

Working title:**Person-centred care and HIV: challenges and solutions****Authors:**

Tristan J Barber^{1,2}, John Saunders³, Nina Barnett^{4,5}

- 1 Chelsea and Westminster NHS Foundation Trust, London UK
- 2 Imperial College London, UK
- 3 Centre for Clinical Research in Infection and Sexual Health, Institute for Global Health, University College London
- 4 London North West University Healthcare NHS Trust
- 5 Medicines Use and Safety Team, NHS Specialist Pharmacy Service

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Summary/ Abstract

Person-centred consultations (PCC) are fundamental to effective health care communication and its use is embedded within key clinical guidance. There are three aspects to PCC: use of the best available research evidence, clinical expertise of the clinician and the patient's circumstances, goals, values and wishes. Balancing these three aspects in the context of HIV prevention and management can be challenging and we use three case examples to highlight these.

Background

Person-centred consultations (PCC) are fundamental to effective health care communication. Embedded within key guidance from many organisations, including the World Health Organisation (WHO),¹ the General Medical Council (GMC)² and the General Pharmaceutical Council (GPhC)³, PCC incorporates use of clinician skills, evidence-based knowledge and patient perspective to provide personalised, co-ordinated care which enables people to make the most of their lives.^{1,4} This was recognised as far back as 1996, when *Sackett et al.* discussed the key features for effective evidence-based practice, including the patient's perspective in their definition (Figure 1).⁵

[Figure 1]

At the heart of a PCC approach is an understanding of what is important to the individual and how this informs their desires for treatment and care, pioneered by the HIV health and patient community. From this starting point a shared understanding between the individual and clinician can be achieved and used to tailor a personalised care plan, in line with the principles of shared decision making.⁶ Indeed, this consideration of what an individual prioritises in order to meet their needs is paramount and a core feature of the *GMC Guidance (2008)* on consent in line with the recent *Montgomery vs. Lanarkshire Health Board* ruling (2015).^{2,7} This UK Supreme Court judgement supports PCC by expecting all clinicians to identify what is important (material) to the person they are treating, in terms of both outcomes and associated risks. Clinicians are required to discuss reasonable alternatives to the treatment offered so that the person, working with the clinician, can proceed with an informed choice. Similar legislation has existed for some time in the United States (USA),⁸ Canada⁹ and Australia,¹⁰ which is closest to UK Law.¹¹

There can be challenges for the clinician around balancing a person-centred approach (patient's circumstances, goals, values and wishes) with the strength of the evidence base and our own experience in managing these complex situations. We use here three case examples to highlight potential challenges relating to PCC and HIV prevention and treatment.

Case 1

Patience is a 34-year-old woman who presents at a UK clinic, having recently moved from the USA for work. She has been HIV positive for 10 years and is stable on emtricitabine/tenofovir alafenamide (FTC/TAF; Descovy[®]) and dolutegravir (DTG).

In the past, she was taking a multi-tablet regimen of FTC/tenofovir disoproxil fumarate (FTC/TDF; Truvada[®]) with raltegravir (RAL) 400mg twice daily. She says she was initially switched to Truvada with DTG so that she could have a once daily regimen, and then from Truvada to Descovy as she was told it's a 'much safer treatment for her bones and kidneys'. She has never tried abacavir as her previous doctor said it might increase her risk of heart attacks. She has not had side effects to any HIV medications.

She has a lot of faith in her treating physician from the USA and is happy with her medication. She finds it hard to believe that anyone would not agree that her current regimen is the best not only for now, but also for her long-term health. Patience is seen without any transfer letter so her new clinician asks if she is happy for them to contact her physician in the US for more information, in particular, for information on the result of any previous HLA B5701 test and details of the rationale for switching therapy.

Patience is given a two-month prescription for Descovy[®], asked for a urine sample to test for proteinuria and has a full set of HIV baseline blood tests taken, including an HLA B5701. She is asked to return in 6 weeks' time, following discussion at the local multidisciplinary team (MDT) 'virtual clinic'. In the interim a medical summary, received from her previous clinician in the USA, provides no reason for commencement of TAF according to the UK TAF policy and the local MDT does not approve TAF for treatment. Patience is very angry with this decision and challenges her clinician to explain why she is being denied a 'superior' treatment.

Case 2

James, a 24-year-old gay man, is seen in clinic for pre exposure prophylaxis (PrEP) follow up. He started PrEP 18 months ago at which time he was not always using condoms with sexual partners and had been diagnosed with syphilis and rectal gonorrhoea in the preceding six months. He has been using a daily PrEP regimen and apart from initial short-lived nausea, James has not experienced any side effects, reporting excellent adherence. Mild proteinuria had been detected on a couple of visits however serum creatinine and estimated glomerular filtration rate has always been within normal range.

During previous visits James has reported sexualised drug use and symptoms of anxiety. He has been attending regular one to one psychology sessions over the past six weeks. For the last nine months James has been in a relationship with an HIV positive man who is taking antiretroviral therapy and has an undetectable viral load. They are not using condoms together, have agreed to a monogamous relationship and James has not had any other partners in the last three months.

James understands the data regarding 'undetectable=untransmissible' but would like to continue PrEP. He becomes increasingly agitated and anxious when he is told by his clinician that, according to national guidelines, he is no longer eligible for PrEP. He cannot afford to pay for it generic or otherwise. James asks the clinician how he can know that there is no risk of him getting HIV and says that if he is not prescribed PrEP and subsequently gets HIV it will be the clinician's fault.

Case 3

Steve is a 30-year-old man who meets eligibility criteria for PrEP. Whilst taking a past medical history, Steve mentions that he has a hereditary renal condition which causes progressive and irreversible renal failure resulting in end stage renal failure in the next 15 to 20 years. Currently his renal function is normal, he has no co-morbidities and is not taking any nephrotoxic drugs. He is keen to start PrEP, despite acknowledging the possible side effects and impact on his kidneys. Steve gives his consent for his clinician to discuss this with his nephrologist and the HIV MDT before a final recommendation is made.

Multidisciplinary colleagues raise concerns about the potential to accelerate his renal disease, the risk of acquiring HIV and the potential implications of life-long antiretroviral therapy. The potential contributions of other harm reduction strategies, including clinical psychology support, are highlighted. While the team acknowledge that the likelihood of renal toxicity is low, there is concern regarding a lack of evidence surrounding the use of PrEP in an individual with this specific condition. It is agreed that Steve can be offered PrEP, with close renal monitoring, an assessment with the psychology team, and ensuring that he is aware of both the known risks and the limitations of evidence in his situation.

Discussion

The cases described above illustrate a variety of challenges faced by HIV clinicians and patients.

For Patience and her clinician, a key component of care will be to agree a shared understanding of what constitutes 'superior' treatment, which could relate to virological suppression, clinical outcomes, or cost. By understanding the meaning of 'superior' in Patience's view and avoiding judgement, the clinician can address

her concerns, discuss the clinical and research evidence regarding bone and renal health, giving Patience the tools to weigh up the pros and cons for the alternative offered.

For James, the focus on biomedical methods of HIV prevention (U=U and PrEP) may obscure the potential benefits of a more holistic prevention approach that includes behavioural interventions for someone who may be feeling both frightened and angry. Whilst best available evidence would suggest that James is not at risk of HIV acquisition from his regular partner, he may have underlying anxieties about his relationship, or the trust within and the agreed monogamy. In this context, a flexible approach guideline is helpful, identifying his concerns that can allow PrEP provision. This creates a bridging step to gain trust with the patient and engage him in discussion about some of the other issues he is experiencing that may warrant further exploration, or psychological referral and support, for example. PrEP may therefore be seen as part of a pathway and enable risk reductions whilst supporting James and reassessing anxieties around PrEP cessation at a later stage.

For Steve, whilst the evidence base would support the use of PrEP to reduce his risk of acquiring HIV, there is a lack of evidence concerning potential harms when using PrEP in someone with his renal condition. He may appear nervous and uncertain or, indeed, overconfident and cavalier with regard to possible risks. From a clinical perspective, reducing potential exposure to nephrotoxic drugs would seem prudent given the seriousness of any potential acceleration of renal disease, drawing on the evidence base for event based dosing or modified daily dosing. However, the potential acquisition of HIV may have an impact of his renal health as well as wider mental and physical health implications. Thus an open and frank discussion about the balance of concerns and the (lack of) available evidence, including the use of other HIV prevention interventions, is required in provision of PCC to Steve.

Patient's perspective

Exploring patient attitudes, personal preferences, concerns, beliefs and values, is an essential part of PCC in order to reach a shared decision.¹² Patience may feel frustrated at what she considers suboptimal care and the inequity of her situation. There may be further anxieties around navigating and new health system in the context of moving to a new country and starting a new job. While UK guidelines do not recommend

prescription of her current treatment, the decision to delay a switch until Patience has settled into her new job and life in the UK supports mental and physical health outcomes in the immediate future.

While James's fears and worries could seem irrational to the treating clinician, it is important to not make James feel that he has to deceive his clinician in order to be prescribed PrEP (by saying that he is having other partners) when he would prefer to be open and honest. Encouraging reflection may elicit deeper insights rather than attempting to deny access to PrEP initially and shared goal setting may also be useful in terms of achieving a PCC approach. For instance, by agreeing and setting a timeline for review whilst acknowledging the apparent tension between guidelines and patient wishes.

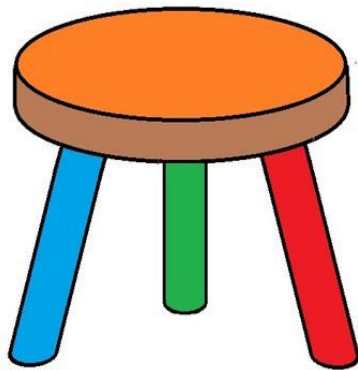
For Steve, the requirement of a renal transplant in the future is a certainty, regardless of whether or not he uses PrEP. He has made it clear that his main concern is reducing his risk of acquiring HIV. While he may choose an option that the clinician would not have chosen, the benefit to the clinical relationship is that there is potential to explore his personal preferences for HIV risk reduction strategies. This could lead to agreeing another way forward in the future, especially through the combination of interventions and the use of PrEP in the short term or whilst risk is greatest.

Neither use of the best available evidence nor exploring the patient's perspective is sufficient without clinical expertise - *'the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice'*.⁵ Drawing upon clinical expertise allows for *'more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care.'*⁵ Clinical experience allows practitioners to support patients in linking their own perspectives to what they hear and understand by the description of evidence they are presented with. Patience may need to have some time to reflect on what 'superior' really means, whilst James and Steve may need support in weighing up the risks and benefits of treatment when their questions are not readily answered by available guidelines and must be considered in a more psychosocial and 'real world' context as to how the evidence may positively or negatively engage with their perceived quality of life.

Conclusion

Clinicians have a duty, set out in professional guidance and legislature, to inform individuals of reasonable alternatives relevant to their care even if it cannot be provided by the service. Some may mistake PCC as a proxy for giving the patient what they demand. However, PCC is a process of understanding and negotiating with patients, ensuring both clinician and patient understand what is important from their perspective, why this is important to them and allowing both to contribute to decision making. There are challenges to this approach which require the clinician to operate in a more reflective, less prescriptive role. This can be especially difficult when operating within the time constraints of a busy clinic and when observing or experiencing emotions of anxiety, fear, frustration or anger. However, PCC supports optimisation of the benefit of prescribed treatment and improved health outcomes by partnering with the patient to co-create and implement their ongoing care plan.

Figure 1: The three aspects of person-centred care



- ✓ **Best available research evidence**
- ✓ **Clinical expertise of the practitioner**
- ✓ **Patient's circumstances, goals, values & wishes**

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References

1. World Health Organisation, 2007. People-Centred Health Care A policy framework, Western Pacific Region: World Health Organisation Geneva
http://www.wpro.who.int/health_services/people_at_the_centre_of_care/documents/ENG-PCIPolicyFramework.pdf [Accessed 27 Feb 2018].
2. General Medical Council. Good medical practice. Consent guidance: partnership. 2008. Available at: http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_partnership.asp [Accessed 27 Feb 2018].
3. General Pharmaceutical Council. Standards for pharmacy professionals. May 2017. Available from: https://www.pharmacyregulation.org/sites/default/files/standards_for_pharmacy_professionals_may_2017_0.pdf [Accessed 27 Feb 2018].
4. Health Foundation, 2014. Person-centred care made simple, London: The Health Foundation.
<http://www.health.org.uk/publication/person-centred-care-made-simple> [Accessed 27 Feb 2018].
5. Sackett DL, Rosenberg WM, Gray JA, et al. Evidence based medicine: what it is and what it isn't. *BMJ* 1996;312(7023):71-2.
6. National Institute for Health and Care Excellence. Shared decision making. February 2018
<https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making> [Accessed 26th march 2018].
7. *Montgomery v Lanarkshire Health Board (Scotland)* [2015] UKSC 11. Available from: <http://www.bailii.org/uk/cases/UKSC/2015/11.html> [Accessed 27 Feb 2018].
8. *Canterbury v Spence*, 1972. 464 F. 2d 772 United States.
9. *Reibl v Hughes* 1980. 2 SCR 880. 114 DLR (3d). Canada.
10. *Rogers v Whitaker* 1992. HCA 58. Australia.
11. Holden ACL. The future of failure to warn in dentistry after Montgomery: reflections from Australia. *Br Dent J* 2018;224(1):11-14. doi: 10.1038/sj.bdj.2018.1
12. Elwyn G, Durand MA, Song J, et al. A three-talk model for shared decision making: multistage consultation process. *BMJ* 2017;359:j4891. doi: 10.1136/bmj.j4891