REACH: a mixed-methods study to investigate the measurement, prediction and improvement of retention and engagement in outpatient HIV care

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Scientific summary

The REACH study

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Scientific summary

Background

The number of people living with human immunodeficiency virus (PLWH) in the UK is estimated to be 107,800 and continues to rise. Although those who are diagnosed promptly and treated successfully with antiretroviral therapy (ART) now have a similar life expectancy to that of the general population, PLWH who engage poorly with human immunodeficiency virus (HIV) care have poorer health outcomes and are at risk of increased mortality. ART also reduces the HIV viral load, thereby reducing the risk of onwards transmission of HIV. Maintaining PLWH in care may furthermore reduce the costs of emergency department visits and hospitalisations, as well as the cost of missed outpatient attendances, which can be as high as 25% in London.

In order to achieve these individual, public health and financial benefits, PLWH must be aware of their HIV status and have sustained engagement in care (EIC). Studies have found that PLWH in the UK are more likely to disengage if they are female, younger, of black ethnicity and not on ART. They are also likely to have complex social needs, poorer mental health and be affected by HIV stigma. However, engaging PLWH in care remains a major challenge and the evidence on the factors that need to be addressed is limited. There have, furthermore, been no trials to evaluate interventions to improve engagement in HIV care in the UK.

The ultimate aim of the Retention and Engagement Across Care services for HIV positive patients in the UK (REACH) study is to ensure the effective use of resources to improve engagement in HIV care and optimise health and economic outcomes.

Objectives

The REACH study set out to explore HIV outpatient attendance in PLWH, in order to develop cost-effective interventions to optimise EIC. Its objectives were to:

- examine HIV outpatient attendance patterns among PLWH
- identify predictive factors of disengagement
- investigate the potential health and financial costs of disengaging from care
- develop a retention risk assessment tool
- understand the situational, environmental, behavioural and social factors influencing outpatient attendance
- develop intervention models to improve EIC, to be tested in future studies.

Methods

We conducted a mixed-methods study in three phases, involving secondary analysis of routine clinical data and primary data collection. Phase 1 was an analysis of data from the UK Collaborative HIV Cohort (UK CHIC) study. We developed an algorithm to identify whether patients were in care or out of care for each month of follow-up, incorporating a time-updated measure of patients' treatment and health status. The EIC algorithm was used in group-based trajectory analysis to identify individuals following similar progressions of attendance over time. The algorithm enabled examination of the association between background factors and the proportion of months that patients were engaged in HIV care; and the association between EIC and mortality. We examined EIC before starting ART and its association with mortality and the cost of laboratory tests after ART initiation.

Phase 2 was a quantitative and qualitative examination of patient experience. The quantitative component comprised a cross-sectional survey among patients recruited from seven London HIV clinics (from May 2014 to August 2015). We recruited regularly attending patients who had attended all intended HIV clinical appointments in the past year, irregularly attending patients who had missed one or more intended HIV clinical appointments in the past year, and non-attending patients who had experienced a period of non-attendance for 1 year or more that ended within the past year. Patients self-completed an anonymised questionnaire containing 80 questions, which took about 20–30 minutes. Questionnaire responses were linked to clinical data by clinic staff. Questions were based on variables from the COM-B ('capability', 'opportunity', 'motivation' and 'behaviour') model, which proposes that behaviour occurs as an interaction between three necessary conditions of capability, opportunity and motivation.

Survey data were analysed to develop a 'retention risk tool' that may help clinicians identify newly diagnosed patients at risk of disengaging from care. Variables were considered for inclusion in the model if they were potentially predictive of future disengagement at the time of diagnosis. Multivariable backwards-stepwise binary logistic regression was used to select the best set of variables predicting poor attendance. Standard methods for assessing model effectiveness were applied. Survey data were also analysed to examine the factors associated with membership of the three attendance groups.

The qualitative component of phase 2 involved exploratory, face-to-face, semistructured interviews with a purposively selected sample of men and women recruited via the HIV clinics where survey recruitment took place (from June 2014 to February 2015). Participants were recruited to ensure maximum diversity in attendance pattern and key characteristics. Interviews took 60–90 minutes and were based on a topic guide developed from the COM-B model, as described above. Participants were given a £20 high street voucher for taking part. We also conducted two focus groups (FGs) with PLWH who had all experienced a prolonged period of non-attendance. The groups were made up of (1) gay men and (2) black African men and women (January 2015). Participants were recruited via community contacts and were paid £30 for participation. The data from the patient interviews and the FGs were combined and a thematic analysis was conducted using framework.

Phase 3 was a key informant study to examine how to optimise engagement in HIV care from the service provider perspective. The sampling frame was defined according to key constituencies in the field of HIV service provision: clinical services, public health, academia, community support, health promotion and policy. Interviews were based on a topic guide and took about 30 minutes. A thematic analysis was conducted.

Data from phases 2 and 3 informed the development of interventions to improve engagement in HIV care, for which preliminary analyses of the costs were undertaken.

Results

Phase 1: patterns and associations with engagement in HIV care

Phase 1 involved use of the EIC algorithm in a group-based trajectory analysis to examine patterns of attendance for patients who were diagnosed during three 3-year periods from 2000 to 2002 ($n = 6110$), from 2003 to 2005 ($n = 6747$) and from 2006 to 2008 ($n = 5615$). We compared the interpretability and statistical fit of the models for each of the three diagnosis periods, for one to five trajectories. The best model for all three diagnosis groups included four trajectories. As this analysis resulted in three different models (one for each of the 3-year diagnosis periods) and the interpretation of the trajectories was not clear, we used the proportion of time in care as a more straightforward and flexible measure of engagement for further analyses.

Our exploration of associations with the EIC measure included 44,432 patients, contributing 3,021,224 months of follow-up. Univariable analysis indicated that EIC was higher in later calendar years and for those who were men, aged > 45 years, of white ethnicity, who acquired HIV through sex between men, had higher nadir and current cluster of differentiation 4 (CD4) counts and had been recently first seen at the clinic. In multivariable analysis, after controlling for the other factors, there was no strong association between gender and EIC, those currently on ART had higher levels of engagement, only those of 'other' ethnicities appeared to have poorer EIC and, after adjustment for the nadir CD4 count, current CD4 count did not provide any independent association with EIC.

We examined the association between the EIC measure and health outcomes. After adjusting for fixed covariates and ART status, higher EIC was associated with improved mortality and a combined measure of acquired immunodeficiency syndrome/mortality at least 1 year into the future. Further analysis indicated that those with lower EIC had poorer CD4 counts both at the time of EIC assessment and over the subsequent 12 months. We found an association between EIC before starting ART and mortality after starting ART that was attenuated after adjustment for fixed covariates and post-ART CD4 counts and viral loads. Overall, the analyses indicated that higher levels of engagement in HIV care is strongly associated with reduced mortality at all stages of infection. Our analysis of the economic costs of disengaging from care showed only small differences in EIC before starting ART and costs of lab tests after ART initiation.

Phase 2: analysis of survey data

Patients taking part in our survey during phase 2 ($n = 983$) comprised 550 regular attenders (RAs), 269 irregular attenders (IAs) and 164 non-attenders (NAs). Survey data were used to develop a retention risk tool to identify newly diagnosed patients at risk of disengaging from care. We used binary logistic regression to examine 17 variables that were potentially predictive of future disengagement from care and significantly associated ($p < 0.05$) with poor attendance. The final model included age at diagnosis, having children, recreational drug use, drug/alcohol dependency, not enough money for basic needs and use of public transport to get to the clinic.

We conducted multivariable analyses of factors relating to irregular and non-attendance, adjusting for the clinic that the respondent was attending, age, gender and education. Our analysis indicated that irregular attendance (missed appointments) was associated with being female, younger, diagnosed with HIV for longer, having children, symptoms of neurocognitive impairment, poorer recent health, diagnosis of depression, complex needs according to the HIV and AIDS Reporting System (HARS) category 3 criteria, HIV-related hospitalisation, drug/alcohol dependency issues, uncertainty about being in charge of life, telling family about HIV status, not getting help when sick in bed and not having money for basic needs. Non-attendance (period of disengagement from care) was associated with being female, younger, less educated, diagnosed with HIV for longer, having children, not being registered with a general practitioner (GP), not being a homeowner, recreational drug use, drug/alcohol dependency issues, telling family about HIV status, not getting help when sick in bed, not having money for basic needs and not feeling listened to by the nurse.

Phases 2 and 3: analysis of qualitative data

Phase 2 included patient interviews with 10 RAs, 13 IAs and 10 NAs. We conducted two FGs with (1) four gay men and (2) six black African men and women. Phase 3 involved 19 semistructured interviews with service providers and funders. We interviewed six health-care professionals, two public health experts, three academics, six representatives from community support/health promotion and two policy experts. All qualitative data from phases 2 and 3 were integrated into the findings that follow and presented under the three headings of capability, motivation and opportunity.

Capability

Capability included physical capability whereby patients missed appointments if they felt unwell, although feeling ill could provide the impetus to return to care when patients had stopped attending. Psychological capability to attend was adversely effected when people had used alcohol or recreational drugs and others said they sometimes simply forgot their appointments. Poor knowledge about HIV increased fear and self-stigma and better understanding was associated with better EIC. Peer support was a key channel through which knowledge and empowerment were gained.

Motivation

Motivation to attend the HIV clinic was challenged when people did not want to think about HIV or felt well. Depression was particularly prevalent among IAs and NAs who talked about an inability to do anything when they were depressed. Poor self-efficacy and low self-esteem also undermined EIC. Some patients avoided the clinic when they had not taken their medication; they felt embarrassed or did not want to be 'told off'. On the other hand, the clinic provided a safe place where patients could talk about HIV.

Opportunity

Opportunity incorporates social influences and some people were afraid that someone would find out about their HIV status when they attended the clinic. Most patients had good relationships with clinic staff, providing good reason to attend, but communication problems could contribute towards disengagement. Partners could also motivate patients to attend or undermine and de-motivate them. Peers could be very powerful in helping people engage with care. Opportunity was affected by financial and social issues, child care and work responsibilities, which meant that some patients did not prioritise their HIV care.

Interventions to improve engagement in care

We identified four interventions based on our findings and put together a preliminary analysis of their costs. The first three interventions are targeted at people who have disengaged from care or are at risk of doing so. Intervention one involves structured peer involvement, offering up to eight one-to-one sessions with a peer worker and costing £538 per patient for 6 months. Intervention two is a one-stop-shop weekly multidisciplinary clinic including a consultant, nurse specialist, psychologist, social worker and peer caseworker, costing £398 per patient for 6 months. Intervention three is a weekly clinic with a consultant and nurse specialist at an alternative location, such as a library, GP surgery or pharmacy, costing £302 per patient for 6 months. The fourth intervention was proven to be successful in the USA through the use of clinic-wide co-ordinated messaging to encourage attendance, with a one-off cost of £2 per patient.

Conclusions

The REACH study has shown the adverse health impacts of disengaging from HIV care. We have identified a range of factors associated with disengaging from care and developed a retention risk tool to help determine who is at risk of suboptimal EIC. Our findings have demonstrated the importance of the wider health and social context in managing HIV care effectively and suggest that interventions need to address broader issues that impact on health-care utilisation. We have developed two complex interventions providing holistic approaches to care which benefit from the strengths of peer support and aim to manage the multiple psychological, social and economic issues which deter optimal engagement in HIV care.
We have developed a third intervention that provides an alternative clinic setting for people with concerns about disclosing their HIV status. Our fourth intervention uses co-ordinated messaging to encourage attendance and improve communication with all patients.

Future research priorities

1. Full health and economic evaluation of the four interventions that we have identified through implementation within robust clinical trials.
2. Testing of the predictive power of our retention risk tool across different clinic populations and settings.
3. Analysis of the economic costs of disengaging from HIV care based on a wide range of NHS resource use.

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