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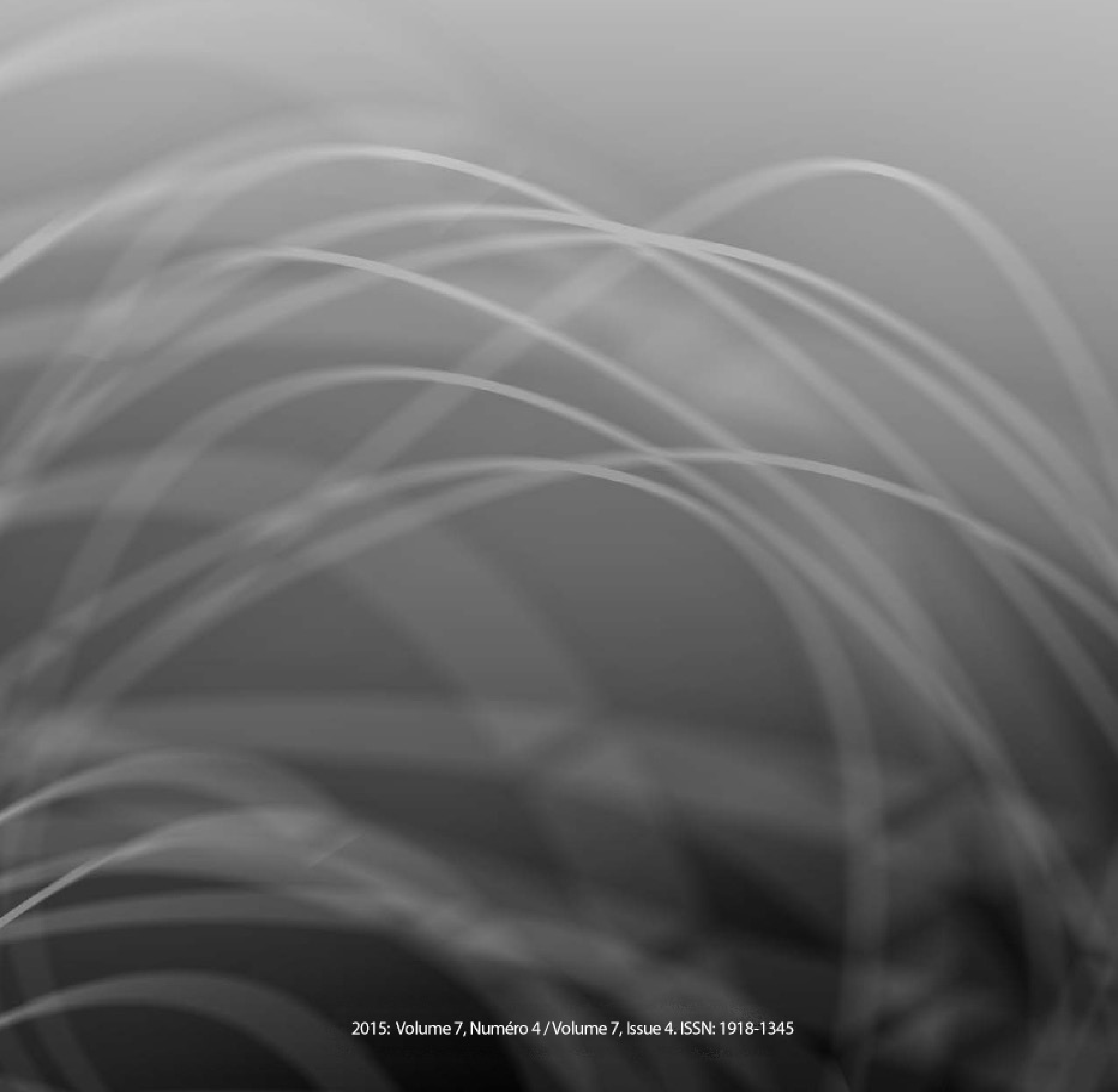

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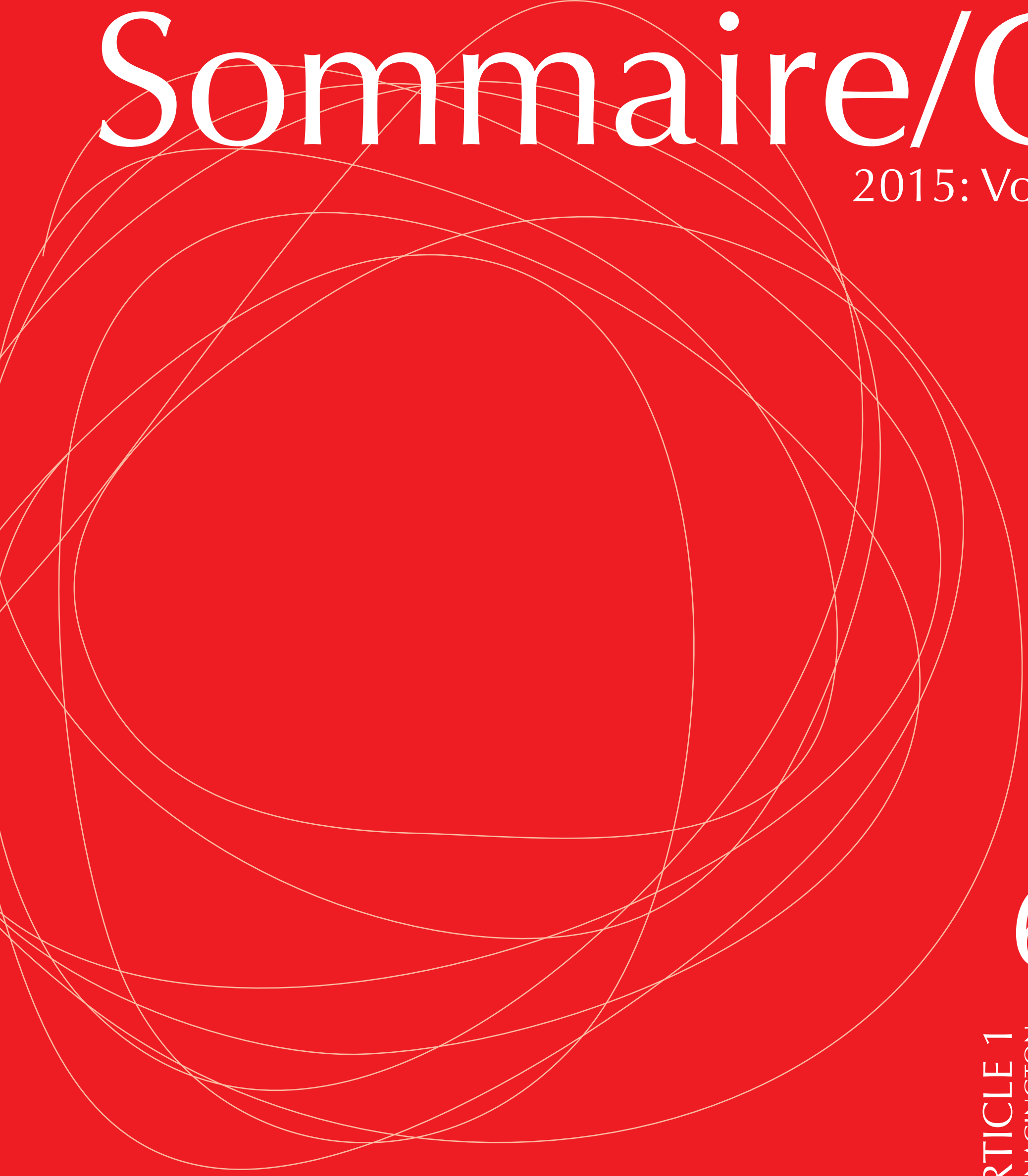

Éditorial/Editorial

Nous avons été interpelés par l’article de Jessica Nadeau publié il y a quelques semaines dans Le Devoir et notamment par la réaction du ministre de la Santé Gaétan Barrette lequel, après avoir été confronté aux allégations de la présidente de la FIQ Régine Laurent relativement à « la loi du silence » qui règnerait dans différents milieux de soin, a tout simplement nié la présence de ce phénomène. Les données empiriques que nous avons recueillies dans le cadre d’une recherche qualitative récente réalisée auprès d’une quarantaine d’infirmières soignantes provenant de divers centres hospitaliers du Québec indiquent clairement que ce phénomène est très présent dans ces milieux. Les résultats de notre étude révèlent que c’est principalement par peur de représailles que les infirmières hésitent à parler, à s’exprimer, à dénoncer une situation inacceptable et même à en aviser leur propre syndicat. Parmi les représailles auxquelles les infirmières participantes ont fait référence, notons diverses formes de harcèlement, de violence, de confrontation, d’intimidation ou de menaces, de pertes de privilège, d’ostracisme, d’exclusion d’un groupe par discrimination et d’abandon de la part des collègues. Les participantes rapportent avoir subi de la part des autorités, de l’acharnement, des sanctions fréquentes comme « de passer au bureau », avoir été l’objet de notes disciplinaires annexées à leur dossier, mais également diverses formes de coercition, comme des suspensions et même le congédiement qui, bien que moins courantes, sont bel et bien présentes. Dans presque chacun des cas où une infirmière nous a indiqué avoir dénoncé une situation qu’elle considérait comme intolérable ou inhumaine, celle-ci a dû subir des indignités en lien avec ces actes de dénonciation, le plus souvent en public, devant ses propres collègues, ce qui a nécessairement pour effet de démultiplier les effets délétères de ces indignités.

Selon les propos transmis par les participantes, ces menaces serviraient non seulement à les faire taire ou à les inciter à se soumettre à certaines directives, elles serviraient également à briser la solidarité qui aurait pu se créer entre des infirmières qui entreprennent d’initier certains changements. La gestion par la peur serait un outil permettant d’annihiler les actions communes entreprises par les infirmières pour transformer l’ordre établi. La transgression de ce qui constitue en quelque sorte une règle tacite proscrivant l’expression libre des infirmières soignantes et brisant ainsi cette « culture » du silence, consisterait en un risque trop grand aux yeux des infirmières soignantes qui craignent tout simplement de se faire congédier si elles agissent de la sorte. Celles-ci se tairont ou auront tendance à confiner les critiques qu’elles émettent à la sphère privée, craignant la fuite de leurs discours dans la sphère publique.

Fait important, les résultats de notre étude révèlent également une déprofessionnalisation graduelle de l'exercice infirmier à la faveur d'une technicisation du soin liée en partie à une forte surcharge de travail. Nos résultats nous permettent de prendre la mesure du sentiment d'aliénation et d'oppression des infirmières soignantes exerçant dans les hôpitaux. Le pouvoir disciplinaire hospitalier qui, par l'entremise d'une vaste gamme de technologies politiques comme la surveillance, le monitorage bureaucratique des activités de soin et le temps supplémentaire obligatoire (TSO) concourent à la subjectivation des infirmières soignantes et notamment à leur dépolitisation. Les infirmières finissent par se soumettre à l'autorité, à intérioriser et à croire légitimes les prescriptions de cette autorité. Elles nous disent se sentir systématiquement exclues des processus décisionnels et privées du droit de s'exprimer librement et de se faire critiques relativement à ce qui a été convenu par les décideurs. Cela a pour effet de les détourner, non seulement de leurs revendications les plus élémentaires, mais également de leurs idéaux d'autodétermination professionnelle. Nos résultats indiquent que toute forme de contestation autonome de la part des infirmières est systématiquement minée par le pouvoir hospitalier, ce qui perpétue les inégalités et reproduit les rapports domination qui ont cours au sein des centres hospitaliers.

Un des résultats les plus intéressants de cette étude réside dans le fait qu'un certain nombre des infirmières interviewées s'objectent en conscience, déploient des actions de non-coopération individuelles et collectives, font preuve d'actes de désobéissance civile de manière à établir un rapport de force pour que leurs revendications soient prises en compte. Il apparaît toutefois que les actions des infirmières sont parfois l'objet de stratégies de récupération par le pouvoir hospitalier. En plus d'être hautement récusées par le pouvoir en place, les actions directes des infirmières s'avèrent être des plus fragiles et leur potentiel émancipateur, plutôt provisoire. Cet état de fait force les infirmières à agir de manière créative afin de réinventer continuellement leurs stratégies de résistance face aux technologies politiques déployées à travers le dispositif hospitalier. Certaines d'entre elles disent vouloir briser l'isolement, se (re)solidariser et (re) prendre la parole afin de se libérer des contraintes instituées.

Notre étude conclut à une dérive autoritaire grandissante dans ces milieux hospitaliers, de sorte que les infirmières n'aient « aucune raison apparente » de perturber le statu quo hospitalier. Dans une profession où l'on valorise une éthique fondée sur la compassion, nous faisons maintenant face à une « éthique » fondée sur l'efficacité, la performance et l'optimisation, s'articulant directement sur le registre sémantique de l'économie de marché. Il est clair que la gouvernance antidémocratique actuellement en vigueur dans ces milieux continuera d'imposer aux infirmières des souffrances qu'elles ne peuvent plus supporter. De plus, nous sommes d'avis qu'il faut impérativement que les ordres professionnels et les syndicats, dont le rôle a été critiqué par plusieurs infirmières soignantes dans le cadre de cette étude, interviennent de manière décisive afin de participer au renouvellement de la démocratie hospitalière. Nous sommes persuadés que l'émancipation des infirmières passe par la décolonisation de leur imaginaire afin qu'elles puissent ouvrir la voie à une réappropriation des enjeux dont les autorités en place veulent les déposséder. Nous considérons, enfin, que la formation infirmière, en plus de répondre aux exigences du marché et de la grande entreprise, devrait pouvoir fournir les ressources intellectuelles permettant la remise en question du système dans lequel les futures infirmières seront engluées; une formation générale, humaniste et critique qui leur permettrait de mieux saisir la réalité politique complexe dans laquelle elles évoluent, à en comprendre les enjeux et à faire face aux défis qui se présenteront à elles notamment en prenant position dans les débats de société.

Le déclencheur
Article de Jessica Nadeau du 30 septembre 2015, Le Devoir : La FIQ s'attaque à la « loi du silence »

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Abstract

With the advent of effective anti-viral regimes ageing with HIV has become an increasingly common phenomenon, gay men being the largest sub-group. It has been examined from multiple academic perspectives, the most prominent of which are medical and sociological research. Within this literature HIV as well as a gay identity has been described as causing “accelerated ageing”. However, any such acceleration has always been considered to be occurring in relation to the normative standards of heterosexuality and/or an HIV negative status, leaving HIV positive gay men viewed as somehow deficient to their HIV negative heterosexual counterparts. A queer theoretical approach is adopted to explore the potential ways in which ageing with HIV as a gay man could be conceptualised beyond the ideas of heteronormative deficiencies. In particular queer theoretical readings of vulnerability, temporality and kinship are explored to provide a theoretical basis for future empirical work into this topic.

Key Words Ageing, gay men, HIV, queer theory

The utility of queer theory in reconceptualising ageing in HIV-positive gay men

MAURICE NAGINGTON

Introduction

This article has two aims: to review the contemporary medical and sociological literature about ageing as a gay man with HIV; and, to review the utility of queer theory for rethinking the possibilities for living and ageing with HIV as a gay man. Whilst not wishing to ignore the wider range of literature, film and art that has arise around the topic of ageing as a gay man with HIV, fitting all of this into one paper is not achievable and instead merits subsequent paper(s).

HIV as a medical and social phenomenon has radically and repeatedly changed over its history. Possibly one of the most radical changes has been the ability for people to live with HIV, rather than die from AIDS through the introduction of highly active anti-retroviral therapy (HAART). This revolution in medical treatment has meant that many sections of the World’s population are now for the first time beginning to age with HIV. This brings with it many medical and social challenges for everyone effected by HIV. However, in England[1] gay men remain the predominant social group who are affected by HIV and worldwide gay men continue to be disproportionately impacted upon by HIV with many countries still seeing an increase in HIV incidence amongst gay men rather than the decreases observed in other demographic groups such as women of a child-bearing age.[2] In addition the majority of gay men continue to live within societies which can broadly be understood as heteronormative or homophobic. The way in which this creates complexities and difficulties for older gay men has been considered in a number of different areas, but not for its impact on ageing with HIV as an older gay man.

However, before progressing further it is important to recognise that during the AIDS crisis when so many people died, ageing with HIV was a 'problem' that many could only have dreamt of. Equally, ageing with HIV was and remains a dream for huge sections of the world's population with no access to effective treatments. Hence, there is potential for strong emotions to arise out of any critique around HIV and ageing. However, it is hoped that the utility of this article in critiquing HIV and ageing for older gay men may be the first step in helping developing services for this relatively novel but growing area. To be clear it is not the aim of this article to present specific recommendations for practice or policy. For this to take place robust consultation with all stakeholders, in particular older HIV positive gay men, would be required. Instead, what this article offers is a critique of the prevailing discourses that affect older gay men ageing with HIV.

Queer theory

Queer theory is often considered to have branched from post-structuralist philosophy with founding theorists including authors such as Foucault, Butler, and Sedgwick. Defining queer theory is likely lining oneself up to fail as one of queer theory's key tenants is to produce resistance(s) to definitions. However, it is possible to outline some key ideas that are relevant to the understanding of the medical and sociological literature that this article goes onto discuss, namely: queer theory's approach to sexuality and gender; and queer theory's understanding of the relationship between subjects and society as a whole.

Queer theory has always had a primary aim to deconstruct contemporary Western understandings of sexuality and gender.[3,4] Authors such as Sedgwick have argued that there is a foundational inadequacy in the social categories that describe individuals stating simply that "people are different from one another"[5 p22] and that despite a plethora of modes of positioning people socially through categories such as gender, class, nationality, sexuality, ability/disability "even people who share all or most of our positionings along these crude axes may still be different".[5 p22] As such Sedgwick is arguing that gender and sexuality cannot be deployed as ultimately meaningful categories in themselves. Instead as argued by Foucault[6] categories of gender and sexuality have continually been differentially constructed by and in relation to the range of different discourses (though most significantly religious and medical) which allow gender and sexuality to be knowable within society at large. However, regardless of the discourses that make gender and sexuality knowable there remains an important interaction between knowledge and power:

> Knowledge linked to power, not only assumes the authority of 'the truth' but has the power to make itself true. All knowledge, once applied in the real world, has effects, and in that sense at least, 'becomes true'. Knowledge, once used to regulate the conduct of others, entails constraint, regulation and the disciplining of practice. Thus, there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time, power relations.[7 p27]

Whilst such an argument helps understand how power and knowledge work on a societal level it is not always productive in developing an insight into the ways that power and knowledge function on a more individual level. Butler[3,4] expands on Foucault's work through developing the concept of performativity which suggests that subjects are only recognised as subjects by others when they take on and perform socially acceptable discourses of gender and sexuality; this may include but is not limited to ways of dressing, talk, working, grooming, socialising, and social interests. In this respect Butler argues that these ways of knowing gender and sexuality and the power that enforces them has a foundational involvement in creating subjects who can both enter into society and simultaneously construct it. This is not to say that there is an entirely deterministic approach to subjectivity and society. Instead, key to the concept of performativity is the continual requirement for performance and whilst this could be viewed as merely being continually subjugating, Butler argues that it's the continual requirement to perform one's identity that allows for novel performances to be explored and enacted.[8] However, such a process of constantly becoming a subject can result in an "uneasy practice of repetition and its risks, compelled yet incomplete, wavering on the horizon of social being".[9 p30] Thus the nature of the performative process whilst producing and reinforcing subjectivity also brings with it a degree of vulnerability, especially for those who push and challenge the current horizons of how gender and sexuality are made knowable in society.

Building on the flexibility theorised in the concept of performativity, queer theorists have attempted to develop ways to resist normative discourses of sexuality and gender. For example, Dean[10] theorises that kinship can be brought about by a sharing of the HIV virus amongst gay men which in turn both resists heteronormative structures of kinship as well as re-writing HIV not as a pathological entity but as a way of creating community and connections. Contrastingly, Edelman[11] has suggested that any consideration of the future and reproduction is itself symbolic of the heteronormative desire to reproduce and thus the queer political struggle must be to remove oneself from any aims to reproduce identities (be that gay, lesbian, male, female) into the future. However, Muñoz has argued that such a radical deconstruction of societal categories requires in itself a privileged position.[12] Thus such a radical form of queer politics may itself be argued to be caught up with homonormative privileges associated with whiteness, physical abilities, social class, gender expression and of course youthfulness. In addition Summerskill highlights in her British oral history of older gays and lesbians that whilst some people long for the days in which queers were essentially placed outside of society by being criminalised (until 1967 in England and Wales) enabling them to "just be and do without having to have an identity",[13 p59] the gaining of a viable and decriminalised identity allowed a generation of gay men to "escape the amorphousness… it allowed us to express our identity".[13 p59] Hence, both theoretically and empirically expression of one's sexuality in a way which allows connection and sociality with others is fundamental to human experience and the radical political approaches like Edelman's are empirically disconnected from research on contemporary queer lives.

Successful ageing

In addition to sexuality and gender, ageing has also been critiqued using post-structural philosophy. On its most basic level successful ageing has been most frequently defined in biomedical terms generally focussing on the absence and/or amelioration of disease and disability.[14] Such a narrow focus has been critiqued and developed to encompass multiple components of ageing such as: life expectancy, life satisfaction, mental wellbeing, autonomy and maintaining a sense of self, maintaining social connections and social engagement.[14] However, the creation of discourses of success, despite their potentially laudable aim of suggesting that ageing can be a positive process ultimately results in also producing those who are unsuccessful. Such a lack of success is then frequently suggested to be the result of individual choices thereby side-lining how systematic inequality negatively affects the ageing process.[15] Alternatives have been suggested such as 'harmonious ageing' which critiques 'successful ageing' as constantly trying to defer the natural processes of ageing.[16] Instead, harmonious ageing emphasises interdependence and suggests different roles and responsibilities arise for those who are older. For example particular reference is made to the role in which elders play in the family as the repository of wisdom and guidance. However, whilst such a concept frees ageing from ideas of success and failure it continues to connect particular bodies with particular societal roles. Queer theory has for some time criticised the processes by which certain bodily anatomies are read as being certain genders and similar critique has begun to be applied to ageing, with Twigg arguing that the ageing body is "not natural, is not prediscursive, but fashioned within and by culture".[17 p60] Such critiques combined with queer theoretical insights can be used as the basis for a more in-depth consideration of ageing with HIV as a gay man.

Summary of theoretical background

In summary queer theory can be used to critique and deconstruct the way in which discourses on a societal level simultaneously make subjects knowable whilst reinforcing the power that discourses have to construct. This deconstruction and critique is often achieved by theorising and empirically exploring performances of gender and sexuality that draw on non-heteronormative discourses, hence it is well suited to critically exploring gay men ageing with HIV and producing alternative ways of knowing.

Section I – literature review

Introduction

The methodology for this review can broadly be described as a critical discourse analysis approach.[18] A queer approach to discourse analysis recognises a tension when writing and researching about social categories such as "gay" or "male". Yet, as discussed above, whilst some authors such as Edelman have argued for the deconstructions of all categories, such a nihilistic approach doesn't seem to be one that can be productive in the short to medium term when social disparities exist for those who currently identify with particular gender and sexual identities. Instead the productive approach appears to be to analyse the ways in which these social categories become knowable via medical and sociological knowledge. For simplicity and readability the first part of the literature review is sub-divided into two areas, namely: gay male ageing, and ageing with HIV. These two themes will then be summarised towards the end. The discussion section after this then attempts to reframe this knowledge by reading it against queer theory to enable an alternative way of knowing gay male ageing with HIV. Hence, it is not possible at the beginning of this review to provide a clear definition of any of the key terms used, but it will be possible to explore the meanings commonly ascribed and the possibilities that exist for alternative meanings to be utilised.

The literature was identified by searching three key databases, MEDLINE, CINAHL and ASSIA. Key search terms used were: gay, queer, MSM; old, older, ageing, aging, aged, elderly; HIV, AIDS. Inclusion criteria were: papers about adults; medical, nursing, epidemiology or social science papers; primarily about older gay, queer or MSM; papers concerned with ageing; papers written after HAART was available. Exclusion criteria were: papers primarily arts based; non-peer reviewed papers; pre-clinical lab based studies of ageing using either human or animal cells. Fourteen articles were found: MEDLINE n=7, CINAHL n=2, ASSIA n=4, one additional article was found by reviewing reference lists. These fourteen papers form the core of the literature review, other relevant books, international reports and journal articles were also integrated into the review to give context and critical analysis where appropriate.

Gay male ageing

It has been suggested that gay men may age more successfully because over many years of experiencing prejudice they have developed coping strategies such as developing self-supporting community groups.[19,20] However, the literature that is concerned with healthcare outcomes suggests that whatever coping strategies are developed fail to prevent the increased poverty, poorer psychological and medical outcomes as well as increased social isolation that older gay men experience.[21] These worsened outcomes have for a long time been conceptualised as 'accelerated ageing'.[22,23] Whilst 'acceleration' is frequently prized as successful in Western societies,[24] acceleration towards ageing is notably an unsuccessful outcome with models of successful ageing constantly trying to slow down the ageing process.[15] As with successful ageing it is only possible to construct an accelerated form of ageing if one makes recourse to some normative notion of what 'aged' is in order to lay a claim as to what is being accelerated towards. It is not satisfactory to merely state a chronological age (as is so often done) and call everyone beyond this 'old' and everyone before it 'young', then to define what is 'normal' for the old, and by logical extension call everyone exhibiting these characteristics outside of these confines as somehow exhibiting inappropriate, unsuccessful, or accelerated ageing. However, as suggested in the introduction, theories on performativity enable a critical stance to be taken to gay male ageing by considering what discourses and performances maintain the notion of 'normal' ageing and what knowledge allows abnormalities to be identified as 'accelerated ageing'. Within the sociological literature the following themes appears to be considered contributory to accelerated ageing and are reviewed below: heteronormativity, ageism in the gay community, social networks, and homophobia.

Against a wider heteronormative society gay men (and in particular those with HIV) frequently lack the legitimising life narratives present within broader society of marriage, procreation, rearing children and supporting grandchildren to perform ageing in a way that is recognisable as successful.[25] There is a 'natural' and 'successful' flow in heteronormative life courses where ageing is given context within such broader social structures primarily linked to family and reproduction. One could argue that older gay men have no requirement to measure themselves against heteronormative forms of society and that ageing should be contextualised within one's own social groupings. However, the gay male community has also been suggested to be problematic for older gay men where it has been argued homonormativity links discourses of 'youth' with performances of partying, alcohol, drug consumption and liberal approaches to sexual activity[26] with any performance of a sexuality outside of these discourses becoming stigmatised and undesirable. In this respect heteronormative and homonormative approaches to ageing both come to restrict older gay men with contemporary studies of gay male communities confirming that ageism is extensive with few spaces (literal or metaphysical) that affirm older gay male identities[27] leading to reduced social support networks.[28] In addition to the lack of socially viable discourses that are accessible to older gay men, some of the remaining narratives such as cruising which remain a part of many older gay men's lives are tied with notions of shame so that they become suppressed within broader public discourses.[29] Increasing social support via generic services is problematic because of gay men's previous experiences of homophobia at an institutional or individual level often means that many that do access generic support services fear a pressure of going 'back into the closet'[30,31] (i.e. to begin to hide their sexuality having previously lived relatively open lives with regards to their sexuality). Recent anecdotal evidence from hospices suggests that the representation of services in information leaflets and posters is key to encouraging access and that inclusion of same-sex couples in generic literature is an appropriate way to ameliorate the anxieties that exist.[32] However, even if statutory and charitable support is made more accessible the literature suggests that older gay men more frequently rely on social support from their peers, primarily to avoid homophobia, however their peers are also ageing and hence may require care themselves making such social networks more vulnerable to decay than some of the intergenerational support available within heteronormative networks.[28]

In summary, the sociological knowledge about older gay men suggests several difficulties in relation to ageing, including: a lack of formal and informal social support; a lack of identifiable social structures to understand one's ageing within; prejudice from within and without the gay community; and an acceleration to ageing which is ultimately stigmatised.

Ageing and HIV

Medical ageing with HIV

Since the advent of highly active anti-retroviral therapy (HAART) it has become possible for many in the West to live with HIV rather than await one's likely death from AIDS. However, this has had the knock on implication of the HIV positive population ageing. For example in 2010 in the United States 35% of all people living with an HIV diagnosis were over 50,[33] this is expected to rise to 50% by 2015.[34] A similar trend can be seen in the UK[35] and any other country where HAART is becoming common place and widely accessible.[36] It has been regularly stated in the medical literature[37] that HAART allows HIV positive individuals to achieve a 'near normal' life expectancy; with 'near normal' meaning that individuals diagnosed with HIV live on average seven to ten years less than their HIV negative counterparts[38] and that many of the problems associated with 'old age' occur at a younger chronological age for HIV positive individuals, including: liver cirrhosis, renal disease, heart disease, neurological complications, immuno-senncense (weaker immune system), osteoporosis, muscle mass/fat distribution changes, and microbial translocation in the gut (leaky gut).[39] As one can see the list covers almost the entire body and in the medical literature (as with the sociology studies) this has been referred to as 'accelerated ageing'. However, despite the apparent consensus on the lower than average life expectancy uncertainties exist around the possible mechanisms for the medical 'accelerated ageing' exists.[40] Currently in the literature particular prominence is given to the theory that chronic inflammation via long term activation of the immune system has overarching damaging effects to an HIV positive body.[41] Hence it has been argued that in order to incorporate this new understanding of the mechanisms of HIV and ageing there needs to be a move away from focussing solely on the amount of virus in a patient's blood (normally termed viral load, with success being deemed once levels become undetectable) and CD4 cell count (the main immune cells that HIV infects and destroys), towards the measurement of a wide array of different biomedical markers needing to be measured and corrected such as: blood pressure, cholesterol, eGFR (a measure of kidney function), liver function tests, tests for diabetes, as well as monitoring lifestyle factors such as smoking and alcohol intake.[41,42] The measurement of these metrics then results in interventions to normalise the biochemical markers which it has been argued makes lives more enjoyable for those ageing with HIV.[43] However, almost all interventions suggested in the HIV medical literature with regards to ageing are pharmaceutical ones.[41] This goes against the broader medical literature on (non-HIV specific) ageing which clearly suggests medication is at best an adjuvant treatment, if not a last resort, with interventions such as diet and exercise being given at least equal prominence.[44,45]

Sociological aspects to ageing with HIV

Alongside the medical conceptualisations of ageing there are a number of ways in which ageing with HIV has been conceptualised within the sociological literature. Much of the literature highlights the additional difficulties faced by gay men when ageing with HIV, as well as confounding simple cause and effect physiological models of how HIV accelerates ageing.

Maintaining social networks has been suggested to be key to maintaining wellbeing in later life.[46] However, this is problematic for people with HIV as many people living with HIV may have lost many of their close friends to the AIDS epidemic and been estranged from their families due to HIV stigma.[47] This is reflected in a study by Shippy et al.[48] who found that 36% of HIV positive people feel that someone was never or only occasionally available for 'instrumental assistance' (covering practical day to day living tasks), and only 21% felt that they received all or most of the support they needed. In addition only 61% disclosed their status to biological family members which may result in accessing help when the reasons(s) for poor health remain hidden.

Another key protective factor for 'successful ageing' is remaining above the poverty line.[49] However, people with an HIV positive diagnosis more frequently have low socioeconomic statuses and the literature suggests that people from lower socioeconomic backgrounds are both at a greater risk of HIV infection,[50,51] as well as being more negatively impacted on should they be infected with HIV.[52] In addition, recent reports suggest that food poverty (an increasing problem in the UK and many Western countries)[53] disproportionately impacts people taking HAART as many regimes require relatively strict dietary regimes to be effective.[54]

There are several mechanisms proposed for why socioeconomic disparities exist. It has been suggested that prolonged illnesses prior to HAART becoming available prevented many long term infected people from progressing in their careers due to poor health.[55] In addition, overt discrimination by employers has also been reported when a persons' HIV status is found out resulting in discriminatory treatment and even being fired.[56,57] Whilst it is positive to note that such discrimination is now outlawed in many countries enforcing such rights is becoming increasingly problematic with the cuts to legal aid systems.[58] In addition to this, discrimination by healthcare workers may have been experienced personally or been reported via social networks.[49] This makes individuals reticent about seeking healthcare and has been suggested as a mechanism for late presentation and hence poorer outcome both for HIV[59] as well as poorer health and wellbeing in general.[60]

Summary of the empirical literature

In summary the concept of ageing with HIV as a gay man is complex. Whilst attempts have been made to explain the mechanisms for how HIV accelerates ageing in both the medical and sociological literature no single study has accounted and controlled for the plethora of factors that enhance or diminish the experience of ageing for older HIV positive gay men; probably because such a study is not possible. There is however one unifying theme to the above literature, whether one is considering morbidity, mortality, social standing, psychological well-being, or integration into society; older HIV positive gay men are represented as somehow deficient when compared to the older heterosexual and non-HIV infected 'norm' thus making life less liveable by consistently constructing the HIV positive ageing gay male as residing in a social deficit. This is not to suggest that heteronormative HIV positive people don't experience difficulties, prejudice, and medical implications of being HIV positive. However, the additional complications of queer sexualities may frequently be avoided for those presenting as non-heteronormative. Therefore, heteronormativity confers social advantages and protects against some disadvantages. However, this may have less to do with one's self-identification and instead more to do with being identified by others as failing to perform the idealised heteronormative relationship and being treated as somehow less worthy as a result of that identification. Finally, measuring people's functional ability against their chronological age is not something that the older gay male HIV positive population feels is appropriate as many have had different life courses to hegemonic heteronormative ones.[61,62] Queer theory may offer ways of constructing subjectivities without recourse to the normalising processes of medical or heteronormative society.

Part II – Queer Kinship and temporality for older HIV positive gay men

As outlined in part I, the medical and sociological literature can be analysed such that the hegemonies apparent in ageing with HIV as a gay man can be opened up and challenged through utilising alternative forms of knowledge. This will be undertaken by utilising three concepts in queer theory: vulnerability, temporality and kinship in reference to a number of questions: Why is it we see HIV represented as a collection of social and medical deficiencies? What other ways may we be able to understand ageing with HIV so as not to trace its definitions constantly to deficiencies? How may we be able to connect HIV to discourses that allow a movement away from deficiencies and towards one that embraces more than what is 'wrong'? What may this do for our understanding of ageing with HIV as a gay man? Through writing in reference to these key questions the underpinning deficiencies that continually link to ageing with HIV may instead allow a linking to other ideas, other discourses, ones not linked to deficiency; hence the ageing gay male with HIV maybe become knowable in other ways, ways that are more liveable. It is hoped that this will form the basis for novel empirical research examining the cultural as well as phenomenological understandings of ageing with HIV without the implicit idea that deficiencies need normalising in order to bring about 'good' for those gay men ageing with HIV.

Vulnerability

There are of course limitations to these arguments. No amount of queer theory can remove the physiological effects of HIV has on the body, or the side effects of the medication. If one wishes to stay alive there is only one path available – anti-retroviral medications (save the very small numbers of long-term nonprogressors and those who have had bone marrow transplants that confer immunity). Hence, any radical movement away from medical treatments as a discourse in HIV and ageing seems a relatively fruitless polemic. However, it may be possible to turn this limitation into a point of departure that allows a critique of the deficiency discourse apparent in much of the medical and sociological literature by reading the notion of deficiency against Bulter's[63] understandings of vulnerability. For Butler, vulnerability forms a social understanding of the body. All bodies she argues are constantly exposed to others and constantly relying on others for their survival. For example, in an interview with Sunaura Taylor (an artist and disability rights activist), Butler explores this idea by examining the concept of 'going for a walk' for someone in a wheelchair. In it, she argues that "nobody takes a walk without there being a technique of walking, nobody goes for a walk without there being something that supports that walk outside of ourselves. Maybe we have a false idea that the able-bodied person is somehow radically self-sufficient".[64] They go on to argue that we are all vulnerable and constantly having to rely in each other and the space and social processes that society constructs around us. In thinking about the unifying force of vulnerability Butler specifically refutes the idea of subjects who are "radically self sufficient" from the state. Hence, she suggests consideration must be given not only to what makes subjects vulnerable but also to what sustains subjects. In relation to older HIV positive gay men this raises the question that whilst HIV may produce a vulnerability, we are all vulnerable to the effects of illness, poverty and social isolation. What matters therefore is how vulnerability is responded to. For HIV positive older gay men the literature suggests that the primary way that vulnerability is responded to is by medicating. This appears the only logical way to ameliorate ageing with HIV as it engages with the profitable enterprises of the pharmaceutical industry who have repeatedly demonstrated their ability to make medicating problems the first and most natural way of dealing with a raft of deficiencies.[65] Hence, in a similar way to other problems that individuals face ageing with HIV is increasingly becoming a problem with pharmaceutical solutions with little research addressing what it is that can sustain older HIV positive gay men outside of medical-pharmaceutical notions. A turn to queer theory's understandings of temporality and futurity can help break away from these medical-pharmaceutical models towards something distinctively different in the response that can be made to the vulnerability that HIV produces in the ageing gay male HIV positive body.

Temporality

Being vulnerable and the reciprocal nature of being sustained by one another inherently suggests a survival into the future. However, many queer theorists have raised concerns about the heteronormative structuring of the futurity. Put simply:

> Straight time is seen to regulate sexual orderings through legitimizing particular social processes and institutions, which organise how we live and imagine everyday life. By way of contrast, queer theorists have turned to those whose lives have placed them on the edge of sociality organised through heteronormative temporalities, to harness instead the temporal pull of queer (sub)cultures, queer subjects, and queer artistic and literary practices.[66 p6]

In this sense 'time' can be thought of as a structuring aspect to the way in which we imagine ourselves and go on to live our lives but as Stacey highlights time has inherently normative structures. Heteronormativity therefore has the potential not only to rewrite one's current experiences, but also to legitimise what future paths are viable ones to pursue and as demonstrated in the literature the future for HIV positive older gay men is one where there is a constant but essentially unachievable aim of normalising deficits. One potential response to resisting this normalising process is to pursue Edelman's arguments around resisting any notion of pursuing future orientated goals which he suggests are intrinsically heteronormative. He suggests such an approach would achieve jouissance, essentially a kind of nirvana where one just exists in a purely queer moment with no care for the future, the passage of time and certainly not the reproduction of heteronormative social structures.[11] However, there remains a fundamental flaw to Edelman's work, at least in relation to its ability to challenge ageing with HIV; if one were to reject the future and enter into a state of jouissance there is essentially little left that supports the bodily vulnerability that HIV produces. Hence, if the future of ageing with HIV as a gay man is to be theorised in a meaningful and operationalisable way then avoiding a nihilist approach to the future is necessary and alternative queer theoretical concepts require exploration.

Kinship

Theorising older gay male HIV positive subjectivities in relation to queer forms of kinship offers a resolutely embodied and socialised production of the future whilst simultaneously situating the meaning and structuring of vulnerability within queer rather than heteronormative frameworks. In many ways the concept of kinship ties the concepts of vulnerability and temporality together. If we are to survive into the future and have our vulnerabilities responded to it is frequently those who we are closest to that we rely on. However, the notion of proximity may be altered for ageing HIV positive gay men. As already explored in the sociological literature, many older HIV positive gay men feel isolated from tradition heteronormative models of kinship, but queer theory offers alternative readings of kinship.

Tim Dean's work offers a starting point in thinking about kinship in relation to HIV. He suggests that HIV allows one to "viscerally connect a body in the present to a period… of socio-sexual relations in the historical elsewhere".[67 p93]

HIV in this sense is not just conceptualised as pathological, creating deficiencies in one's body, but instead can be considered to form kinship networks that give meaning and identity. Dean then extends this line of thinking suggesting that such practices which knowingly expose oneself to HIV "connect their participants to unlived futures… [that] have never occurred to anyone".[67 p94] Hence, HIV can be considered to form networks and connections that extend both into the past and the future. Dean argues that because they have never occurred to anyone (i.e. HIV is a relatively new disease where social practices and norms are constantly evolving) the future is blasted wide open through the virtue of the uncertainty. However, it is on this point that a departure from Dean is necessary. Whilst Dean's aim of reconceptualising HIV beyond its pathological discourses is valid, suggesting that the future is blown wide open because of the vulnerability that HIV creates is questionable. As already suggested, for the future to be sustainable for HIV positive older gay men in the medium to long term some form of medical discourses are required in the shape of HAART treatments. As such Dean's argument about the transmission of HIV create kinship is distinctly curtailed when HAART has been empirically demonstrated to radically reduce the transmission of HIV.[68] There is also the increasing introduction of effective chemoprophylaxis (administering anti-retroviral drugs as prophylaxis) which prevents the seroconversion to an HIV positive status even if inoculation with HIV occurs during sexual activity.[69] Hence there remains a tension between medical discourses that respond to the bodily vulnerability that HIV produces and the possibilities for kinship based on viral exchange. In addition Dean's focus on the necessity for a physical-sexual foundation for queer kinship also acts in a way to exclude those with differential sexual functioning who may not be able to or want to engage in semen exchange and the HIV transmission that accompanies it. Therefore, exploration of wider aspects to kinship networks to include the practical and emotional may also be productive.

Freeman whilst accepting the physical interactions that form kinship also places emphasis on the emotional basis for creating connections between one individual and another.[70] However, she goes on to challenge that such an understanding of kinship easily collapses into a heteronormative framing of a mother-father relationship caring for their children's physical and emotional well-being. Despite this even if we accept a heteronormative writing of kinship it is clear there are temporal aspects that result in one's kinship relations altering over time. For example, one may begin as a son, and will according to a heteronormative temporality orientate one's future self towards becoming a father (with a wife) or other masculine roles such as an uncle. However, within a heteronormative framework one may not 'switch' the gender of these roles to become a mother or an aunt. Whilst one could argue that acts such as adoption alter one's kinship networks, such alterations still require that adoptees who are older than the adopted person (as well as some countries requiring parents and children 'match' in terms of race/ethnicity etc.); as well as many countries still denying same-sex couples adoption rights. However, such heteronormative framings become irrelevant for Freeman who cleaves to the realisation that kinship is inherently malleable and performative which in turn opens up the possibility of building queer kinships that engage in a crossings and mixing of genders, gender roles, and even the temporal directions of kinship. Therefore, if there is to be a true queering of kinship and temporality in relation to HIV positive older gay men it becomes important to question how queer forms of kinship may help re-theorise ageing with HIV without making implicit references to heteronormative temporalities. In summary the performance of being an older HIV positive gay man must be disconnected from its relationship to the heteronormative non-HIV positive subject as well as freed from the delegitimisation of non-heteronormative forms of kinship and kinship must be allowed to respond to vulnerability alongside medical and pharmaceutical measures.

Alternative futures via queer kinship

It is clear that kinship plays an important role in the ways in which older HIV positive gay men live out their lives. However, it is also clear that many HIV positive older gay men do not discuss their diagnosis (and in some cases their sexuality as well) with their heteronormative kinship networks, yet in light of the discussion of queer kinship, the initial question seems to be: what is kinship? If, as Freeman argues kinship can be queered to incorporate many kinds of physical and emotional ties then kinship could become based around many other aspects of one's identity thus resisting the heteronormative temporality of kinships relations. This is not to say one can purely choose who one's kin is. Instead Freeman insists kinship is a performative act that requires social structures to make any performances recognisable as kinship, whilst simultaneously facilitating their continued performance in a reciprocal way into the future. Hence, the final more substantive question is as follows: what ways can a queer form of kinship be made recognisable so that one can imagine a future self interacting in socially viable and recognisable ways that are transmitted through time without reliance on and restriction by heteronormativity? This may be in part achieved by rejecting the discourses that maintain the heteronormative basis for 'older' and 'younger' as being chronological, or the biological basis for kinship, and instead foster kinship and familial ties that are based on more universal social values such as mutual care and support. However, as Freeman suggests there are few alternative terms that can be deployed to describe kinship relations that have the same impact and life-long legitimacy as heteronormative terms. For example, 'mentor' lacks the implied longevity imbued in traditional forms of kinship such as son, or sister. Further research and challenging of these linguistic restraints may be fruitful but examples do already exist within queer cultures of claiming terms like sister, brother, father and mother as meaningful categories to create kinship ties such as in the film Paris is Burning[71] which explored the lives and culture of drag queens in New York in the mid to late 1980s. The kinship relations depicted in this film demonstrate how queer families offered not only a discursive identity, but also mutual care and practical support in the face of the AIDS crisis, poverty and racism in the drag community. However, this film in some respects continues to highlight the way in which kinship frequently continues to exist within homonormative frameworks with very few examples of kinship crossing lines of ethnicity and social class; contemporary research on queer communities continues to highlight the prejudices that continue to fracture queer communities[72] as well as highlighting how performances of gender are policed amongst gay men.[73] There is however evidence in Summerskill's[13] oral history that in the UK before the legalisation of homosexuality, socialisation occurred for some gay men and lesbians with less reference to social class primarily because a camaraderie was engendered that crossed such social divides. It therefore remains thinkable that kinship can occur within queer communities without being disrupted by various privileges of race, class, gender and physical ability, but greater work is needed to understand how these kinship networks can be formed and sustained.

Conclusion

HIV positive older gay men are constructed as in a deficit relationship to those identified as non-HIV positive and heteronormative. The solutions thus far put forward to normalise that deficit and achieve successful ageing are primarily pharmaceutical in nature with few culturally appropriate solutions for how the social difficulties experienced by gay men may be ameliorated. Queer theory allows for alternative readings of ageing with HIV as a gay man and allows for the rejection of heteronormative discourses and thus removes the need to make constant referrals to 'deficients'. Queer forms of kinship offer an opening up of older gay male subjectivities and provide a broad framework for understanding and responding to the social difficulties of having a queer sexuality when ageing with HIV. However, there remain significant prejudices in queer communities that frustrate the formation of kinship networks. In addition, whilst generating kinship amongst older HIV positive gay men is desirable, possibilities for kinship across lines of gender, sexuality, race, physical ability and other social categories should be further explored. Empirical research is now needed to explore what social structures would help the propagation of alternative types of kinship into the future as well as practical actions on breaking down prejudice in and outside of queer communities.

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Abstract
Les savoirs d'économie de la santé et de santé publique ont intégré progressivement des outils liés à la mesure de la quantité et de la qualité de la vie. En définissant la «qualité de vie» et en la mettant en balance d'une valeur économique, ces outils décisionnels, qui contribuent à définir les priorités d'allocation des ressources dans le domaine de la santé, agissent comme les médiateurs concrets de l'extension de la marchandisation de la vie; processus qui peut être analysé par le concept de bioéconomie. En effet, les DALYs et les QALYs, respectivement «disability» et «quality ajusted life years» sont des boites noires souvent trop techniques pour se soumettre à un examen critique des chercheurs, mais aussi pour se soumettre aux discussions des décideurs. Si la perspective critique d'analyse de la bioéconomie a pu s'intéresser à des champs essentiels comme la procréation ou la mort, des outils tels que les DALYs et QALYs, et les conséquences sociales et politiques de leur utilisation, doivent pouvoir également faire l'objet d'une telle analyse à des fins éthiques et socio-politiques.

Mots clés Bioéconomie, DALYs, économie de la santé publique, économie morale, marchandisation, QALYs, santé mondiale, sociologie

De l'économie de la santé publique à la bioéconomie: analyse critique de l'usage des DALYs et QALYs

PIERRE-MARIE DAVID

Introduction

Qu'elles portent sur le médicament, les biotechnologies, ou les stratégies de prévention, les décisions sanitaires s'entourent aujourd'hui d'un ensemble de savoirs économiques et épidémiologiques basés sur la mesure portant la rationalisation de la précaution et des coûts au cœur de la société. Les analyses de coûts liés à la santé sont de plus en plus utilisées dans les États modernes pour favoriser une certaine gestion des ressources publiques depuis les années 1960 et plus singulièrement depuis la fin des années 1970 et la crise pétrolière. Dans le secteur de la santé, les méthodes d'évaluation économiques ont été sollicitées par les décideurs pour des fins diverses depuis les années 1980 et ont notamment permis d'accompagner la grande transformation opérée par les réformes néolibérales transformant la santé en secteur marchant, en particulier dans les pays anglo-saxons. Elles accompagnent aujourd'hui les gouvernants pour comparer, prioriser et décider des différentes stratégies, et donc *in fine* des différentes réalités sanitaires les plus souhaitables pour la société. Cet usage généralisé parait d'autant plus incontrôlé que certaines voix se font entendre pour rappeler qu'une approche morale de l'économie de la santé est nécessaire.[1] Un retour critique sur les principaux fondements et les usages d'outils d'économie de la santé est l'objectif principal de cet article. Un objectif secondaire est de montrer la participation de ces usage à une dynamique sociale plus fondamentale participant à un processus économique de marchandisation de la vie et à une idéologie utilitariste de la vie.

La quantité de vie en terme d'années de vie gagnées a été progressivement intégrée grâce aux statistiques de mortalité développées par le secteur assurantiel. Les décisions ne sont toutefois pas exclusivement guidées par ce «souci de la quantité de vie». En effet, les principes de la qualité de la vie ont progressivement fait leur place au cœur des décisions publiques et politiques de santé. Ainsi s'affirment de manière détournée par l'économie de la santé de nouvelles manières de concevoir et d'affirmer ce qui est bon et juste par un ensemble de normes et de valeurs. Ces valeurs données à la qualité de la vie, dans deux outils que sont le DALY et le QALY, respectivement «disability» et «quality ajusted life years», définissent en creux le prix que les sociétés sont prêtes à payer pour différentes interventions de santé et différents états de vie reliés à leur utilité. Les décisions relatives à l'allocation des ressources dans le domaine de la santé nous semblent ainsi à la frontière névralgique de l'économie morale[2] et de l'économie politique de la santé; frontière qui est au cœur de ce qui fonde les valeurs morales d'une société.

Les sciences sociales n'ont que peu interrogé frontalement cette économie de la santé, à l'exception notable de l'article récent de Kenny.[3] En effet, les débats en sciences sociales sur la question étaient généralement portés par deux visions opposées : l'une de critique radicale des outils économiques et de leur utilisation par principe, et sans nécessairement en comprendre les fondements, l'autre d'acceptation de ces outils au vu de la limitation des ressources et des contraintes économiques et sociales. Les débats autour de ces questions sont d'ailleurs généralement arbitrés par des considérations procédurales techniques, éthiques ou bioéthiques jouant le rôle de dérivatif aux réels enjeux sociaux et politiques.

Quoi qu'il en soit, peu d'étude critiques ont ouvert ces boites noires centrales à la pratique contemporaine de l'économie de la santé. Néanmoins, l'extension de la marchandisation de la vie sans précédent représente une injonction à requestionner les fondements théoriques de tels outils ainsi que les politiques très concrètes qu'ils justifient et qui définissent matériellement les contours d'une «bioéconomie».[4] L'objectif est ici d'essayer de proposer une analyse précise des fondements de certains outils d'économie de la santé maintenant tellement généralisés qu'ils ne sont plus questionnés, avec une perspective de sciences sociales en essayant de comprendre concrètement comment l'utilisation de ces outils participent à une bioéconomie qui n'est pas qu'une désocialisation de la vie, une désymbolisation de l'existence, mais aussi le cœur d'une économie morale globale et utilitariste de la vie.

Approche et visée théorique

La perspective proposée s'axera sur une analyse technique et critique vis-à-vis d'outils aussi centraux que les QALYs et les DALYs, de leur mode de production et du pouvoir qu'ils contribuent concrètement à exercer. Nous montrerons comment ces outils permettent l'édification un contrôle plus avancé et global des populations au travers d'organisations internationales, d'universités, d'institutions de mesure réalisant une biopolitique faite de jeux de pouvoirs et de valeurs morales plus fondamentales sur nos manière de faire société.

Cette approche permettra dans un premier temps de faire apparaître les présupposés moraux qui sont engagés dans ces outils et permettra dans un second temps d'appréhender de manière originale l'«espace politique de la santé»,[2] qui se définit ainsi concrètement par l'usage même de ces outils qui permettent une plus grande gouvernementalité de la vie, mais aussi qui réalisent une étape supplémentaire sur le chemin concret de l'incorporation sociale et politique d'une culture de la vie[5] qui aboutit de plus précisément à sa marchandisation. La question est ici celle du biopouvoir et des jeux de pouvoir, mais aussi celle des valeurs sociales qu'il diffuse. Après avoir présenté brièvement la définition des DALYs et des QALYs il nous faudra réinscrire ces outils dans une dynamique plus profonde faisant de la santé et de la vie un nouveau marché.

La mise en forme économique de la santé et de la vie

L'extension de l'économie à la santé

Les outils d'économie de la santé constituent une autorité d'autant plus difficile à contester que les savoirs qui les fondent sont perçus comme objectifs, et les ressources dans certains secteurs sociaux sont politiquement produites comme rares. Ces outils s'appliquent tous azimuts à divers types de réalités sanitaires, comparant interventions préventives, curatives, internationales ou régionales. Cet usage généralisé permet d'ailleurs de justifier et de naturaliser les fondements théoriques engagés dans la pratique et de redéfinir du même coup les réalités sanitaires qu'ils appréhendent comme une prophétie autoréalisatrice. Il est donc important de revenir à la définition et au fondement théorique de ces outils.

L'analyse coût-efficacité recouvre des méthodes pour mesurer et résumer les informations liant les ressources dépensées pour la santé en termes monétaires et les résultats de santé mesurés en termes numériques (pression artérielle, taux de cholestérol, charge virale) dans un ratio en coût par unité de santé mesurée définissant l'intervention de santé considérée. Si un traitement antihypertenseur permet de réduire la pression systolique de 30 mm de mercure et que son coût est de 30 000 dollars par an on dira que le coût-efficacité de cette intervention est de 30 000/30=1000 dollars par mm de Hg de pression artérielle gagnée.

Cette stratégie permettait ainsi de comparer différents traitements pour une même visée thérapeutique, mais pas de comparer différents traitements pour différentes pathologies, ou différents traitements agissant différemment sur une même pathologie. Par exemple, il était ainsi impossible de comparer un antihypercholestérolémiant et un antihypertenseur dans la pathologie cardiovasculaire. Les résultats intermédiaires en termes de santé n'étant pas comparables, il fallait les projeter sur un même axe pour savoir quelle intervention était la plus coût efficace, c'est à dire pour quelle intervention «on en a pour notre argent» selon l'expression consacrée.

Quantifier la vie par la mort

C'est ainsi qu'en s'appuyant sur les analyses épidémiologiques de morbidité et mortalité les statisticiens ont transformé les résultats intermédiaires de santé en résultat final en terme de survie, à savoir le nombre d'années de vies gagnées. Autrement dit, les résultats de santé des interventions de santé qu'elles portent sur le cholestérol, le paludisme ou la nutrition étaient directement évalués en terme d'années de vie gagnées au niveau populationnel. Cette «grande transformation» a ainsi permis de désencastrer la pathologie de sa spécificité et de créer un espace «propre» en termes de survie s'appuyant sur les statistiques de morbidité et de mortalité. La vie s'est ainsi éclairée et normalisée à la lumière des chiffres de la mort.

Un ensemble d'outils allant des «années de vie sauvées» aux QALYs ou des DALYs s'appuient dans leur construction sur une statistique de la mortalité et de la morbidité permise par le savoir clinique, mais aussi par une volonté de savoir de la part d'organisations assurantielles qui ont permis à différents objets de pénétrer le monde médical et permis d'affiner les statistiques.[a] En effet, la biopolitique du risque à l'échelle populationnelle est bien l'élément fondamental permettant de traduire une pathologie en risque de décès et donc en quantité de survie au niveau populationnel.

Plus concrètement, pour les QALYs et les DALYs, le rapport entre la vie et la mort s'est construit à travers la production des outils et d'échelles de préférence. Par exemple, des échelles sont proposées où 0 représente la mort et 1 la vie en parfaite santé. On demande alors à une personne de positionner une condition de santé sur cette échelle de préférence. Cette méthodologie embarque les présupposés de l'économie libérale, mais aussi une certaine représentation de la vie et de la mort ou plutôt d'un rapport intrinsèque entre la vie et la mort. La mort ne se définit alors plus qu'en rapport à la vie, comme un échec de celle-ci. Jusqu'à quel point ce rapport se subjectifie dans la pensée et la conscience du répondant, il faudrait l'étudier. Quoi qu'il en soit, le projet général qui est aussi derrière l'utilisation de ces outils est logiquement, au vu des fondements explicités, une lutte contre la mort qu'il va falloir endiguer, repousser annihiler par un gain de quantité et qualité de vie. On retrouve alors certains éléments d'une société post-mortelle[6] dont les caractéristiques seraient embarquées dans une variable continue entre le pôle de la mort à l'utilité nulle et celle d'une parfaite utilité pour la vie en santé. La mort devient ainsi quantifiée et représentée comme un échec contre lequel il va falloir lutter, par différentes stratégies de plus en plus technicisées.

La «qualité de vie» s'est ainsi reconstruite comme le résultat d'une pondération nécessaire de la quantité de vie à travers une préférence qui se fixe sur un continuum entre la vie et la mort. Et la préférence accordée subjectivement aux différentes situations de santé est venue compléter le dispositif de quantification de la vie par la mort en lui donnant une qualité.

Qualifier la vie par les préférences individuelles

La méthode retenue est celle des échanges de quantités en fonction des différentes qualités de vie attendues, sur le mode de marchés psychologiques et virtuels. Trois méthodes sont habituellement retenues dans les manuels:[7]

-Échelle analogique visuelle où il est demandé à la personne de mettre le curseur sur échelle de 0 à 100 en fonction d'une condition de santé (0 représentant la mort et 100 la vie en parfaite santé).

-Échange de temps, la question est généralement de savoir combien de temps une personne serait prête à échanger dans une certaine condition de santé pour des années de vie en parfaite santé.

-Pari standard de survie demande aux personnes quelle probabilité de mourir elles seraient prêtes à jouer pour échanger une situation de santé définie.

L'exemple suivant illustre ces méthodes. Une personne atteinte d'insuffisance rénale et régulièrement dialysée trois fois par semaine se voit poser la question suivante : quelle est la préférence de qualité de vie attribuée à cette situation de santé? Première méthode (échelle analogique): où est le curseur sur une échelle visuelle? Deuxième méthode : combien d'années de vie de dialyse êtes-vous prêt à échanger contre une année en pleine santé? Enfin, la troisième méthode consiste à poser la question : quel risque de mourir seriez-vous prête à accepter pour subir une opération qui vous redonnerait une parfaite santé? Ainsi, concrètement le QALY est une année de vie en pleine capacité «perçue» (correspondant au coefficient de 1). Si «on» accorde un coefficient de 0,8 à une situation de santé correspondant à une invalidité, alors 10 années de vie avec cette invalidité correspondent à 8 QALY.

La question que nous pose également en creux cette méthodologie est de savoir qui répond précisément à la question des préférences. Différentes réponses ont été apportées : les malades eux-mêmes, par le biais de leurs associations le plus souvent. Avec cet effet collatéral qu'ainsi se réalise concrètement un mode de subjectivation produisant des citoyens en fonction de leur problème de santé; une étape vers la «biocitoyenneté».[8] D'autres études ont considéré les personnels soignants connaissant «objectivement» les situations de santé comme les meilleures personnes; reposant alors immanquablement la question de la domination médicale sur le ressenti subjectif du malade. Enfin, les instances internationales comme l'Organisation mondiale de la Santé (OMS) ont décidé de répondre par les experts. Les critiques envers une technocratie gouvernant les choix politiques de santé sont alors aussi à considérer. Au-delà des réponses, il faut insister sur le fait que cette question «qui préfère?» devient ainsi un enjeu majeur de la validité de la méthode dans un premier temps, mais aussi de la réalité ainsi produite dans un deuxième temps. De plus, ceci pose la question ontologique de savoir si le sujet de la préférence ne se trouve pas modifié dans le processus même de production des preuves.

Les présupposés ici appliqués sont bien ceux de l'économie néo-classique donnant légitimité à l'économie comme science. Les analyses se centrent au fond sur un individu rationnel autonome dont les préférences individuelles peuvent être identifiées et quantifiées : le fameux *homo economicus*.[b] Les méthodes que nous avons citées (échange temporel, pari standard de survie et échelle analogique visuelle) apparaissent comme des méthodes très ethnocentrées et prenant comme naturel une certaine intériorisation du risque et de l'incertitude. La validité anthropologique est ainsi très limitée, de même que sa validité sociale. Les sciences humaines et sociales tentent de montrer précisément comment la construction sociale des préférences est non seulement délaissée par de telles approches, mais aussi naturalisée. Enfin l'analyse décisionnelle, élément ultime de ce type d'analyse propose un raisonnement populationnel en maximisant la somme totale des utilités, sans tenir compte de la répartition, inégalitaire de ces utilités ou de l'aversion individuelle du risque.[c]

Finalement, du point de vue de leur production ces outils que sont le DALY et le QALY ont une action objectivante et subjectivante. En effet, l'outil ne se fait pas que médiateur d'une réalité, mais il la transforme tout au long des étapes du processus: La santé est transformée en maladie mesurée, en facteurs de risques et en taux de mortalité pour obtenir des années de vie gagnées (objectivation) qui sont alors transformées en années de vie préférées en s'appuyant sur les préférences individuelles (subjectivation). Ce double aspect montre bien qu'un espace spécifique est ainsi créé, un lieu propre au sens de de Certeau.[9] Une certaine conception de la vie peut alors être déployée et appliquée au réel.

Usages et économies morales liées à ces outils

Les DALYs au cœur d'un nouveau réseau mondialisé

Conçus selon le même cadre théorique que les QALYs, les DALYs ont été développés plus tard[10] par des équipes de l'OMS et de la Banque Mondiale. L'objectif des chercheurs ayant mis au point cet outil était en fait la comparaison de la charge des différentes maladies («global burden of disease») pour établir des priorités d'intervention en termes de santé internationale. Les DALYs permettaient ainsi de comparer différentes pathologies sur un axe unidimensionnel. Par exemple, on pouvait comparer le nombre d'années de vie (intégrant morbidité et mortalité) perdues pour une population du fait de pathologies aux symptômes et à la mortalité différentes, par exemple le paludisme et le VIH/Sida.

En 1996, M. Murray, directeur du programme mondial OMS promeut l'utilisation des DALYs apparus pour la première fois dans le rapport de la Banque Mondiale de 1993 intitulé «Investing in health».[d] Cet outil était alors décisif pour faire la distinction des priorités de santé sur des bases économiques et scientifiques et non plus politiques. L'ambition alors affichée est de donner une réponse scientifique à la question : quelle intervention de santé devrait-on prioriser? La réponse s'appuyait sur les QALYs au nord, et plus spécifiquement dans les pays anglo-saxons,[e] et sur les DALYs pour les pays en développement. Cette question nécessitant une réponse était devenue légitime dans le cadre d'une redéfinition de la gestion collective de la santé tant au niveau national qu'international. Au vu de ces éléments politiques généraux sur l'utilisation de ces outils d'économie de la santé, essayons maintenant de présenter certaines des représentations de la santé et de la maladie qui y sont liées tout en essayant de mettre à jour certains effets de cette «dépoliticisation» de la santé.

En effet, l'utilisation de tels outils globalisants a joué un rôle dans la reconfiguration politique des années 1990. L'utilisation des DALYs a précisément permis de passer d'une santé internationale, celle des états à une santé mondiale, se réalisant moins en rapport aux États qu'à des maladies et des stratégies transnationales objectivées par des mesures économiques et scientifiques. Ces savoirs économiques entourant et redéfinissant la santé, malgré les discours sur les droits humains, ont montré une réémergence des théories de la modernisation basée notamment sur la médecine fondée sur les preuves ou données probantes de la science (Evidence Based Medicine) et sur les études coûts-efficacité (Cost effectiveness Analysis) visant à maximiser la santé (estimée en années de survie pondérées de l'incapacité) et minimiser les coûts; autrement dit, revoir toutes les interventions de santé avec le souci de l'optimisation.[11] L'OMS s'affiche alors dans les années 1990 comme leader de ce processus d'optimisation à partir d'outils tels que le DALY qui agrège des organisations telles que la Banque Mondiale, des Universités Nord-Américianes et des coopérations bilatérales. Selon certains auteurs ce moment précis est celui du passage de la «santé internationale» à la «santé mondiale».[12] C'est en effet bien un changement de rapport au politique qui s'opère en mettant au cœur de la décision sociale et politique, la vie quantifiée, standardisée et normalisée scientifiquement et économiquement.

Ce changement politique s'opère sur ce que l'anthropologue Marc Abélès[13] a appelé le passage d'une politique de « convivance » à une «politique de la survie». Il s'agit selon lui de la fin d'une tradition politique entretenue dans le cadre étatique national et «avant tout axée sur l'harmonie synchronique entre des êtres qui se meuvent dans l'univers rassurant de la cité ou qui du moins orientent leurs actions en tenant compte de cet horizon» à une «préoccupation du vivre et du survivre au cœur de l'agir politique» et qui se caractérise par une éthique de la sollicitude où les idées de justice et de droit ne trouvent leur sens que dans la perspective du risque et de la précaution.

Plus précisément, la distinction d'utilisation des QALYs au Nord et des DALYs pour les pays en développement montre d'ailleurs une distinction relative dans les valeurs accordées aux vies. En effet, un jugement différentiel sur la vie s'opère avec les QALYs d'un côté et la perspective d'une amélioration de la quantité et la qualité de vie et allant dans le sens d'un prolongement presque illimité de la vie. La référence particulière aux maladies n'est presque plus nécessaire. De l'autre côté avec les DALYs, l'horizon est limité: premièrement à celui d'une durée de vie prédéfinie comme maximale (celle des Japonais : 82 ans) et deuxièmement à celui de maladies et autres pathologies. On retrouverait ainsi embarquée dans les DALYs une certaine vision verticale de la santé par maladies,[f] alors que les QALYs intégreraient la santé comme un champ global d'améliorations presque illimitées.

Les sciences sociales des sciences ont pourtant montré en quoi les catégorisations scientifiques, y compris celles qui définissent la maladie, sont fondées sur des valeurs culturelles et sur des conflits politiques. Ce qui ne revient pas à dire que les maladies n'existent pas, mais au contraire qu'elles se définissent relativement à un environnement et à un contexte social.[13] Dans une certaine mesure les DALYs intégreraient les limites culturelles propres à l'épistémologie politique occidentale alors que les QALYs permettraient justement de les dépasser en présentant la perspective d'un corps et d'une santé toujours améliorable. L'économie morale globale embarquée dans ces outils serait donc également fondée sur un jugement de valeur différentiel sur la vie : certaines qui seraient à médicaliser, d'autres à améliorer. De nouvelles perspectives différentielles sur la vie se trouvent ainsi disséminées : à qualité, une amélioration sans limites de sa quantité et de sa quantité au niveau occidental et au niveau global une vision normalisée sur les standards occidentaux des maladies biomédicales.

Quand les QALYs et les DALYs voyagent

Une analyse de l'usage des QALY/DALY permet de saisir les orientations de la gestion collective de la santé qui y est liée et les nouveaux modèles de médicalisation ou d'amélioration de la société qui sont embarqués dans cette pratique. L'analyse proposée par Arnesen et Kapiriri, chercheurs de santé publique internationale en Norvège adopte également une approche critique vis-à-vis de ces outils en se basant précisément sur leur mise en pratique.[14] Ils montrent comment ce type d'analyse coût/efficacité amène à des traitements très différentiels de différentes invalidités. Ils comparent notamment l'invalidité due à la malnutrition et l'invalidité due à la dépression. Ils remarquent que celle due à la dépression est fortement surévaluée, au vu des nombreux outils et de la large littérature scientifique qui nous permettent de distinguer différents types de dépression. Alors que du côté de la malnutrition la littérature est beaucoup plus sommaire. La conséquence en se fixant sur les DALYs est ainsi claire : il faut prioriser l'intervention de santé visant à la diminution des symptômes dus à la dépression.

L'application de tels outils mesure et délivre alors de fait une valeur différentielle aux personnes. En effet, les invalides valent moins que les bien portants en terme d'utilité générale, mais aussi d'utilité ressentie. Les très jeunes valent généralement moins que les gens dans leur période productive. Des coefficients de pondération sont ainsi appliqués pour prendre en compte ce qui est le plus souhaitable pour une société. Si les QALY/DALY sont appliqués stricto sensu aux personnes âgées il est peu probable qu'elles bénéficient des prochaines interventions de santé, à part s'il est deviennent majoritaires!

La méthode des préférences imaginées, si nous avons évoqué ses présupposés, a des conséquences très concrètes. En effet, cette méthode peut s'adresser à des personnes malades concernant les pathologies déjà balisées. Toutefois, l'analyse est généralement mobilisée pour évaluer de «nouvelles» interventions de santé avec des conséquences encore imparfaitement définies. Les destinataires de la méthode des préférences imaginées sont donc généralement des personnes en santé au moment du questionnaire. Cette méthodologie revient donc concrètement à mettre sous une forme discursive les différents états de santé proposée et leur désirabilité. C'est ainsi une négation de l'histoire individuelle des états de santé qui se passe et se renouvèle au quotidien. En effet, le ressenti d'un état de santé à un moment donné semble, dans l'expérience vécue, difficilement détachable du travail passé fait sur cette expérience du corps qui est aussi une expérience sociale et qui en fait in fine, la plupart du temps une expérience «vivable». L'exemple évoqué précédemment selon lequel une personne amputée aurait 80% de qualité de vie est difficilement envisageable dans cette perspective. La distinction entre préférence réelle et préférence imaginée est donc fondamentale comme l'a montré dernièrement cette étude inattendue sur la qualité de vie des personnes traitées pour la maladie de Parkinson et dont les symptômes avaient objectivement diminués, mais pour qui la qualité de vie ressentie était finalement moindre que précédemment.[g] La raison avancée semblait se situer au niveau de la personne qui se sentait alors moins entourée. Les aspects relationnels de la personne sont donc parmi les aspects contextuels les plus importants,[h] que l'approche des préférences et des utilités peine à prendre en compte.

Si les QALYs et les DALYs sont ainsi très questionnables vis-à-vis de l'histoire individuelle de la santé, ils le sont tout également vis-à-vis de l'histoire collective des situations sanitaires. En effet, la projection de ces interventions sur un axe unidimensionnel «coût/efficacité» permet de comparer des interventions aux objectifs, aux résultats et aux méthodes très différentes. Une étude espagnole, en se basant sur une telle analyse «coût/efficacité», comparait de manière non contextuelle une intervention visant à faire arrêter de fumer grâce à un traitement médicamenteux et une intervention visant à une prise en charge de l'hypercholestérolémie par un traitement médicamenteux;[15] deux exemples qui n'ont rien à voir, si ce n'est précisément le fait d'être comparables en terme de QALYs. L'exemple de la malnutrition cité précédemment en comparaison de la dépression est également un bon exemple du traitement différentiel qui peut être fait de deux situations sanitaires aux causes et aux portées radicalement différentes.

Ces comparaisons sont fondamentalement biaisées. Le savoir biomédical n'est pas indifférent aux pathologies. Il est beaucoup plus développé pour les pathologies occidentales. Il contribue aussi à naturaliser des situations sanitaires qui ont une histoire et qui ne sont donc pas distribuées de manière aléatoire, mais en fonction d'une organisation structurelle historiquement constituée. Ainsi les problèmes de malnutrition en contexte postcolonial, qui trouvent pour certains d'entre eux leur source dans un système d'exploitation profondément inégalitaire et qui s'est reproduit, ne peuvent pas du point de vue moral de l'historien être traités en comparaison directe et sur le même pied d'égalité que la dépression, dont les données sont produites massivement par l'industrie pharmaceutique. Plus fondamentalement, le fait même de comparer différentes pathologies sur un même axe économico-biomédical contribue à redéfinir les pathologies selon un ensemble de normes et de valeurs qui sont propres à cet axe contribue à l'incorporation de ces valeurs et normes dans l'espace social. Ainsi se redéfinit une économie morale autour d'un contexte technique et économique pris comme une donnée qui définit à la fois la situation sanitaire, et l'opportunité d'intervenir pour en modifier le cours.

La force et la faiblesse de ces outils reposent au fond sur une certaine prétention à l'universel des normes et valeurs utilitaristes occidentales: «un QALY est un QALY » comme le rappellent tous les professeurs d'économie de la santé, qu'on soit atteint de cancer, de dépression, de malnutrition, à Montréal, à Calcutta ou à Bangui. Cet universel s'appuie sur des savoirs...renforcés par une statistique des populations qui contribuent ainsi à la dissémination d'une biopolitique qui trouvera localement sa déclinaison. Il devient alors de plus en plus nécessaire d'étudier localement sa traduction dans des processus de décision culturellement ancrés.

Les leçons d'une expérience locale

L'économie morale qui se définit à travers des outils liant qualité de vie et ressources économiques n'est pas exclusivement liée à leurs fondements théoriques. La manière dont ces outils intègrent le débat public et la prise collective de décision est également importante pour comprendre leur portée sociale générale et plus précisément ce qu'ils «font faire». Un exemple de réappropriation de mise en pratique remarquable des QALYs est celui resté célèbre appliqué en Orégon aux États-Unis. L'expérience de l'Orégon s'est passée dans les années 1990.[16] Il s'agit certainement à l'heure actuelle de l'expérience sociale la plus poussée intégrant l'analyse coût/efficacité et les QALYs pour définir les priorités de santé publique. Un comité réunissant médecins, malades et citoyens s'est réuni avec l'objectif de rendre un maximum de services de santé au maximum de personnes sur le programme Medicaid, assurance médicale permettant la prise en charge des personnes les plus pauvres aux États-Unis. Après plusieurs réunions du comité et séances de consultation publique, des critères sont ressortis quant aux interventions les plus souhaitées. L'efficacité médicale, le coût et la perception de la maladie dans l'opinion publique ont ainsi été retenus comme critères.

L'expérience a été mise en pratique puis arrêtée et largement critiquée. Étonnamment, ce n'est pas la critique portant sur la démarche collective de rationnement, qui plus est sur le programme d'accès aux soins des plus pauvres, qui a été retenu. En effet, ce sont les premières victimes (et leur médiatisation) qui ont fait croître un malaise profond dans l'opinion. Un service de transplantation avait fermé au profit de services materno-infantiles, chaque personne décédée faute de transplantation s'inscrivait socialement comme la faute du programme du plan de réforme Medicaid; programme qui fut dès lors suspendu.

Cette expérience concrète de mise en place d'une réforme basée sur les outils standardisant la vie dans un rapport coûts/efficacité a des conséquences importantes. Elle montre en effet le changement de point de vue après la prise de conscience de la population de la différence entre les morts statistiques et les morts réelles. Statistiquement, les vies prises en charge par les soins materno-infantiles «rapportaient plus» que les vies «à transplanter». Mais la réalité de la vie du transplanté ne pouvant bénéficier de sa greffe pour cause de rationnement était insupportable. Le corolaire de cette prise de conscience est bien sûr la différence fondamentale entre la somme des préférences individuelles ou les préférences collectives construites socialement et politiquement. Le QALY, comme outil scientifique coût/efficacité permet une réponse à la question de priorisation des interventions de santé qui peut s'avérer problématique, notamment en favorisant des choix implicites; un détour qui pose parfois plus de problèmes qu'il n'en résout.

Finalement, cette expérience montre qu'il y avait bien une économie morale portée par les outils qui se heurtait à des normes implicites du «vivre ensemble»; la preuve avec ce comité et les réunions publiques dans lesquelles des valeurs relatives aux biens collectifs ont pu être abordées et discutées. La question se pose alors de savoir si l'outil bioéconomique n'est pas, dans certains cas, plus un inconvénient qu'un avantage, un dérivatif à la question centrale du vivre ensemble et à la nécessité du débat dans la prise de décision.

Conclusion : (Ré)intégrer la mesure de la qualité de la vie dans un processus de décision social et politique

Les présupposés embarqués dans des outils tels que les QALY et les DALY sont non seulement d'ordre économique en donnant une valeur à la vie sur l'axe univoque de l'équivalent argent, mais aussi d'ordre moral en lien avec un système des valeurs utilitaristes. La diffusion de tels outils par des organismes internationaux vient alors renforcer une économie morale globale basée sur une valeur d'échange des vies. Il convient alors de resituer l'usage de tels outils dans le développement plus général d'une «bioéconomie»[4] mondiale participant à la marchandisation de la vie.

Ce constat relativement sombre de la progression de la marchandisation de la vie humaine doit néanmoins pouvoir être discuté au travers d'analyses ethnographiques plus fines pour avoir une vision moins globalisante et permettre de faire ressortir des usages plus nuancés de tels outils économiques. En effet, le contexte politique d'usage de tels outils est fondamental: qu'on se situe dans un contexte politique de régulation étatique des années 1960 ou dans celui des politiques néolibérales, la teinte prise par l'utilitarisme embarqué dans ces outils est profondément différente. De telles études permettraient de saisir les limites de l'acceptabilité de l'usage de tels outils, comme expérimenté en Oregon, et de saisir également des formes de résistance à ce régime d'équivalence des vies sur un axe marchand.

Ainsi, malgré des prétentions universelles d'une réponse biopolitique basée sur les QALYs et les DALYs à la question des priorités dans les interventions en santé, d'autres réponses restent à penser au sein d'un projet collectif. En effet, les QALY et DALY en définissant un espace politique de la santé, donnent une réponse politique et sociale consistant à mettre la création de valeurs économiques au cœur du «vivre ensemble». Il convient alors de construire de nouvelles perspectives permettant de répondre à la question des priorités d'intervention en santé non pas à partir de la valorisation économique des quantités de vie individuelles, mais à partir de la qualité d'un projet collectif faisant advenir un commun qui ne se réduirait pas à l'axe marchand. La fixation du débat sur des alternatives hyper technicisées pour gagner des quantités marginales d'utilité empêche de considérer la réduction des inégalités sociales de santé comme centrale des discussions des politiques sanitaires. L'axe de la justice sociale[17] reste ainsi à affirmer et opérationnaliser[i] comme une alternative à l'axe marchand.

Notes

a.A ce sujet le rôle des organismes assurantiels sont à la source de la généralisation de l'utilisation des thermomètres dans les hôpitaux allemands, de même que les compagnies d'assurance américaines sont à la source des études permettant de préciser le risque cardiovasculaire depuis les années 1940 et prolongés par la fameuse étude Framingham du nom de cette ville du Massachussets. Enfin les régimes d'assurance nationaux proposés par les états providence après la deuxième guerre mondiale sont à la source de cette biopolitique moderne.[18]

b.Voir sur le sujet de l'homo economicus les fameux travaux de Bourdieu dans les structures sociales de l'économie le présentant comme une fiction scolastique portée jusque dans la conscience même des agents.[19]

c.Par exemple si l'alternative est de gagner 50 avec une probabilité de 1 ou de gagner 200 avec une probabilité de 0,5, la théorie retient toujours la deuxième solution puisque de manière statistique la première branche rapportera 50 alors que la seconde 100 (0,5*200).

d.Consulté le 5 mars 2015: http://elibrary.worldbank.org/doi/pdf/10.1596/0-1952-0890-0

e.Cet outil est généralement utilisé par toutes agences d'accréditation de médicament ou d'intervention de santé. La France est un des rares pays occidentaux à y être restée réfractaire.

f. Si utiles aux Initiatives Mondiales de Santé (Global Health Initiatives). Pour une analyse critique de ce mode vertical d'intervention, notamment par rapport au VIH/sida voir Biesma et al.[20].

g.Au sujet des stratégies de cogntive enhancement et de leurs effets ambivalences, voir Forlini et Racine.[21]

h.Voir à ce sujet les études réalisées par la psychologie critique de la santé qui permet de dépasser les caractéristiques individuelles des situations de santé. Pour une synthèse à ce sujet voir Santiago[22].

i.Voir à ce sujet les discussions autour d'un indicateur de création de valeur sociale par Caillé et Weber.[23]

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‘Invalidé’ or ‘Invalid’? Critical Reflections on Health, Self, & Identity

DAVE MERCER

> Only through the experience of trial and suffering can the soul be strengthened, vision cleared, ambition inspired, and success achieved. The world is full of suffering; it is also full of overcoming it.[1 p205]

Introduction

For all of my professional life, vision has been a central, yet largely unacknowledged, part of the work that I do. As a mental health nurse I have been practitioner, educator, and researcher. In each role, ‘sight’ represented a critical component of ‘insight’; whether that be engaging with clients/patients, students, or study participants. Observation, and interrogation of ideas, is essential to the way we help to enable and empower individuals, or explore our own understandings of the world around us. It is a social world mediated and constructed by seeing, talking and sense-making, but each of these can be too easily taken for granted. The following narrative is a reminder of human fragility in the context of healthcare needs that extend beyond the ‘blind’ rhetoric of health policy. It is the personal account of a ‘wounded story teller’,[2,3] where loss precipitated a new way of ‘seeing’ familiar environments. Illness is often spoken about in episodic terms and, if mapped as a journey, charted by the discourse of those in control.[4] Sickness connotes lack of control, adoption of a ‘sick role’,[5] and surrender to the knowledge(s) of a body of experts. Illness is never planned, seldom predicted, often disguised, and easily denied by delusions of invulnerability.

A short time ago I was working away from home on a research project that involved qualitative observation and interpretation; watching, note-taking and, later, re-telling everyday events within appropriate theoretical frameworks. Sitting alone in a hotel room, with a flickering but silent television for company, evenings were spent re-working hastily scribbled observations while they remained fresh in mind. It was a commonplace activity, defined by confidence and personal satisfaction. Like all original inquiry the accompanying sensation of uncertainty was balanced by an informed sense of self-identity as 'social researcher'; in short, I felt in charge of the situation.

This intellectual labour, like any creative and meaningful work, constructed and embodied what Marx characterised as 'species being',[6] in part approximating to Maslow's[7] ideal of 'actualisation'. The latter has sadly been abased, and abused, by several generations of 'nurse tutors' whose focus on a 'hierarchy of needs' is usually removed from concerns about relations between the individual 'self' and the state. Within the constraints of historical and material social relations, it is suggested humanity can reclaim and re-shape lives in opposition to an overpowering sense of 'alienation'. These ideas, though, are more than philosophical abstractions. They are central to understanding what is, increasingly, spoken about as 'the core business of healthcare'; neo-liberal language that commodifies compassion, and reduces caring to a profit-driven and target-directed enterprise, where market forces represent the basis of political liberty.[8-10]

I spent a considerable part of my academic career in healthcare as a researcher and writer, where journal publications need to be submitted in accordance with a universal and formulaic set of rules, and an account of 'research design' is pivotal; a failure to include this section inevitably results in rejection of the manuscript. In contrast, this article derives from personal experience expressed as an illness narrative (e.g. Roberts[11], Richman[12]).

The discussion that follows is an attempt to breathe new life into old theoretical perspectives in the context of a life-changing experience of serious illness – recounted by an 'insider' who became an 'outsider'. To describe it as reflective narrative rather than a scholarly paper is only partly accurate, capturing a dissonance between the two worlds of 'patient' and 'provider', and prompting the question of what we really mean by an 'evidence-base for practice'? Informed by the work of critical thinkers, and writers, such as Szasz[13-15], Goffman[16,17], Foucault[18,19], and Kafka[20] it is, at heart, a few pages from the diary of a 'man' who felt himself transformed into a 'disattended social object'.

A brief note on 'method'

What follows is a 'story' but, arguably, 'all research can be considered a form of story-telling',[21 p151] and this recognition is particularly important in the domain of health inquiry. It is acknowledged that narrative is one way of making sense, or meaning of life, and has evolved as a vital branch of interpretive approaches to exploring the social world: 'Critical exploration of both the content and structure of stories is therefore vital to qualitative health research'.[22 p1648] For critical discourse analytic work, in its many guises, language and text are central to, not only data collection and analysis, an epistemological critique of dominant knowledge(s) and techniques of knowledge production.[23,24] Giving expression to those groups marginalised, and oppressed, by social structures and systems, offers a space for 'resistance' to powerful institutions and ideologies; research with potential to empower and emancipate.[25,26]

More specifically, the 'illness-narrative' plays an important role in the way that individuals make sense of ill health and manage, rather than cope, with their experiences. Moving emphasis from the modernist appropriation of the corporeal being, in medical technology and treatment, Frank's[1] 'wounded story teller' lives in a 'remission society'. Rather than Parsons[5] 'patient' who was expected to comply with medical language and power, the postmodern narrator shares her/his story/suffering as a way of staying well and helping others.[21] In this way, it is suggested that from autobiographical forms of self study '...a radically different understanding of the nature of research and subject/object relations has emerged'.[27]

Retinal and social detachment: 'Falling to pieces'

In clinical terms, retinal detachment describes the moving away of the retina from the main wall of the eye, the light sensitive membrane which receives images and transmits them to the brain, causing loss of vision where separation occurs. It constitutes a medical emergency, and without immediate treatment the entire retina may detach leading to vision loss and blindness. This, though, says nothing about how it feels. Diagnosis of the 'condition' came some days after 'symptoms' first appeared – incremental visual disturbances in the sight of the right eye, flashing lights and shadowy shapes that drifted across a screen of vivid colours. It was not, initially, a permanent loss of vision. When the eye was rested, or held stationary, things could look much as they always had, and it was easy to attribute the strange experiences as a product of strain or tiredness. Indeed, in the triage of the Ophthalmic Accident and Emergency Department, the first contact with healthcare services, an attending nurse remarked that my eyesight was 'fine'. Of course, during the eye test I was passively standing, looking at a Snellen chart in one fixed direction. This was not reassuring and, despite supportive words from my partner, Ashay, three anxious hours were spent waiting to see a physician.

The first intervention was an attempt to reattach the damaged retina using a laser, an uncomfortable procedure undertaken in a small, hot, and airless room. Sitting upright, with sweating hands clenching the grips of a device designed to keep my head static, an intense beam of light was fired into the eye. Punctuated by sharp sounds, that resembled the firing of an air rifle, was a painful burning sensation at the back of my eye. I cannot estimate how long this took, but imagine it seemed greater than was actually the case. I was left feeling nauseous and faint as the doctor walked from the room, muttering only that I should arrange a follow-up appointment at the Out-Patient Clinic. There was no member of staff present and, again, it was Ashay who ventured into the laser-suite to help me collect myself. Two weeks later I was informed the laser work had not been effective, the damage was worse, and the remaining option was a vitrectomy under general anaesthetic. This is an invasive surgical procedure commonly used to fix a retinal detachment, where vitrious gel which pulls on the retina is removed from the eye and replaced with a bubble of liquid gas.

At this point I was reminded that in the 'old days', 'removal of the eye' would have been necessary to reduce longer-term pain; a somewhat perverse interpretation of 'breaking bad news'. My only response was to ask, with a degree of timidity: 'That option's not still on the table is it?' When, during the process of recovery, the retina in my left eye also detached the attending consultant declared that 'the chances of it happening at the same time are about the same odds as winning the national lottery'. I easily grasped the statistical rarity, but found the comparison more than a little unsettling. During all of this, little was explained, and the chance to talk was minimal. The nicest and most sensitive person, I recall, was a consultant anaesthetist immediately prior to the operation. This was not reflected in what ensued.

Care and compassion: 'A numbers game'

Wandering from one hospital department to another for a series of tests and examinations in the 'production-line' of treatment it was hard not to notice, for me at least, the '6C' stickers on the floor coverings; permutations of six factors identified by the Chief Nursing Officer for England (CNO) at the NHS Commissioning Board, and the Director of Nursing at the Department of Health, to sustain high-quality services;[28] care, compassion, competence, communication, courage, and commitment. I was hunched over, feeling down, and looking down. Unconcerned, others walked over them, contributing to eventual erosion; a metaphoric display of missed messages that has dogged the history, and present, of how care and compassion are conveyed to embryonic practitioners, and maintained in qualified staff. These six constructs, none of which are divisible, represent the latest 'mystery' in a healthcare creed that genuflects before dual deities of policy directive and pseudo-science. It can be argued that for too long nurse educators, managers, and policy makers have been playing a 'numbers game'; an obsessive belief that the most important aspects of empathic, enabling, approaches can be numerically indexed and quantified. Positing another 'C' for inclusion on the list, how about picking between context or collectivism?

I spent only a couple of days on the 'recovery' ward, which was large and mostly filled with empty beds for those in transit. Waking up from nineteen hours without food, and no meal available, the offer of tea, with toast and biscuits was incredibly appealing. Asking for both, I was harshly rebuked by a female Health Care Assistant (HCA) and informed that it was a choice between either one or the other. This reaction was explained by an embarrassed student nurse, who had been similarly chastised, as something that paralleled the 'less eligibility' policy introduced in the Poor Law Amendment Act to deter people claiming 'poor relief' by making conditions inside Victorian workhouses worse than those outside.[29] My experience brought a novel twist to the ideology of a 'deserving' and 'undeserving patient'. It was commonly accepted that some individuals would lie to gain extra portions and, to deal with this, everyone was assumed to be dishonest. The young student remarked that 'To me, putting the patient at the centre of care is what nursing's all about, that's what I've been taught, but this is what happens'; a lamentable episode that underpins the whole problem.

With mediated stories of declining standards of care in the NHS, a body of international literature attests to the negative impact of a 'hidden curriculum' in healthcare training across professional disciplines.[30] Quantitative studies, typically using some form of validated empathy rating scale, have recorded incrementally reduced scores throughout the duration of professional education programmes,[31] but explanations of this finding are best served by inquiry which situates its rationale and design in clinical culture and the ethnography of the ward.[32,33] Medical students, for example spoke about oppressive, discriminatory and prejudicial attitudes which were expressed as a process of 'learning through humiliation'.[34] Nurse respondents in research studies can clearly articulate the constituents of respectful and dignified care, but struggle to deliver this within organisational systems and cultures. Jakobsen and Sorlie[35] theorise this in the context of contemporary society, where healthcare represents one sub-system of a market-driven, global, economy in which workers have a 'colonised status'. A short time spent as a patient in a large, inner city, teaching hospital made these critical commentaries more understandable, if not acceptable.

Nurse education: 'A house of mirrors'

In contemporary nursing curricula, the concept and practice of 'reflection' has assumed pivotal prominence as a way of engaging learners with the emotional labour of caring. Typically, it contributes to a portfolio of skills that approximate to a set of nationally agreed, or imposed, domains that represent eligibility to register with the professional body, the Nursing and Midwifery Council. Mapped against the learning outcomes of a three-year undergraduate programme, the emphasis is on acquisition and ongoing development of clinical competencies marked by degrees of progressive sophistication. Having previously expressed reservations about the value of reflection, I contend that promoting a 'looking glass world'[36] can potentially invert understanding unless it is anchored in a more robust theoretical critique of healthcare cultures; something entirely different from a criticism of individuals.[4]

Reflective practice in nursing and healthcare education is typically formulaic, based upon uncritical acceptance and implementation of specific 'models' (e.g. Gibbs[37]), much like attempts in the 1980s to systematically plan care, or develop a theoretical basis for caring. Emphasising cyclical stages, disconnected from bigger socio-political debate, reflection is reduced to an individual, and at best interpersonal, exercise. Ng and colleagues (2015) make this same point in relation to medical education, identifying two relevant theoretical orientations of reflection; respectively, 'epistemology of practice' and 'reflection as critical social inquiry'. They note: 'These directions offer medical education research broad and deep potential in theories of reflection, particularly in relation to knowledge creation within uncertain and complex situations, and challenging of dominant discourses and structures".[38 p469, emphasis added]

Previous ministerial calls for nurse education to 'return to the bedside'[39] have re-emerged in recent proposals to introduce an 'apprenticeship' in caring[40] where 'student nurses will be asked to do up to a year of practical training in basic care before they turn to the textbooks' as part of recruitment and admission to healthcare courses. This represents a damaging rhetoric that de-politicises health education at a time when it has never been more needed. A 'sociological imagination'[41], critical social policy, and an 'archaeology' of nursing knowledge/science[42,43] have been relegated to the fringes of curriculum content. Educational programmes, like modularised jigsaws, often allow 'pieces of the picture' to go missing.

Moving pre-registration nurse education into the higher education sector could be, controversially, interpreted as squandering great potential advances for the profession, and sacrificing what was most valuable in the old hospital-based 'schools of nursing'. An ethos of corporatism now characterises both healthcare and university systems.[44,45] Though student nurse tuition fees are still funded through the NHS, via Clinical Commissioning Groups (CCGs), the educational culture is undoubtedly compromised by neo-imperialist international expansion of the 'global campus'; investment of foreign capital and ever expanding IT strategies of 'on-line' provision, with profit as the driving force. Multiple intakes per year of student nurses, with large cohort numbers is, arguably, not the best approach to teaching and learning in a vocation where inter-personal relations are central to communicating the core values of caring practice.

A production-line of care: 'Belief and betrayal'

Overall, this experience was a painful one. Not physical pain, which was well controlled, but the hurt of betrayal and loss. For over three decades I have proudly worked in, and steadfastly supported, the NHS as an institution founded on ideals of welfare and justice.[46] Working in the broad field of mental health, and specific domain of high-security forensic services, the struggle for advocacy, service-user involvement, and social inclusion has a respected pedigree.[47-49] Likewise, an increasingly vocal and influential contemporary cadre of 'experts by experience' where narrative, understanding, and bearing witness to illness are part of 'the resources through which patients make sense of their condition, and thus reflect upon and evaluate the very notion of a desirable outcome'.[50 p165] Offender-patients, for many people, are not a popular client group – spoiled identities and master-statuses constructed from a dual stigma of 'criminality' and 'madness',[16-19] forged in the powerful institutional discourses of law and psychiatry. With colleagues in the UK, and internationally, I supported professional (practice) and intellectual (praxis) avenues to offer 'voice' to service-users and staff in marginalised peripheries of service provision (e.g. Holmes et al.[51,52]). At the time of my illness, I was jointly working on a project to evaluate the introduction of recovery-based care in maximum security settings.[47]

The ideals of working in collaboration and partnership are now accepted as foundational in any caring relationship across the spectrum of caring services. In contrast, as 'patient', rather than 'person' it felt very different. The standards of caring varied widely between genuine attempts at 'being human(e)' to an almost callous disregard, which meant that the overall experience could only be rated in negative terms; of anticipating the worst, and being pleasantly surprised by small acts of kindness. I felt old, alone, and unheard in an organisation where previously, in 'another life', I had been respected and valued. I experienced familiar territory as the 'product' of a monolithic machine, of being 'passed around', interspersed by interminable waiting, while being told next to nothing. Nursing care, generally, was ritualised; temporality measured by the unchanging rhythm of medicine rounds, routine observations, and mealtimes – all done, or dispensed, without 'talk'.

Postural positioning meant that time in hospital was spent lying down on my left side for fifty minute periods broken up by ten minutes of respite. Apart from visiting times, interaction was minimal; this regime continued for two weeks following discharge. Usual pastimes, like reading, were impossible and enforced idleness provided ample opportunity to think and to reflect. I began trying to make sense of things by 'writing inside my head'; memorising chunks of 'text', and eventually putting them to paper in a childish scrawl, it marked the beginning of 'recovery'. Acknowledging that surgical skill and medical technology had, likely, salvaged some degree of sight, something was very wrong. It resided in a total failure to recognise, let alone implement, the central message of healthcare educators – the intrinsic, unconditional, worth of those seeking help in time of need. Given colossal investment in support for student nurses undergoing clinical practice (academic tutors, placement co-ordinators, link tutors, practice education facilitators, mentors, and sign-off mentors) invites the question: 'How could this be so'?

Recent healthcare scandals, and high-profile inquiry reports[53,54], have posed similar questions. In the spirit of Wright Mills[41], there are no simplistic ways of translating 'private troubles' into 'public issues', but the culture of caring in relation to health education is in need of critical attention and interrogation. Some ideas about how we might begin working towards this are expressed [see text box 1] as observations and opportunities:

Conclusion

Shortly before the events outlined in this paper took place, myself and a colleague were commissioned by NHS North West to undertake an evidence review into 'NHS values and behaviours'[55] precipitated by reported 'failings' in UK health and social care services (e.g. CQC[56]). National and international evidence, in relation to the core values of caring, was appraised and presented as a narrative review. Discussion about care and compassion, and conjecture about how best to embed these within healthcare cultures, was told from the perspective of 'objective outsiders'. In contrast, it was a sudden experience of ill health which precipitated an illness narrative that centred on the same sort of issues, where the evidence was experiential, but the story-teller remained an 'outsider'; this time in terms of dignity,

Text Box 1

-Re-politicise health and healthcare curricula, where nurse educators work collectively with trade union members, community activists, and social movements to defend the principle of socialised welfare.

-Conceptualise nursing as a political force in the larger struggle for human rights and social justice.
Support critical nursing research that locates practice in the context of social structures such as sexuality, gender, ethnicity, and disability that promote division and discrimination.

-Avoid isolating nursing, as a professional group, from academic related disciplines within the university system. Good 'health science' requires strong links with departments like clinical psychology, sociology, critical criminology, and anthropology.
Recognition that 'clinical skills' are essential to competently practice as a nurse, but 'critical skills' are what shape the way that job is actually undertaken.

-In the UK there is a statutory requirement (NMC) that to hold a teaching post in a nursing department the member of staff has to be a registered nurse and that registration has to be 'live'. This precludes the employment of individuals who may possess a wealth of skills in the biological, behavioural, or social sciences.

respect, and the process of care as 'subjectively' constructed.

The quote from Helen Keller that introduced this account was cited in a journal publication titled 'Finding Meaning in Suffering' that describes the contribution of patients, as 'wounded story tellers', to the art and practice of nursing: 'The process of caring for a suffering person is painful for the nurse and requires exceptional effort on the nurse's part, but the very act that drains the nurse can also create the fuel for compassionate care'.[1 p205] This sentiment expresses perfectly the message that I have tried to convey. I cannot claim that the illness experience was 'transcendental', but it was certainly 'transformative'; a story remembered in the dark, and written as the light began to filter through.

As a final word, and note of levity, I recall many years ago a nurse tutor bitterly complaining to me that his students knew more about 'Foucault on the eye, than the physiology of the eye'. There is much to be learned from the wisdom and curiosity of the young, where our role as health educators is to enable rather than to prescribe.

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APORIA
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