

## DISCUSSION PAPER

# The experience of long-term diagnosis with human immunodeficiency virus: a stimulus to clinical eupraxia and person-centred medicine

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The biopsychosocial challenges of living with human immunodeficiency virus (HIV) have changed over time and they dictate the need for relevant medical services. The meaning of an HIV diagnosis has moved from a terminal to a manageable condition with the development of antiretrovirals, bringing profound changes to the experience of living with HIV and the meaning and use of diagnostic labels. Six biological stage-related categories in the literature of psychological medicine of HIV are critiqued. Long-term HIV highlights the inadequacy of physician-centred, acute-care medicine in chronic illness and its exclusion of preventive, psychological and rehabilitative modalities. ‘Eupraxia’ is presented as a conceptual framework for chronic care medicine, referring to best practice, wellbeing, best interests, and (public) welfare, through facilitated but collaborative approaches. A public-centred service model is proposed, using idiographic assessment and treatment by clinicians as patient delegates (proxies), monitoring joined-up care, providing group-based biopsychosocial treatment, facilitating autonomous and self-managing behaviour by the public, removing professional and practice hierarchies, and implementing real-time clinical and managerial accountability with public ownership and involvement. This model is superior in its health- and cost-effectiveness but can only work within a nationalized system that focuses equally on standardized outcomes and evidential and personalized health outcomes.

**Keywords:** Best practice, Patient-centred medicine, Chronic illness, Personalised treatment, Clinical design, Eupraxia

## INTRODUCTION

The global pandemic of human immunodeficiency virus (HIV) infection is now well over two decades old. Much has been learned from it, but its duration provides continued as well as new challenges. Two new challenges in particular are to understand the experience of living long-term with HIV and letting this inform the design of

medical services. Pharmaceutical polytherapies — generically called highly active antiretroviral therapy (HAART) — were developed for HIV in 1996, and caused a sea-change in the way that people with HIV could be cared for medically. HAART consists of using two or more classes of anti-HIV medication, each class interfering with HIV replication at a different point in its cycle. Agents within established classes are slowly added to the armamentarium, as are — more rarely — new classes. There is also a vast array of other pharmaceuticals used in the

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management of HIV-associated disease not directly targeted at HIV itself. While the pharmaceuticals have saved lives where they are available, they are often toxic and, despite established knowledge of these toxicities, they continue to be under-evaluated clinically.

The main toxic effects include nausea, fatigue and diarrhoea, which can range from minor irritations to severely disabling conditions. Physiological side-effects include rashes (sometimes fatal), pain conditions (peripheral neuropathic, stomach, joint, and muscle), paraesthesias (numbness, prickling, and tingling), altered sense of taste, dry mouth, dry eyes, hair loss, fevers, dizziness, headache, menstrual irregularities, reduced ability to digest and eliminate food, appetite loss, nausea and vomiting, lipodystrophy, lipoatrophy, and myoatrophy.<sup>1</sup> Other side-effects include alterations to haematological, immunological, neurological, hepatic, pancreatic, renal, cell-metabolic and vascular functions that are sometimes fatal; some of these are also caused or exacerbated by direct viral effects on the body. There are increased risks of vascular problems such as heart attacks and non-haemorrhagic stroke; immunologically related problems such as secondary infections, cancers (blood, skin, vaginal and anorectal), allergies, and autoimmune disorders, as well as endocrine and metabolic disorders, notably diabetes. Specific neuropsychological and neuropsychiatric problems include alterations in consciousness, ranging from light-headedness to seizures, balance and movement disorders, alterations in mentation, ranging from minor memory deficits to frank dementia, other psychoses, and sleep problems.<sup>2</sup> There are also a variety of diffuse syndromes that result from the sudden reduction of viral interference with immune system function and the consequent readjustments among immunological network components — the so-called ‘immune reconstitution inflammatory syndrome’.

While enumerating such challenges is relatively simple, they have to be suffered on

top of the physiological depredations of HIV itself within a larger context of psychological and psychosocial problems relating to stigma and discrimination, disability, employment, family, social networks, and national politics, all of which cause greatly increased risks for physiological and psychological illness and disability and can be equally life-threatening.<sup>3</sup> However, the prevailing model of physician-dominated, acute-care medicine disparages non-pharmaceutical interventions, despite the fact that each of these problems is susceptible to techniques in psychological and behavioural medicine, with significant consequences for health and medical service costs.

As pharmaceutical interventions in HIV disease have become more sophisticated, the meaning of a diagnosis of HIV infection has moved mostly from a catastrophic terminal illness to a manageable lifelong condition, if the infection is diagnosed early enough; late presentation of infection — significant among Africans in Europe — still leads to frequent premature death. However, most people — if diagnosed early enough — can now survive for 20 or more years using current pharmaceutical interventions and excellent adherence. Many people have chosen not to.

A delayed focus on the experience of living with HIV has followed this incremental success on the pharmaceutical front. While physicians have always focused above all on quantity of life and symptom suppression, people with HIV have focused on the real issues that are clinically often ignored — how to lead ‘normal’ lives despite infection, illness or risk of death. It is almost as if there are two diseases, which intersect in the clinic.

It is worth noting that some people recently diagnosed with HIV resume their lives with few physical challenges, despite often-significant mental challenges. Some of these are relatively very lucky and, for both physiological and psychological reasons, never need take antiviral medications; they develop a quiescent infection with which

they develop a dynamic ‘truce’ that may or may not persist through perturbations such as trauma or co-infections. In contrast, some people are unlucky or unskilled and face repeated, sometimes catastrophic, problems in living with HIV. The reality of living with HIV over time can be extremely challenging, and the experiences in long-term diagnosis can tell us a lot about how effective we are medically.

### DEFINITIONS OF LONG-TERM DIAGNOSIS

In biomedicine, diagnoses function as heuristic labels based on accepted codifications of disease as well as conceptual guides for practice. However, labels are not only used by clinicians: the person in care has to be informed of, grasp and acknowledge a diagnosis in order for it to inform health-related behaviours, which requires both a willingness to accept the label and an ability to find it useful. ‘Long-term diagnosis’ is a functional and relatively unladen label that does not presuppose a professional or social bias, while stipulating that HIV infection must have been determined at some time. This is in contrast to the view that illness is purely professionally diagnosed, but also raises important challenges in distinguishing psychological and psychosocial factors in the labelling of illness and disability, given the serious consequences.<sup>4,5</sup> It is a first point in emphasizing the collaborative and social nature of medicine, rather than regarding it as an objective, pseudo-scientific process.

The definition of a ‘long-term diagnosis’ does not fit any neat biological categories but depends on both biological and psychological variables: not only is there a detectable viral infection, but it is one that is perceived and responded to, both immunologically and psychologically, by the infected person. Additionally, the label ‘long-term diagnosis’ provides flexibility for grey-area situations: for example, consider a woman who comes from an HIV-endemic area, who may not

have been formally diagnosed but has lost all her family to HIV disease over a period of 10 years, and who supposes that she is also infected. When this is confirmed subsequently, when she is able to access medical services, how long has she really been living with HIV? Does a difference in the date of biological diagnosis allow for the experience suffered between those dates? Biologically, there is no difference between the physician-centred approaches to management of a late presentation of a benign infection and the prompt presentation of a more recent and more virulent infection. For psychological medicine, the difference can be marked, and suggests that diagnoses should include such psychological and social factors, not least because including psychological and behavioural medicine within primary and specialist care can also lead to better health outcomes.<sup>6</sup>

The definition of ‘long-term diagnosis’ depends, in part, on the length of infection, on where someone entered the trajectory of HIV as an acknowledged condition, when the diagnosis of HIV infection was made in relation to the availability of effective pharmaceutical treatment, and also self-definition in terms of a person’s experience with illness and hope. But how long is ‘long’? In the beginning of the pandemic, a ‘long time’ was 5 years; now it is more likely to be seen as 10–15 years. In areas of the world where treatment is not available, the lower threshold is relevant still. Long-term diagnosis is unusual in that it is both objective and subjective, professional and personal. It also contains two types of experience: the experience of those who have never suffered apparently from HIV or its treatment, and of those who have suffered and survived.

The purpose of understanding the meaning of long-term diagnosis is that it is a tool for analysing two related issues: first, what can help people at least minimally ‘survive’ over the long term, both biologically and psychologically, and more importantly, what can keep people so well that they do not need to present for long-term clinical care. This must inform our design of medical services.

## HIV IN THE LITERATURE OF PSYCHOLOGICAL AND BEHAVIOURAL MEDICINE

Historically, there are six categories in this literature, which have focused on biological stages of infection and the tasks of both the clinician and the person in care at each stage. First, there was a focus on the high-risk uninfected and aspects of primary prevention through behavioural change. Second, there was the group of 'worried well' (a poignant and revealing oxymoron), i.e. people who are HIV-negative or unable to determine their serostatus. This group was the focus of much early work on how to manage anxieties with the threat of an unknown illness; it is now relatively neglected in the clinical literature, following the wider availability of HIV testing and treatment in the West, but is still highly significant in developing countries. Third, there was a huge focus on the newly diagnosed and the adaptations that their new status required, with subsequent distinctions between those with relatively recent infection and those with long-standing infection ('seroconversion' *v.* 'late presentation'); much of this literature has revolved around the psychological management of seroconversion crisis or unanticipated catastrophic illness, and the pharmaceutical management of the presenting physical illness. The fourth category concerns psycho-educational issues for the recently diagnosed and questions of when to start medication (if available), the appropriate choice of medication, the management of side-effects, and the incorporation of medical behaviours (e.g. pill-taking, clinic visits) into an existing lifestyle. The fifth category contains a large grey area, populated by isolated foci on medical and health behaviours, such as public-associated (although not physician-associated) variables in medication adherence, pharmaceutical toxicities, structured treatment interruptions, recreational drug and steroid use, secondary prevention, and general issues of adjustment; more recently, it has included behavioural and psychological

self-management interventions. The sixth category, where the psychological literature coheres once more, concerns adjustment to disability, anticipatory grief, death and dying, and chthonic issues.

As mortality and morbidity decrease over time, so the range of the fifth stage-related category of literature increases. Somewhere in this fifth category lies the issue of long-term diagnosis, with the challenges it provides in creating new ways of thinking about chronic illness and more sophisticated and integrated clinical care. However, the theoretical and conceptual problems posed by the experience of long-term diagnosis in HIV cuts right across these neat, stage-related categories, which suggests that a thorough re-conceptualization of the literature would be useful: categorizations, like diagnoses, are worthwhile only insofar as they are useful and should be re-examined regularly. Other commentators have noted the inadequacy of the stage-dependent approach to process analysis in illness, suggesting alternatives.<sup>7</sup>

With the progress of HAART and diversification within the group of long-term diagnosed, the value of studying the needs of this group beyond the challenges of simple physical survival has been recognized late. Although the field is in its infancy, previous research has focused on the ethos of self-empowerment, methods in narrative psychology in the development of identity over the course of an illness, the integration of traumatic experience, health promotion efforts to understand how the meaning of self is constructed, and attitudinal approaches.<sup>8,9</sup> However, this is apparently the first paper to create a conceptual structure of the definitions, experience and challenges of long-term diagnosis with HIV that is relevant to the broader field of medicine.

### THE EXPERIENCES OF LONG-TERM DIAGNOSIS WITH HIV

People with HIV risk diverse, repeated biopsychosocial stressors that compound

and concatenate over time. Many of the physiological stressors have been cited above — e.g. pharmaceutical toxicities. The psychological stressors in each category of long-term diagnosed — and the clinical interventions required — have been significantly different according to which category reflects the person's lived experience: historically, there have been three categories of people with long-term diagnoses, which now co-exist. These three groups are defined primarily by whether they had survived a 'long time' before, during or after HAART became available to them, and can be viewed in terms of whether someone was diagnosed with a terminal illness, a catastrophic illness, or a chronic, manageable condition.

In the first and earliest group, the clinical literature dealt primarily with issues of survivor guilt and loss, focusing on existential questions of why they survived when so many others had died or were dying, traumatic loss, and grief.<sup>10,11</sup> In the second group, when HAART first became available, the literature dealt with the Lazarus syndrome and renegotiated hope and social roles.<sup>12,13</sup> In the last group, the focus has reduced to a pharmaceuticalization of HIV as a 'chronic manageable disease', noticeably in tandem with a surge in physician denialism ('you'll be fine as long as you take your pills') and a loss of public empowerment and community coherence. There is no direct clinical literature here on long-term experience, only indirect reference requiring inference, as the issue has been de-psychologized and reduced to the pharmaceutical.

A common problem for all three groups with long-term diagnoses is the struggle to retain hope, not least through a sense of control over one's life and health. The experience of this challenge distinguishes these groups and has significance for integrated medical practice. The most common aspect is a loss of 'life narrative' — i.e. the way in which the diagnosis of HIV and the socio-medical expectations at the time of diagnosis have affected a person's ability to plan and

dream for the future. Related to this, there is also often-severe damage to a person's 'assumptive world' — the things that 'normal' people take for granted, like being able to grow up, being able to have a public relationship, get married, have children, and so on; these assumptions may already have been damaged in the process of growing up or living as a socially or economically marginalized person, such as a gay man or an immigrant.

In this way, the diagnosis of HIV has often precipitated the sense of a provisional existence and still can.<sup>8,14</sup> In response, people are prompted to develop alternative ways of conceiving and living within time, which compensates for the loss of the temporal assumptions that existed prior to the diagnosis of HIV.<sup>15</sup>

In the absence of grounding existential reference points, there is enormous psychological stress at times of transition between prognostically related illness categories — e.g. from well to symptomatic, long-term non-progressor to progressor, or dying to living again. People liken it to being toyed with, as a mouse is by a cat. Psychologically, there is often a concomitant and serious diminution in the ability to trust, specifically and generally, with the generation of a reactive cynicism or hostility to protect the person from the significance of repeated encounters with loss and diminishment; this provides fodder for significant clinical conflict, especially in a system that does not detect or respond to personal needs but promotes a one-size-fits-all approach to medicine — what may be called 'pills by numbers'. Furthermore, diverse mechanisms are used to create a sense of control over the course of an unpredictable illness, or reduce the awareness of a lack of control; many of these mechanisms are maladaptive for mental or physical health in the long term. A medical service that remains unaware of — or disparages — these psychological and behavioural issues fails to provide adequate care for — and can cause serious harm to — a person undergoing medical

treatment: psychological and behavioural responses affect not only the frequency of presentation for medical care over time, but also the severity of presentation, the course of disease, and survival.

The manner in which one develops a sense of meaning and control in living with chronic illness determines how successful one is in successfully adapting to and integrating it into a life larger than the illness itself, which is the essential goal of rehabilitation medicine. In studies of the meaning of chronic illness in general, consistent themes arise: interrupted hopes and dreams, experiencing the body as a hindrance, victimization by the illness, isolation and aloneness in illness, managing the family, striving to endure, reformulating self and identity, re-creating a sense of future, managing dependency, struggling for both legitimization and normality, and seeking balance and a life worth living.<sup>14,16–19</sup> Furthermore, there are developmental, family and care-giver issues that impinge upon this process across the entire lifespan.<sup>20–23</sup> Fundamentally, there are issues around hope, mastery and control, and how such efforts to reduce vulnerability through adaptation relate to behaviourally dependent medical outcomes.<sup>24–27</sup>

### MEETING THE CHALLENGES OF LIVING LONG-TERM WITH HIV

Perhaps the most significant lesson for the practice of medicine followed the ‘successful’ introduction of HAART, after which dramatic health improvements and the much-touted Lazarus syndrome were also accompanied by unexpected psychological and behavioural responses: following initial excitement among the affected public, non-adherence to medication rose sharply; people risked death and sometimes achieved it through what may be called passive suicide.<sup>28</sup> The failure of medical practice to address issues such as reduced identity and the fears in envisioning a future again while no longer having substantial support proved

that facing death was easier than facing life from a much reduced position. The reliance on a purely biological approach to medicine and a lack of integration of psychological and rehabilitative medicine into chronic care medicine failed to anticipate or responsibly address this outcome, creating increased dependency by the public on acute care and later palliative medical services, with much-increased costs.

The practice of medicine can help make life with chronic illness worth living — or it can make it worse. Clearly, living long-term with HIV is an epitome of the challenges to providing relevant and effective medical care for chronic illness. Common problems have been identified in the process of help-seeking through medicine: having limited choices, lacking adequate information to make choices, lacking psychosocial support, being ignored by clinicians in respect of their needs, conflicts in the meaning of illness, and active disempowerment of the public — to name a few.<sup>29–31</sup> The response to the challenge of living with HIV is to determine how medical practice can minimize the disablement of people not simply by the illness itself but, significantly, by the clinicians providing care; a particular goal is to reduce both the public’s and clinicians’ dependence on each other, as well as to reduce clinical conflict with difficult doctors and/or difficult members of the public.<sup>32,33</sup>

There are two reasons for helping the long-term diagnosed to meet such challenges successfully: first, to provide the best medical care possible (an individual good); and second, to reduce in the long term the need for medical care in both the person seeking care and related individuals and groups (a public good). Two approaches can be taken: one (the more common) is the acute care, pharmacotherapeutic approach of addressing individual illness episodes, which has proven itself over decades to be short-term, costly, ineffective, and to the sole benefit of pharmaceutical companies and physicians as their primary clinical agents;<sup>34</sup> the other is to address the larger

challenge of living well in the long term — an approach integrating preventative and therapeutic medicine across the three domains of biopsychosocial medicine. Understanding the reality of living long-term with HIV shows clearly that, as with any chronic illness, more is needed to live with health than pharmaceutical therapy can provide.

Designing services to address the larger challenge requires an understanding of several related issues: what happens to the ‘patient’ as a person, not just a body, during illness and during care-seeking; what are the natural resources needed for resilience and resistance to illness socially, behaviourally, psychologically, psychophysiological, and physiologically; what forms of medical practice can provide support for and strengthen those biopsychosocial factors of resilience to promote long-term wellness, rather than someone being just ‘not physically ill’; how this service would be truly relevant to the public’s medical needs; and, finally, what sorts of training, staff and service design are needed to provide this? Only some of these issues can be reviewed here.

### CREATING EFFECTIVE MEDICAL SERVICES FOR THE CHRONICALLY ILL

The development of services that are designed from the public up to be effective and also efficient requires a new model of care; elements of the new model have been mooted repeatedly, ever since Engler first raised the concept of a biopsychosocial model of illness, and are most well known in the nursing and rehabilitative traditions of medicine.<sup>35</sup> In order to propose a person-centred model, the concept of ‘eupraxia’ is introduced as a positive conceptual framework for medicine, where medicine is defined as ‘the prevention, diagnosis, treatment, and rehabilitation of illness’,<sup>36</sup> not solely the ability to diagnose physical disease and prescribe pharmaceuticals.

The Attic Greek word ‘eupraxia’ contains a constellation of meanings integrating ‘wellbeing’, ‘best interests’, and ‘good practice’; in this way, it refers evenhandedly both to the person in care and the clinician, implicitly reflecting a collaborative and interdependent model of medicine. Eupraxia has other meanings: in clinical biomedicine, it refers to what is more accurately described as ‘praxia’, or ‘the (normal) ability to perform coördinated movements’. Physicians’ use of the term and failure to reflect the meaning of ‘eu-’ (‘good’) shows a semantic neglect, tellingly indicating the lack of a conceptual framework for ‘health’ and the significance of context; a ‘lack of illness’ is no more the binary opposite of ‘ill’ than ‘centre’ is of ‘left’ or zero is of minus one. This lack of conceptual structure for positive aspects of health illustrates the core problem of a pathocentric, biomedical approach to chronic illness. However, a eucentric approach is not new: in fact, it was included in the Preamble to the Constitution of the World Health Organization in 1948, and it is high time that medicine incorporated it within clinical practice.<sup>37</sup>

The positive conceptual framework provided by eupraxia allows a person-centred approach to medicine and arises from diverse research and policy in the nursing, psychological, behavioural and rehabilitative frameworks within medicine. Eupraxia requires a balanced, collaborative approach to care, as opposed to polar models that are either physician-centred (autocratic) or consumer-oriented (rights-focused and litigious), neither of which works, as evidenced equally by the Bristol Inquiry and the insurance problems besetting US clinicians.<sup>38,39</sup> In the UK, this promotes a resentful dependency on autocratic care, and in the US, a high-risk atmosphere of clinician–public negotiation. Both polar models beggar financially and professionally the contrasting UK and US healthcare systems, for the same reason: a failure to develop public-centred models of medicine. Furthermore, in both the UK and the US, the legal concept of ‘duty of care’ has developed in such a way

that the public is encouraged through litigation rewards to abjure responsibility for self; this aligns by chance with an autocratic, physician-centred model and reduces further any incentives to change the practice of medicine or restore it to its wider definition. Largely as a consequence of these different but physician-centred models of medicine, public self-determination, self-management and self-regulation tend to be experienced as a loss of physician control or, at best, unprofessional practice, leading to clinical conflict and poorer health outcomes.

The USA has pioneered many of the developments in psychological and behavioural medicine relevant to the eupraxic model, through biobehavioural approaches to primary and specialist outpatient care.<sup>40</sup> However, the US delivery systems are constrained by the restricted applicability of corporate medicine, given its separation from the 'public good' and 'welfare' — yet further connotations of the word 'eupraxia'. Nationalized systems of medicine can go further than corporate medicine in implementing these developments, integrating biological, psychological, behavioural and social medicine within all levels of medical services, from primary to end-of-life care. Sweden, with a nationalized medical service, has introduced the Esther model — a patient-relevant approach to service design — and the USA has been developing other models.<sup>6, 41–43</sup> Developments in the UK, with the remains of a nationalized medical service at risk of becoming corporatized,<sup>44</sup> have introduced the concepts of a patient-led National Health Service (NHS) as well as public and patient involvement at all levels of commissioning,<sup>45</sup> but without understanding of the diversity of concepts involved or how to operationalize them,<sup>46</sup> these policies have been slow to be implemented, discoordinated and conceptually impoverished, and risk being swamped — or simply rebuffed — by the corporate and/or physician lobbies.

If HIV is an epitome of the challenges facing people living with chronic illness and

a defining challenge to the design of effective medical services, then we can ask how medical services can be designed and delivered to meet the paradigmatic challenge of living long-term with HIV — i.e. minimizing physical illness and maximizing personal health through the maintenance or enhancement of meaning and control in the face of chronic illness, while subsuming illness into a larger sense of life. First, medicine must be rescued from an acute care, physician-centred and pharmacotherapeutic model and delivered through a person-centred and biopsychosocial framework.<sup>47</sup> Such a model of eupraxic medicine revolves around assessing presenting members of the public idiographically to create person-centred treatment goals,<sup>47</sup> using clinicians (probably nurses) with cross-disciplinary training as clinical proxies for the public in care, integrating care across a multidisciplinary team; planning person-centred treatment; balancing personalization with standardization; integrating service design and provision, including group-based provision; facilitating positive self-determination and skilled self-management through self-regulation as seen in the Harvard, Miami and Stanford models of behavioural medicine; integrating systems to provide joined-up care, flattening professional hierarchies where the public's perspectives are paramount, not those of one particular profession; eliminating the silo protection of status by profession; focusing on the evidentiary effectiveness of professional contributions in relation to health outcomes across multiple domains; promoting public involvement at all levels, and creating inherent systems of real-time clinical and managerial accountability. These innovations have been outlined elsewhere.<sup>49</sup>

In this way, medicine will be designed from the public up, not the physician down, and will be cost- and health-effective through having implementable meaning and relevance to the lives of the public. Thus, medicine may be practised for the public's health and good, which is surely its point.

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