year-forward-view (accessed May 2018).
38. Goodwin N, Dixon A, Anderson G, Wodchis W. *Providing integrated care for older people with complex needs: lessons from seven international case studies*. King's Fund. 2014. Available at: www.kingsfund.org.uk/publications/providing-integrated-care-older-people-complex-needs (accessed April 2018).

Correspondence: Shaun Watson
Shaun.watson@nhs.net