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Editorial



Breaking the fourth wall: Integrating quality into HIV care

When a novel infectious agent is discovered, its clinical and epidemiological course is uncertain. Some agents appear and disappear without trace, infecting perhaps only one individual, whereas others expand to affect the lives of millions, sometimes over decades, as we have seen recently with SARS-CoV-2. The first report of AIDS appeared in the medical literature in 1981¹. Later, the causal virus, HIV, was identified², followed by both the development of widespread diagnostic tools and therapies in an arc of scientific progress that should be celebrated on this World AIDS Day in 2021.

The global goals have moved on to the 90-90-90 target adopted by the UNAIDS in 2014³, by which 90 per cent of people living with HIV would know of their status, 90 per cent of that 90 would receive sustained antiretroviral therapy, and a further 90 per cent of those on therapy would have an undetectable viral load globally. The ambitious aim was to achieve these targets by 2020, and though that has not occurred, there have been many success stories; the present aim is to move to 95 per cent for each of these parameters in the next decade⁴. In addition, it has been suggested that a fourth 90 be added, which is health-related quality of life $(QoL)^{5,6}$, partly in response to the idea that simple suppression of HIV viral load does not manage many of the HIV-associated problems that are related to a host of factors, including increased inflammation, persistently aberrant immune responses, side effects of therapies, stigma and other psychosocial challenges^{5,6}.

Although the idea has had a lot of support^{5,6}, it also comes with a number of inherent difficulties, the greatest of which is the problem of measurement. Quality may be, by its very nature, qualitative. The first three goals of the UNAIDS have conceptually easy outcomes to assess. However, the improvements in QoL that are produced by good clinical care may be hard to measure. In addition, there are components of good clinical care that are especially hard to quantify, such as compassion or kindness. Hopefully, both are common in HIV clinics but are hard to enumerate. Perhaps, to borrow the words of Justice Potter Stuart of the United States Supreme Court when referring to the topic of what makes something pornographic, quality is something we cannot define well, but "we know it when we see it"⁷.

One traditional way of evaluating quality in healthcare has been the development of key performance indicators (KPIs), where individual elements of care, usually the most easily measurable such as hepatitis A immunity and sexual health screening rates in people living with HIV, are used as surrogates for care, in general. An example of this has been seen in the British HIV Association Audit Tool^{8,9}. However, such outcomes may be subject to Goodhart's Law^{10,11} originally related to the areas outside of medicine but applied to the healthcare settings now¹². It can be paraphrased as "When a measure becomes a target, it ceases to be a good measure". It signifies that such targets tend to become an end in themselves for the purpose of funding and other non-patient-related outcomes. In many settings, including healthcare, metrics have been described as leading to perverse outcomes, such as dissuading cardiac surgeons from operating on patients considered to be more risky or leading hospitals to keep patients alive in intensive care unit beyond 30 days to improve outcome figures¹³. In addition, those outcomes chosen to be KPIs can be process driven rather than outcome driven and are not always generalizable from setting to setting.

Four common metrics are used at a health organization level to define quality of performance. These include service level, service cost, customer satisfaction and clinical excellence¹⁴. A traditional approach to improving quality is the quality cycle model (PDSA) attributed to Deming¹⁵ in

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the context of improving engineering outcomes (Plan- Do- Study- Act). It is simple in concept and can be aligned with health service quality systems, though developing the tools to do so which are applicable across different settings can be a difficult problem. Using engineering-type approaches can be attractive and useful, though it is to be remembered that the object of the engineering approach is to build every car in a factory to the same quality, whereas there is a great inherent variability in human patients.

As Antela et al¹⁶ have pointed out that there are multiple OoL tools available, including many that are HIV-specific. The further shift is now towards patient-reported outcomes (PROs). These place the patient at the centre of the healthcare system and of their individual care¹⁷ and are focused on data that can only be obtained from the patient, including health-related QoL – the actual type of quality proposed to be assessed for the fourth 90. Consequently, PROs, which provide information on the impact of the disease and its treatment, from a patient's perceptive, are now integrated commonly in prospective clinical trials and clinical quality registries¹⁸ often designed around specific questions. These can generate unique information on the impact of a medical condition and its treatment from the patient's perspective. To create a generalizable score useful in clinical trials and registries, and possibly within individual institutions, equally applicable across all settings, is ambitious. It is more likely that a useful tool can be developed at a local or regional level, as suggested in Spanish guidelines by Antela et al¹⁶ because of social, cultural and clinical variations in different settings.

Perhaps more important than PROs. is patient-centred care, because it is not a concept that relies on markers or validation across clinics. The Institute of Medicine (IOM) defined patient-centred care as "Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions"¹⁹. There are six dimensions of patient-centred care endorsed by the IOM²⁰ which state that care must be "(i) respectful to patients' values, preferences and expressed needs; (ii) coordinated and integrated; (iii) provide information, communication and education; (iv) ensure physical comfort; (v) provide emotional support – relieving fear and anxiety; and (vi) involve family and friends". To a certain extent, these outcomes can be measured in terms of PROs, However, individuals should be placed at the centre of care and may want their care to be managed in a different way to

what might be objective, universal 'best practice' but is more suitable for them as individuals.

Maintaining contact, engagement and treatment has always been the priority. It is a priority embedded in the hierarchy of the three 90s where effective treatment is predicated on diagnosis and the availability of therapy and engagement in care. We cannot measure well the QoL of those whose HIV has not been diagnosed or treated. Overall, the use of qualitative indicators is relatively uncommon in infectious diseases management, perhaps because in many cases, patients get better quickly, whereas chronic diseases are more amenable to measuring typical quality indicators. A very large number of QoL tools already exist for people with HIV, suggesting a lack of consensus on what is required for such a tool²⁰.

At the time of the COVID-19 pandemic, HIV care has had to be flexible to maintain the good health of our patients. Measures of quality should be adaptable. sustainable but ideally embedded in routine care. Some of the key principles can go back to Deming¹⁵; a focus on leadership as viewing quality as important, measuring things so that one knows how one is doing and being able to see if changes actually lead to better outcomes, focusing on things that actually benefit patients and allowing everyone in the organization to have a voice in what should be improved, especially patients. Perhaps, it is late to explain the title in the last paragraph breaking the fourth wall is a film making term that signifies the ability for the actors to break the narrative and talk directly to the audience. In itself, it may not lead directly to measurably better care, but it is a wonderful thing to celebrate that in addition to diagnosis, treatment and engagement we are adding quality as a pillar of HIV care on this World AIDS Day.

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References

- 1. Centers for Disease Control (CDC). Pneumocystis pneumonia Los Angeles. *MMWR Morb Mortal Wkly Rep* 1981; *30* : 250-2.
- Barré-Sinoussi F, Chermann JC, Rey F, Nugeyre MT, Chamaret S, Gruest J, *et al.* Isolation of a T-lymphotropic retrovirus from a patient at risk for acquired immune deficiency syndrome (AIDS). *Science* 1983; 220: 868-71.
- The Joint United Nations Programme on HIV/AIDS. 90-90-90 – An ambitious treatment target to help end the AIDS epidemic. Available from: http://www.unaids. org/en/resources/documents/2014/90-90-90, accessed on December 15, 2021.
- 4. The Joint United Nations Programme on HIV/AIDS. *Fast-Track: Ending the AIDS Epidemic by 2030.* Geneva: UNAIDS; 2014.
- Lazarus JV, Safreed Harman K, Barton SE, Costagliola D, Dedes N, dial Amo Valeso J, *et al.* Beyond viral suppression of HIV. The now quality of life frontier. *BMC Med* 2016; *14*:94.
- 6. Webster P. UNAIDS survey aligns with so-called fourth 90 for HIV/AIDS. *Lancet* 2019; *393* : 2188.
- 7. Gewertz P. On "I know it when I see it". *Yale Law J* 1996; *105* : 1023-47.
- Michael S, Gompels M, Sabin C, Curtis H, May MT. Benchmarked performance charts using principal components analysis to improve the effectiveness of feedback for audit data in HIV care. *BMC Health Serv Res* 2017; 17: 506.
- Catumbela E, Certal V, Freitas A, Costa C, Sarmento A, da Costa Pereira A. Definition of a core set of quality indicators for the assessment of HIV/AIDS clinical care: A systematic review. *BMC Health Serv Res* 2013; 13:236.

- Goodhart C. Problems of monetary management: The U.K. experience. In: *Papers in monetary economics*, Vol. 1. Sydney: Reserve Bank of Australia; 1975.
- 11. Strathern M. 'Improving ratings': Audit in the British university system. *Eur Rev* 1997; 5: 305-21.
- Crawford SM. Goodhart's law: When waiting times became a target, they stopped being a good measure. *BMJ* 2017; 359: j5425.
- London Review of Books. Kept alive for thirty days. Available from: https://www.lrb.co.uk/the-paper/v40/n21/stefan-collini/ kept-alive-for-thirty-days, accessed on December 15, 2021.
- 14. Bandyopadhyay JK, Coppens K. The use of six sigma in health care. *Int J Qual Product Manag* 2005; 5 : 1-12.
- The W. Edwards Deming Institute. PDSA cycle. Available from: https://deming.org/explore/pdsa/, accessed on November 10, 2021.
- Antela A, Rivero A, Llibre JM, Moreno S, the RET Group. Redefining therapeutic success in HIV patients: An expert view. J Antimicrob Chemother 2021; 76: 2501-18.
- Deshpande PR, Rajan S, Sudeepthi BL, Abdul Nazir CP. Patient-reported outcomes: A new era in clinical research. *Perspect Clin Res* 2011; 2: 137-44.
- Akinosoglou K, Antonopoulou S, Katsarolis I, Gogos CA. Patient-reported outcomes in HIV clinical trials evaluating antiretroviral treatment: A systematic review. *AIDS Care* 2021; 33: 1118-26.
- Wolfe A. Institute of Medicine report: Crossing the quality chasm: A new health care system for the 21st century. *Policy Polit Nurs Pract* 2001; 2: 233-5.
- Zhang Y, He C, Peasgood T, Hulse ESG, Fairley C, Brown G, et al. Use of quality of life instruments for people living with HIV: A global systematic review and meta-analysis. Available from: https://papers.ssrn.com/sol3/papers.cfm?abstract_ id=3938014, accessed on November 2, 2021.