APORIA

LA REVUE EN SCIENCES INFIRMIÈRES • THE NURSING JOURNAL

Vol.1, Numéro 3/Vol.1, Issue 3. ISSN: 1918-1345

Sommaire/Content

Vol.1, Numéro 3/Vol.1, Issue 3

Éditorial/Editorial

L'université, lieu de connaissances et de découvertes est de plus en plus critiquée par certains penseurs qui remettent en question sa croissante association avec diverses industries de même que des agences militaires. Sachant que les fonds publics dédiés à la recherche se font de plus en plus rares, les compagnies privées et l'industrie militaire jouent un rôle grandissant dans l'octroi de fonds aux chercheurs dont ces derniers ont besoin afin de conduire leurs recherches. Par conséquent, la frontière entre les secteurs public et privé s'amenuise entraînant la dépolitisation de la recherche et de l'éducation.

Ce qui est problématique c'est que cette tendance, aux répercussions majeures sur les plans politique et éthique, est normalisée au sein des universités. Celles-ci obéissent de plus en plus à des agendas imposés par les compagnies privées et l'industrie militaire. L'université, en tant que lieu de recherche et d'enseignement supposés indépendants sur le plan intellectuel, constitue l'un des derniers remparts publics où le débat d'idées peut et doit prospérer ; elle est plutôt devenue un espace cartographié par des intérêts corporatistes et où se dénoue une crise liée à son rôle ambigu dans l'espace public.

À la lumière de l'incursion constante des intérêts privés sur les campus universitaires, il est clair que les questions relatives à la production des connaissances, la propriété intellectuelle et la diffusion des savoirs doivent être problématisées et discutées. Le rôle des universités au regard de ces trois grands axes doit aujourd'hui être clarifié et, surtout, protégé. La mainmise d'intérêts divers, qu'ils soient privés, gouvernementaux ou militaires dans les affaires de l'université résulte non seulement dans la valorisation, voire l'imposition, de certains types de recherches mais aussi dans l'orientation de plusieurs aspects du fonctionnement universitaire tels que l'embauche des professeurs, les cours à offrir, la gouvernance de l'université, et ce qui peut être rendu visible ou ce qu'il faut taire. Ces intérêts extérieurs imposent des valeurs et des pratiques et produisent des identités.

Cette problématique n'est pas récente et a été soulevée à maintes occasions. Cependant, au rythme où les connaissances doivent être produites et diffusées, combiné à la chasse effrénée pour obtenir des fonds de recherche, desquels dépend largement la carrière des professeurs-chercheurs, ce type de questionnement est non seulement négligé mais parfois même méprisé par plusieurs, dont les professeurs-chercheurs eux-mêmes. Henry Giroux soutient que le travail académique dépasse considérablement l'enseignement d'habiletés mécaniques et instrumentales de manière à outiller les étudiant(e)s pour répondre aux besoins du monde corporatif. Il affirme que ce travail académique doit au contraire favoriser la création de forums ouverts propices à l'expression d'idées nouvelles, voire subversives, à la critique des cadres théoriques courants, à la problématisation des limites théoriques actuelles et à la mise en lumière des relations de pouvoir et des processus politiques à l'œuvre dans les sociétés contemporaines. Dans le contexte actuel de pénétration sauvage d'intérêts privés et gouvernementaux dans la sphère universitaire, l'université est, et doit rester, un lieu démocratique (et de démocratisation) où l'engagement citoyen est au cœur de sa mission.

Aporia a comme objectif de permettre la diffusion de savoirs multiples et l'équipe éditoriale du journal s'engage à respecter cet objectif en créant un espace où les chercheurs, les étudiants, les professionnels et le public peuvent s'investir dans la réflexion critique et le dialogue et, ce faisant, se réapproprier des finalités qui leur sont propres.

Amélie Perron
Éditrice

Éditorial/Editorial

We have chosen to focus the editorial in this issue of Aporia on a trend that is of significant concern in universities: that of the growing corporatisation and militarisation of the academic sphere, which has been condemned by many thinkers. As public funds dedicated for research are cut and researchers struggle for shrinking pools of money, corporations and the military play an ever-expanding role in providing much needed funds to pursue academic research. The line between the public and the private realms becomes blurred in the process to the point that it barely exists anymore, thus depoliticizing research and education.

What is more concerning is that this trend, which poses serious political and ethical issues, has become normalised in universities, effectively turning them –and their researchers, teachers, students and staff– as merely an instrumental extension of private corporations, working to fulfill specific, narrow agendas. The distinction between public and private interests is obscured. Universities constitute a space where research and education are carried out in an autonomous manner. As one of the few remaining public spheres where critical dialogue can and must occur, they have become a site where a crisis is unfolding, a crisis of agency.

In light of the current growing corporatisation and militarisation of university campuses, we believe issues related to the production of knowledge, the ownership of research and the dissemination of information need to be problematised and discussed. The role of universities which is central to these processes needs to be clear, but above all, it needs to be protected. Corporate control over universities dictates much more than the nature of research. It also dictates what is allowed to become public knowledge, what faculty should be hired and promoted, what kind of undergraduate and graduate courses are "needed", how the university is governed, how hierarchies operate, and what –or who– is given visibility or silenced. It dictates values and practices, it produces identities.

This issue is not new and it has been raised elsewhere. However, given the fast pace at which information is produced and published and the relentless pursuit of research grants, upon which one's academic career heavily rests, such matters are easily dismissed as scholars and students alike "go with the flow". We fully agree with Henry Giroux, who argues that academic work encompasses much more than preparing students for the workforce, teaching them instrumental and mechanical skills to operate effectively in a corporate world. Rather, it aims to provide a safe and open forum where ideas, may they be radical, can be developed and critiqued, theoretical boundaries can be pushed, ideologies can be identified and challenged, and power relationships and political processes can be uncovered. It is a space where democracy and engaged citizenship are given their full scope and meaning.

Aporia aims to make knowledge accessible. In light of this disturbing phenomenon, the editorial team remains committed to this objective and to providing an open, public forum where academics, students and professionals can engage in critical reflection and dialogue and reclaim their own sense of agency.

Amélie Perron
Receiving Editor

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Abstract
Nursing knowledge is diversely represented and contested, among academics and clinicians within and outside of nursing. This paper explores several Foucauldian concepts in relation to subjugated, local, naïve and situated forms of knowledge. We argue that these concepts relate closely to the mundane world of nursing and are useful for thinking about, teaching and researching everyday nursing practice. The discussion is tied back to data and analysis from a postmodern ethnography of nurses' assessment practice in an Australian acute psychiatric setting. We show how Foucauldian analysis of nurses' knowledge can usefully foreground taken-for-granted aspects of skillful practice.

Key Words discourse, everyday, Foucault, nursing knowledge, place, time

Foucault's Concept of "Local Knowledges" for Researching Nursing Practice

BRIDGET HAMILTON &
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Introduction

Nursing knowledge has been a contested site for as long as there have been nursing scholars. We are interested in nursing knowledge as it is expressed in everyday nursing actions, and de-coupled from idealised frameworks for nursing identity, such as: the expert intuitive nurse;[1] the evidence-based nurse;[2] or the popular ideal of the caring nurse.[3] Some scholars have emphasised the need for nurses to explicitly learn and rely on theoretical models of nursing[4] (such as Carper)[5] to inform their practice and others still have promoted the notion of praxis, whereby nurses are encouraged to rely on reflection and action. We suggest that all of these recommendations place a somewhat cumbersome burden on nurses, dividing those exemplars whose practices fit with the respective privileged frameworks, from others who practice nursing in the mundane, messy world of everyday work. This paper teases out several Foucauldian concepts in relation to knowledge. We argue that these concepts relate closely to the mundane world of nursing and are therefore useful for thinking about, teaching and researching everyday nursing practice. We aim to illustrate how the concept of situated knowledge can usefully foreground taken-for-granted aspects of skillful practice.

In wishing to critique the notion of (some) nurses' exemplary use of knowledge, our thinking is aligned to that of Purkis and Bjornsdottir.[6] The primary criticism of ideal models of knowledge is the way such models exclude or undervalue ordinary practice and knowledge. Pointing to faults in similar conceptualizations of the relationship between nursing knowledge and practice, they present nurses as intelligent practitioners whose knowledge is "activated" in specific contexts.[6 p248] They rely on Latour's[7] notion of knowledge as transformed in the work with a patient in a particular context. While their argument foregrounds and weaves together what they consider to be scientific knowledge of nursing and knowledge of each patient in context, we still perceive in their argument a lack of engagement with the effaced knowledge of the organizing demands in nursing, or in other words with what it is possible to know and do in a particular clinical context.

In this paper, whatever it is that nurses might know, about patients and about clinical practice, is viewed as emerging from forms of knowledge or discourses that are considered true, however wide or narrow their remit. Conversely, we suggest that nurses may either bypass or tenaciously hold onto forms of knowledge that are all but disqualified and silenced, not having achieved the status of truth. Such forms of knowledge are referred to as local and subjugated.[8]

The Foucauldian concepts of local, naïve and subjugated forms of knowledge are presented here as useful tools to enable elaborating and investigating of the resistant and productive character of nursing knowledge, in everyday practice. These ideas were developed for use in the doctoral study by the first author (BH), involving a postmodern ethnography of nurses' assessment practices in acute psychiatry settings. The study was approved through an institutional (hospital) ethics review, according to the requirements of the national body overseeing ethical conduct of research in Australia.[9] Eleven nurse participants gave their informed consent and names included in field data are pseudonyms. The research methods used in this study are published elsewhere.[10] This paper is primarily theoretical, but fieldwork and analysis from this postmodern ethnography are used to illustrate the potential of this Foucauldian perspective.

Foucault's ideas regarding truth and discourses are first outlined here, to provide context for an exploration of the ideas of subjugated local and naïve knowledges in nursing.

Foucault on knowledge, discourses and social practices

Knowledge and its claims to truth are the starting point for this theorising of nursing knowledge. For Foucault, discourses were the scaffolding for knowledge construction in the social world. Discourses determined what could be considered, known and upheld as truth. Throughout his entire corpus, Foucault frequently directed attention to the place and activity of knowledge and discourses of truth in Western society. In a lecture entitled "Technologies of the Self", Foucault said:

> My objective for more than twenty-five years has been to sketch out a history of the different ways in our culture that humans develop knowledge about themselves: economics, biology, psychiatry, medicine and penology. The main point is not to accept this knowledge at face value but to analyse these so-called sciences as very specific 'truth games' related to specific techniques human beings use to understand themselves.[11 p224]

Here we see a clear link between truth and self-definition, in the light of his later work on subjectivity. Earlier, his focus was on the link between knowledge and power in the development of the dominant forms of knowledge and truths of the human sciences.[12-15]

Academics such as Saussure[16] and his critic, Derrida[17] were interested in discourse principally in a linguistic sense, closely investigating and theorising language in use.[18 p109] However, as Rabinow noted, Foucault "never intended to isolate discourse from the social practices that surround it".[19 p10] Where nurses have often struggled with a perceived distance or a 'theory-practice gap' between knowing and doing in nursing,[2] knowledge for Foucault is intrinsically caught up in local power relations, in the site and activity of knowledge production and use.

Rather than laboring a definition of discourse per se, Foucault focused on the activity of discourses and offered many illustrations of discursive practices from the human sciences. For example, it is through the detailed examination of the way prisoners are housed and observed by prison guards that Foucault[15] built his analysis of modern power. Knowledge and discourses are similarly dealt with here as "systems of thought that are contingent upon as well as informing material practices, not only linguistically but also practically".[20 p49]

Since Foucault considered that discourses were actively produced in discursive practices, discrete discourses could not be sustained in isolation, but were alive in temporal and local contexts of practice. It follows that discourses are far from stable entities, rather they are constantly reproduced, contested and incrementally altered, as they are practiced.[21] Discourses link and refer to other discourses, such as when biomedical discourses are adopted by clinical researchers and power is drawn from certain discursive practices of scientific experimental methods and of measurement, within the broad discourses of natural sciences.

Competing and shifting discourses

The existence of competing discourses is evident for example in Foucault's extensive analysis of the competing discourses of unreason and madness in the early development of the discipline of psychiatry.[13] The power of dominant discourses over marginal discourses is explored in the work of poststructural feminist scholars. Weedon[22] argues that dominant discourses appear natural in society, resting on an established and institutional power base, and serving to main the status quo. This feminist view of dominance calls for a response of concerted resistance by the oppressed to overthrow or shift discourse and practice. However, Foucault himself rejected the notion of the absolute or totalising power of any discourses:

> …we must not imagine a world of discourse divided between accepted discourse and excluded discourse, or between the dominant discourse and the dominated one; but as a multiplicity of discursive elements that can come into play in various strategies.[23 p100]

If discourses are bound up in networks of power relations, it follows that the existence of discourses (such as biomedicine) necessarily gave rise to counter-discourses (such as holism, or alternative therapies). Ways of acting and explaining action are viewed as arising out of power exchanges and the use of available language and knowledge. In turn, these exchanges promote further and constantly changing actions, knowledge and language use, or discourses.[23]

Though he rejected the idea of any discourse as all-powerful, Foucault did recognise the persistence of some discourses that others would call hegemonic. In particular, he was scathing in his analysis of the domination of scientific discourses in the game of truth in Western society:

> In societies like ours, the 'political economy' of truth is characterised by five important traits. Truth is centred on the form of scientific discourse and the institutions which produce it; it is subject to constant economic and political incitement…; it is the object, under diverse forms of immense diffusion and consumption (circulating through apparatuses of education and information whose extent is relatively broad in the social body,…); it is produced and transmitted under the control, dominant if not exclusive, of a few great political and economic apparatuses (university, arour, writing, media); lastly it is the issue of a whole political debate and social confrontation ('ideological struggles').[24 p131-2]

Even so, Foucault saw instability and contestation as inherent within discourses. In his own research, he displayed a preference for exploring resistances and anomalies associated with dominant discourses. He drew attention to resistances in his analyses of many kinds of disciplinary systems: the army, the hospital, the prison, the monastary, the school, the family. His work elaborated forms of knowledge that were subjugated within dominant discourses.

Subjugated forms of knowledge

Foucault[8] identified two connected and subjugated forms of knowledge: erudite historical knowledge and disqualified local knowledge. The first was dear to him, as a meticulous student of classical philosophy and historical practices. The second kind of knowledge, disqualified local knowledge, demands particular attention for its substantial relevance to nurses' knowledge. Foucault[8] defined subjugated forms of knowledge as follows:

> … I believe by subjugated knowledges one should understand something else, something which in a sense is altogether different, namely a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated; naïve knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity. I also believe that it is through the re-emergence of these low-ranking knowledges, these unqualified, even directly disqualified knowledges (such as that of the psychiatric patient, of the ill person, of the nurse, of the doctor – parallel and marginal as they are to the knowledge of medicine - that of the delinquent etc.) and which involved what I would call a popular knowledge (le savoir des gens) though it is far from being a general commonsense knowledge, but is on the contrary a particular, local, regional knowledge, a differential knowledge, incapable of unanimity and which owes its force only to the harshness with which it is opposed by everything surrounding it – that is through the reappearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work.[p82]

A modest body of research articulates elements of nurses' knowledge that are local and naïve; yet, are identified as essential to nursing work.[25-29] In our view, the knowledge identified in such studies accords with Foucault's[8] definition of subjugated forms of knowledge. Through a close range study of psychiatric nurses' knowledge produced in everyday assessment practice, the first author articulated several subjugated and disqualified elements of nurses' knowledge.[30]

Illustrating subjugated nursing knowledge

The box below contains field notes and subsequent analysis from this empirical research of nursing assessment practices in an acute psychiatric unit.[30] See page 10 for Box 1: Field notes and analysis of subjugated practice and knowledge.

Box 1: Field notes and analysis of subjugated practice and knowledge

After handover, and once the nursing shift leader had allocated all patients to the care of individual nurses for the shift, the nurses' first activity in relation to those patients was commonly to find and see them in the ward. On one afternoon shift I followed Nurse Ewan, as he sought out his allocated patients, in preparation for the afternoon's work.

> After handover, Nurse Ewan looked at the whiteboard and jotted down on the back of his handover sheet the names of patients allocated to him. He commented that he didn't know any of these patients well, although he had worked with one patient the previous day and another early in his admission. Nurse Ewan did not pick up patient files, rather he picked up the obs[ervations] foldera and walked through the ward. He exchanged a greeting with one patient on his list and a couple of sentences with another, returning to the office once he had seen all five allocated patients. He stood at the reception desk and, unbidden, he ran through his impressions of the five allocated patients and the approach he might take with each.
>
> Field Ewan #2

Nurse Ewan began his work with patients by circulating through the ward and briefly observing all of them. Two other nurses, the Clinical Specialist, Nurse Beth and the Group Program nurse, Nurse Carl, had no patients allocated directly to their care, yet they also made a point of circulating through the ward soon after handover, looking into the High Dependency unitb and seeing the patients for themselves, as one practice which informed their day's work. At this point I wish to emphasise the precedence and ubiquity of nurses' use of observation within the ward.

These nurses favoured observing the patients first-hand, apparently relying on their own senses and the immediate and 'live' information thus produced, over other static and written information available to them in the patient file. An aspect of this live information was their observation of the patient in an immediate social context, including the patient's interaction with the physical environment, with other patients and with staff. Thus, seeing the patient for themselves produced a situated, beginning knowledge of the patient.

Also, when nurses cared for unfamiliar or particularly unwell patients, the nurse often established and maintained a line of sight from themselves to one or more patients, as a taken-for-granted nursing activity. On a morning shift, Nurse Greg adjusted his position in the room as he spoke briefly with me, so that he could also see two patients at a glance:

> Continuing our conversation, we both sat down in the High Dependency (HD) unit chairs. But within a moment Nurse Greg was up from his chair, leaning towards a bank of windows and glass door leading out into the HD courtyard. Nurse Greg said "I always look," indicating he wanted to see the patients who were in the courtyard. I leaned forward also, seeing that two patients were standing and smoking out of Nurse Greg's line of vision when he sat in the chair. Nurse Greg then remained standing, within line of sight of the patients and frequently glanced away from me in the patient's direction, while we spoke for a few minutes.
>
> Field Greg #1

Nurse Greg's comment "I always look" indicated that he was conscious of his watchfulness at that moment. This comment was both striking and helpful to me, because there were many occasions during participant observation when I [observer] noticed nurses shifting their position in the room to maintain watch over patients as they spoke with me [observer], but no other nurses made such comments. Indeed, when I interviewed nurses about their inclination to see patients, or to keep an eye on patients, nurses invariably re-framed such work as 'meeting patients'. Nurses' common silence and about their obvious watchfulness suggested to me that the subject position of watching nurse was both taken-for-granted and subjugated by nurses in their daily work. Only in the precise moment of looking did Nurse Greg freely concede that he 'always looked'. Nurses' taken-for-granted privileging of the immediate knowledge they gained through observation in the time and space of the ward is highlighted through this analysis.

a The 'obs folder' contained a single page for each patient currently on the unit, noting their bedroom number and their location in the unit at pre-set time intervals. Detailed analysis of the routine assessments practices associated with this folder is provided elsewhere.[31]

b The open-door Acute Psychiatric Unit consisted of two 22-bed acute wards; each of these contained a locked, three-bed High Dependency area or 'HD unit'

Using the analysis in Box 1 as an example, we suggest there is a dynamic association between everyday nurses' practice and disqualified forms of knowledge, in nurses' situated assessments of patients. Nurses both exercised knowledge and gleaned valuable knowledge through circulating and briefly observing patients, and by maintaining a line of sight between themselves and particular patients. Yet, the extensive practice knowledge enacted in skilful observation was subjugated by the nurses themselves, who instead spoke of 'meeting patients'.

Also, the situated knowledge gained about patients and about what nurses needed to do was formed, enacted and frequently over-written in the course of a shift. What the nurses knew by seeing and what nurses did in the moment had little prominence in handovers, ward rounds or patient files. This knowledge was often and implicitly useful for work in the moment but rarely explicitly acknowledged. Indeed, what nurses knew was not articulated or privileged in the clinical setting, either as knowledge to be foregrounded in clinical team negotiations or to be preserved in written documents. In this second sense then, nurses' knowledge was subjugated, amid the work of the unit.

We wish to define two additional terms, to support our investigation of subjugated forms of knowledge in nursing. The concept of "locatedness", as developed by Malpas[32], a theorist in social geography and the concept of "situated knowledges", as developed by critical feminist, Haraway[33], both extend the theoretical work of Foucault, in regard to subjugated forms of knowledge. The concepts of locatedness and situated knowledges are examined in terms of how they intersect with Foucault's work. We then return to the extracts and analysis of field data to enrich the discussion of locatedness and situated knowledges in nursing.

Local, situated knowledge and place

Local knowledge for Foucault refers to knowledge that is specific to a situation and to human actors, and which is recognised as such by the actors, in contrast to knowledge that makes grander truth claims.[8] Increasingly, programs of health geography[34] have attended to intersections between place, clinical practice and knowledge. A strand of social geography that is useful to our argument is the work of Malpas[32,35] on the "locatedness" of knowledge.[32 p189]

For Malpas[32], knowledge is inseparable from location or place of its production, a proposition that is overlooked in modern presentations of universal facts and truths, which are plucked from their place of production and widely disseminated. He described how any location encompasses space and place and differentiates space from place. Space is a concept aligned to scientific enterprises; areas of space can be measured producing knowledge such as a map reference, whereas place refers to an experience of place, is embodied, requires a knower and relies on subjective meaning-making.[32] Malpas[35] noted that modern research, which analysed the role of location in a particular form of knowledge, tended to privilege the objective domain of space over the subjective phenomenon of place. He recognised a "tendency, across a wide range of domains, for space to assert itself in a way that not only obscures and conceals place…".[35 p2348] However, Malpas insisted that these were two interdependent elements of local knowledge.

By exposing the power relations within locatedness, Malpas[35] made clear how science and objectivity distance themselves from subjective experience and thereby gain power to make totalising truth claims. Thus, it is part of the activity of the discourses of science to obscure the locatedness and politics of knowledge. Once biomedical evidence or an evidence-based practice is defined, it is understood to apply in many contexts, far removed from the site and agents of its production. A feminist view of situated knowledge adds another element to this discussion of subjugated knowledge relevant to nursing.

Haraway[33] provided a distinctive feminist critique of scientific knowledge in her theorising of situated knowledge. Like Malpas[32,35], she was critical of claims of objectivity in scientific knowledge, whereby the knowing subject holds the elevated status of one who speaks absolute truth from nowhere, in the sense that objective knowledge is set apart from the context of time, space and experience.[33] The local knowledge produced through ethnography is also in this sense subjugated knowledge, in contrast with objective scientific methods of inquiry that emphasise generalisability. Haraway elevated a particular reflective form of situated knowledge, as knowledge which declares its situation and the partiality of its power relations. Although Foucault did not himself prescribe reflexivity, in his view of the intrinsic place of any knowledge we see sympathy with Haraway's call to reflexivity. To ethically account for the power relations in the research process and in the knowledge produced, reflexivity is an important component of ethnographic research.

Nursing knowledge located in place

Nurses have researched the situatedness of their knowledge and valued a sense of place.[36,37] In a study of an Italian intensive care unit, Goopy[36] built a picture of nursing practice as a local, cultural activity. By studying local practice and knowledge in detail, she aimed to counter the dominant Anglo-American ideas and assumptions of universal standards of nursing practice in intensive care settings. In the ICU unit that was the focus of her ethnography, Goopy found that far more doctors were employed than nurses, and they shared tasks in ways that are distinctive from "the model that has been taken as a universal given".[36 p148], which defines the roles of doctors as intermittently present and providing clinical direction while nurses are continuously present and providing the volume of prescribed care. Instead, in this unit nurses were legally prohibited to, for example, suction patients and many doctors were on hand to do such work. Nurses worked in pairs to provide routinised aspects of care and deferred all aspects of the relationship with patients and families to doctors. Such forces as the industrial, organizational and legal frameworks, the immediate social relations between nurses in this cultural context, all shaped nursing practices at odds with Western professional norms.

Likewise, Malone[37] attended to the meaning of the place of emergency departments. Reviewing arguments and ethnographic data from earlier research, Malone described how nursing culture is diversely produced, as a result of changes to both the place and time of nursing care. Where organizations institute efficient pathways, short lengths of stay and rapid home care, then nursing practices become more "distal", disengaged from patient experience, with dangerous potential to undermine nurses' everyday clinical and moral decisions. The work of these researchers and Malpas'[35] insistence on tying knowledge to location supported our interest in investigating the locatedness of psychiatric nursing assessment practice. The tabled extract from the ethnographic research illustrates how nursing practice of assessment was closely linked to the space of the ward (Box 1).

In the field notes and analysis provided, nurses' work was intimately tied to considerations of place and space. Nurses could draw on medical knowledge of mental status examination and theoretical nursing knowledge of engagement, which are both predicated on verbal interactions of particular types and are not explicitly tied to physical spaces or places. Yet, nurses in this ethnography relied first and prominently on observation of the patient in the immediate space of the ward, to know something of the patient that was vital to beginning and doing nursing work. Elsewhere we have explicated the knowledge of patients that was produced and used by nurses through observations.[10,31] Here, we emphasise the locatedness/situatedness of nursing knowledge, providing tangible instances for a later discussion of subjugated nursing knowledge.

The theorising of Foucault[8], Malpas[35] and Haraway[33] all serve to problematise the elements of medical and nursing knowledge that are aligned to biomedical discourses, disrupting their dominance. Time is another aspect of situatedness that is important to an analysis of nurses' knowledge and prominent in the same field data.

Local knowledge and time

In modernity, time is "quantified, linear and historicised"[38 p14] so that social events can be placed in time, using stable means such as external markers including the date on the calendar, or the time on the clock. A modern linear concept of time is also future-oriented and privileges progress, which is typified in nurses' documenting plans at the point of admission and working towards goals. In order to have status within the biomedical setting of a hospital, nursing knowledge of events and patients must be cast in linear time.[39] Such a concept does not legitimise immediate experience and perceptions in time, referred to by Parker[38] as a patient's or nurse's "inner time".[p14]

The dissonance for nurses working both in linear time and with a patient's inner time creates considerable tension and practical dilemmas.[39] Parker[38] described nursing as existing between competing temporalities: patient time, medical time and managerial time. These different temporal positions are associated with different and often incommensurate demands, for relief of suffering, for cure and for efficient throughput. They are also allied to different modes of assessment practice. Nurses are required to attend to patients' immediate experience and fluid perceptions, while also appraising patients' clinical progress and rationing their own time and attention, according to an institutional regimen.

In contemporary healthcare settings the tension for nurses may be intensified, where nurses' and patients' embodied experience of time[39] are at increasing odds with the pace of activity in linear time.[40] Both Parker[38] and Newton [40] pointed out how time is accelerated or compressed in late modernity, through contemporary developments such as advanced communication technologies and economic rationalism. This discussion of tensions in nursing temporality highlights the fleeting and potentially vexed nature of everyday nursing knowledge. In this way, temporality is tied to a critique of the ways nurses communicate assessments and the low status of some forms of nursing knowledge.

Nursing knowledge situated in time

Nursing is often described as an oral culture, whereby nurses' knowledge is transmitted and kept alive through the acts of telling and retelling.[41] The formulations of such knowledge may not be erudite, being shaped for brevity and efficiency or for conveying imprecise details of impressions or affect.[42] Many such details of knowledge are important to accomplish nursing work through a shift; yet, they are not recorded in written form and are not retained beyond their last telling, in contrast to those details that are noted in the patient file and remain for posterity.

As the fieldnotes and analysis (in Box 1) suggested, nurses commonly conducted assessments whilst circulating in the ward and when maintaining a line of sight. These assessments were intensely practical and foremostly pitched at the immediate circumstances of individual patients, often in relation to and in comparison with the circumstances of other patients within the ward. This comparison was important to shift-working nurses, both for providing timely care and for organising nurses' own workloads. But in order to be of interest beyond nursing and in the setting of a weekly ward round discussion, such 'mundane' nursing knowledge would have to be compared with the patient's conduct over a longer time frame, so it could be worked into a discussion of patient progress. Nurses' mundane knowledge of patients in the ward space and in small increments of time was of little or no interest outside of the shift-working nursing audience, precisely when it did not provide an account of progress.

These concepts of knowledge as located, situated and fleeting accord with the postmodern interest in the diversity of truths, tied to context in time, place and language. The recognition that there is a standpoint from which any particular truth comes, connects with the concept that human identities or subjectivities (of nurses, patients) are situated and unstable, rather than fixed.[43]

We have argued that knowledge related to nurses' assessments of patients can be viewed in many respects as situated, rather than as absolute and enduring. The concept of situated knowledge can usefully foreground taken-for-granted aspects of skillful practice. Further, this kind of analysis can give substance to a discussion of the power and status of nurses' knowledge. The contest between dominant and subjugated forms of knowledge can be investigated, by probing the status of specific knowledge upon which nurses rely in their daily work.[8] The discussion of situatedness as a characteristic of subjugated nurses' knowledge is supplemented next by a discussion of the subjugation or disqualification of ordinary or naïve nursing knowledge.

Naïve forms of knowledge

Naive knowledge is commonly contrasted with scientific and medical knowledge; this contrast is productively theorised by Foucault, who asserted the value of naïve forms of knowledge. Sociologist Carl May[44] showed how Foucault has been used in medical sociology to problematise the dominant medical knowledge of patients and thus to reformulate the question of power in medical settings.

The definition of patients as bodies and as pathology has been problematised through analyses of medicine's construction of patients (instead/also) as social cases, thus drawing attention to "discourses of the social" in medicine.[44 p472] May adopted this approach to usefully construe nurses' biomedical knowledge of patients' objectified bodies, symptoms and diagnoses as "foreground" knowledge and nurses' social knowledge of the patients' idiosyncratic and private subjectivity as "background" knowledge, also essential to nurses' work.[44 p472]

Naïve nursing knowledge

Nurses' everyday knowledge is often theorised by nurses and other researchers as social, ordinary or informal knowledge, reflected in nurses' use of the ordinary spoken lexicon,[44,45,46] or as "practical commonsense" knowing.[47 p57] Overtly gendered and potentially sexist portrayals of nurses' informal knowledge draw a parallel between nurses' intimate knowledge of patient's bodies and mothers tending to infants.[47,48] Such gendered accounts are then associated with nurses' mother-like emotional attachments to patients. Nurse-patient attachments can be devalued as expressions of unprofessional partiality towards patients, which might cloud nurses rational/clinical judgment, so that on occasions nurses' knowledge of patients can be disregarded.[48] Even though the psychiatric nursing workforce is equally male and female,[49] the gendering of nurses' knowledge persists in images of the intimate character of psychiatric nursing work.[47]

In several ways the naivety and ordinariness of nurses' knowledge can be used in power contests to dismiss nurses' knowledge as not authoritative, being merely tied to the nurses' subordinate place, and as natural and unskilled.[48] The tenuous status of nurses' naïve knowledge echoes Foucault's description of disqualified knowledge, as both "insufficiently elaborated" and "located low down on the hierarchy, beneath the required level of cognition or scientificity".[8 p82]

We include here (see Box 2) a second extract from the ethnographic research analysis,[29] of a journal extract from the first author's own practice, as an illustration of the use and subjugation of naïve knowledge in everyday nursing.

This example again shows how nurses' assessments were intensely practical and pitched at the immediate circumstances of individual patients, in comparison with the circumstances of other patients within the ward. Clearly this knowledge was not, of itself, compelling to non-nurses. The lack of interest of non-nurses in the plain knowledge of patient conduct in the here-and-now can be seen in this extract and analysis.

Within nursing scholarship there is considerable interest in theorising ordinary nursing knowledge as productive for patients' sense of being cared for and understood.[50,51] Likewise, some nursing research articulates the tacit nature of nurses' knowledge as essential to nursing work.[28] Nurses' use of ordinary knowledge and lay understandings is also upheld by Allen,[52] where this knowledge is recast as vital to nurses' role in mediating between patients, administrators and other clinical staff. Though mundane nursing knowledge may be increasingly theorised and eruditely discussed, the feminist interest in women's intimate and embodied knowing will continue to intersect with Foucault's notion of naïve forms of knowledge, because it aligns the nurse with the patient, whose knowledge is considered lay or ordinary. This work in the academic arena serves to partly offset the unease expressed, both in academia and among nurses themselves, regarding nurses' informal or lay knowing of patients.

Foucault had a particular purpose for reviving disqualified forms of knowledge, beyond defining them as a class of knowledge: he found them vital to the studies he called genealogies. Foucault defined his genealogy as a "union" (rather than an opposition) of scholarly historical knowledge and naïve, local specific knowledge [8] (p.83). Through this union, he showed how particular historical events and contests of power produced certain forms of knowledge, discourses, and subjects. Such a critique can be potent in redressing or resisting the disqualification of forms of knowledge nurses rely on each day.

Foucault's principle of tying theoretical concepts to very specific, detailed and situated practices, in order to more fully critique regimes of truth, power relations and subjectivities, is a great strength in his analysis. This principle prompted us to explicitly tie particularities of practice and context in a project of ethnographic research. In doing so, we brought

Box 2: Journal data and analysis of subjugation of naïve knowledge

The minutiae of a patient's capacity to conform to a daily routine, in concert with twenty others patients in the unit, was important knowledge for our everyday nursing. It was prominent in the knowledge nurses readily called forth, as is evident in this journal extract:

> At 8.50a.m. the shift leader told me [researcher] I would be attending the weekly ward round (9.00a.m. – 10.15a.m.), where two of my five allocated patients would be discussed. I had never worked with these two men before this day and had introduced myself to them very briefly at the breakfast table. But in the absence of the primary nurse I was to contribute a nursing view at ward round. I glanced around the ward office and saw that the patient files were gone, so I could not read the file, to embellish what I knew. I moved on to attend to another patient. At 9.15a.m. I was called away by the shift leader to join the meeting, in a room off the main corridor.
>
> I glanced at my handover sheet and skipped through name, age, diagnosis of depression, length of admission. I then said: "His mood seems not to be very low, he slept better last night than the one before, had a light breakfast and is still in his pyjamas. Maybe I'll encourage him to the gardening group ..." I faltered. I had nothing more to say. The nurse unit manager, the consultant and the registrar looked at me blankly. We were all silent for a few seconds. The nurse unit manager coloured slightly. I felt embarrassed to have nothing but this mundane information to offer the review meeting. The consultant led a brief discussion about the patient's response to medication and concluded that he might need to remain on the unit for a week, following a change in dose.
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Working only part time as a nurse on the wards, my knowledge of patients was perhaps dominated by such here-and-now appraisals of conduct and mundane knowledge. But my experience was not unique, as the wards were typically staffed by some nurses who were casually employed, alongside those who worked fulltime. The details I had at hand were certainly of value to me, to determine that this reportedly depressed man was eating adequately, moving about and perhaps requiring some prompting to dress and join in potentially satisfying activity. I needed to know that his depression was not impeding these abilities, to understand how I must assist him meet his fundamental daily needs. Nothing I'd noted from handover or my own brief appraisal signaled urgency, in comparison with other patients in my care.

forward subjugated forms of knowledge, aiming to ensure the relevance of the study beyond the lifetime of the local context.

This conceptualizing and researching of the productivity of everyday knowledge has implications and utility for nursing education, clinical supervision and the formation of more nuanced professional nursing subjectivity. If nursing academics, clinical nurse educators and senior practicing nurses take up such ideas, they are equipped to move beyond standardized notions of assessment practice, which include reliance on talk over observation, on formal, structured approaches to interviewing and on silencing of the nurses' knowledge in medically-dominated clinical team discussions. Such ideas have dominated in the education of nurses, undermining an articulation of the skillful nurses' everyday contribution to clinical team activity and to the movement of patients through hospital settings, including acute psychiatry.

Conclusion

Foucault's concepts of competing discourses, associated discursive practices and forms of knowledge, encompassing naïve and local knowledges which are often subjugated or disqualified, together provide ample scope to explore the value of diverse knowledge in nurses' mundane practice. Having considered directly some important concepts and their application, in regard to truth and knowledge in psychiatric nursing assessments, we conclude this paper by returning to Foucault's overarching view of knowledge.

Increasingly through Foucault's works, knowledge was intimately tied to the practices and effects of power, to the extent that he coined the term power/knowledge to represent their interdependence. "The important thing here, I believe, is that tuth isn't outside power or lacking in power".[24 p131] The nursing academy has an investment in the erudite knowledge of nursing, whilst clinical nurses pragmatically take up temporally and spatially situated forms of knowledge and lay understandings of patients, in their everyday work. As nurses and academics seek to gain territory for nursing knowledge as it is diversely portrayed, sometimes in competition with non-nursing clinical colleagues, it is likely that nursing knowledge will continue to be a site of contestation.

References

1.Benner P. From novice to expert: excellence and power in clinical nursing practice. California: Addison Wesley Publ Co, 1984.

2.Newell R, Gournay K. Mental health nursing : an evidence-based approach. New York: Churchill Livingstone, 2000.

3.Gordon S, Nelson S. An end to angels. American Journal of Nursing 2005;105(5):62-9.

4.Carper BA. Fundamental patterns of knowing in nursing. Advances in Nursing Science 1978;1(1):13-23.

5.Fawcett J, Watson J, Neuman B, Walker PH, Fitzpatrick JJ. On nursing theories and evidence. Journal of Nursing Scholarship 2001;33(2):115-9.

6.Purkis ME, Bjornsdottir K. Intelligent nursing: accounting for knowledge as action in practice. Nursing Philosophy 2006;7(4):247-56.

7.Latour B. The powers of association. Sociological Review 1986; Monograph:264-80.

8.Foucault M. Two Lectures: 7 and 14 January, 1976, The College de France. In: Gordon C (ed). Power/knowledge: selected interviews and other writings 1972-1977. New York: Pantheon Books, 1980; 78-108.

9.National Health and Medical Research Council. National statement on ethical conduct in research involving humans. Canberra: AusInfo, 1999.

10.Hamilton BE, Manias E. Rethinking nurses' observations: psychiatric nursing skills and invisibility in an acute inpatient setting. Social Science & Medicine 2007; INFORMATION MISSING HERE.

11.Foucault M. Technologies of the self. In: Rabinow P (ed). Ethics: subjectivity and truth. New York: The New Press, 1994;223 - 51.

12.Foucault M. The order of things: an archaeology of the human sciences. 1994 Vintage Books ed. New York: Vintage Books 1970.

13.Foucault M. Madness and civilization: a history of insanity in the Age of Reason. New York: Vintage Books, 1965.

14.Foucault M. The birth of the clinic: an archaeology of medical perception. New York: Vintage Books, 1973.

15.Foucault M. Discipline and punish: the birth of the prison. New York: Vintage, 1977.

16.Sassure FD. Courses in general linguistics. London: Peter Owen, 1960.

17.Derrida J. Positions. Chicago: University of Chicago Press, 1981.

18.Breakwell C. The relationship between critical care nurses' practice and the medical record [PhD]. Melbourne:

LaTrobe University, 2001.

19.Rabinow P. Introduction. In: Rabinow P (ed). Ethics: subjectivity and truth. New York: The New Press, 1994:XI-XLII.

20.Alvesson M. Postmodernism and social research. Buckingham: Open University Press, 2002.

21.Fox NJ. Discourse, organisation and the surgical round. Sociology of Health & Illness, 1993;15(1):16-42.

22.Weedon C. Feminist practice and poststructural theory. Cambridge: Blackwell, 1992.

23.Foucault M. The will to knowledge: the history of sexuality: Volume 1, an introduction. London: Penguin, 1978.

24.Foucault M. Truth and power: an interview with Allesandro Fontana and Pasquale Pasquino in June, 1976. In: Gordon C, ed. Power/knowledge: selected interviews and other writings 1972-1977. New York: Pantheon Books, 1980; 109-33.

25.Yoshioka-Maeda K, Murashima S, Asahara K. Tacit knowledge of public health nurses in identifying community health problems and need for new services: a case study. International Journal of Nursing Studies, 2006;43(7):819-26.

26.Welsh I, Lyons CM. Evidence-based care and the case for intuition and tacit knowledge in clinical assessment and decision making in mental health nursing practice: an empirical contribution to the debate. Journal of Psychiatric and Mental Health Nursing 2001;8(4):299-305.

27.Pope C, Smith A, Goodwin D, Mort M. Passing on tacit knowledge in anaesthesia: a qualitative study. Medical Education 2003;37(7):650-5.

28.Hardy S, Garbett R, Titchen A, Manley K. Exploring nursing expertise: nurses talk nursing. Nursing Inquiry 2002;9(3):196-202.

29.Crook JA. How do expert mental health nurses make on-the-spot clinical decisions? a review of the literature. Journal of Psychiatric & Mental Health Nursing 2001;8(1):1-5.

30.Hamilton B. Shifting subjects: An ethnography of nurses' assessment practice in acute inpatient psychiatry [PhD]. Melbourne: University of Melbourne; 2008.

31.Hamilton B, Manias E. The power of routine and special observations: producing civility in a public acute psychiatric unit. Nursing Inquiry 2008;15(3):178-88.

32.Malpas J. Place and experience: a philosophical topography. Cambridge: Cambridge University Press 1999.

33.Haraway D. Situated knowledges: The science question in feminism and the privilege of the partial perspective. simians, cyborgs and women: the re-invention of nature. London: Free Association Books, 1991; 183-201.

34.Carolan M, Andrews GJ, Hodnett E. Writing place: a comparison of nursing research and health geography. Nursing Inquiry 2006;13(3):203-19.

35.Malpas J. Bio-medical topoi: the dominance of space, the recalcitrance of place, and the making of persons. Social Science & Medicine 2003;56(11):2343-51.

36.Goopy SE. Taking account of local culture: limits to the development of a professional ethos. Nursing Inquiry 2005;12(2):144-54.

37.Malone RE. Distal nursing. Social Science & Medicine 2003;56(11):2317-26.

38.Parker J. Space, time and radical imagination: nursing in the here and now. Journal of Advanced Nursing 1996;24(6):1103-4.

39.Young V. Pieces of time. Nursing Philosophy 2002;3:90-103.

40.Newton T. Crossing the great divide: time, nature and the social. Sociology 2003;37(3):433-57.

41.Street A. Inside nursing : a critical ethnography of clinical nursing practice. Albany: State University of New York Press, 1992.

42.Parker J, Wiltshire J. The handover: three modes of nursing practice knowledge. In: Gray G, Pratt R (eds). Scholarship in the discipline of nursing. Melbourne: Churchill Livingstone, 1995; 151 - 69.

43.Simpson D. Situatedness, or why we keep saying where we're coming from. California: Duke University Press, 2002.

44.May C. Nursing work, nurses' knowledge, and the subjectification of the patient. Sociology of Health and Illness 1992;14(4):472-87.

45.Crawford P, Johnson AJ, Brown BJ, Nolan P. The language of mental health nursing reports: firing paper bullets? Journal of Advanced Nursing 1999;29(2):331-40.

46.Irving K, Treacy M, Scott A, Hyde A, Butler M, MacNeela P. Discursive practices in the documentation of patient assessments. Journal of Advanced Nursing 2006;53(2):151-9.

47.Barrett RJ. The psychiatric team and the social definition of schizophrenia: an anthropological study of person and illness. Cambridge: Cambridge University Press, 1996.

48.Ceci C. Gender, power, nursing: a case analysis. Nursing Inquiry 2004;11(2):72-81.

49.Clinton M. Scoping study of the Australian mental health nursing workforce 1999. Canberra: Mental Health and Special Programs Branch Commonwealth Dept. of Health and Aged Care; 2001. Report No.: 0642735204.

50.Holdsworth N. From psychiatric science to folk psychology: an ordinary-language model of the mind for mental health nurses. Journal of Advanced Nursing 1995;21(3):476-86.

51.Clarke L. We aim to differ: a response to Dame June Clark. Nursing Standard 1999;13(41):35-6.

52.Allen D. Re-reading nursing and re-writing practice: towards an empirically based reformulation of the nursing mandate. Nursing Inquiry 2004;11(4):271-83.

Acknowledgements:

The ethnographic study out of which this paper developed was undertaken with the support of an Australian Postgraduate Award. Thanks also to colleagues at the School of Nursing, University of Melbourne for sharing scholarly insights.

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Abstract
The goal of this paper is to expose the hidden facet of the interface technology-body through a theoretical application of the concept of pharmakon to the field of HIV/AIDS. Based on the works of Plato and Jacques Derrida, the concept of pharmakon is explored and situated within the interface technology-body. Thus, the main objective of this theoretical piece is to discuss how HIV medications as pharmakon are involved in the creation of new forms of corpo/reality for people living with HIV/AIDS, namely the cyborg and the mutant. Inspired by Haraway's cyborg and Cronenberg's mutants, the ambivalent quality of technology is explored through the technological figure and the monstrous figure, two different but complementary representations that expose the bodily experiences of Highly Active Antiretroviral Therapy (HAART).

Key Words body, HAART, HIV/AIDS, medication, pharmakon, technology

(Re)Thinking the Corporeality of HIV/AIDS in the Post-HAART Era: A Critical Perspective

MARILOU GAGNON

Introduction

Looking back at our history, we recognize that the human body is an important generator and recipient of technology.[1] As part of a wider interactive system, human beings have been known to respond to their internal and external environments through the practical application of knowledge and techniques, also known as technology.[1] In light of the advancements that have taken place in the twentieth century, we are now entering an era of great possibilities in the fields of science and medicine. In fact, we are living in a society that is more technologically dominated than ever before, one in which "productive techniques and knowledge are moving inwards, to invade, reconstruct and increasingly dominate the very contents of the body".[1] Therefore, there is a definite need to reflect on the uncertainty of what the body is and what it will become in the presence of technology and more precisely, biotechnologies. The goal of this paper is to discuss the interface technology-body as it relates to the field of HIV/AIDS and the in/corporation of Highly Active Antiretroviral Therapy (HAART). Based on the work of Plato and Jacques Derrida, the concept of pharmakon will be explored and situated within the interface technology-body. The main objective will be to discuss how HIV medications as pharmakon are involved in the creation of new forms of corpo/reality for people living with HIV/AIDS, namely the cyborg and the mutant.

Revisiting Plato's pharmacy: the pharmakon from Plato to Derrida

Pupil of Socrates and founder of the Athenian Academy, Plato (428-347 BC) is an inaugural figure in Western philosophy and he remains widely influential in contemporary thinking.[2] Through his work, Plato distinguishes philosophy as a subject and a method by insisting on its difference from other forms of thought such as rhetoric and poetry.[3] Often described as a literary philosopher, Plato is famous for his use of dialectics as a method to structure and to formulate his arguments.[3] His writing style is unique because it is structured in a dramatic form, either as a monologue or a dialogue, and it is typically centered on Socrates as the ideal figure of philosophy.[3] In the Phaedrus, one of many Platonic dialogues, a fictional conversation between Socrates and Phaedrus explores the relative merits of the lover and the non-lover (as sexual partners and thinkers), of rhetoric and philosophy and of speech and writing.[2] In a specific segment of this dialogue, Socrates attempts to convince Phaedrus that speech is superior to writing by referring to the Egyptian myth of Teuth, an inventor-god whose creations include numbers, calculation, geometry, astronomy, games and writing.[2] In the legend, we encounter Teuth's character during the exhibition of his arts to Thamus (Ammon), the great god-king of all Egypt.[2,4] When it comes to writing, Teuth says: "This discipline, my King, will make Egyptians wiser and will improve their memories: my invention is a recipe (pharmakon) for both memory and wisdom".[4] To this declaration the King replies: "Teuth, my master of arts, to one man it is given to create the elements of an art, to another to judge the extent of harm and usefulness it will have for those who are going to employ it. […] The fact is that this invention will produce forgetfulness in the souls of those who have learned it because they will not need to exercise their memories, being able to rely on what was written, using the stimulus of external marks that are alien to themselves […]".[4] For King Thamus (Ammon), writing (pharmakon) is not a remedy but a poison for the memory and the wisdom of those who rely on this art (techne). In Plato's Phaedrus, the pharmakon introduces itself into the dialogue with the richness and the ambivalence of its meaning as both a remedy and a poison. However, it remained unexplored in its original form, as an "undecidable" concept that inhabits both the curative and the poisonous, for many centuries before Jacques Derrida was able "to detect the play of undecidability in the foundational texts of Plato".[2]

Jacques Derrida (1930-2004) is a contested philosopher who has profoundly influenced the poststructuralist movement.[5] "Best known for having forged the term "deconstruction", Derrida follows the work of Nietzsche and Heidegger in elaborating a critique of Western metaphysics, by which he means not only the Western philosophical tradition but everyday thought and language as well".[6] In Plato's pharmacy,[4] Jacques Derrida formulates a critique of Western philosophy and literature by deconstructing the Phaedrus as it symbolizes a longstanding tradition of "logocentrism" – the domination of the spoken word over the written word.[6] By focusing on the translation of pharmakon, Derrida displays how Western thought is profoundly structured in terms of dichotomies or polarities: "good vs. evil, being vs. nothingness, presence vs. absence, truth vs. error, identity vs. difference, mind vs. matter, man vs. woman, soul vs. body, life vs. death, nature vs. culture, speech vs. writing, and [remedy vs. poison]".[6] Through Derrida's analysis, we come to understand that dichotomies are more than oppositional entities as they are positioned along a hierarchical order that reflects politics of domination – politics of meaning.[6] As such, the pharmakon – as both remedy and poison – is caught in a chain of significations that is not primarily grounded in the intention of Plato, but rather in what is left unsaid through the play of words.[4] As demonstrated by Jacques Derrida, the common translation of pharmakon into languages that are the heirs and depositaries of Western metaphysics is as violent as it is impotent: "it destroys the pharmakon but at the same time forbids itself access to it, leaving it untouched in its reserve".[4] For many centuries, Plato's pharmakon has been confined to a vocabulary (recipe, remedy, philter, receipt, cure) that neutralized its ambivalence, decontextualized its meaning and consequently, prevented its interpretation. Through the work of Jacques Derrida, the pharmakon becomes an ambiguous word that uncovers hidden meanings in Plato's work and in the settings of the Phaedrus.[7] However, Derrida's goal is not to reconstitute the entire chain of significations of the pharmakon but only some of their meanings, and some of their effects, most of which are related to the Platonic problematic of writing.[7]

"In addition to using the word [pharmakon] to denote medicinal remedy or poison, Plato like other ancient Greeks, used [it] to mean a host of other things, such as pictorial colour, painter's pigment, cosmetic application, perfume, magical talisman and recreational intoxicant".[7] In Plato's pharmacy, writing as pharmakon is simultaneously taken away and taken from the myth of Teuth to explore its undecidability and ultimately, to formulate a critique of Plato's oppositions which are expressed through the mouth of King Thamus (Ammon): "speech is good vs. writing is bad, true memory is internal vs. written reminding is external, speech carries the essence of knowledge vs. writing carries the appearance of knowledge, spoken signs are living vs. written marks are lifeless".[2,4] For Jacques Derrida, the opposition between hypomnesis (re-memoration, recollection, consignation) and mneme (living, known memory) is a response to Plato's own suspicion of the pharmakon (writing).[4] It is also indicative of the philosophical debates that were taking place in ancient Greece between the philosophers (those who know/speak) and the sophists (those who appear to know/write). The dialogue between Teuth and King Thamus (Ammon) reveals that the remedy and the poison "are not simply opposed in their meanings but are arranged in a hierarchical order which gives the first term priority, in both the temporal and the qualitative sense of the word".[6] In deconstructing the myth of Teuth, Derrida reveals the ambiguity of the pharmakon (writing) as both a remedy for hypomnesis and a poison for mneme, and the politics involved in the translation of the pharmakon as a remedy.[4] In doing so, he recognizes the ambivalent quality of the pharmakon (writing) by revealing its capacity to be simultaneously beneficial and detrimental – to be undecidable.

Technology and body: HIV medications as pharmakon

"At the close of the twentieth century, many predicted that "we" were entering a "biotech century", an age of marvelous yet troubling new medical possibilities".[8] Far from being the presage of a distant reality, this statement reveals that the biotech movement is nothing more than a continued effort to surpass the limitations of the human body.[1] Yet, it also implies that the twenty-first century signals the coming together of biology and technology in the "flesh machine"[9] – a phenomenon that is both promising and disturbing for the human body. The more we gain control over the human body, the more uncertain it becomes as the boundaries between flesh and technology are rapidly vanishing.[10] Therefore, "the idea of technological bodies […] raises the possibility that spatial and functional arrangements of the organic properties of our bodies have been altered in line with the structures of society, and to an extent challenges the conventional notions of what it is to be and have a body".[1] According to Klugman,[11] medicine is an essential gatekeeper in determining which human-machine connections to permit and to develop. As a result, it is actively involved in the production, the prescription, and the consumption of biotechnologies – "biological procedures and techniques that seek to transform the living body" [translation].[12] By definition, medications "are substances that have the capacity to change the condition of a living organism" and as a result, they constitute a form of biotechnology.[13] While medications are rarely examined as part of the larger framework of technoscience studies, they should be considered as technologies of the body because "the often seamless incorporation of pharmaceutical technologies within the corporeality of bodies demonstrate the seemingly non-existent boundaries between technologies and bodies literally and discursively".[14] However, the interface technology-body is hardly ever discussed in relation to medications, and most importantly in the presence of the all-encompassing "therapeutic" discourse.

As powerful technical and symbolic devices, medications acquire a force and a status in society.[13] They are not only the products of human culture but the producers of it "as vehicles of ideology, facilitators of self-care, and perceived sources of efficacy".[13] As such, individuals use and professionals prescribe medications according to meanings – emanating from a complex psycho-social-cultural matrix subject to constant revision – which they attribute to health, illness, to the body, and to their identity. These meanings are profoundly "guided by imperatives of production, consumption and order under the guiding principle of efficiency".[9] Much like Teuth's pharmakon, the medication has traditionally been (re)presented as a remedy to prevent the failures of the human body, to improve its functions and to surpass its limitations: the medication is a recipe (pharmakon) for human survival and longevity. Therefore, it must be confined to a vocabulary (recipe, remedy, philter, receipt, cure) that neutralizes its inherent ambivalence, decontextualizes its meaning and consequently, prevents its interpretation beyond curative efficacy. Yet, Martin[15] notes that medications are typically regarded with ambivalence and are usually surrounded with two sets of meanings – one positive (remedy) and one negative (poison). Interestingly, she suggests that within the Western pharmakon, the negative facet of medications and their negative meanings are displaced to the side and kept out of awareness.[15] However, because medications are used and their effects resonate over time throughout individuals and collectivities, their meanings change and can no longer be viewed through one pole (the curative pole) of the interface technology-body.[16] In the field of HIV/AIDS, the use and the effects of Highly Active Antiretroviral Therapy (HAART) have drastically changed over the past decade. The meaning of HAART has also been profoundly affected by the lipodystrophy syndrome, a body-disfiguring syndrome featuring adipose tissue depletion and accumulation in specific areas of the body such as the face, the upper and lower extremities, the buttocks, the breasts, and the dorsocervical spine.[17] In light of this disturbing phenomenon, there is a definite need to critically examine how HIV medications (as pharmakon) are currently re-crafting the interface technology-body.

"In modern medicine, therapeutic substances are invested with the capacity and mission to either cure, prevent or manage illness, while illness, in turn, opens up bodies to the presence and powers of these substances".[18] Therefore, the discovery of the human immunodeficiency virus (HIV) was the very first step in developing a pharmaceutical response to the HIV/AIDS epidemic.[19] It not only opened up the body to the presence and powers of therapeutic substances but also secured HIV infection as a disease in need of curative response.[20] Since then, the introduction of Highly Active Antiretroviral Therapy (HAART) and the development of medical technologies (viral load, CD4+ count, genotype, and phenotype) have generated a "scientific computation" of the HIV/AIDS illness which excludes, and often conflicts with the lived experience of HIV-positive individuals.[21] "For some, it may seem that HIV medications have so successfully altered HIV/AIDS from a lethal infection, to a potentially manageable chronic illness that there is no need to contest the existing terrain".[22] However, the initial optimism that surrounded HAART more than a decade ago is rapidly vanishing as the interface technology-body is producing results that are conflicting and highly ambivalent.[23] While antiretroviral therapy is undeniably successful in preventing the replication of the virus, its restorative power is complicated by its manifold transformative potential to produce unpredictable results on the bodies of people living with HIV/AIDS.[18] Paradoxically, most of the unintended effects of antiretroviral therapy, including the disfiguring effects of lipodystrophy, are caused by its optimal use as a remedy.[24] Therefore, the adverse outcomes of HIV medications pose a significant challenge to the "normal" therapeutic sequence (disease-therapy-outcome) by revealing that HIV medications are as much poisonous as they are curative.[18]

According to Walby[25], "any biotechnological intervention inscribes itself into a complex dynamic of corporeal animation and relationship, which redistributes its intended [and unintended] effects according to its own shifting logic". In the field of HIV/AIDS, "lipodystrophy is a striking example of a particular biotechnical inscription being processed and redistributed by a body in unintended ways".[18] As a significant iatrogenic effect, the lipodystrophy syndrome demonstrates how the in/corporation[26] of HIV medications is a process that is "indeterminate rather than predictable, contextual rather than causal".[18] Much like Derrida's pharmakon, HAART cannot be discussed in terms of the dichotomies that characterize the therapeutic discourse: good vs. bad, therapeutic vs. toxic, desired effects vs. adverse effects. Instead, we need to recognize HIV medications as both poisonous and curative and acknowledge their "capacity to be beneficial and detrimental to the same person at the same time".[18] As suggested by Derrida, the sole interpretation of HAART as curative "erases on a certain surface of its functioning, the ambiguity of its meaning as pharmakon".[4] The remedy evokes the "transparent rationality of science, technique, and therapeutic causality, thus excluding […] any leaning toward the magic virtues of a force whose effects are hard to master, a dynamics that constantly surprises the one who tries to manipulate it as master and as subject".[4] By obscuring the poisonous pole of HIV medications, "biomedicine strives to master the indeterminacy and excess, the transgressions of pharmakon, the shadow that haunts the tradition and threatens to undo its work".[18] Whether they are assimilated into the logic of biomedicine or construed as contradictory to it, the unintended effects of HIV medications partly dislocate the restorative value inherent to the interface technology-body.[18] Consequently, the designation of lipodystrophy as a side effect of HIV medications is part of a broader strategy that aims at displacing the poisonous to the side and keep it out of awareness – out of meaning.[15] Much like Teuth's pharmakon, Highly Active Antiretroviral Therapy (HAART) has been presented by the scientific community as a recipe for the therapeutic management of HIV/AIDS since its introduction in 1996. Looking back at Plato's pharmacy, it is quite obvious that the stated intention of Teuth (herein representing the scientific community) is precisely to stress the worth of his product; thus, "he turns the word [pharmakon] on its strange and invisible pivot, presenting it from a single one, the most reassuring of its pole".[4] The response of king Thamus (Ammon) informs us about the hidden meaning of the pharmakon, by suggesting that its harm and usefulness are not to be judge by its creator but rather by those who are going to employ it (e.g. people living with HIV/AIDS). Interestingly, Jacques Derrida points out that "Plato is suspicious of the pharmakon in general; even in the case of drugs used exclusively for therapeutic ends, even when they are wielded with good intentions, and even when they are as such effective".[4] In light of Plato's pharmacy, Derrida considers that "there is no such thing as a harmless remedy [because] the pharmakon can never be simply beneficial.[4]

Technology and body: re-crafting the corpo/reality of HIV/AIDS

Looking back at our history, one is forced to recognize that technology has exerted a profound impact on the bodies and the environments of human beings.[1] As part of their response to their external and internal environments, human beings have changed themselves and their physical capacities through the practical application of knowledge and techniques (technology).[1] In recent years, the in/corporation of biotechnologies has proven itself to be a promising way to penetrate the flesh of the living organism and to change its condition.[13] As such, "technoscience and the biomedical industry complex (e.g. hospitals, clinics, "hard science" laboratories, pharmaceutical companies) have increasingly infiltrated and re-formed the conceptions of health, illness, the body and what it means to be human".[14] In the field of HIV/AIDS, the introduction of Highly Active Antiretroviral Therapy (HAART) has transformed the human body into a hybrid of living material and chemical substances.[18] More importantly, "its use has generated new and durable links between humans and biotechnology, productive links that define diseases and create new identities by reorganizing the bodies [of people living with HIV/AIDS]".[18] While the boundaries between flesh and technology are rapidly vanishing, very few authors consider the uncertainty of what the body is and what it will become in the presence of HIV medications. Yet, "when technologies interact with the specificities of both bodies and subjectivities, a multitude of possibilities arise",[14] such as the creation of new forms of corpo/reality for people living with HIV/AIDS, namely the cyborg and the mutant.

The human-machine connection: people living with HIV/AIDS as cyborgs

The term cyborg (the cybernetic organism), was first introduced by Manfred E. Clynes and Nathan S. Kline in a 1960 article on humans in space.[27] At that time, both scientists were defining the cyborg as a self-regulating man-machine system, an organism in which were incorporated exogenous components to extend self-regulatory control functions and as such, promote an optimal adaptation to new environments (mainly space).[27] Essentially, Clynes and Kline used the term cyborg to designate "an artificially enhanced [self-regulating] human being who was capable of surviving in space or on other planets without the need of an Earthlike biosphere".[11] Since 1985, the concept of the cyborg has acquired additional meanings through the influential work of Donna Haraway[28-30] and the publication of the famous Manifesto for Cyborgs.[28] According to Haraway, "the cyborg is a cybernetic organism, a hybrid of machine and organism [and] a creature of social reality as well as a creature of fiction".[29] The cyborg is a metaphorical entity that restructures socialist-feminist politics around science and technology, and provides a new space to redefine the bodies and identities of women.[29] It is a creature that inhabits a post-gender world – it is neither male nor female – since it has no origin in the Western world and the dichotomized structure through which human beings are conditioned as man or woman.[29] Using the cyborg imagery, Haraway redefines the interface technology-body as unifying, revolutionary and emancipating for the world wide web of genderless techno-beings. Based on the idea that cyberculture provides an opportunity to alter our current view of the social relations of science and technology, the Manifesto for Cyborgs is controversial because it not only asks women to redefine their subjectivities but "to explore the potential and the risk of being cyborg – neither wholly man, woman, nor machine".[31] Yet, Haraway's work "is rarely, if ever, located, problematised or discussed critically".[31] This is the case even though the cybernetic organism has only been presented through the most reassuring of its pole – as a recipe (pharmakon) to become a posthuman. Since the publication of the Manifesto, the cyborg "has played a key role in the ongoing under-recognition and under-theorisation of gender issues on the part of mainstream cybertheorists".[31] On the other hand, it has provided insightful discussions on what the human body is and what it will become in the biotech century. While, "the cyborg horrifies some people and thrills others",[32] it remains a provocative figure that exposes interface technology-body in unparalleled ways.

As a key mediator of the human-machine connection, medicine is an important producer of cyborgs – of coupling between technologies and bodies.[10-11,28-29,33-34] However, while the current progress of modern medicine offers us unprecedented control over our bodies, it also generates a growing fear of the iatrogenic effects of biotechnologies.[10] Haraway notes that the reconfiguration of the human body by science and technology evokes a strong ambivalence because "it is not clear who makes and who is made" through the connection human-machine.[29] As such, the fabricated union between organism and machine is not without risks and could eventually lead to an "irreversible dehumanization",[35] although it seems today that we are less of a person without it.[15] Within the "technological clinic" or the "transhuman bodyshop" of modern medicine,[10] being a cybernetic organism is considered to be a desirable state, one that outweighs its potential risks. However, "the cyborg is a contested location"[36] since it is all "about transgressed boundaries, potent fusions, and dangerous possibilities" between animal/human, organism/machine and physical/non-physical.[29] Considering the ambiguous quality of the interface technology-body we ask: Could the cyborg ever become an unwelcome figure in society? Despite the fact that Donna Haraway confirms the existence of good cyborgs and bad cyborgs in a 1990 interview, those two figures have not (to our knowledge) been explored by cybertheorists.[36]

Based on these findings we ask: Could the machine eventually be threatening for the cyborg? If so, how would the cyborg body react in the presence of unintended effects of technology? What becomes of the hybrid when technology rebels against the complexity of the human body? How can the cyborg be in control (as suggested by Haraway[29]) when it is essentially defined as an "unbounded creature"?[26]

Donna Haraway argues that we, as cybernetic organisms, can be responsible for machines because "they do not dominate or threaten us".[29] For people living with HIV/AIDS, this statement is very problematic because it does not recognize the ambiguous quality of the interface technology-body and in doing so, denies the risks of being a cyborg. It is also contradictory to Haraway's previous statements on the uncertainty of the cyborg body and the inexplicable outcomes of the human-machine connection.[29] Since the advent of Highly Active Antiretroviral Therapy (HAART), medicine can turn HIV-positive individuals into cyborgs by restoring lost immunity through the suppression of viral replication, normalizing the internal and the external configuration of the HIV-positive body, reconfiguring the immune system as a battlefield for survival and enhancing the physical capacities of those who can no longer regulate their own immunity.[37] Reconfigured by technology, the bodies of people living with HIV/AIDS are coded automatons that must be read, regulated, measured and controlled through biotechnologies and medical technologies (viral load and CD4+ measurements/monitoring, genetic profiling, genotyping / phenotyping).[18,24] Subsequently, people living with HIV/AIDS are constantly "disassembled and reassembled"[29] under the technological gaze of medicine to secure their status as legitimate cybernetic organisms. Acting as the mediator of the human-machine connection, the primary goal of HIV medicine is to produce cyborgs that in/corporate the benefits of biotechnologies, namely longevity and survival. However, the iatrogenic effects of HAART challenge the one and only representation of the cybernetic organism as a desirable product of the interface technology-body. Consequently, people living with HIV/AIDS are not only cyborgs in-the-making but troubling figures of otherness that define the connection human-machine as a site of differentiation.

With the introduction of Highly Active Antiretroviral Therapy (HAART), becoming cyborg is indicative of a new mode of existence for people living with HIV/AIDS,[38] one that is being defined by the unintended effects of technology (e.g. lipodystrophy). In other words, "continued use of [HIV medications] generates new and durable links between humans and biotechnology, productive links that define diseases and create new identities by reorganizing bodies".[18] Therefore, the HIV-positive cyborg is a "contested location"[36] since it is all about transgressed boundaries between technology and body, potent fusions between curative and poisonous and dangerous possibilities between organism and machine.[29] Disfigured by the unintended effects of HIV medications (lipodystrophy), the cybernetic organism redefines biotechnologies as pharmakon – neither remedy nor poison. It embodies the unpredictability of the interface technology-body along with the benefits and the risks of being cyborg – neither human nor machine. By calling attention to the unintended effects of biotechnologies, the visibility of the HIV-positive cyborg disrupts social order by invading the reality and the imagination of individuals and collectivities.[24] As a social creature, this cybernetic organism is extremely ambivalent – neither infectious nor safe – because it threatens the boundaries between the sick and the healthy. More than a decade after the introduction of Highly Active Antiretroviral Therapy (HAART), people living with HIV/AIDS have become the unwelcome cyborgs of society – regenerated figures of monstrosity.

Regenerating the monster: people living with HIV/AIDS as mutants

Throughout history, the monstrous figure has always been positioned outside the course of nature[39-40] because it carries "the weight of not just difference, but of différance".[41] In other words, "monsters speak to both radical otherness that constitutes an outside and to the difference that inhabits identity itself".[42] As an object of knowledge and a mythical creature, the monstrous figure challenges the boundaries of the normatively embodied self in ways that confirm and secure the limits of the human body.[29,42-43] Therefore, "the monster is always whatever we are not"[43] and it continues to change as human beings evolve over time.[43] In light of the technological advancements that are taking place in the twenty-first century, the monstrous figure is going through yet, another transformation that mirrors the reconfiguration of human beings as cyborgs. For Shildrick[41] and Haraway[29-30], the cybernetic organism can be interpreted as monstrous because it is a creature that challenges what it means to be human and to have a body. However, the cyborg "has very little connection with the familiar and mythical secure world of humanism"[41] in which the monstrous figure is constructed as the natural symbol of otherness.

Since Aristotle, the term monstrosity has been used "to describe forms of corporeal excess, deficiency or displacement, not just those bodies which are malformed by disease, accident, or birth, but widely to depict all beings that are deviation from the common course of nature".[42] Contrarily to the cyborg, the monster symbolizes nature's faux pas in the fabrication of the human body and consequently, the powerlessness of human beings against the complexity of their own bodies. Since Haraway's cyborg is clearly not a product of nature, defining it based on a term (monster) that comes from a longstanding tradition of naturalist thought is ultimately hazardous. Subsequently, there is a need to distinguish the monster from the cybernetic organism when examining the interface technology-body even though they are both complementary figures that contribute to a deeper understanding of the in/corporation of HIV medications and the involvement of this process in the creation of new forms of corpo/reality. By considering the monstrous figure as part of a new existence for people living with HIV/AIDS, the goal is to move beyond the cyborg discourse in order to recognize the complexity of living organisms and therefore, the participation of nature in the interface technology-body.

In the midst of the twentieth century, the traditional monstrous figure vanished from popular culture and was replaced by a new mythical creature known as the mutant. However, what appeared to be an important change in Western imagination was nothing else than a transformation of the outdated monster into a creature that embodied the uncertainty of the upcoming technological era. While the mutant took on a life of its own as a fictional character, it also became a central topic to modern science and medicine. Ever since the discovery of the human genome sequence in 2001, its constituents have become the most promising (and disturbing) sites for technological intervention.[44] The concept of mutation has also acquired new meanings because of a greater understanding of human genetics and its involvement in the "limitations" of the human body (e.g. illness, deformities, intellectual disabilities, deficiencies).[44] In addition, mutants (individuals living with biological mutations) have become valuable subjects in the quest to identify the perfect or normal genome.[44] So far, a small minority of the mutations that alter the meanings of genes have been recognized as beneficial for the evolution of the human race, and through this process the majority of living mutants – those whose genes are naturally or artificially altered – have been represented as ambiguous creatures that challenge the core of our existence (human genome).[44] Over the past twenty-five years, the human immunodeficiency virus has become an important producer of living mutants by immortalizing itself into the genes of otherwise "normal" human beings.[19] At a cellular level, the HIV virus is transported into the nucleus of the host cell (T-lymphocyte) in order to insert its double-stranded proviral DNA (deoxyribonucleic acid) within the DNA of the host cell chromosomes.[19,45] By reprogramming the genes of the T-lymphocyte cell, the human immunodeficiency virus creates its very own factory and consequently, secures its capacity to replicate and survive within the human body. However, like many other retroviruses, the HIV virus is prone to mutate at an astonishing rate in the course of its replication – a phenomenon that allows the HIV virus to evolve constantly as environmental pressures change in the host (e.g. medications, vaccines or illness).[19,45] Scientists have recently discovered that the exposure of the human immunodeficiency virus to antiretroviral agents causes permanent changes of the HIV genome (mutations) and leads to the emergence of drug-resistant variants that are no longer responsive to therapeutic measures.[46] Therefore, the cellular pathogenesis of HIV has set in motion a biological process through which people living with HIV/AIDS have developed undesirable mutations that attest to the complexity of the human body. In light of the advancements that have taken place in the field of HIV/AIDS, namely the use of HIV medications, people living with HIV/AIDS have become more than living mutants, they are the monstrous figures of the technological era.

In popular culture (literature, movies, television), the monster has always been portrayed as a character that evokes fear and fascination, a creature that is far from being "normal" but similar enough to disturb the normatively embodied individual.[42] Until the 1980s, the concept of monstrosity was a recurrent theme in Western cinematography with the creation of monstrous figures that were always positioned outside the course of nature because of their physical otherness. Apart from Mary Shelley's Frankenstein, very few creators were willing to explore the monster as a product of science and technology and as a hybrid of human and machine.[47] As a result, the work of cinematographer David Cronenberg is one of great interest when attempting to explore the monstrous figure of the technological era, namely the fictional character of the mutant.[48] In the majority of his movies, Cronenberg represents the human body as an object of experimentation that can be manipulated, transformed, ripped apart and broken down.[48] As such, his characters are typically generated from an experimental process that expands the limits of the human body to a point where it is no longer controllable or habitable.48 For Cronenberg, mutants are living beings or objects that have undergone a transformative process – either a biological mutation or a metaphorical mutation.[48] Based on movies such as "The Fly" from 1986, "Dead Ringers" from 1988, "Scanners" from 1981 and "The Brood" from

1979, Cronenberg's mutants are represented as either male or female.[48] While there is an interesting connection to be made between his construction of the female mutant and the longstanding tradition of describing women's bodies as monstrous,[47] his conceptualization of the interface technology-body is of greater use to the current discussion. For David Cronenberg, the mutation is related to the practice of medicine and its manipulation of the human body through technology.[48] With regards to the unintended effects of HAART, namely the lipodystrophy syndrome, the similarities between the living mutants of HIV medicine and Cornenberg's fictional figures are both disturbing and alarming. Similarly to Jeff Goldblum's character in "The Fly", people living with HIV/AIDS are currently experiencing a physical transformation as a result of unexpected "experimental mutations".[48] Caused by an unknown pathogenesis, lipodystrophy is an unforeseen product of science and medicine that causes an abnormal redistribution of adipose tissue in the body by disturbing the functional and structural integrity of adipocytes. As a result of the unintended effects of HIV medications, people living with HIV/AIDS undergo a troubling metamorphosis, one that is worthy of a horror script à la Cronenberg: "[…] I would look at myself in the mirror and not see the same person I used to be";[49] "[…] I don't see my body as before. If I look at myself in the mirror I see it old, it's wasting";[49] "[…] almost alienated from my body there's this inbuilt distance between who you are now and what you're seeing […]".[50] From Haraway's cyborg to the extreme representation of Cronenberg's mutants, technology is pharmakon because it serves the seed of life as a remedy and the seed death as a poison – it is ultimately the pharmakon that signals the end of what it means to be and have a body.[4]

Final remarks

The goal of this paper was to expose the hidden facet of the interface technology-body through a theoretical application of the concept of pharmakon to the field of HIV/AIDS. Based on the works of Plato and Jacques Derrida, this interpretation of the pharmakon served as a pivotal element in formulating a critique of the in/corporation of Highly Active Antiretroviral Therapy (HAART). The main objective was to discuss how HIV medications are involved in the creation of new forms of corpo/reality for people living with HIV/AIDS. Inspired by Haraway's cyborg and Cronenberg's mutants, the ambivalent quality of technology was explored through the technological figure and the monstrous figure, two different but complementary representations that expose the bodily experiences of HAART. What this essay argues is that the pharmakon – as both remedy and poison – is caught in a chain of significations that is not solely contained in what we have presented but rather in what was left unsaid voluntarily through the play of words.[4] Underneath our interpretation of the interface technology-body are the experiences of people living with HIV/AIDS who in/corporate the essence of the pharmakon – the promise of a remedy, the dangerousness of the poison, the ambivalence of life itself and the death of what it means to be a normal human being.

References

1.Shilling C. The Body in culture, technology and society. London: Sage, 2005.

2.Collins J, Mayblin B. Derrida for beginners. Cambridge: Icon Books Ltd, 1996.

3.Annas J. Plato: a very short introduction. New York: Oxford University Press, 2003.

4.Derrida J. Dissemination. Chicago: The University of Chicago Press, 1981.

5.Sarup M. An introductory guide to post-structuralism and postmodernism (2nd ed.). Georgia: The University of Georgia Press, 1993.

6.Johnson B. Translator's introduction. In: Derrida J (ed) Dissemination. Chicago: Chicago University Press, 1981; vii-xxxiii.

7.Rinella MA. Revisiting the pharmacy: Plato, Derrida, and the mortality of political deceit. POLIS: The Journal of the Society of Greek Political Thought 2007;24:134-53.

8.Rose N. The politics of life itself: biomedicine, power and subjectivity in the Twenty-First Century. New Jersey: Princeton University Press, 2007.

9.Critical Art Ensemble (CAE). Flesh machine: cyborgs, designer babies, and new eugenic consciousness. New York: Automedia, 1998.

10.Williams SJ. Modern medicine and the "uncertain body": from corporeality to hyperreality. Social Science & Medicine 1997;45:1041-9.

11.Klugman CM. From cyborg fiction to medical reality. Literature and Medicine 2001;20:39-54.

12.Keck F. Des biotechnologies au biopouvoir, de la bioéthique aux biopolitiques. Multitudes 2003;2:179-87.

13.Van der Geest S, Reynolds White S, Hardon A. The anthropology of pharmaceuticals: a bibliographical approach.

Annual Review of Anthropology 1996;25:153-78.

14.Mamo L, Fishman J. Potency in all the right places: viagra as a technology of the gendered body. Body & Society 2001;7:13-35.

15.Martin E. The pharmaceutical person. BioSocieties 2006;1:273-87.

16.Cohen D, McCubbin M, Colin J, Pérodeau G. Medications as social phenomena. Health 2001;5:441-69.

17.Grinspoon S, Carr A. Cardiovascular risk and body-fat abnormalities in HIV-infected adults. New England Journal of Medicine 2005;352:48-62.

18.Persson A. Incorporating pharmakon: HIV, medicine, and body shape change. Body & Society 2004;10:45-67.

19.Pratt RJ. HIV & AIDS. A foundation for nursing and healthcare practice (5th ed). London: Arnold, 2003.

20.Van der Geest S, Reynolds Whyte S. The charm of medicines: metaphors and metonyms. Medical Anthropology Quarterly 1989;3:345-67.

21.Persson A, Race K, Wakeford E. HIV health in context: negotiating medical technology and lived experience. Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine 2003;7:397-415.

22.Rosengarten M. The challenge of HIV for feminist theory. Feminist Theory 2004;5:205-22.

23.Newman C, Persson A, Ellard J. “We just don’t know”: ambivalence about treatment strategies in the Australian community-based HIV media. Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine 2006;10:191-202.

24.Persson A. Facing HIV: body shape change and the (in) visibility of Illness. Medical Anthropology 2005;24:237-64.

25.Walby C. IatroGenesis: the visible human project and the reproduction of life. Australian Feminist Studies 1999;14:77-90.

26.Van Loos J. Risk and technological culture: towards a sociology of virulence. London: Routledge, 2002.

27.Clynes ME, Klyne NS. Cyborgs and space. In : Gray CH (ed). The cyborg handbook. New York: Routledge, 1995; 29-33.

28.Haraway D. A manifesto for cyborgs: science, technology, and socialist feminism in the 1980s. Socialist Review 1985;80:65-108.

29.Haraway D. Simians, cyborgs, and women: the teinvention of Nature. New York: Routledge, 1991.

30.Haraway D. The Haraway reader. New York: Routledge, 2004.

31.Hamilton SN. The cyborg, 11 years later: the not-so-surprising half-life of the cyborg manifesto. Convergence 1997;3:104-20.

32.Gray CH. Cyborg citizen: politics in the posthuman age. New York: Routledge, 2002.

33.Lewis BE. Prozac and the post-human politics of cyborgs. Journal of Medical Humanities 2003;24:49-63.

34.Smith Z. Technological bodies: feminist cyborg constructions. Convergence 1997;3:36-42.

35.Mansfield N. Subjectivity: theories of the self from Freud to Haraway. New York: New York University Press, 2000.

36.Penley C, Ross A, Haraway D. Cyborgs at large: interview with Donna Haraway. Social Text 1990;25/26:8-23.

37.Gray CH, Mentor S, Figueroa-Sarriera HJ. Cybergology. In: Gray CH (ed). The cyborg handbook. New York: Routledge, 1995; 1-14

38.Kull A. Speaking Cyborg: technoculture and technonature. Zygon 2002;37:279-87.

39.Huet M-H. Monstrous medicine. In: Lunger Knoppers L, Landes JB (eds). Monstrous bodies/political monstrosities in early Modern Europe. Ithaca: Cornell University Press, 2004; 127-147

40.Paré A. On monsters and marvels. Chicago: The University of Chicago Press, 1982.

41.Shildrick M. Posthumanism and the monstrous mody. Body & Society 1996;2:1-15.

42.Shildrick M. Embodying the monster: encounters with the Vulnerable Self. London: Sage, 2002.

43.Hanafi Z. The Monster in the machine: magic, medicine, and the marvelous in the time of the scientific eevolution. Durham: Duke University Press, 2000.

44.Leroi AM. Mutants: on genetic variety and the human body. New York: Viking Penguin, 2003.

45.Weeks BS, Alcamo IE. AIDS: the biological basis (4th ed.). Massachussets: Jones and Bartlett Publishers, 2006.

46.Geretti AM. Antiretroviral resistance in clinical practice. London: Mediscript Ltd, 2006.

47.Lykke N. Between monsters, goddesses and cyborgs: feminist confrontations with science. In: James L, Woodward K, Hovenden F (eds). The gendered cyborg. London: Routledge, 2000; 74-87.

48.Cardon P. La mutation fantasmée: le cas de Cronenberg. Critique 2006; Tome LXII (709-710):580-590.

49.Varas-Diaz N, Toro-Alfonso J, Serrano-Garcia I. My Body, My stigma: body interpretations in a sample of people living with HIV/AIDS in Puerto Rico. The Qualitative Report 2005;10:122-42.

50.Tate H, George R. The effect of weight loss on body image in HIV-positive gay men. AIDS Care 2001;13:163-9.

Acknowledgments

I would like to acknowledge the financial support of the Canadian Institutes of Health Research (CIHR). I would also like to thank those who have provided valuable feedback, especially Dr. Dave Holmes, Dr. Meryn Stuart, and Dr. Denise Moreau.

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Abstract

This paper investigates the ‘space’ and ‘place’ of disabled bodyspace in healthcare. The manner in which the body is mapped depends on perspective and location. Disabled women have had little input in ‘mapping’ the medical technological landscape in which they find themselves. With the advent of Disability Studies and Disability Geography, social and cultural elements of disability and impairment have begun to emerge. The voices of disabled women are reshaping the terrain of the body reflecting the reality of bodily difference from a positive viewpoint.

Key Words body technology, disability, healthcare, women

Remapping the Medical Terrain on Our Terms

NANCY HANSEN

Introduction

This paper investigates the “space” and “place” of disabled bodyspace in relation to medical technology. The manner in which the body is mapped depends on perspective and location. Women with disabilities have had little input in “mapping” the landscape in which we find ourselves at present. With the advent of Disability Studies and Disability Geography, social and cultural elements of disability, impairment and technology have begun to emerge.[1] The voices of women with disabilities are reshaping the terrain of the body and technology, reflecting the reality of bodily difference from a positive viewpoint.[2]

Bodies out of place

Western society has yet to develop a “comfort level” with so-called “messy” or “leaky” bodies and accordingly, there is an assumed right of public “correction”.[3] It is as if the presence of impairment or disability is threatening and destabilizes the “natural” boundaries of normalcy.[4] This need to “correct” may have its origins in the widely held belief that able-bodiedness is a condition highly coveted by people with disabilities.[5]

Disability or impairment is not seen as a natural variation in human biology but rather as biology “gone wrong”.[6] The level of access or accommodation provided often remains tentative and rudimentary. The doctrine of separate not equal appears to remain intact.[7] There appears to be an aversion to providing a “space” for people with disabilities.[6] Indeed, “reasonable accommodation” is often code for “minimum” as to nature and cost and it is implemented in such a way that established patterns are minimally disrupted.[7,6] The nature of the built environment and accommodations within it go a long way in illustrating the value placed on social participation of individuals within the community.[7] Devalued population groups are often referred to on the basis of race (e.g. blacks), gender (e.g. women), age (e.g. the elderly), and ability (e.g. the disabled).[8] In this manner difference is transformed through reductionism to sameness and the complexities of daily life are ignored.[9,6] Groups are effectively silenced through generalization.[10] The boundaries between the community, the individual and the body are fluid although they are often presented as fixed and unchanging.[11] Certain bodies have yet to "belong".[12] People with disabilities would seem to get caught up in a cycle of limited social expectation on the part of the able-bodied mainstream, perhaps fuelled by a combination of factors ranging from lack of exposure to people with disabilities in regular social situations to projected discomfort levels arising from the assumed helplessness regularly associated with varying levels of physicality. As a result, people with disabilities may spend significant amounts of time and energy negotiating their way through public spaces.

In Western society individual worthiness, indeed "humanness", is often defined on the most primitive level by the body.[13] The presence of people with disabilities challenges the entrenched social ideals of what is the acceptable adult body. In many ways people with disabilities are viewed as not fully human by society at large, although this form of dysfunctional reductionism is rarely perceived or acknowledged within the collective social consciousness. Disability is not readily subsumed as part of identity in the same manner as gender, ethnicity, and sexuality have been.[6] A "normal body" (whatever it may be) is equated with a "normal" life although the parameters of the concept are not clearly defined 6. Social understanding of disability and impairment seems to be one-dimensional.[9] Many times the level of engagement would seem to be evaluated in unsophisticated ways, namely in terms of the individual's apparent dysfunction.

"Civilizing" influences

A limited understanding of disability hence gets all too readily coupled with the common misunderstanding that a perceived physical difference somehow informs a lack of maturity or emotional development. It would seem that disability is often equated with a lack of development or immorality.[4] There would appear to have been a colonizing approach adopted toward those individuals with disabilities in Western society. In the possible belief that the appropriation of certain levels of able-bodiedness can turn people with disabilities into something approaching the norm, normalizing or corrective are measures are often presented as a "civilizing" influence ostensibly for the betterment of the individuals toward whom it is directed. Here "civilizing" stands for being able to fit in with the expected time-space routines of respectable Western society. In many ways medical authority is perceived as the "civilizing" agent.[14] Indeed, those individuals perceived as acquiring greater degrees of "able-bodiedness" are more readily "accepted" by the majority, at least in certain contexts.[10,6]

The body: re-mapping the terrain

The body is never a single physical thing so much as a series of attitudes toward it.[15] Society subjectively defines certain characteristics as valuable, while others are to be avoided or eliminated.[16] Gesler and Kearns[17] explain how this subjective process is used to validate differential treatment:

> The strategy is often used in constructing cultural difference is to naturalize it or make it appear as though it is only natural, the way of the world, an understood truth, not subject to question. Naturalization serves also to legitimise a system of difference.[17]

Western society arbitrarily imposes fixed bodily expectations on its membership.[18] Acceptable shape, size, colour, height, sexuality and physicality are all culturally mediated.[19,16]

> Concepts of race, gender and class shape the lives of those who are not black, poor or female, so disability regulates the bodies of those who are "normal". The concept of normalcy by which most people (by definition) shape their existence is in fact tied inexorably to the concept of disability. Normalcy and disability are part of the same system.[20]

Agents of normalization

Medical science mirrors the cultural norm and "profoundly shapes our assumptions about what a normal body is …".[21] Medical science is often presented as the benign purveyor of information concerning impairment and disability.[4] Medical professionals are not immune to the widely held perceptions concerning disability and impairment.[22] Globalizing, outdated images of disability and incapacity may colour expectations.[23,24] Functional limitation and difference continue to dominate the discourse in medical school training.[25] The focus remains correction or normalization.[13] Often disability is framed as an apparent failure of medical science where "cure" is not an option.[25] A lack of knowledge concerning disability and "quality of life" issues may influence healthcare decisions and not reflect the reality of daily life with disability.[25,24] Disability is often not as debilitating as it is presented and many individuals lead full lives.[24] However, a possible lack of information or awareness of disabilities and related support services can create greater difficulties for the women seeking information concerning their changed circumstances.[23] In many ways physicians are "gatekeepers" to the broader social mainstream 9. Medical professionals provide needed authorization for required non-medical provisions and accommodations, yet often fail to recognize their crucial role in liberation and independence for people with disabilities.[23,25]

Disability may be equated with the non-standard deviant population.[26,20] Genetic research will not eradicate impairment or disability, nor will it abolish affliction.[27] In reality, only a minuscule portion of disability or impairment results from genetic difference.[24] The disability rights movement has largely ignored the concept of impairment perhaps because of assumed links to the medical or pathology model of disability.[28,29] Avoiding the intimate aspects of disability or impairment has meant that much of the disability/abnormality dichotomy remains intact and unchallenged.[30,31]

According to Thomson[32], public and private environments are designed for the non-disabled privileged body. Fear of difference is arguably the underlying rationale, although it is rarely articulated as such.[33,16] In many ways disability has been a pivotal factor in defining cultural norms of the body.[34] As a society we have yet to develop a comfort level associated with impairment, pain, or fatigue that ventures much beyond avoidance.[29] Women with disabilities for example are viewed as somewhat removed from the "normal",[32] and here the disability/abnormality/pathology continuum is firmly entrenched.[16] Science objectifies and dominates much of the discussion about disability,[16] while assumptions about the static nature of disability and impairment permeate the discourse.[35]

Society has medicalized disability in much the same way that it has childbirth.[36] The elements of contested control, choice and integrity over, for and of the body present in much of mainstream feminist writing are found here, the difference is only a matter of degree. Technology presents opportunities for disabled and non-disabled women alike, and this possibility has been touched on in Haraway's[37] writings about feminism and cyborg technology. However, disabled writers approach such theorizing with reservation, maintaining that it presents an oversimplification of technology and the body, ignoring the real-life complexities that impairment presents.[34,38] The high cost associated with technology is an insurmountable barrier to disabled men and women, most of whom live in poverty. Reliance on technology, while in some cases facilitating action, may create a reluctance in society to remove other barriers, thereby leading to further social isolation.[39]

Standard tests for non-standard bodies

Diagnostic tests are a standard element of the health care regime.For example, women are routinely sent for breast examinations. However, when impairment and disability are present the experience may not be "routine". It is as if disability is disruptive to established practice:

> I also found it very difficult to stand to get the test done, to get a mammogram. …, you've almost got to like arch your back to get your breast between the: plates, and I think the woman (the technician) was just completely not used to, somebody that wasn't flexible and wasn't the same shape as all the rest of her patients. I had to take the rest of the day off and lie down because my back was so sore. (Electra, Glasgow)
>
> I had a lump in my breast that needed to be … investigated but I was aware that a mammography would not be practical and so it turned out. So when I did go up to the hospital to have to go through the process I didn't, I couldn't do that bit but I could do the scan. And … that was ok. It was fine, I didn't have to move out my wheelchair. (Rainbow, Edinburgh)

Rainbow also spoke of the need to bring her own equipment for certain procedures at times:

> [E]very place which … requires you to be sitting other than in your wheelchair. For me a hoist that is absolutely necessary. I can take a hoist that I have, and it fits in my car. However, if my GP needed to examine me it would probably be done on my bed at home. (Rainbow, Edinburgh)

Jennifer relates her experience during the quarterly visit to the eye clinic:

> [W]ithin the hospital eye service … in the eye clinics, doctors are very bad at not introducing themselves, nurses don't introduce themselves. … [W]hen I'm getting my eyes examined I have … to wear a contact lens and I have to take it out. So I have no useful vision, once I take my lens out, I'm completely blind.. … They have no visual impairment awareness whatsoever. … and it's something that's extremely frustrating, 'cause it's quite humiliating for me when they say, … have a seat over here and … they're sort of thinking why are you not moving forward, but if you can't see what's in a room, it's really difficult to know where a chair is. (Jennifer, Stirling)

It would appear that the arrival of "non-standard" bodies on the scene is unexpected and "out of place". Therefore, in many cases women with disabilities must adapt and manoeuvre in an environment that is largely unprepared for them.

The “knowledge” question: who “knows”

Many women with disabilities have a detailed knowledge and an understanding of their impairments drawn from daily life experience. Yet, medical personnel often do not utilize this resource.[23] Most of the women I spoke with talked of instances where this knowledge was questioned or dismissed when seeking medical treatment:

> [I]t’s an absolute lottery, as to which doctor you are going to see. And that person … could have no knowledge of you whatsoever. … a condition within my eyes has changed, and that has needed quite specific treatment. But, I think that, it took longer to get under control, because I was being seen by different people. They were starting from scratch each time… I insist on seeing the senior consultant [specialist] and … the last time I was there I refused to see the doctor who had taken my notes off the top of the pile, ….what the doctor had said to me was, … ‘you can’t see the consultant because if everybody wanted to do that, it would hold up the whole clinic, and if you want to do that, you are going to have to wait a long time’. And I said to her, well that’s fine, I’ll just wait. (Jennifer, Stirling)

Meranda and Jess spoke of the difficulty communicating with their consultants [specialist]:

> I mean this is a man with a communication problem. ... He really couldn’t get his head round this, and I became aware of that from the point when I was referred to him … And I would have understood that if he had actually explained it to me, but he did not explain it to me. So he wasn’t using, quite aside from the disability, he wasn’t using my knowledge of myself. The patient’s knowledge of herself, to help in this situation. (Meranda, Glasgow)

> I used to go to the pain clinic … The first couple of times I went there I felt … At the time you were telling him something he was contradicting you saying well that can’t happen. He is telling you that there’s nothing wrong with you apart from your weight. Your weight gets blamed for everything … I had a back brace which didn’t fit properly and I was told to go home and just get used to it. .. and it was a case of well you [cannot] be that bad if you refuse certain things. … these symptoms just do not sound like the condition you have. And then I asked ‘How many people he had seen in my condition’. ‘One’. He had read everything in a book. … I haven’t been back for a good few years. (Jess, Falkirk)

Sally and Hazel talked about the difficulty they have at times, trying to impart the specifics of their impairment to health care professionals in order to avoid serious health complications:

> If I get a chest infection it does cause a pile of difficulty because my rib cage is quite constricted … I don’t know that the GPs always understand that, … they … say ‘well we don’t like to prescribe antibiotics’ ... They treat you like they’d treat anybody and … it’s difficult to … try and explain to them ‘well actually … it’s a bit more difficult for me’. (Sally, Edinburgh)

> Quite a lot of times if you’re given a new drug you have to ask, … what the effects are and I have to say I double check for instance if a new drug has steroids in them because I am not allowed to have them in them in one of my drugs for epileptic. Because it happened once, I don’t believe that everyone will remember. (Hazel, Stirling)

Rainbow’s experience with her specialist demonstrates what can be achieved through respect, communication and understanding:

> It’s kind of strange because with most doctors nowadays I can tell them exactly what I need and … we talk about it from that point … I met my longstanding consultant … and knew that he was dead straight with me but with a wry sense of humour, which I appreciated. … and he’s just so direct and I know that he’s in control … but in control without putting me on the sidelines and he very clearly said to them ‘Rainbow knows her lungs better than any of us she knows what she needs’. And that is just so supportive. (Rainbow, Edinburgh)

The “place” of technology in health care

Discussions concerning technology clearly meant different things to different people and explored a wide range of topics. Fred, a physician with a disability, speaks of technology as providing an assistive role to people with disabilities:

> I think technology clearly can be important either in assisting the disabled person to … not be so disabled … by allowing them to do things they wouldn’t otherwise do and I suppose also by … technology it just doesn’t apply to disabled, I think it applies more generally, ... technology can often be useful in providing information to patients and people with disabilities in a way that is … perhaps easier for them to assimilate, and that they’ve more time to assimilate. And … things like having good web sites that people can go to actually is very helpful ..., because we know that whether someone is disabled or not, the amount of information that gets across at any consultation. (Fred, Physician, Glasgow)

The internet is a key health information access tool for many of the women that I interviewed:

> We use the Internet for health information … because they have it in here and it’s easily accessible for us if we need it. …On my own condition. … Because it’s quite a rare condition that … even my GP had problems trying to get information on it. (Jess, Falkirk)

> I think for the first time I’ve been able to type the name of my impairment in on the Internet and it came up with information whereas in libraries … anywhere else that I’ve, medical dictionaries even, looking up

> the name of my impairment … doesn't…happen. So ... the Internet's definitely got … better access to information. (Sally, Edinburgh)

> Well its normally … quite good because he [Doctor] has got a computer so sometimes they can punch it up on the computer and give you wee leaflets and things like that. (Kylie, Stirling)

Asch[24] documents how the nature disability can be distorted and is often presented as complete dependency. Similarly, Molly speaks of the negative manner in which disability is often presented in terms of genetic screening:

> I think that it's… that the way it's, … sold to people is very negative … I think it's very ... disability is a life less worth living attitude that's taken. And I don't think people are given the full range of facts, I don't think people are supported to consider well if a person has this particular condition, ok there might be these kinds of limitations in their life, but there are lots of people who are living very valuable and fulfilled lives who do have this particular condition. (Molly , Health Service Administrator, Glasgow)

The technology for large or non-print formats is readily available but mainstream society has yet to recognize it as a regular part of the information network. Jennifer talks about the lack of access to health information available in these alternative format materials:

> [T]here's really no information available in accessible formats [accessible to people with vision impairments]. So usually … in terms of … some information … I'm sent out a letter, then I can read that sort of stuff using a closed circuit television. (Jennifer, Stirling)

Rainbow tells of the lack of simple physical access technology in a health care setting:

> The provision of more hoists, particularly, at health care centres could be very useful. (Rainbow, Edinburgh)

Internet technology has made accessing health care and impairment information much easier for some women with disabilities. However, it would appear that there is as yet some way to go in making the links between technology and disability as being a "natural" part of the health care environment.

> [I] think it's very important that the disabled and disabled groups continue to push at the health care professions. And continue to push at medicine. I mean medicine … is changing but it needs a stimulus. and medicine in some ways is a very conservative profession and will not change unless there is some stimulus. Or will not change from what it thinks is important unless there is some external stimulus. It will change in detail, it will change in scientific approach … but in terms of the broader perspective whilst there will be individuals who may change, the profession as a whole won't change unless there is continuing stimulus from the outside. (Fred, Physician, Glasgow)

Conclusion

Health service professionals and the disability rights movement can together play an important role in moving away from "perfect body syndrome". This will require significant attitudinal shifts at a fundamental level re-examining tenets and moving well beyond tinkering with the existing system.[25] Every "body" is a natural part of humanity.[13] Deeply held truths about what comprises the "woman's body" require critical and creative analysis outside of the narrow objectifying boundaries of science.[13] We need to reject simplistic approaches that embrace physical and cognitive essentialism in favour of diversity.[13,27] There are real consequences to the choices we make and these choices should be motivated by respect and understanding rather than ignorance.[27] In many ways, it represents the natural progression in how the disability movement has created a new group of perspectives beyond the overreaching normative which has gone before. Knowledge, science and technology are not exempt from critical analysis and here the authority of medical science cries out for critical mediation.[25,27] Above all, the disability/pathology dualism must be abandoned in favour of a model that values and respects bodily difference rather than fearing it.[32,27]

References

1.Hansen N. Passing through other peoples spaces: women with disabilities, geography, and Work. Unpublished PhD. Thesis, University of Glasgow, Glasgow, Scotland, 2002.

2.Hansen N. Health care settings and sites: making a place and space for disabled women: a post colonial approach. Unpublished. CIHR Post-Doctoral Research Fellowship Health Care Technology and Place Programme, administered by University of Toronto, undertaken at the University of Glasgow, 2003.

3.Longhurst R. Bodies: exploring fluid boundaries. London: Routledge, 2001.

4.Sibley D. Geographies of exclusion. London: Routledge, 1999.

5.Silvers A. The crooked timber of humanity: disability ideology and the aesthetic. In: Corker M, Shakespeare T (eds). Disability/postmodernity: embodying disability theory. London: Continuum, 2002; 228-44.

6.Michalko R. The difference that disability makes.

Philadelphia: Temple University Press, 2002.

7.Kitchin R. Disability, space and society. Sheffield: Geography Association, 2000.

8.Corker M, Shakespeare T. Mapping the terrain In: Corker M, Shakespeare T (eds). Disability/postmodernity: embodying disability theory. London: Continuum, 2002; 1-17.

9.Titchkosky T. Cultural maps: which way to disability? In: Corker M, Shakespeare T (eds). Disability/postmodernity: embodying disability theory. London: Continuum, 2002; 101-11.

10.Price J, Shildrick M. Bodies together: touch ethics and disability. In: Corker M, Shakespeare T (eds). Disability/postmodernity: embodying disability theory. London: Continuum, 2002; 62-79.

11.Tremain S. On the subject of impairment. In: Corker M, Shakespeare T (eds). Disability/postmodernity: embodying disability theory. London: Continuum, 2002; 32-47.

12.Longhurst R. The geography closest in-the body …the politics of pregnability. Australian Geographical Studies 1994; 32(2):214-23.

13.Thomas C. The “disabled” body: from disgust to aberrance to pity. In: Real bodies: a sociological introduction. London: Palgrave, 2002; 64-78.

14.Hughes B. Disability and the body In: Barnes C et al (eds). Disability studies today. Cambridge: Polity Press, 2002; 58-76.

15.Davis L. Bending over backwards: disability, dismodernism and other difficult positions. New York: NYU Press, 2002.

16.Young, I. The scaling of bodies and the politics of identity. In: McDowell L, Sharp J (eds). Space, gender and knowledge: feminist readings. London: Arnold, 1997; 218-31.

17.Gesler W, Kearns R. Culture/place/health. London: Routledge, 2002.

18.Morris J. Framed: a feminist perspective. In: Pointon A, Davis C (eds). Framed: interrogating disability into the media. London: BFI, 1997; 21-30.

19.Butler J. Gender trouble: feminism and the subversion of identity. London: Routledge, 1990.

20.Davis L. Enforcing normalcy: disability, deafness and the body. New York: Verso, 1995.

21.Leach Sculley J. Postmodern disorder: encounters with molecular models of disability. In: Corker M, Shakespeare T (eds). Disability/postmodernity: embodying disability theory. London: Continuum, 2002; 48-61.

22.Begum N. The general practitioner’s eole in ahaping disabled women’s lives. In: Barnes C, Mercer G (eds). Exploring the great divide. Leeds: Disability Press, 1996; 157-72.

23.Barnes C., Mercer G. Disability: medical needs to social rights, In: Tovey P (ed). Contemporary primary care: the challenges of change. Buckingham: Open University Press, 2000; 82-96.

24.Asch A. Prenatal diagnosis and selective abortion: a challenge to practice and policy. In: Ard C, Asch A, Conrad P, Geller LN (eds). The Double-Edged Helix: Social Implications of Genetics in a Diverse Society. Baltimore: Johns Hopkins University Press, 2002; 123-50.

25.Basnett I. Health care professionals and their attitudes toward and decisions affecting disabled people. In: Albrecht G et al. (eds). Handbook of disability studies. Thousand Oaks: Sage, 2001; 450-67.

26.Hahn H. Disability and the reproduction of bodily images: the dynamics of human appearances. In: Wolch J, Dear M (eds). The power of geography: how territory shapes social life. London: Unwin Hyman, 1989; 370-88.

27.Kerr A, Shakespeare T. genetic politics: from eugenics to genome. Cheltenham: New Clarion Press, 2002.

28.Morris J. Us and them? community care and disability. Critical Social Policy 1991; 33:22-39.

29.Wendell S. The rejected body: feminist philosophical reflections on disability. New York: Routledge, 1996.

30.Crow L. Including all our lives: renewing the social model of disability. In: Barnes C, Mercer G (eds). Exploring the great divide. Leeds: Disability Press, 1996; 55-73.

31.Pinder R. Sick but fit or fit but sick? ambiguity and identity in the workplace. In: Barnes C, Mercer G (eds). Exploring the great divide. Leeds: Disability Press, 1996; 135-56.

32.Thomson R. Extraordinary bodies: figuring physical disability in American culture and literature. New York: Columbia University Press, 1997.

33.Baird V. Difference and defiance. The New Internationalist 1992; 233(July):4-7.

34.Dorn, M. Beyond nomadism: the travel narratives of a cripple. In: Nast H, Pile S (eds). Places through the body. London: Routledge, 1998; 183-206.

35.McDowell L. Gender, identity and place: understanding feminist geographies. Oxford: Polity Press, 1999.

36.Wendell, S. Towards a feminist theory of disability. In: Davis L (ed). The disability studies reader. New York: Routledge, 1997; 260-78.

37.Haraway D. Simians, cyborgs and women: the reinvention of nature. London: Free Association Books, 1991.

38.Meekosha H. Body battles: bodies, gender and disability. In: Shakespeare T (ed). The disability reader: social science perspectives. London: Cassell, 1998; 163-80.

39.Sheldon A. Disability technology and Social Change: the case of information and communications technology. Paper presented to Disability Studies Seminar- Disability and Social Policy Past, Present and Future Edinburgh December 2-4,1998.

Acknowledgments

The research is drawn from a CIHR Post-Doctoral Research Fellowship administered through the Health Care Technology and Place Program at the University of Toronto with additional funds being provided by the University of Glasgow. I would like to thank the fourteen Scottish disabled women who so graciously gave of their time and provided great insight throughout the process. Their names have been changed and each woman chose her own pseudonym.

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Résumé
Les Canadiens ont à une certaine époque pensé qu'ils avaient le meilleur système de santé du monde. Aujourd'hui, ils en sont moins sûrs et, surtout, ils se demandent si ce système est viable et si les valeurs qui le sous-tendent survivront à l'épreuve du temps. Ici comme ailleurs, les coûts de la santé flambent. Les systèmes de soins, qu'ils soient bismarckiens, beveridgiens ou libéraux sont en crise. Les gouvernements ont entrepris divers chantiers de réforme car le statu quo est devenu insoutenable. Au Canada, les thèmes débattus aujourd'hui sont les mêmes qu'il y a une dizaine d'année. Quelles réformes engager ? Comment remettre sur les rails un système de santé public mal en point et condamné à un rendement bien en-dessous de son potentiel ? Comment bâtir un système à la fois accessible et efficient, dans un contexte ou les initiatives sérieuses sont soit, trop difficiles à mettre en œuvre, soit politiquement ingérables ? Cet article allie une analyse des questions conjoncturelles à une réflexion sur les problèmes structurels du système canadien de santé.

Mots clés dépenses de santé, partenariats public-privé, réforme des soins de santé, système canadien de santé

Guérir le système de santé canadien dans un contexte de crise cumulative de l'offre et du financement : enjeux, défis et opportunités

H. SANNI YAYA

Introduction

La santé a toujours été une valeur importante dans les sociétés humaines. Patrimoine ou capital sociétal pour les uns, produit des comportements et des conditions de vie pour les autres, elle a occupé une place centrale à travers les cultures et les âges parce qu'elle est la condition de toutes les autres conditions d'exercice de la vie.[1,2] Depuis quelques décennies, le champ de la santé connaît un regain d'intérêt au point de devenir une priorité sociale fondamentale pour tous les gouvernements à l'échelle planétaire qui continuent d'y consacrer une part importante de leurs ressources.[3,4] Symbole d'une démocratie solidaire et témoin du niveau de développement d'une collectivité, la santé est longtemps apparue comme un bien particulier auquel il est difficile d'appliquer le calcul économique car elle se situerait hors du champ de l'économie.[5,6] C'est d'ailleurs ce qui explique le dilemme qu'il y a à opposer le paradigme de la rationalisation des coûts, propre à la science économique à celui des besoins sociaux et humains, propre aux sciences de la vie, à la morale et l'éthique. D'ailleurs la théorie économique elle-même considère la santé comme un champ qui s'inscrit dans la catégorie des services collectifs et des biens publics. En tant que bien non marchand, certains estiment qu'elle ne peut donc théoriquement faire l'objet d'une discrimination entre ceux qui en bénéficient car est elle indivisible et non exclusive et, qui plus est, sa disponibilité et son accessibilité ne devraient pas être réduites parce qu'il y aurait trois consommateurs au lieu d'un.[7,8]

Mais au-delà de ces principes, force est de reconnaître que la santé est devenue au cours des dernières années une lancinante énigme pour les pouvoirs publics. De nombreux experts s'accordent pour dire que les systèmes publics de santé ne sont pas viables à long terme sans des réformes profondes dans la façon dont ceux-ci sont financés.[9,10] En effet, si la santé n'a pas de prix, elle a un coût que de plus en plus de gouvernements ont du mal à supporter. Le champ de la santé est aujourd'hui devenu un espace politiquement structuré dans lequel se jouent des luttes valorielles et où des choix difficiles et peu consensuels sont nécessaires. Les données relatives à l'évolution des dépenses en santé dans les pays de l'OCDE font apparaître une constance commune : de façon générale, la croissance réelle des dépenses en santé dans les pays membres a été plus rapide que celle de leur PIB. En 2006 par exemple, la part des dépenses en santé est passée en moyenne, de l'ordre de 8,9 % du PIB contre 8,4 % en 2000 et 5,3 % en 1970.[11] Cette progression des dépenses n'est à priori pas problématique car les sommes investies en santé tiennent à plusieurs raisons. Les soins et les services de santé constituent un secteur à forte intensité de main-d'œuvre, ce qui implique des coûts élevés pour un personnel hautement qualifié (médecins, infirmières, personnel de soutien et, de plus en plus, gestionnaires et administrateurs). En outre, la santé met en œuvre des technologies onéreuses, compte-tenu des progrès dans l'imagerie, la thérapie génique, la pharmacologie et la biotechnologie. Par ailleurs, même si le phénomène ne semble avoir joué qu'un rôle relativement limité, il faut s'attendre à ce que le vieillissement de la population, en raison de la structure des coûts liés à l'âge, accentue à la hausse les dépenses de santé.[12,13,14]

L'augmentation des dépenses de santé pose, à long terme, la question de leur soutenabilité par le financement public. Encore aujourd'hui, plusieurs gouvernements peinent à trouver le juste équilibre entre les objectifs contradictoires que constituent des enjeux comme la qualité des soins, l'accessibilité, l'universalité, l'équité du système, la liberté des acteurs (patients et professionnels) et la maîtrise des dépenses correspondantes. En fait, il faudra à l'avenir commencer par se questionner sur ce à quoi nous attachons le plus d'importance en matière de soins de santé, de prestation des services ou de liens entre les prestateurs de soins et les patients.[15]

L'exercice a été entrepris dans plusieurs pays et des réformes destinées à améliorer la productivité des systèmes de santé, le contrôle de l'offre ou encore la réduction de la demande de soins ont été initiées. Dans plusieurs pays, les gouvernements ont essayé d'augmenter le fardeau fiscal afin de contrôler la pression inflationniste du système, mais ils ont du se raviser en raison de l'impopularité d'une telle politique. D'autres avant eux ont choisi d'imposer des contraintes sur l'offre, mais ils ont tôt fait de se rendre compte que cette approche pouvait conduire à un « apartheid médical ». Les plus intrépides ont fait le pari de réformes structurelles, qui ont tantôt pris une tournure radicale par la mise en œuvre de changements majeurs sur une courte période (approche big-bang), tantôt séquentielle (par l'adoption d'un plan de mise en place des changements par étapes) ou incrémentale (en prônant de légers ajustements dans le rôle de certains professionnels clés de santé).[16,17,18,19] Le système de santé au Canada a historiquement joué un rôle crucial dans l'édification de la nation. Universel et accessible jadis, il faut reconnaître qu'il a très bien servi les collectivités. Même si les canadiens n'ont jamais été aussi bien en meilleure santé et qu'ils ont collectivement, au cours du dernier siècle, bénéficié de changements sociaux fondamentaux conjugués à une vague déferlante de mesures nationales de santé publique, on est bien forcé de se rendre aujourd'hui à une triste évidence : la pérennité du système canadien de santé est gravement menacée. Pénurie de ressources humaines, manque de médecins et d'infirmières, épuisement professionnel du personnel médical et paramédical, accroissement des erreurs médicales, exclusion du système de soins d'une partie de la population, rationnement des soins, services d'urgence engorgés, insatisfaction du public, profondes inégalités d'accès en matière de santé et d'accès aux services, bref, la liste des maux qui minent le système de santé est longue.[20]

L'accroissement exponentiel des besoins, les profondes mutations qui ont affecté l'organisation des soins de santé, les contraintes fiscales et financières de mêmes que les multiples contingences socio-économiques et politiques forcent donc aujourd'hui les gouvernements à se réajuster et à faire des choix difficiles et déchirants afin de remplir adéquatement leur rôle de puissance publique et de pivot de l'organisation sociale et économique. C'est dans ce contexte de crise cumulative de financement, de l'offre et de la qualité de soins de santé, que se pose aujourd'hui l'épineuse mais nécessaire question des issues de secours pour le système de santé au Canada. Autrement dit, comment les gouvernements peuvent-ils sortir de cette impasse programmée qui semble de plus en plus inéluctable ? Dans quelles mesures les pouvoirs publics peuvent-ils assurer les soins de santé dont la population a besoin et qu'elle réclame, et ce, d'une manière efficiente ? Sur quelles bases et à quelles conditions est-il encore possible de préserver le système canadien de santé dans un contexte où la santé au Canada accapare une si grande partie de la richesse nationale, c'est-à-dire près de

40% des budgets provinciaux ?

La régulation des prix et du volume d'activité dans le secteur de la santé est-elle une option à considérer ? Le déplacement des coûts sur les patients est-il équitable et socialement acceptable dans une démocratie solidaire comme la nôtre ? Les mesures de plafonnement budgétaires constituent-elles comme le prétendent certains, un pacte avec le diable ? Peut-on encore dans le contexte actuel se permettre de déconnecter les soucis fiscaux des gouvernements du fonctionnement du secteur de la santé ? Est-il normal ou souhaitable, lorsqu'on peut faire autrement, de subordonner la prestation de soins au seul souci de l'équilibre financier des pouvoirs publics ? C'est à ces questions que tente de répondre cet article. Umberto Eco disait qu'« à tout problème complexe, il y a une solution simple. Mais, elle est généralement mauvaise ». À notre avis, une partie des réponses aux maux qui minent le système de santé au Canada se trouve d'une part dans l'analyse même de son fonctionnement et des réformes qui l'ont façonné et d'autre part, dans une redéfinition du modèle sanitaire en santé publique car celui-ci semble incapable de faire face aux actuels bouleversements culturels, sociaux, démographiques et épidémiques qui sont ceux de notre époque.

Le système de santé canadien a-t-il encore un avenir ?

Le système canadien de soins de santé a toujours donné lieu à des débats enflammés en raison de sa particularité. Combinaison des plans de santé de 10 provinces et de 3 territoires qui fonctionnent indépendamment, mais qui répondent et dépendent à la fois du gouvernement fédéral, le système de santé canadien est soumis à un ensemble de conditions que les provinces et territoires doivent respecter.[21] Parmi celles-ci, mentionnons la gestion publique du régime, son intégralité, son universalité, sa transférabilité et son accessibilité. Mais on sait aussi que ces conditions sont de plus en plus remises en question, la dernière en date étant la décision de la plus haute instance judiciaire du pays qui s'attaque de façon explicite à la gestion publique du système d'assurance maladie afin de permettre, en parallèle, le développement d'un système d'assurance privée. La caricature du dinosaure à la dérive utilisée par certains pour caractériser le système de santé canadien peut sembler inutilement provocatrice. Mais elle décrit à notre avis, une situation bien réelle, dans un contexte où les systèmes de santé dans la majorité des pays industrialisés présentent de plus en plus de dysfonctionnements et apparaissent de moins en moins viables. Au Canada, les pouvoirs publics constituent la source principale du financement de l'assurance maladie. L'intervention de l'État se justifie parce que ses tenants estiment que les gouvernements doivent pouvoir remédier à l'épineuse question de l'équité sociale qui est intrinsèquement liée au fonctionnement d'un marché privé de l'assurance. L'argument principal est que les firmes privées refuseraient de couvrir les personnes qui constituent un haut risque ou tenteraient tout simplement de les contraindre à payer une prime relativement élevée pour compenser ce risque. La problématique de l'équité d'accès, indépendamment de la capacité des individus à payer, a donc amené les gouvernements à fournir une protection universelle à leurs citoyens par l'entremise de régimes provinciaux d'assurance-santé co-financés par les autorités fédérales et les autorités provinciales ou territoriales.[22]

Ceci ne veut pas dire pour autant que le secteur privé soit totalement absent du domaine de la santé au Canada. Même si des firmes d'assurance privées existent, leur étendue demeure limitée et elles ne peuvent théoriquement pas couvrir des services fournis en vertu des régimes provinciaux. Contrairement à certains pays, la prestation directe des soins de santé aux citoyens demeure le fait du secteur privé. D'ailleurs, les groupes de pressions qui militent pour une ouverture plus grande du système de santé au secteur privé oublient trop souvent que les citoyens canadiens règlent majoritairement au moyen de fonds privés, une plus grande partie de leurs dépenses que la moyenne des pays industrialisés. Cela est également vrai pour ce qui est des dépenses en médicaments : la proportion du financement privé au Canada est supérieure à celle de la plupart des pays avec des niveaux de développement comparables.[11] En outre, l'immense majorité des professionnels de la santé est en pratique privée, même si les soins médicaux et hospitaliers qui y sont fournis, ainsi que la rétribution de ces services, font l'objet de réglementations gouvernementales.

Les maux qui minent le système de santé au Canada sont trop complexes pour se résumer à un débat public versus privé car les solutions, rarement simples et linéaires, ne se sont jamais de l'ordre de la simplification. La nature du financement de la santé sera toujours une question épineuse et des études plus poussées sont nécessaires pour examiner comment et à quelles conditions, l'assurance publique et l'assurance privée pourraient associer leurs efforts pour aider à renforcer nos systèmes de santé. C'est pourquoi il est fondamental de déterminer quel est le cadre réglementaire appropriés car l'avenir appartient aux systèmes de santé intégrés et capables de fonctionner de façon cohérente pour le plus grand bénéfice des populations. Si depuis la révolution hygiéniste, les Canadiens ont vu une amélioration de leur état de santé général, il faut bien admettre que d'autres pays ont de meilleurs résultats. Bien entendu, la comparaison des systèmes de santé est complexe et ne vise aucunement à éprouver la supériorité d'un système sur l'autre. Chaque système doit être évalué en fonction des ressources dont il dispose et non pas de celles qui auraient pu être consacrées à la santé mais qui ont servi à un autre usage. Ceci dit, une telle comparaison a néanmoins le mérite de permettre d'observer des corrélations qui ne peuvent être interprétées comme la preuve de relations causales et d'examiner des singularités qui ne sont pas facilement interprétables, mais qui permettent de réfuter formellement certaines relations causales.

Aussi imparfaites ou incomplètes qu'elles soient, certaines données dont on dispose aujourd'hui permettent de dresser un portrait du système de santé canadien et de réviser des idées préconçues. Si le Canada fait mieux que la moyenne des pays de l'OCDE à certains égards, il faut souligner que les indicateurs, dans bien de cas, ne sont guerre reluisants [11], et ce, pour plusieurs raisons :

•Les dépenses en santé selon les données de 2008 pour le Canada représentaient en 2006 10% de son PIB, ce qui dépasse la moyenne de 8.9% enregistrée dans les pays de l'OCDE. Le pays dépense également en moyenne 3678 dollars US en santé per capita, comparativement à une moyenne de 2824 dollars US. Et pourtant, le système de santé canadien affiche des performances inférieures à celle d'autres pays qui en dépensent beaucoup moins comme le Danemark ou la Nouvelle-Zélande.

•Plus de 70% des dépenses en Santé au Canada proviennent de fonds publics, comparativement à 73% dans la moyenne des pays de l'OCDE. En fait, l'assurance privée représente 13 % des dépenses de santé au Canada, soit deux fois plus que la moyenne des pays développés. Clairement, le privé est davantage présent dans le domaine de la santé au Canada.

•L'un des problèmes les plus urgents du système canadien de soins de santé est celui d'assurer une bonne planification des ressources humaines. Plus d'un million de personnes travaillent dans ce système, assurant les soins quotidiens à la population. Ils en forment l'épine dorsale et la prestation de soins accessibles et de grande qualité dépend de la présence au bon endroit des bonnes personnes aux bonnes compétences. Les récentes données indiquent que le nombre de médecins par rapport à la population est demeuré inchangé au Canada depuis 1990. En effet, le nombre de médecins par 1000 habitants est de 2.1 ce qui reste en dessous de la moyenne de 3.1 enregistrée dans les pays de l'OCDE.

•Le nombre d'infirmières en 2006 est de 8.8 par 1000 habitants, ce qui est également plus bas que le taux moyen de 9.7 des pays de l'OCDE. Même si le Canada a réussi à gérer la décroissance dans ce secteur en réduisant sensiblement le contingentement universitaire, ceci ne suffira pas à régler la situation à long terme.

•L'espérance de vie, qui a toujours été considéré comme une mesure utile du bien-être et qui est en partie fonction du niveau de vie et de la qualité des soins de santé disponibles dans un pays donné est de 80.4 ans au Canada. Si ce taux est légèrement au dessus de la moyenne de l'OCDE qui est de 78.9 ans, il demeure nettement inférieur à celui d'autres pays comme la Suisse, l'Australie, l'Islande ou encore le Japon où on enregistre des moyennes nettement supérieures.

•Les dépenses en médicaments délivrés sur ordonnance augmentent au Canada à l'instar des autres pays et à un rythme plus rapide que les autres catégories principales de dépenses de santé. En fait, la part du total des dépenses de santé consacrée aux médicaments a connu la plus forte croissance au cours des vingt dernières années et elle continue de devancer la plupart des autres secteurs de la santé, y compris le secteur hospitalier. Avec une somme de 639 USD par personne en 2006, le Canada arrive en deuxième position, tout derrière les États-Unis (843 dollars US).

La problématique de l'accroissement des dépenses en santé : déconstruire des mythes tenaces et profondément erronés

L'accroissement des dépenses en santé a conduit les différents niveaux de gouvernement (provincial, territorial et fédéral) au Canada à mettre en œuvre des stratégies afin d'encadrer, limiter et rationnaliser leur niveau, jugé excessif. Le secteur de la santé représente de toute évidence un axe d'activités important dans l'économie canadienne. Mais il est indéniable que les pouvoirs publics ne peuvent pas y consacrer davantage de ressources, dans la mesure où l'accroissement des dépenses de santé limite aussi les possibilités budgétaires des gouvernements à se consacrer à d'autres objectifs sociaux, y compris ceux qui auraient pu avoir une incidence positive sur l'état de santé de la population.[23] Sur fond d'une crise structurelle, systémique et complexe d'une médecine qui absorbe une part considérable de ses ressources, le système de santé au Canada doit aujourd'hui faire face à ses vieux démons et gérer les tensions économiques, institutionnelles et organisationnelles qui minent à la fois l'ambition et les efforts des pouvoirs publics de proposer une infrastructure sanitaire à la hauteur des attentes des citoyens tout en tenant compte des moyens disponibles. Au cours des dernières années, l'objectif des gouvernements fût donc d'essayer de réduire les coûts administratifs du système de santé et de reporter les économies ainsi réalisées sur le diagnostic, les thérapies et les soins de prévention. Mais de plus en plus de recherches sur le sujet suggèrent que les pouvoirs publics ne doivent pas se borner à considérer les problèmes immédiats des finances et des déficits publics, mais qu'ils doivent se pencher sur la question plus large de l'efficience de la prestation des soins de santé et de ses implications pour le bilan économique global.[24]

Dans un système comme le nôtre qui exclut totalement ou pour une grande partie les mécanismes de marché dans la détermination de l'allocation des ressources et dans l'adéquation de l'offre et des besoins, les objectifs en matière de prestation de soins devraient s'articuler sur des critères comme l'efficience, l'équité et la distribution et enfin, l'éthique. Le premier exprime la capacité du système à proposer ses services pour un maximum de satisfaction compte tenu des contraintes économiques, politiques et structurelles. L'efficience suppose aussi la recherche de nouvelles formes d'organisation sociosanitaire susceptibles d'améliorer la productivité des moyens de santé. Ceci suppose que l'amélioration des résultats en matière de santé implique que les gouvernements s'interrogent à savoir si l'accroissement des ressources fournies aux services de santé en général ne prive pas de ces mêmes ressources, d'autres programmes plus efficaces. Quant au deuxième, il résulte de la logique de répartition des ressources en santé selon l'origine (ethnique, de genre, d'âge, etc.) et les moyens des individus et englobe des aspects comme le respect de la dignité de la personne, la confidentialité, l'autonomie de l'individu, la rapidité et la qualité de la prise en charge et l'accès à des réseaux d'aide. En d'autres termes, les citoyens doivent avoir accès à un minimum incompressible de soins de santé, et le traitement ne doit pas être fonction uniquement du revenu mais plutôt des besoins réels de soins. De plus, il faut que les individus se voient offrir une certaine protection contre les conséquences financières de la maladie, et le paiement de cette protection doit être lié au revenu et non pas fondé sur le risque individuel. Enfin, la dimension éthique se rapporte au principe fondamental de justice sociale qui devrait caractériser tout système de santé.[25]

On ne peut nier aujourd'hui le fait que les questions liées au système de santé au Canada se sont rapidement intégrées dans une problématique économique, pour devenir elles-mêmes des catégories économiques, dans un contexte où le système est resté cantonné sur un modèle de gestion de l'offre caractérisé par l'absence de dispositif de régulation qui tienne compte d'une réalité en mouvance. Un ensemble complexe de facteurs cumulés a contribué à l'augmentation des dépenses en santé. Mais l'état actuel des connaissances ne permet pas de les identifier tous et d'en déterminer l'importance relative. Les prédictions démographiques estiment que d'ici 2031, l'arrivé des baby boomers ferait passer la proportion des 65 ans et plus de 13% à 22% du Canada.[26] Bien que plusieurs invoquent l'argument du vieillissement de la population pour justifier l'accroissement des dépenses en santé et l'urgence de nouvelles réformes, il semble que l'effet attendu du vieillissement de la population ne soit pas aussi dramatique. Les estimations réalisées par Oxley et MacFarlan[27] suggèrent que les effets liés au vieillissement, à l'augmentation des revenus et à l'extension de la couverture des assurances n'expliquent qu'une partie de la croissance globale des dépenses. Evan et al.[13] renchérissent en faisant remarquer que les prédictions sur le système de santé, faites à partir des données actuelles, ne sont pas fiables. En effet, selon les données de 1970, on aurait dû assister aujourd'hui à une augmentation importante du nombre de jours d'hospitalisation mais en réalité, on a assisté à une chute des hospitalisations des deux tiers. Il ne suffit donc pas de prendre les données actuelles et de les projeter dans l'avenir. On doit aussi prendre en considération l'évolution des habitudes de vie, les découvertes de traitements plus efficaces et la mise en place de nouvelles politiques. Dans les faits, il semble possible de contenir l'effet du vieillissement de la population par des interventions préventives, de meilleurs traitements, et une emphase plus importante sur la réadaptation.

Selon Zhihong et al.[28], les nouvelles technologies qui ont émergé depuis une vingtaine d'années sont en partie responsable de l'augmentation des coûts en santé. En particulier, les technologies reliées à l'imagerie médicale (MRI, CT/PET Scan) utilisées de plus en plus pour établir les diagnostics sont extrêmement coûteuses. En particulier, les technologies reliés à l'imagerie médicale (MRI, CT/PET Scan) utilisées de plus en plus pour établir les diagnostics sont extrêmement coûteuses. Même si la génétique humaine et les traitements qui en découlent sont prometteurs, ils se révèlent très coûteux. L'imperfection du marché qui caractérise les technologies médicales et le fait que les pouvoirs publics en soient les principaux acheteurs n'incite nullement les fournisseurs à être compétitifs et à en diminuer les coûts.[2] Mais il est indéniable que l'allongement de l'espérance de vie lié au vieillissement de la population et l'accroissement des nouvelles technologies ne suffisent pas à justifier une augmentation du financement du système de santé publique.[29] L'existence de ces technologies n'implique pas qu'il faille les utiliser à tout prix. S'il est admis que certaines innovations médicales peuvent contribuer à la réduction des coûts en permettant des traitements plus rapides et efficaces et en contribuant à l'amélioration de la productivité dans des domaines tels que la diminution des erreurs médicales, la réduction des soins non justifiés, mais aussi à l'amélioration de la qualité des soins de santé, d'autres technologies d'imagerie par exemple sont extrêmement dispendieuses.[30] Il incombe donc aux administrateurs de gérer l'utilisation des nouvelles technologies et de choisir celles qui sont à la fois abordables et indispensables. Les défis auxquels doit faire face le système de santé au Canada sont d'abord liés à une meilleure gestion de nos ressources.

La préoccupation économique et budgétaire des gouvernements pour une maîtrise des dépenses en santé souffre également à notre sens d'une faute de logique. En effet, il est peu probable que les citoyens qui sont couverts par une assurance maladie universelle qui leur garantit des soins plus ou moins accessibles, ainsi que le paiement ou le remboursement direct de la majeure partie leurs dépenses, décident volontairement de limiter leur consommation. Par ailleurs, à cette forte demande en soins de santé, répond une offre médicale et paramédicale en pleine expansion. Les professionnels de la santé se demandent logiquement pourquoi ils n'offriraient pas tous les services que réclament à la fois leurs clients, qui sont toujours solvables du fait de l'assurance dont ils disposent, et qu'exige le respect de leur éthique professionnelle devenue beaucoup trop élastique. Il n'est d'ailleurs guère surprenant de constater que les autorités publiques se heurtent à la fois à la résistance des malades et des professionnels à cet égard. En clair, même s'il est difficile de faire des projections de dépenses en matière de santé pour les gouvernements au Canada pour les vingt prochaines années, dans la mesure où certaines variables restent incertaines, les données dont on dispose actuellement suggèrent que l'importance des dépenses publiques en santé va croître, non seulement en niveau absolu, mais certainement aussi en proportion du revenu national.

En affinant notre analyse et en dépit du fait que les effets du vieillissement sur les dépenses en santé au Canada soient encore minimes, il convient de rappeler que la structure par âge de la population jouera un rôle déterminant à long terme, considérant le fait que la santé se dégrade avec l'âge et que les dernières années de l'existence sont celles où la demande de soins est la plus forte. Par ailleurs, des études réalisées aux États-Unis montrent que la majeure partie de l'augmentation des dépenses relatives aux groupes d'âge relativement élevé correspond à une utilisation plus importante des technologies coûteuses.[31]

Nous sommes d'avis qu'il est impérieux pour les gouvernements de chercher un meilleur équilibre entre les soins en régime hospitalier et les soins ambulatoires, étant donné que la technologie médicale facilite désormais le traitement des malades en dehors du cadre hospitalier. Il faut faire preuve d'ingéniosité et d'imagination afin de trouver des réponses alternatives qui ne passent pas nécessairement par une coupure dans les soins. En outre, les prestataires de soins de santé devront veiller à ce que les technologies médicales ne soient pas utilisées de façon abusive dans des domaines où les avantages marginaux sont faibles et les coûts élevés. C'est déjà par exemple le cas avec l'utilisation de la chimiothérapie au-delà d'un certain point. En même temps, il faut veiller aux effets pervers d'une telle démarche en évitant que ces technologies ne soient sous-utilisées dans les domaines où il est possible d'obtenir un bon rapport coût-efficacité, comme c'est le cas lorsque des thrombolytiques sont administrés suite à un infarctus. L'innovation dans les technologies de santé a été l'un des facteurs explicatifs de l'augmentation des dépenses observée dans le passé, et nous pensons que le moment est venu de soumettre celle-ci à un examen plus rigoureux et minutieux afin de faire des choix conséquents et éclairés afin que seules les technologies qui procurent des améliorations appréciables soient intégralement financées par les ressources des contribuables.

Le système canadien de santé s'est particulièrement détérioré au cours des dernières décennies et ce, en dépit de l'injection de milliards de dollars additionnels par les gouvernements. Cette situation amène à se demander si une augmentation des dépenses, comme le souhaitent diverses associations professionnelles et groupes de pression, suffirait à sortir le système de santé de son impasse. Il nous semble que d'autres changements sont requis, dans un contexte où la réduction des dépenses en santé s'est surtout faite par une forme implicite de rationalisation économique et par des mesures coercitives. Même si l'on fait le pari que des ressources financières supplémentaires sont nécessaires, il est illusoire de penser que les pouvoirs publics pourraient actuellement les combler. C'est pourquoi ceux-ci réfléchissent de plus en plus à la possibilité de nouer des partenariats entre secteur public et secteur privé afin de réduire la charge globale qui pèse sur les finances de l'État.

Les partenariats public-privé pour l'optimisation du système de santé : argument valable ou légende à déboulonner ?

L'augmentation croissante des dépenses en santé et les importants déficits publics engendrés au cours des dernières années poussent les gouvernements à envisager une rationalisation des dépenses en santé, à une époque où les besoins se font de plus en plus grands, et où les ressources, sont, de plus en plus limitées. La santé n'a peut-être pas de prix (logique d'efficacité), mais elle génère un coût (logique d'efficience) que les États ont de la difficulté à supporter, compte tenu des pressions financières qui pèsent sur eux. À cela, il faut ajouter qu'en dépit des avancées médicales, les services hospitaliers sont graduellement exposés à une baisse de la qualité des soins prodigués aux patients, à l'accroissement des erreurs médicales et à l'augmentation de la mortalité intra hospitalière. Depuis quelques années, les milieux politiques s'acharnent à limiter la croissance des coûts du système de santé. Plusieurs estiment que le passage de l'État providence à l'État stratège et régulateur doit s'imposer également dans le domaine de la santé. Le renforcement de la concurrence dans le secteur de la santé publique force les pouvoirs publics à étudier des alternatives en matière de financement et d'organisation. Les partenariats entre l'État et les prestataires privés ou partenariats public-privé (PPP) apparaissent dans ce cadre comme une forme de coopération intéressante parce qu'elles permettraient l'optimisation des ressources et la répartition efficace des risques, en plus d'accroître la capacité des États à maintenir une vue d'ensemble stratégique de la prestation des soins de santé dans un cadre responsable et viable.[32]

Nishtar[33] précise que lorsque l'on parle du secteur public, on réfère habituellement aux paliers fédéraux et provinciaux, aux administrateurs municipaux, et à toutes les agences gouvernementales ayant le mandat d'offrir un service public. Le terme privé quant à lui se subdivise en deux catégories : 1) à but lucratif, ce qui englobe les entreprises commerciales de toutes tailles et 2) à but non lucratif, c'est-à-dire les organisations non gouvernementales sans but lucratif. Deber[34] réussi à bien nous éclairer en ajoutant une importante nuance souvent oubliée lorsqu'on examine la question du public et du privé en santé. L'auteure propose de distinguer la question du financement (financing) de celle de l'offre de services (delivery). En combinant ainsi les dimensions public/privé et financement/offre de services, il est plus facile de mieux saisir la complexité des enjeux. Au Canada, le financement du système de santé est majoritairement public (70%) et se fait par le biais des différents paliers de gouvernements. Cependant, l'offre des services est majoritairement privée. Les services de santé ne sont donc pas directement dispensés par l'État. Lorsqu'on parle donc de partenariats public-privé en santé, il est toujours utile de préciser la dimension à laquelle l'on réfère.

Au cours des dernières années, le terme général ASD (Alternative Service Delivery) a été utilisé pour regrouper les options possibles des biens et services en matière de santé qui autrement, seraient exclusivement dispensés par le secteur public. Selon Bettignies et Ross[35], la sous-traitance, les contrats de services ou de gestion et même la privatisation pure et simple sont des concepts qui peuvent être regroupés sous la tutelle des ASD. Les partenariats public-privé sont en somme, l'évolution du principe de sous-traitance et ils impliquent habituellement le regroupement de responsabilités diverses par rapport à un même projet. Nikolic et Maikisch[36] explorent et définissent les différents types de PPP les plus fréquents dans le domaine de la santé que sont les contrats de services, les contrats de gestion, les contrats de construction, d'entretient et d'équipement, les contrats hybrides, les concessions, les initiatives des financements privé et la privatisation. Les contrats de services sont habituellement spécifiques et peuvent par exemple, toucher à un service comme les analyses de laboratoire ou les services alimentaires, et visent à profiter de l'expertise et l'expérience du privé pour améliorer la qualité et l'efficacité des services. Quant aux contrats de gestion, ils supposent un transfert de l'autorité administrative vers le privé, ce qui suppose que le privé a l'autorité et la responsabilité complète en matière de gestion, ce qui inclut la gestion des ressources humaines et financières. Les contrats de construction, d'entretient et d'équipement sont davantage courants et sont établis pour le développement, la revitalisation ou l'entretient des infrastructures des soins de santé.

Les contrats hybrides constituent pour leur part une combinaison des différents contrats mentionnés précédemment afin de répondre à un besoin ou à une situation particulière. Dans les contrats de type concessions, l'État demeure propriétaire de l'établissement mais le secteur privé s'occupe de l'opérer et l'entretenir. Ici, le privé assume aussi les nouveaux investissements. De manière générale, les concessions transfèrent la majorité du risque de l'investissement vers le secteur privé. Toutefois, le gouvernement fournit souvent une garantie de protection au partenaire privé dans le cas de revenus plus faibles que prévus. Quant aux initiatives de financement privé, ils constituent des contrats de concessions qui comportent un investissement relativement important de capital de la part du privé dans les soins de la santé.

Les partenariats public-privé ont fait et continuent encore de faire l'objet de vives controverses, de débats acrimonieux et de contestations dans de nombreux pays entre partisans et opposants. Aux critiques acerbes des milieux syndicaux et de certaines organisations professionnelles, il faut également ajouter les réticences des milieux universitaires et même de certains professionnels de la santé qui doutent à la fois du pragmatisme, du réalisme et de l'efficacité de cette approche.

À contrario, les partisans des PPP allèguent que cette avenue est bénéfique d'autant plus que les PPP permettraient de réaliser des économies d'échelle pouvant aller de 15 à 25%, ce qui paraît substantiel et non négligeable dans le contexte économique actuel.[37] Mais au-delà des considérations idéologiques et des questions mathématiques, il nous apparaît nécessaire de faire évoluer le débat actuel sur les partenariats public-privé en santé en dépolarisant ceux-ci de leurs courants idéologiques et de leurs considérations dogmatiques et paradigmatiques. D'un point de vue strictement économique, les travaux de Bettignies et Ross[35] dressent une liste intéressante des avantages possibles des partenariats public-privés en santé. L'argument principal, c'est que la mise en concurrence des fournisseurs de soins de santé permettrait de réduire les coûts et d'augmenter la qualité. Si certains avantages présumés de ces partenariats sont discutables, il faut néanmoins admettre comme le soulignent les auteurs que la qualité d'un système de santé n'exige d'aucune façon que la prestation des soins soit impérativement assurée par un monopole public.

Ceci dit, les partenariats public-privés ne sont pas toujours synonymes d'économies. Dans leur étude sur les expériences de plusieurs pays sur ces partenariats en santé, McKee et al. [38] affirment que la construction de nouvelles infrastructures sanitaires fût généralement plus dispendieuse. Les auteurs ajoutent que des dépenses additionnelles sont ultérieurement assumées par l'État en raison du non respect des contrats par le partenaire privé. La réalité, c'est que le chemin qui mène vers des partenariats réussis en santé peut être long et parsemé d'embuches. L'introduction de mécanismes peut faciliter dans une certaine mesure l'ajustement de l'offre à la demande sanitaire en permettant la réduction des coûts et l'apport de ressources additionnelles. Le succès des partenariats public privé est intrinsèquement lié à la perspicacité de l'appareil public et à la capacité de l'État à prévenir les abus et superviser de façon compétente et rigoureuse, les activités du partenaire privé. Les expériences étrangères en la matière constituent une source importante d'information. Mais une grande prudence est de mise car un succès à l'étranger n'est pas garant d'un succès au Canada. En effet, les mœurs et coutumes, la situation économique et sociale, le climat politique et l'histoire de chaque pays influencent grandement la réussite ou l'échec de réformes. Les travaux menés par Zhihong [28] dans divers pays de l'OCDE permettent de faire les constats suivants : 1) un système de santé mixte (public-privé) n'affecte pas négativement les soins de santé dans ces pays. En effet, un système de santé peut être public et universel sans pour autant que les soins soient quasi-exclusivement fournis par des établissements du secteur public. La France dans ce cas précis en est l'exemple le plus édifiant; 2) en incitant les établissements de santé à chercher constamment à améliorer la qualité de leurs services et à se démarquer des concurrents, les pouvoirs publics les encouragent ainsi à innover et à réduire les coûts du système.

Au-delà de ce qui précède, il faut souligner que les partenariats public-privés en santé sont loin d'avoir fait leur preuve et il y a lieu de se demander si l'on peut aujourd'hui, de façon réaliste, appuyer une réforme du système de santé au Canada avec des hypothèses aussi difficiles à vérifier. Il n'est pas inutile de se demander si système de soins taraudé par une logique économique marchande et des décisions en matière d'affectation et de répartition des ressources peuvent-elle reposer sur l'unique critère d'efficience.[22] À cela, il faut ajouter que le financement privé des services médicaux, loin de renforcer le système public en « libérant » du temps et des ressources et en réduisant les listes d'attente, contribue à le dévaloriser sans compter que la mise en œuvre de régimes à financement mixte entraîne une gestion et une comptabilité lourdes. En outre, en matière de financement et prestation de soins, Higgins[39] soutient que l'implication du privé conduit souvent à une surprestation de services et à la suppression de certains programmes de prévention, non rentables (santé communautaire, sida, réadaptation et autres). Quoi qu'il en soit, il semble que les soins de santé ne peuvent être comparés dans une perspective purement économique, à des biens usuels de consommation car ils échappent aux lois du marché. S'il est indéniable que le système de soins de santé au Canada a longtemps fonctionné comme un « système ouvert » et que la perversion des incitations à la consommation médicale devient un objet d'inquiétudes, les abus en la matière ne représentent qu'un infirme pourcentage et il semble a priori difficile voire impossible de limiter la consommation médicales par des mesures exclusivement financières.[40,41,42].

La prestation privée des services de santé n'a de sens que dans la mesure où l'État peut en contrôler le rendement et imposer des critères de qualité. Or, un tel contrôle se révèle souvent coûteux et nombre de services de santé sont trop complexes pour être soumis à une telle surveillance. Les études économiques de l'OCDE[43,44] ont récemment démontré que la part des gouvernements en assurances comme en prestations exerçait une influence négative sur le niveau des dépenses. En d'autres termes, plus la santé est étatisée, moins les citoyens consomment de soins, ce qui tranche radicalement avec certaines idées véhiculées par plusieurs intervenants dans le débat. Les États-Unis représentent le pays qui dépense le plus en proportion de son revenu per capita et où la part du secteur privé est la plus élevée. Inversement, l'Angleterre à une époque était le pays qui dépensait le moins grâce à la National Health Service (NHS). Ce système de santé est financé par les deniers publics et fournit la majorité des soins de santé, comme les soins de premier recours, les soins ambulatoires, les soins de santé relatifs aux affections de longue durée, l'ophtalmologie et les soins dentaires. Cette comparaison suggère que le développement de régimes privés d'assurance maladie peut augmenter les dépenses totales de santé, sans nécessairement alléger la charge publique.

En matière de prestation directe de services, les données empiriques ne permettent pas non plus de conclure que des partenariats avec le secteur privé permettraient d'améliorer hors de tout doute la qualité de service et de réduire les listes d'attente. L'engorgement des services de santé et les listes d'attente ont souvent été cités au Canada comme la démonstration de l'inefficacité du système de santé public. Les citoyens et professionnels de santé qui connaissent ces frustrations pensent, à tort ou à raison que le secteur privé pourrait être un remède. Hughes et al.[45] rapportent que les pays ayant fait recours au financement privé pour les systèmes de services de santé publics, ont tout de même enregistré des temps d'attente très longs, comparativement à ceux où le système de santé bénéficie d'un financement public.[45] De plus, Duckett[46] dans une étude en Australie a démontré qu'à l'intérieur d'un même pays, les temps d'attente dans les hôpitaux privés sont plus importants dans les régions ou l'on dispense, en parallèle, davantage des soins de santé privés. Il semble que le phénomène s'applique aussi dans une certaine mesure à l'Angleterre selon les travaux de Besley et al.[47] Plus près de nous, dans la province canadienne du Manitoba, DeCoster et al.[48] ont réalisé qu'alors que les patients qui doivent débourser des frais supplémentaires afin de subir une chirurgie de la cataracte au privé, ceux-ci devraient attendre 26 semaines alors que le temps d'attente dans le système n'était que de 10 semaines. Enfin, les études américaines montrent que les patients qui bénéficient de soins auprès d'établissements privés de santé sont exposés à un risque accru de mortalité que ceux qui fréquentent les établissements publics traditionnels.

On peut a priori considérer que les exemples qui précèdent comme anecdotiques. En dépit du fait qu'ils sont loin de traduire à eux seuls, la quintessence du rôle du secteur privé dans le financement et la prestation des soins de santé et que les expériences étrangères méritent d'être prises pour ce qu'elles valent en raison des différences entre les systèmes de santé en matière d'acquisition, de financement et de prestation des soins, nous estimons qu'ils méritent tout de même d'être pris au sérieux. Il semble aujourd'hui difficile de donner une réponse claire et sans équivoque aux questions sur la réforme du système de santé. Une implication plus grande non contrôlée et mal maîtrisée du secteur privé dans le système de santé au Canada n'est pas une panacée et peut se révéler une incongruité dont les effets pourraient être néfastes sur l'accessibilité et la qualité des soins aux populations. En même temps, nous sommes d'avis que le privé a et aura un rôle à jouer aux côtés du secteur public dans la fourniture, la construction d'infrastructures de santé, et le financement et la gestion des soins de santé. Mais c'est faire preuve de témérité que de préconiser un modèle de rôle que devra jouer le privé dans un système public de santé. Celui-ci, nous le présumons, est fonction des valeurs, des choix de société, de l'expérience et de la réalité propres à chaque pays.

De nombreuses questions restent encore en suspens et on peut se demander à quels principes socio-économiques, politiques et réglementaires un système public-privé de financement et de prestation de soins de santé pourrait se conformer. Des recherches approfondies sont nécessaires afin de mieux éclairer les gouvernements sur une meilleure optimisation des ressources en santé et sur les façons dont le secteur privé pourrait mieux compléter le système de santé public. Mais au-delà du débat public-privé, l'enjeu véritable pour le système canadien de santé en est un de gestion et de réorganisation. Le défi des pouvoirs public aujourd'hui est d'utiliser de façon optimale les moyens d'une bonne gouvernance, afin de façonner un système de santé qui respecte, dans la mesure du possible, les préférences individuelles et les besoins des usagers. La question du financement est donc essentielle, mais insuffisante. D'autres aspects comme la continuité, l'intégration, et la coordination des services de soins de santé sont à considérer.

Conclusion

Depuis quelques années, le système de santé canadien est soumis à des forces de changement à la fois rampantes et soudaines qui suscitent chaque fois des débats enflammés certes, mais peu de bouleversements véritables. Ici comme ailleurs, les coûts de la santé explosent et professionnels, administrateurs et citoyens sont montrés du doigt. Quant au pouvoir politique, il semble démuni face à l'ampleur de la crise et n'a trouvé dans son arsenal que des outils issus du compliqué qui préconisent une rationalisation économique à l'emporte-pièce. Les questions liées à l'organisation de ce système occupent de plus en plus l'avant-scène et il faut s'attendre à ce que les effets conjoints du développement de nouvelles techniques médicales et du vieillissement de la population aboutissent à une progression des dépenses de santé qui soit plus importante que celle de la richesse produite. Lorsqu'on cherche à rendre compte du dynamisme des dépenses de santé, les innovations techniques apparaissent comme le principal facteur de hausse du coût de la santé, loin devant la démographie. Deux phénomènes s'opposent : d'une part, comme dans le reste de l'économie, le développement des technologies médicales permet de réaliser des économies d'échelles; d'autre part, il autorise des traitements qui n'auraient pas été possibles auparavant, engendrant ainsi des coûts supplémentaires.

Ces constats commandent une réforme ambitieuse. En dépit de la relative unanimité sur l'urgence des réformes par la majorité des observateurs, leur nature et leur contenu restent encore imprécis. Si l'économie canadienne a longtemps brillé grâce à certains de ses aspects (fonctionnement des marchés des biens et du travail, capacité d'innovation, etc.), son système de santé présente en revanche des insuffisances sérieuses. Bien plus coûteux que ceux d'autres pays comparables, il ne semble pour autant pas plus efficient que la moyenne et le niveau record atteint par les dépenses en santé rend les défis et les enjeux d'autant plus cruciaux et délicats. L'appel à une plus grande place au secteur privé au chapitre du financement, de la prestation des services et de la gouvernance du système de santé ne résiste pas encore suffisamment aux évidences scientifiques. Ceci ne signifie pour autant pas qu'il n'y a pas un rôle que le secteur privé peut jouer dans notre système de soins de santé.[49] Il est possible que les défis liés à la conjoncture actuelle puissent trouver en partie des solutions dans le cadre d'un système public. Toutefois, l'expérience montre que les gouvernements ne devraient pas avoir peur d'explorer les avenues offertes par un système mixte en mettant en place des balises claires sur la place du privé, une réglementation appropriée, des garanties de soins pour les patients quels que soient leurs revenus et la pérennité du système public.

Au cours des dernières années, les gouvernements se sont donnés comme objectif de bâtir un système de santé qui protège la santé des individus tout au long de leur vie et de réduire l'incidence des principales maladies et des principaux traumatismes qui en résultent. Si ces efforts ont indéniablement porté fruit en ce sens qu'ils ont jadis été utiles pour résoudre des problèmes de santé, le modèle sanitaire qui est le nôtre se révèle aujourd'hui incapable de faire face aux actuels bouleversements culturels, sociaux, démographiques et épidémiques qui sont ceux de notre époque. Il semble aujourd'hui difficile de changer les habitudes des uns et les intérêts acquis des autres : les médecins font de leur autonomie et de leur spécialité, l'alpha et l'oméga de leurs pratiques; la fonction du médicament comme seule garantie de la santé s'étend; les administrateurs du système semblent animés par une logique budgétaire qui l'emporte sur une gestion économique et médicale; l'hôpital et la médecine curative monopolisent le système de santé et l'équation médecine = santé est la seule considérée par la classe politique et les faiseurs d'opinions. Le développement des technosciences et la forte intervention médicale qui caractérisent nos sociétés contemporaines se sont doublés d'un changement paradigmatique quant à leur objet. D'une médecine qui se voulait sociale et collective et qui misait sur une approche écologique de la santé grâce à la prise en compte de ses principaux déterminants, nous sommes passés à une nouvelle définition de la santé comme supercatégorie normative et qui est principalement centrée sur une idéologie de la guérison au détriment de la promotion sanitaire et qui trop souvent échoue, en dépit des discours prometteurs, à prendre en considération les facteurs non médicaux qui ont des répercussions sur le bien-être des individus.

Dans un contexte où de nombreux pays s'enfoncent dans le désert sanitaire et que nombre de professionnels de santé se détournent du système[50], il est impératif de trouver le meilleur équilibre entre contraintes budgétaires et soins à la population, dans un esprit de responsabilité, sans défendre l'indéfendable et sans restructurer nos systèmes de santé à l'aveuglette. Certaines tentatives de réformes à la hache semblent aujourd'hui menées avec beaucoup d'amateurisme technocratique et bureaucratique, une concertation de façade, et un discours sur la responsabilité fiscale qui, au nom du mieux, fait souvent le mal.

Références

1.Hawe P, Shiell A. Social capital and health promotion. Soc Sci Med. 2000;51(6):871-85.

2.Commission on the Future of Health Care in Canada. Building on values: the future of health care in Canada. Saskatoon, Sask.: The Commission, 2002.

3.Baxter D, Ramlo A. Healthy choices: demographic and health spending in Canada 1980-2035. Report 26, July.

Vancouver: The Urban Futures Institute, 1998.

4.MacKinnon JC. The arithmetic of healthcare. Canadian Medical Association Journal 2004;171:603-4.

5.Cutler DM, Rosen AB, Vijan S. The value of medical spending in the United States, 1960–2000. New England Journal of Medicine 2006;355:920-7.

6.Yach D, Bettcher D. The globalization of public health: threats and opportunities. American Journal of Public Health 1998;88:735-8.

7.Jones AM, Rice N, Basho d'Uva T, Balia S. Applied health economics. London: Routledge, 2007.

8.Kielhorn A, Graf von der Schulenberg JM. The health economics handbook (2nd Ed.) Chester: Adis International, 2000.

9.Angus DE, Begin M. Governance in health care: dysfunctions and challenges. Transactions of the Royal Society of Canada 2000;VI(X).

10.Tuohy CJ. Accidental logics: the dynamics of change in the health care arena in the United States, Britain and Canada. Oxford University Press, 1999.

11.OECD. OECD health data 2007. Paris: OECD, 2007.

12.Cremieux PYP, Ouellette P, Pilon C. Health care spending as determinants of health outcomes. Health Economics 1999;8(7):627–39.

13.Evans RG, McGrail KM, Morgan SG, Barer ML, Hertzman C. Apocalypse no : population aging and the future of health care systems. Canadian Journal of Aging 2001;20:160-91.

14.Hébert R, Dubuc N, Buteau M, Desrosiers J, Bravo G, Trottier L et al. Resources and costs associated with disabilities of elderly people living at home and in institutions. Canadian Journal of Aging 2001;20(1):1-22.

15.Imbeau L, Chenard K, Dudas A. Les conditions de la viabilité d'un système public de santé au Canada. Étude no 11, mémoire présenté à la Commission sur l'avenir des soins de santé au Canada, 2002.

16.Gauld RDC. Big Bang and the policy prescription: health care meets the market in New Zealand. Journal of Health Politics, Policy and Law 2000;25(5):815-44

17.Lisac M. Health care reform in Germany: not the big bang. Health Policy Monitor 2006; Available from URL: http://www.hpm.org/survey/de/b8/2. Accessed 15 May 2009.

18.Wilensky G. Incremental health system reform: where medicare fits in. Health Affairs 1995;14(1):173-81.

19.Aaron HJ, Reischauer RD. The medicare reform debate: what is the next step? Health Affairs 1995;14(4):8-30.

20.Canadian Institute for Health Information. Waiting for health care in Canada: what we know and what we don't know. Ottawa: 2006.

21.Health and Welfare Canada. Canada Health Act. Ottawa: Government of Canada, 1984.

22.Deber R. Getting what we pay for: myths and realities about financing Canada's health care system. Health Law in Canada 2000;21(2):9-56.

23.Naylor CD. Health care in Canada: incrementalism under fiscal duress. Health Affairs 1999;18(3):9-26.

24.Sting M, Wilson D. Efficiency versus wquality: health reform in Canada. Fernwood Publishing, Halifax, and Regional Centre for Health Promotion and Community Studies, University of Lethbridge, 1996.

25.Aday LA. Equity, accessibility, and ethical issues: is the U.S. health care reform debate asking the right questions. American Behavioral Scientist 1993; 36(6),724-40.

26.Hebert R. The big boom: what CIHR's Canadian longitudinal study on aging means to the baby boomer. Healthcare Quarterly 2003;6(3):19-20.

27.Oxley H, MacFarlan M. Health care reform: controlling spending and increasing efficiency. OECD Working Paper Series: Economics Department: 149. Paris: OECD, 1994.

28.Zhihong K, Fulford J, Park DE. Reforming the Canadian healthcare system. A Report by the Vancouver Board Trade. May 2006.

29.Donaldson C, Mitton C, Currie G. Managing medicare: the prerequisite to spending or reform. CD Howe Institute Commentary 2002; 157:1-21.

30.Weisbrod B. Healthcare quadrilemma : an essay on technological change, insurance, quality of care and cost containment. Journal of Economic Literature 1991;XXIX.

31.Himmelstein DU, Woolhander S. National health insurance or incremental reform: aim high, or at our feet? American Journal of Public Health 2003; 93:102-5.

32.Reich MR. Public-private partnerships for public health. Nat Med. 2000;6:617-20.

33.Nishtar S. Public-private partnerships in health – a global call to action. Health Res Policy Syst. 2004;2:5.

34.Deber R. Delivering health care services: public, not-for-profit, or private? Discussion Paper No. 17, Commission on the Future of Health Care in Canada, August 2002.

35.Bettignies JE, Ross TW. The economics of public-private partnerships. Canadian Public Policy 2004;(30):135-54.

36.Nikolic IA, Maikisch H. Public-private partnerships and collaboration in the health sector: an overview with case studies from recent European experience. Health, Nutrition and Population (HNP) Discussion Paper. October 2006.

37.Jütting J. Public-private-partnership and social protection in developing countries: the case of the health sector. Paper presented at the ILO workshop on the extension of social protection, Geneva, 1999.

38.McKee M, Edwards N, Atun R. Public-private partnerships for hospitals. Bulletin of the World Health Organization 2006;84(11):890-6.

39.Higgins J. The business of medicine: private health care in Britain, Londres: Macmillan Education Ltd, 1988.

40.Sloan FA. Not- for-profit ownership and hospital behavior. In: Anthony JC, Newhouse JP (eds). Handbook of Health Economics, Amsterdam: Elsevier Science, 2000;1141-1174.

41.Donaldson C, Currie G. The public purchase of private surgical services: a systematic review of the evidence on efficiency and equity. Institute of Health Economics, 2000, Working Paper, n° 00-9.

42.Rosa JJ. Les dépenses de santé doivent augmenter. Le diagnostic d’excès de consommation qui sert à justifier le rationnement administratif des soins n’est pas fondé. Le Figaro économie, vendredi 2 mars 2001.

43.OCDE. Les systèmes de santé des pays de l’OCDE. Faits et tendances 1960-1991. Études de politiques de santé 1993;3.

44.OCDE. La réforme des systèmes de santé : étude de dix-sept pays de l’OCDE. Études de politiques de santé 1994;5.

45.Tuohy CH, Flood CM, Stabile M. How does private financing affect public health care systems? marshalling the evidence from OECD nations. Journal of Health Politics, Policy and Law 2004;29(3):359-96.

46.Duckett SJ. Private care and public waiting. Australian Health Review 2005;29(1):87-93.

47.Besley T, Hall J, Preston I. Public and private health insurance in the UK. European Economic Review 1998;42(3-5):491-7.

48.De Coster C , MacWilliam L, Walld R. Waiting times for surgery: 1997/98 and 1998/99 Update. Manitoba Centre for Health Policy, 2000.

49.Currie G , Donaldson C, Lu M. What does Canada profit from the for-profit debate in health care?” Canadian Public Policy 2003;29(2):227-51.

50.Egger D, Lipson D, Orvill D. Achieving the right balance: The role of policy-making processes in managing human resources for health problems. Discussion Paper no 2 Under Issues in Health Services Delivery (Human Resources for Health). Geneva: World Health Organization, 2000.

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