

HIV at 40: Reflections on Interdisciplinary working in HIV healthcare

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Introduction

The medical, behavioural, and psycho-social journey in response to HIV has been extraordinary over the past four decades, and was characterised by interdisciplinary working,

The concept of interdisciplinary working, captured in the work of Jonathon Mann (1998) points to how medical, behavioural, and social responses define and conceptualise salient healthcare issues, determining what we believe can be done and, more importantly, what is actually done.

In the early years of the HIV pandemic, there were no effective medical treatments, meaning the diagnosis carried a high degree of mortality. As a result, medical and public health responses were forced to change, collaborate, and adapt to align with broader human rights issues, consider structural determinants of health and incorporate the impact of marginalisation, stigma, and poverty into the design of effective responses and treatment delivery.

These responses provided early frameworks for closer multi- and inter-disciplinary interventions that have come to characterise care provision for people living with HIV in the UK and internationally.

This article explores the development of interdisciplinary approaches to HIV care, with the main focus on NHS HIV clinics. Examples of practical interdisciplinary approaches are provided to suggest that working in an interdisciplinary way best serves the complex and inter-relating needs of the HIV population (British HIV Association; BHIVA, 2018, British Psychological Society, British HIV Association & Medical Foundation & Sexual Health; BHIVA, BPS & MEDFASH, 2011; Warner & Rutter, 2020).

How HIV brought focus to psychosocial issues

Unusually for the profession of applied psychology, psychologists and psychological theory and knowledge they were centrally involved from the outset in defining problems and shaping responses.

Psychologists were at the forefront of challenging standard public health messages to change individual behaviour (e.g. decreasing sexual partners, consistent condom use), to a greater understanding of underlying factors that conferred vulnerability to HIV acquisition. These factors included marginalisation and powerlessness due to stigmatised group membership (gay/bisexual men, intra-venous drug users, sex workers etc.), the contribution of prior trauma experiences on behaviour and the inadequacy of traditional public health

models (Beeker, Guenther-Grey, & Raj, 1998; DiClemente & Peterson, 1994; Kelly, Murphy, Sikkema, & Kalichman, 1993).

HIV nursing had to quickly establish adaptive and novel responses to working in rural and urban settings with varied prevalence, evolving in response to patient need and service provision. In high prevalence areas, size and complexity of caseloads provided opportunities for nurses to become highly skilled in specific aspects of care. In contrast, low prevalence areas were unlikely to support a multidisciplinary specialist workforce and nursing roles expanded accordingly to deliver services traditionally provided by social workers and psychologists in other contexts (Tunncliffe, Piercy, Bowman, Hughes & Goyder, 2013)

Increased acknowledgement of the limits to individual professional roles happened for several reasons. Firstly, many clinicians and researchers responding to the challenge of HIV/AIDS came from the communities most affected. Gay men, community activists and people from minority ethnic groups therefore had a dual role regarding forging the responses to HIV prevention, both as members of at-risk communities and as professionals with service delivery responsibilities (Slevin, Ukpong & Heise, 2008; Rabkin, McElhiney, Harrington, & Horn, 2018; Kleppe, & Caldwell, 2011). This led to greater understanding of the personal impact and lived experience of HIV. This, in turn, promoted service user involvement in service design and delivery.

Secondly, for many years HIV/AIDS was a life-limiting illness for which there was no effective medical treatments. Therefore, the focus became the person living with the condition and quality of life, not the symptoms. Nurses, psychologists/counsellors and other professionals developed collaborative relationships within healthcare and linked with the HIV peer support community. When new medications were developed, activists fought hard to access timely treatments (Smith & Whiteside, 2010; Killen, Harrington & Fauci, 2012), which profoundly influenced how clinical trials were conducted. Regulatory agencies and pharmaceutical companies were actively challenged to respond urgently to the situation (Koen, Essack, Slack, Lindegger, & Newman, 2013).

Lastly, developments in treatment over the past 25 years have changed health prognoses from mostly terminal/palliative to long-term and manageable. HIV is now, in developed countries at least, seen as a health condition with good medical outcomes.

However, the stigma attached to HIV remains, which has a negative impact on mental health, effective coping, and long-term medication adherence (Rueda, Mitra, Chen, Gogolishvili, Globerman, et al., 2016).

Interdisciplinary vs. multidisciplinary: The subtle difference

Despite considerable advancements in HIV medical treatment, morbidity and mortality remain of concern (BHIVA, 2018). This is often linked to complex psychosocial issues, as well as systemic factors affecting prompt diagnosis and medication adherence (Beima-Sophie, Begnel, Golden, Moore & Ramchandani et al., 2020; Nightingale, Sher, Mattson, Thilges, & Hansen, 2011; Pence, Mugavero, Carter, Leserman, Thielman et al., 2012).

Increasing recognition of the complex interplay between physical and mental health needs resulted in closer multidisciplinary working, highlighting the overlap in many healthcare worker roles (Ndoro, 2014).

The benefits of multidisciplinary working relate to each profession bringing its strengths. For example, doctors bring biomedical expertise and in the on-going management of HIV, nursing has become central to the delivery of person-centred care (Bolton & Gillett, 2019; Vance, Struzick & Raper, 2008). Psychologists have expertise in formulation and intervention, particularly for complex clinical presentations and trauma-related issues (Garzonis, Mann, Wyrzykowska, & Kanellakis, 2015; Pudalov, Swogger & Wittink, 2018). Multidisciplinary care advocates that professionals each work from an individual position of expertise, albeit alongside each other. However, this can sometimes be experienced by service users as people looking after different parts of them, rather than integrated and co-ordinated care.

There is, therefore, a call for the integration of knowledge, joint working and a shared response to issues, working alongside people living with HIV, to understand and meet inter-relating needs (BHIVA, 2018, BPS & MEDFASH, 2011; Warner & Rutter, 2020). Interdisciplinary working differs slightly in its ethos, being defined more as integrating and synthesising approaches to care delivery (Giusti, Castelnuevo & Molinari, 2017). It can be achieved within teams, or indeed between teams/services, as there can be overlaps across many issues (e.g., TB, Hep C, pregnancy, sexual health issues, child to adult transition) (BHIVA, 2018).

The development of interdisciplinary care: A UK example

Given the complex needs of many people living with HIV, due to issues such as stigma, prior trauma and marginalisation, there can be considerable overlap between clinicians in terms of the focus on wellbeing (Croston & Rutter, 2020; Watkins-Hayes, 2014). Treatment progression has reduced distress relating to symptoms and side-effects, meaning clinician focus, perhaps particularly for specialist nurses, has remained person-centred and less focused on the medical model.

This is likely due to growing awareness of associations between psychological distress and adherence (Leserman, 2008; Smart, 2009), with consistent adherence being central to treatment effectiveness. Therefore, there is a natural leaning toward working together, which may originate in the clinic but can extend beyond this as networks develop.

This is what happened in the experience of the authors. Relationships that were established and then grew between psychology and nursing on the ground, developed into broader connections across services and professional groups/bodies.

On reflection, we could pinpoint the birth of this shift for us, to the connections made over The National HIV Nurses Association (NHIVNA) first audit. The NHIVNA chair at the time

opted to audit the “*Standards for psychological support for adults living with HIV*” (BPS, BHIVA & MEDFASH, 2011).

The standards acknowledge the varied mental health needs amongst a diverse HIV population and advocated a stepped model of psychologically-informed care to be delivered by all HIV clinicians. In stepped-care models, the complexity of patient need is matched by increased specialist skills and expertise on the part of the health professional.

However, as non-mental health HIV practitioners will have contact with service users with all levels of psychological issues, including highly complex, professionals with specialist mental health qualifications should provide support to the whole team through activities such as consultation, supervision, facilitation of reflective practice, teaching, and training.



This was therefore, considered an area of great importance, and after the NHIVNA chair initiated the audit proposal, clinical psychologists were invited to get on board. A working group was formed consisting of representatives from nursing, the HIV community, psychology, academics and Directors/Executives from National bodies. An audit proforma was co-produced by all, and nursing psychology shared the responsibility for the write up.

The audit results, and the result of the results

In brief, the findings of the audit indicated that, where psychological distress was identified, the stepped-care model was generally implemented. However, there was a lack of consistent psychological and cognitive screening, as well as inconsistent mental health history taking and risk documentation. The audit showed many HIV services lacked policies around mental health, risk and adherence, and there was also limited teaching/training regarding psychological issues, reflecting that many HIV services lacked access to in-house mental health professionals.

On discussing the audit results and obstacles to the comprehensive delivery of psychologically-informed care in HIV services, the working group defined a range of recommendations. These included the suggestion to develop a training package to support care professionals working at the non-specialist levels of the stepped-care model.

Recommendations were made for the development of clearer pathways for psychological assessment, consistent documentation of mental health needs and risk and standardisation of psychological and cognitive screening assessment tools. An annual nursing review of care and the development of local mental health policies, risk and adherence were also suggested. It was from this list of 'to do's' that the interdisciplinary relationships began to grow and cement.

Robust relationships; Rich work output

On the back of the audit results enhancing skills in the delivery of psychologically-informed care was considered a priority. The nursing audit lead formed another working group, again consisting of nurses, psychologists, community experts and national body chairs.

We worked together to co-create a training programme, growing from a range of perspectives, considering the broad and varying needs of the HIV population, as well as the learning needs of those delivering healthcare. The teaching resource was designed to be co-delivered by nursing and psychology. Pilots of the training have received positive feedback and there is the hope that the project can be rolled out nationally over time.

The publication of the audit results, alongside other contemporary guidance focusing on treatment post-diagnosis (e.g. BHIVA monitoring guidelines 2015) led to conversations around how to ensure salient assessments were carried out in accordance with existing guidance (BHIVA, 2012; BPS, BHIVA & MEDFASH, 2011). Ideas were formulated around creating an annual health review model for people receiving HIV care. This could address the lack of focus on mental health and cognitive screening in clinics, by inclusion in a review protocol. This afforded another opportunity for collaboration between medicine, nursing, and psychology.

As the concurrent chairs of NHIVNA and the BPS faculty for HIV and sexual health now had a solid working relationship, clinical psychology input was welcomed onto the annual health review project. This not only embedded the presence of psychological screening into a practical guide for HIV care, but also allowed psychological influence of broader areas addressed by the review, such as sexual health and function.

As a primarily nurse-led project, psychologists were able to learn about the breadth of the specialist nurse role and share ideas about how to realistically incorporate assessments and conversations about psychological issues, particularly when in-house mental health provision is unavailable. Once again, the worlds of health and mental health were sharing ideas and working together to ensure a holistic approach to healthcare and wellbeing. The annual review standard was published in 2018 with the hope it will begin to guide practice in HIV services across the UK.

As the professional bonds between clinicians deepened through interdisciplinary projects, working together became the norm. Joint study days were organised, and a clinical psychology presence was regularly requested for HIV nursing conferences, through presentations or participation in expert panels. The invites were reciprocated when the BPS HIV and sexual health faculty organised educational events, with a view to accessing specialist knowledge regarding complexities of the nursing role in ongoing HIV care provision. As a result, further networking occurred and more relationships were founded, with each becoming increasingly familiar with the expertise and priorities of the other. Although the roots of the relationships were between nursing and psychology, there was also outreach to psychology from medicine when it came to updating the BHIVA standards of care (2018).

The sharing and combining of knowledge eventually culminated in the plan to write a book focusing on psychological issues within HIV care (Croston & Rutter, 2020). Again, this idea was driven by a well-developed professional relationship, and utilised firmly established networks to draw together knowledge from a range of professionals. The endeavour spanned several years; however, it finally came to fruition and was published with the intent of being a guide for non-mental health professionals working, or interested, in HIV care. It was hoped that by bringing emphasis to HIV-related psychological issues, that individual clinicians and teams would bring this to their work and advocate for the holistic approach that is so needed within the field.

Reflections on the feedback loop

Specialist physical health services for long-term conditions create an ideal opportunity for cross-connection between medical, nursing and mental health colleagues. However, busy work schedules and service pressures can sometimes mean independent focus on service user needs, contacting each other only when necessary.

Whilst multidisciplinary working remains fitting for many purposes, our experience of actively working alongside colleagues from other professions on broader issues of care has proven particularly enriching. It is perhaps fair to reflect that psychologists have benefitted from the pragmatic realism of nursing colleagues in particular, and their ability to move projects forward in a manner that makes a real difference to clinical care. This way of working has also highlighted the complexity of care that nurses deliver in HIV services, and collaboration across disciplines has created a framework for shared knowledge and mutual support.

Of course, although inter-professional connections are the focus here, we must not forget the engagement with experts by experience, which is historically common (although still requires improvement) to HIV projects and developmental work.

Just as working alongside people living with HIV helps care professionals understand what is required in terms of healthcare provision, different professionals linking up in a meaningful way helps us all understand what is required from each other. Recognising strengths and limitations not only identifies where mutual support is useful but can also help shift professional blind spots and help us think outside of our usual frameworks.

Without the relationships and connections, clinical work is more likely to happen in silos and be less holistic as a result. By truly working together, we can develop tools to support the delivery of optimum HIV care, guided by standards and clinical frameworks already steeped in broader interdisciplinary thinking.

It follows then, that these frameworks, are primed to be delivered in a more integrated fashion, rather than being adapted at the point of care delivery. Could it then be posited that clinical guidance encouraging interdisciplinary working, fosters professional relationships on 'the ground floor'? Cohesive teams are likely to deliver high quality care, and positive evaluation of this work may cement clinical relationships, perhaps leading to further clinical and strategic collaboration?

However, different professions working alongside each other may not be without its challenges, due to range of factors including (although not exclusive to) conflicting priorities, opposing perspectives and imbalances in power distribution. Additionally, team dynamics can be complex, and the development of connections may well come with ruptures.

Nevertheless, as we know, if managed effectively, relationship ruptures can be a great source of learning as they can inform us of the positions of others, and the rationales behind those positions. With open communication, perhaps supported by reflective practice, the repairing of ruptures may actually facilitate team cohesion.

Conclusion

The UNAIDS 90-90-90 targets for epidemic control have been achieved across many Western countries. However, this requires support structures to maintain medication adherence, mood and quality of life, as well as psychological coping mechanisms to counter experiences of HIV stigma. HIV stigma can negatively affect the happiness, mental health, self-esteem, sexual and social relationships among those living with HIV and can arguably be considered the most important unaddressed issue affecting quality of life for this population. The challenge for all clinicians will be to both facilitate the development of these skills and support those not yet ready to manage independently.

The involvement of service users is crucial to the development of strategies to achieve these goals. However, service user participation is not yet completely embedded in the design and delivery of clinical services, and this remains a barrier to full collaboration.

Continued focus on health-related quality of life for people living with HIV, proposed as the fourth 90 (Lazarus, Safreed-Harmon, Barton, Costagliola, Dedes et al., 2016), means we are challenged to move beyond clinical solutions and the sole focus on viral suppression. This is best addressed from a shared perspective.

Reflecting on our own experiences, there is great value in forming robust professional relationships, and we hope to continue to strive on together to address the needs of the HIV population. Our experience has taught us that not all ideas “have legs”, however, it is the process of collaboration that underpins meaningful progress.

As we look forward there are projects on the agenda and our reach is extending internationally, thanks to European HIV nursing conferences and nursing links with the European society of person-centred care.

After working in an interdisciplinary manner for many years now, we are strong believers that we can improve healthcare for people living with HIV much further together, than we ever could working strictly within our own disciplines. When aiming to deliver the highest standard of care possible, we are convinced that this will best be achieved collectively.

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CUT BITS

The challenge to healthcare professionals is how to provide effective and comprehensive health care to address often complex clinical issues while involving the service user as an expert in their health concerns (Erskine, Griffith, DeGroat, Stolerma, Silverstein et al., 2013; Fewster-Theunte & Velstor-Friedrich, 2008; Knowles, Chew-Graham, Coupe, Adeyemi, Keyworth et al., 2013).

The use of the biopsychosocial model in medicine and healthcare delivery varies across health conditions and services (Kusnanto, Agustian & Hilmanto, 2018; Wade & Halligan, 2017).

Although traditionally, psychology roles may have been mostly built around one-to-one therapy, changes in keeping with ‘new ways of working’ and the adoption of stepped-care models into physical healthcare have led to a broadening of responsibilities and expectations.

As advocated by relevant guidance, gradually, (where resources allow) psychologists have expanded their direct care to include, among other aspects, supporting the teams to deliver psychologically-informed care, via consultation, supervision, teaching/training, and the introduction of reflective practice models (British Psychological Society, British HIV Association & Medical Foundation & Sexual Health , 2011; Garzonis,et al, 2015; Kurtz,2020).

Interdisciplinary working differs slightly in its ethos, being defined more as integrating and synthesising approaches to care delivery (Giusti, Castelnovo & Molinari, 2017). This might mean combining knowledge and practices and effectively working

An interdisciplinary approach could be considered particularly applicable to HIV services, given the clear associations between psychological issues and health outcomes. As already outlined, HIV is chronicled as a complex area to work in, due to historical trauma of many forms (on an individual and societal level) and the ongoing problem of stigma affecting groups that are often already socially marginalised (Campbell, 2020; Watkins-Hayes, 2014).

Additionally, of course, an interdisciplinary approach does not necessarily have to be direct clinical work, but can take the form of teaching/training, research, and service development.

Given the difficult and often traumatic socio-political context of HIV, nursing and medical colleagues in the field often have heightened awareness of psychological impact of living with this condition.

in response to a historical interest, which was further developed by in-service contact with clinical psychology.

It follows then that if existing clinical frameworks are already informed by multiple perspectives, they are primed to be delivered by multidisciplinary teams in a more integrated fashion, rather than being adapted at the point of care delivery. It could then be posited that clinical guidance that encourages interdisciplinary working, leads to the fostering of professional relationships on 'the ground floor'.

A cohesive team could be considered more likely to deliver high quality care, which could perhaps be evaluated by an interdisciplinary audit or service review? And can we predict that positive feedback could cement clinical relationships and lead to further collaboration both clinically and strategically?

The responses to the HIV epidemic have required significant changes to the ways in which individuals and professions have worked traditionally. These changes have arisen from a collaboration that have changed the boundaries amongst activists, clinicians, academics, policy makers and people living with HIV. Tackling multi-faceted, complex, inter-twined development challenges requires tools – research, policy, and practice – that are broad based, inclusive, and long ranging.

Working together towards shared goals has been the cornerstone of interdisciplinary working which, we argue, have demonstrated benefits and outcomes in the management of HIV. These benefits do not ignore that interdisciplinary working can be difficult as there are challenges to implementing shared goals into different professional roles and contexts.

There can be significant differences to the methods by which goals can be achieved, there can be a contest for dominance to the dominant paradigms in each discipline and the potential for mismatched priorities. However, interdisciplinary working at its best can result in a new and holistic perspective on the individual, fresh and broader research insights, complementariness, and positive interdependence.