The Meaning Management Challenge: Making Sense of Health, Illness, and Disease

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The Meaning Management Challenge
Making Sense of Health, Illness & Disease

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Making Sense Of:
‘Health, Illness and Disease’
The Meaning Management Challenge:  
Making Sense of Health, Illness and Disease

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Zhenyi Li and Thomas Lawrence Long

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Making Sense of Health, Illness and Disease: The Meaning Management Challenge

Zhenyi Li and Thomas Lawrence Long

Health care is a social process where the meanings of health, illness and disease are negotiated among individuals and within communities. Their common task is to manage a dialogue on the meaning of a problem or diagnosis in order to agree on what to do about it. Meanings of health, illness and disease have been assigned by each culture and each member of that culture. Nothing appears more difficult in this globalising millennium when there are greater chances that care givers, receivers, and governing bodies from different cultures have to interact and collaborate more frequently and closely. Notions related to health, illness and disease that make sense to one group of people may frustrate another group due to the differences between their cultures.

Such a challenge can be overcome by proper meaning management, a process that can effectively and appropriately help each party in health care interact to collaborate with each other. In other words, people have been looking for a system that makes sense of health to everyone. Health science, a possible hope that can unify terms, concepts, and communication, has been proposed as the Esperanto to bridge the gaps and overcome the cultural incongruence in health care. But does it work this way or not? Why and how can it succeed or fail? In the summer of 2009, scholars from various disciplines and from around the globe met to explore their viewpoints in the 8th Global Conference: Making Sense of Health, Illness and Disease at Mansfield College, University of Oxford, in England, hosted by Inter-Disciplinary.Net. Versions of their peer-reviewed chapters are collected here.

The chapters in this collection, representing the multidisciplinary character of the conference, provide a careful exposition on health, illness, and disease from disciplines that are sometimes neglected or dismissed by so-called pure science or medical research. Each chapter, from its unique disciplinary and cultural perspective, reminds us of the necessity to be aware of the limitations of medical science, the danger of theoretical binarisms, the impact of political and economical agendas on health care institutionalisation, and the indispensability of continuous conversations with people from different disciplines, professions, organisations, institutions, and cultures. All of the eleven chapters, in general, point to the same issue: the meaning management of health, illness and disease, involves a socio-cultural course of action in which the right of each participant to make sense of health, illness and disease should be respected, and humility in modern biomedical sciences toward diversity ought to be emphasized.
In the first section of this book, four chapters identify health care as a socio-cultural process, which cannot be simply viewed as a ‘pure’ scientific task. Examples of health disparities, particularly racial discrimination studied by Marguerite Cognet, Emilie Adam-Vezina, and Sandra Bascougnano (‘Discrimination in Health Care Services’), reveal that immigrants and minorities receive different treatments due to their ‘ethnic’ or ‘racial’ basis. They find that the so-called ‘pure’ and ‘objective’ sciences of health care or medicine often produce unequal treatments to different patients because Western medical practitioners tend to stereotype visible minorities according to their skin colours, family origins, social status, and other factors that differentiate them from the majority. Therefore, it is obvious that health care practice, where interpersonal interactions between care provider and receiver are inevitable, is socio-culturally bound.

Just as immigrants may come into conflict when they are transplanted onto Western soil, Western models of health care provision do not export readily to other lands, despite the West’s best intentions. In the case of Rwanda, as David MacDonald Matthews reminds us in ‘Global Rhetoric, Local Actors: Community Health Workers and the Concept of Participation in Rwanda,’ local community health workers must negotiate between the Western biomedical interventions that they have been trained to advocate and the indigenous traditional healing practices. In this setting they also face another obstacle: the Rwandan government’s refusal to provide regular funding for compensation. Originally imagined as having clear advantages of training, political prestige, and economic opportunities, Rwandan community health workers have found themselves without compensation for the significant time commitment that their work entails. Matthews points out that in the process of making sense of health, illness and disease, the participants are not simply physicians and patients. Government, advocates, funding institutions, as well as international laws and regulations are often influential and many times decisive.

Health care disparities do not only take place far away. Resources are also problematic in Western rural communities that are isolated from the dominant industrialized or suburban communities. Julie Son, Shevon Harvey, and Kim Shinew examine this problem in ‘Rural Community Leaders’ Perceptions of ‘Health’ Leisure: Resources, Needs and Constraints.’ This analysis of interviews with leaders from diverse organizations in an impoverished, racially diverse rural community discloses a considerable local understanding of the need for health promotion education, chronic illness prevention, and leisure opportunities for youth. However, the participants also identified fiscal and cultural constraints on health programs, including a lack of infrastructure, of low-cost leisure, and of culturally-informed programs. Industrialized food production has made an unhealthy diet (high in fats, sodium and sugars) the least expensive and the most appealing to
communities living in poverty. Racial or ethnic communities likewise may reinforce less nutritious eating by cultural food-ways that are unhealthy.

Intercultural health communication studies remind us that every culture constructs health beliefs (including theories of disease) and health systems, which in the case of Western medical science often places the empiricist physician at odds with patients’ cultural values and beliefs. As Zhenyi Li reports in ‘‘Their Natures are Similar, Their Habits Make Them Different’: the Cross-cultural Challenges for Chronic Disease Primary Prevention in Canada and the World’ disease prevention and health promotion programs originally designed for a Euro-American population may not produce the same outcomes in Asian or Asian-immigrant cultures. Based on three research projects that focused on cross-cultural distinctions among East Indian-Canadian, Chinese-Canadian, and Mainland Chinese populations, Li argues that people still have different attitudes and behaviours due to their cultural differences when they share and agree on similar ‘biomedical’ knowledge related to chronic disease. Hence, primary prevention, which looks like a simple health promotion procedure, cannot be standardized when less or no consideration has been paid to different cultural values.

Nevertheless, a question remains: if socio-cultural factors are so obviously critical to health care, how do people and organizations collectively neglect or degrade them? The struggle of power in discourse, the ‘secret’ behind the ‘victory’ achieved by modern Western medicine, and the political and economical hidden agenda are illustrated in four chapters in Section Two of this book.

In modern discourse, medicine has been metaphorically narrated in military terms according to Abraham Fuks. In 'The Military Metaphors of Modern Medicine' Fuks examines the ways in which the healing arts have been likened to warfare, with the result that the patient becomes a body that becomes a battlefield for a reified disease process. In addition to the success of medical rhetoric, fear of losing health, anticipation for professional intervention, and logic of conflict resolution have narrowed people’s focus to modern medicine, as if it is the only possibility, the only power, and the only hope to conquer disease and illness.

Reviewing recent online forums devoted to self-injury behaviours and its members, Brossard in his ‘Construction of a Non-medical Point of View Regarding Medicine and Health: An Example of Self-injury Internet Forums’ describes how modern medical science powerfully marginalized and muted individuals living with self-injury behaviours. In general, Brossard argues that self-injury was systematically defined as a ‘mental disorder’ and set up as a ‘taboo’ in social life so that the identity of ‘self-mutilation’ for the members and community, the power of self-definition for their behaviours, and the possibilities to acknowledge subtle diversity in the community were
suppressed until the Internet provided them forums to express their viewpoints.

Archie Graham in ‘Ethics and Cultural Politics in the Debate Between Scientific Medicine and Alternative Health Practices’ illustrates such suppression from his own experience as a patient. He points out that treatment of diseases based on bio-medical, mechanical micro-based approaches, which represent themselves as neutral and equal in every person, has systematically marginalized and denied the ‘other’ therapies practiced in many cultures for centuries. Again, this form of cultural dominance evinces a struggle for power rather than a truly caring heart for people with diseases. Health care, in fact, cannot be industrialized since each person experiences health and disease differently. The dogmatic vocabulary of dismissal of alternative practices as ‘unscientific’ or ‘superstitious’ constitutes a ‘victory’ of modern medicine through wide and institutionalised recognition of its legitimacy, power, and monopoly of making sense on health, illness and disease.

Sandip Talukdar, in his ‘Assessment of Capacity, the Person, and Ethical Questions’, questions the assessment of patients’ capacity and consent in the subsequent enforcement of the Mental Capacity Act 2005 in Britain. Capacity assessment, according to Talukdar, is debatable so that the extent of governmental intervention and institutionalisation are dubious. Without a wide consultation and respect to individuality, how can legislation such as the Mental Capacity Act in UK be enforced? It is again the struggle of power that one day may take over our own decision-making capacity when caring of our own health. In other words, the right to make sense of health, illness and disease, which should belong to each individual, can be deprived systematically when modern medicine controls the power of discourse, organisations like hospital and caring facilities institutionalise the practices, and government applies its legislation power, as well as businesses such as pharmaceutical and insurance industry lobby to set up hidden political and economical agendas.

The third section of this book includes chapters proposing approaches of resolving such a bias to return to the people the right of making sense of health, illness and disease.

Larisa Kruglova, in her ‘Integrative Approach for Estimation and Correction of Human Psychophysiological State’, argues that treatment should be individualized based on research findings on physio-therapeutic studies. It is not proper to group people with similar physical conditions by neglecting the needs for individual-oriented health care, Kruglova argues. However, the integrative approach proposed in her chapter is not denying modern medicine. In fact, it recognizes the advancement of medical sciences and incorporates medicamentous therapy that focuses on physical factors, with psychotherapeutic practices that emphasize individuality.
In ‘Cracking Up and Back Again: Transformation through Music and Poetry,’ Diane Leslie Kaufman and Karen Deborah Goodman introduce the use of poetry therapy and music therapy as approaches to healing. Creative arts therapies, with evidence-based positive outcomes, enhance group cohesion, benefit individuals to escape from past burden and fear, and cure broken souls. In other words, these therapies help individuals regain the power of making sense of health, illness, and disease with support from a group and its facilitators instead of from medication. Poems and songs, which seem to be long forgotten ‘medicines’, are created by people for their wellness, happiness, and togetherness. These, along with many other creative arts, shall be continuously remembered and used for individuals and groups to make sense of health, illness, and disease.

Joel Minion, Peter Bath, and Kendra Albright examine in ‘From Sponge to Source: Health Information in the Lives of Gay Men Living with HIV’ how configurations of sexual orientation can likewise construct a distinct cultural identity. This qualitative study analyses the stages of self-education among a sample of gay men, from the point when they first learned that they were HIV-positive to later stages in their management of HIV. The development of the gay men’s information practices parallels the distinction between disease-as-pathology and illness-as-experience models, with an early limited period when the men ‘soaked up’ biomedical knowledge about the virus and treatment options before moving into the long-term phase of living with and managing HIV infection from day to day. Physicians provided critical information in the shorter initial stage, while HIV support agencies and organizations served as sources of knowledge for the management phase. In that second phase, the study participants came to a greater degree of self-efficacy and came to understand themselves as sources of information for others, not merely consumers of others’ information. Again, the research findings suggest that the return to individuals from institutions of a right to sense making can achieve productive meaning management.

HIV is also the landscape for contention among competing and dissenting views of epidemiology, health practices, and cultural representation, which Thomas Lawrence Long explores in ‘AIDS and the Paradigms of Dissent.’ Although health care standards are based on a negotiation of consent or consensus, a paradigm of scientific knowledge (to use Thomas Kuhn’s terms), the scientific revolutions in virology, immunology, and HIV/AIDS exemplify both consent and dissent. Early in the 1980s, a medical consensus coalesced around a viral agent (HIV) as the cause of AIDS, which led to a health practices consensus formed around a binarism of ‘safe’ and ‘unsafe’ sex practices. A social consensus eventually developed around a meaning of the HIV-infected as the sentimentalised victims of disease. However, the emergence of two opposing political and social ideologies in the United States in the 1980s, the Religious Right and
the gay rights movement, delineated a discursive field in which competing representations of the medical and social meanings of the disease were contested.

In conclusion, these eleven chapters help readers to revisit the meaning management of health, illness, and disease from a socio-cultural perspective, to critically analyse the power struggles of medicine, and to suggest a contextual approach to achieve a more effective and appropriate communication among participants in health care. As Fuks points out, fairly frequently in modern medical practices, lost is the person of the patient and lost is the voice of the patient, who becomes merely a passive landscape on which the physician launches a campaign. However, this book reveals the fact that making sense of health, illness and disease is fundamentally a socio-cultural course of action, that every participant has the right to make sense, and humility in modern biomedical practice should be emphasized.

Two brief notes are worth adding here as we became aware of them during the editing process of this book. First, the victory of modern biomedical practice has dominated our way of thinking about and perceiving health, illness, and disease to a great extent. Illness and disease, for example, are not real when we cannot ‘name’ them without proper ‘medical’ terms, formally known as diagnosis and prognosis. Symptoms become not curable when we cannot ‘assign’ the meaning of a treatment to a term recognised in medicine. Likewise, therapies become suspect when we cannot find them in the biomedical realm. There is an urgency to (re)establish a common vocabulary for participants in health care, literally every person in this world, so that themes, perspectives and approaches discussed and suggested in this book can be realized and practised. Without such a reestablishment, the modern medical bias can dominate and block the meaning management and exchange.

Second, although the dimension of time is not highlighted in any of the chapters, it is crucial in making sense of health, illness, and disease. When our editing work was delayed, we started to notice anxiety, questions, and uneasiness in the process of meaning management of this project. We all hoped that our viewpoints might have been seen sooner, our voices been heard more quickly, and our scholarly well-being been attended to in a more timely fashion! This reminds us that in health care practice, time is an essential factor that influences the quality, satisfaction, and efficiency of meaning management between participants. The editors apologize for the delay in publication, although we found it ‘makes sense’ because the dimension of time might have been included in this book, and the ‘therapy’ of editing often takes more time than anticipated. So ought it to be emphasized in the process of making sense of health, illness, and disease.

This fine collection of articles, we hope you will agree, has been worth the wait.
Section 1

The Socio-cultural Perspective
Discrimination in Health Care Services

Marguerite Cognet, Emilie Adam-Vézina, and Sandra Bascougano

Abstract
Several studies on social disparities in health agree that the analysis of the factors contributing to the production of these disparities conceals a grey area in the study of the quality of health care itself. In other words, once legal and economic obstacles are settled and individuals have access to health care services, is the medical care provided of equal quality for all or does a differential treatment interfere that cannot be explained only by health status? We will present results from a study dealing with the quality of medical care for patients suffering of HIV-AIDS and/or tuberculosis. This research took place in three public hospitals in Paris. We followed 94 patients receiving medical care and we were able to get a better understanding through their doctors (17) of the motives for therapeutic and clinical decisions. The analysis shows that patients, because of ethnic classification, may receive particular treatment especially regarding their compliance and inclusion in clinical studies.

Key Words: Discriminations, differential treatment, health, social disparities, HIV-AIDS, tuberculosis, decisions making, doctor-patient relationship, representations of the otherness, compliance.

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1. Introduction
Our study explores racial discrimination in health care services and we conducted this research for two years.1 We didn’t look for the impact of racial discrimination on access to medical services, but for this impact on the way services were delivered, in other words on the relationship between practitioners and patients. The main objective was to know if patients living with HIV-AIDS and/or tuberculosis could be discriminated on ‘ethnic’ or ‘racial’ basis. In this research, the discrimination in health is defined as an illegitimate and arbitrary differential treatment.2 In other words, there has to be not only a different treatment in the course of the therapeutic follow-ups, but moreover, this difference of treatment is ‘illegitimate.’ Its justification is not acceptable because it doesn’t suit to the aimed objective and the operated means. And ‘arbitrary’ that is based on postulates, which presuppose behaviour or capacities on the basis of subjective criteria, of prejudices or stereotypes. Let us clarify that the differential treatment is heard as much as a
lack of care than a therapeutic over investment, which the clinical observation and the only biological data do not justify. The differential treatment in health, deliberate or not, conscious or not, produces differences of therapeutic trajectories, independently of the differences justified by the clinical status of the patients.

We explored, among others, two working hypothesis. First, the political model of integration of the foreigners participate at the construction of a matrix of representations which bases the existence of groups is ethnicised and/or racised. In France, it is expressed by individuals’ assignments in categories such as *Maghrébins, Africains, Antillais or Noirs.* We could note that practitioners use in most cases the ‘African’ ethnonym, sometimes in that of ‘West Indian’ and very seldom in that of ‘blacks’ - but it is not contradictory with a racist vision in the health care sphere. These discursive and referential choices undoubtedly give an account of concerns differentiated in relation to those that they receive and classify as ‘African’ of those that they classify more as ‘West Indian’ and of the ‘poor Black’ adequacy of the ethnonyms expressed by perceptible differences. The individuals whom they categorised as ‘African’ re-group (rightly or wrongly) patients whom they classify as foreigners, or even irregular foreigners and to whom they lend a difficult financial situation. They appear as a group of very vulnerable patients and more at risk of not being able to be in charge at best of their health. Those whom they call then ‘Africans’ constitute well one of the populations in the middle of their preoccupation, as had been the case of the ‘homosexuals’ if we look at the history of AIDS. It seems that those they do not classify in this group and therefore which they can re-group under other ethnonyms like ‘West Indian’, ‘North African’ or ‘Asian’ (once again, let us underline that here it is about self-defining origin classification in the Weber meaning of the ethnicisation) do not preoccupy them in the same way. The second hypothesis is who the health practitioners’ are under the influence of such representations, which predispose them to consider behaviours of differentiated treatments as they classify the patients in a ‘ethnic’ and/or ‘racial’ group.

2. Methodology

Our methodology is divided in three integrated and mixed sectors: quantitative approach with questionnaire and qualitative approach with interviews and observations. The research took place in three public hospitals in Paris, more precisely among services that set in charge of the infectious diseases (HIV-AIDS and tuberculosis). The data concerning the therapeutic trajectories were collected on a sample of 94 patients followed for HIV-AIDS and/or tuberculosis, connected or not. A part of the data was collected in the files of the patients, the other one directly with the individuals. The
practitioners (n=17) of these patients later answered an interview where they have been asked to explicit their decisions about their patients.

The data concerning the patients were analysed with statistical treatment. Three dependent variables were held: 1- The stake under surveillance of compliance; 2- The degree of correspondence of the medical practices towards experts’ recommendations; 3- The inclusion of the patients in clinical studies. These dependent variables were analysed by a series of variables sending back to the social demographic characteristics of the patients and the second series reporting appropriate characteristics for their health status.

3. Social Demographic Profiles of Patients

The population of patients composing the sample consists of adults in the full strength of age. Men are the majority (65%). Half of the sample is immigrants (47%). It is mainly ancient immigrants; only 15% live on the French territory since two years or less.

More than half of the immigrants (57%) are settled in France for more than five years. At the time of our study, 17% had obtained the French nationality, 12% were still in irregular migration situation, and all the others held a resident’s permit.

Near of a quarter of the individuals born in France are children of immigrants (23%) and finally, considering the born countries of the individuals or those of their two parents, on 10 people persons of our sample:

Four (39%) come from Sub-Saharan Africa or the Caribbean (born there or children of parents born in a Sub-Saharan Africa country or in the Caribbean);

Five (49%) come from Europe (very mainly French people born in metropolitan France of both parents also been born there);

The last one (12%) come from North Africa (born there or children of parents born there).

For all the referees at the time of the research, 92% benefited from a health care cover from French legislation. 6% were under the cover of the state’s medical help (AME) reserved for migrants with irregular status; only 2% have declared having no health care plan.

Immigrants have an educational level less superior than the natives of France (2 immigrants reached a high educational level; they are 6 on 10 for the natives of France). Near three quarter (72%) had an employment at the time of the study (6 immigrants on 10 versus 8 on 10 at the natives of France).

In household incomes, the native of sub-Saharan Africa or the Caribbean are more often in the lowest income brackets (38% versus 22% for people born in North Africa and 13% for natives of France).
4. Therapeutic Itineraries

Analysis revealed that the medical basic practices (frequency of appointments, medical exams, prescriptions of antiretroviral drugs and tuberculosis treatment) followed experts’ recommendations. No differential treatment based on migratory status and family origins appeared concerning that element. But the differential treatment at the rate of the origin can be observed in certain decisions: 1) The probability for a group of patients to be put under surveillance of compliance while taking their medical treatment; 2) The probability for a group of patients to be included or not in a protocol of clinical study (cohorts, physiopathology studies, therapeutic and epidemiologic trials).

Naturally, we must issue reservations considering the weakness of our sample, and these analyses must be studied in a new study before validating them. However, if we consider these analyses as the fruit of a pilot study on a still little studied subject, they have a completely interesting value.

After a brief presentation of these analyses, we will review the reasons given by the practitioners to justify their medical decisions and orientations, taken for their patients.

5. The Influence of Differential Treatment on the Therapeutic Itineraries

The analyses of logistic regressions which concern the probability to be or not be put under surveillance of compliance during the course of medical treatment revealed that after the control of clinical data (conformity at the expert medical recommendations and with other social demographic characteristic such as sex, age, educational and socio-economic level, socio-professional categories), the migratory profile and the family origin are excellent predictive factors. The variable of family origin is even more powerful than the migratory profile to predict the stake under surveillance of compliance.

Otherwise, patients of family origin from sub-Saharan Africa or the Caribbean and those of family origin from North Africa have a higher probability (58 more chances for patients from sub-Saharan African origin and 16 more chances for patients from a North African origin) to be put under surveillance of compliance than patients from France.

However, the analyses also confirm the role of the socio-economic level and the influence of two other variables - the anteriority of the disease diagnosis and the state of gravity of the disease.

In the end, the analysis confirms that in every case, the patients classified as ‘Blacks’ because of their family origins have a stronger probability than all other patients to see himself put under surveillance of compliance. That probability resists even if other variables are introduced. The probability is besides, increased when these patients are in the quartile of
the poorest incomes, and when besides, their diagnosis is recent with a symptomatic stage (gravity stage 2) - that is they are not in an asymptomatic stage (because there mostly, they are without medicinal treatment) but what they are not either at the aggravated stage. Also, the inclusion in protocols of clinical studies seemed widely determined by these same variables. The patients who have a very strong probability to be included in a study are on one hand the European men for whom is recorded a mode of contagion by homosexual contacts (100% or all of them participate at least in one study, either therapeutic trials or essays or cohorts) and on the other hand, 8 out of 10 African or Caribbean women recorded a mode of contagion by heterosexual contacts participate in a study but only studies of cohorts.

The patients of all other profiles, that is African and Caribbean men, men and native women from North Africa, whatever their supposed mode of contamination, have less probability or none at all, to be included in a clinical study.


Ethnicity and/or race appeared, in the statistical analysis, as vectors of differential treatment. This report finds certain lightings in practitioners' speeches. ‘Africans’ in particular, even if they can be said compliant in the facts, they are seen as patients more ‘at risk’ by non compliance than all other patients. This risk is linked to, according to the practitioners, a whole series of obstacles which raise themselves in front of these patients: a) Their culture may produce more denial in front of the disease than other patients, more difficulties to understand how the disease may influence their health and affect their whole life or more constraints and difficulty to take their medicine; b) Their migrant situation implying more mobility between the country of origin and France, thus more risks of contagion and of interruption of treatment; c) Their legal situation which returns their right for the more or less precarious stay and, in a more or less bound way; d) Their economic situation which defines the other priorities on their daily schedule that those to take charge of their disease; e) And finally, their conditions of daily life which can imply that they simply have no access to a refrigerator when we know that certain treatments are sensitive to heat.

Independently of the merits or not, of these obstacles, we noted that most of the time, the doctors presuppose these obstacles and their consequences much more than they verify them systematically. It is here at the same time about common representations (he so goes away of the approach of ‘culture’) but also of one certain knowledge of experience acquired according to their years of practice.
7. Conclusion

In conclusion, this study brings a certain number of new elements in the study of discriminations. It certifies first of all that discrimination exists in health as in other spheres of the society if it is to a minor degree. Let us say here again that no differential treatment was noticed in medical basic practices. This discrimination takes the form of a differential treatment which can play made at the same time in the form of an over investment in care to the immigrant’s patients (overrepresentation in protocols of surveillance of observance) and in the form of a deprivation of care (less participation in clinical studies and particularly in therapeutic trials). It shows then that the processes, which drive to this discrimination rest on a great extent on representations of otherness. Because they are fluently carried in the society, they are taken back by the professionals of health.

Notes

1 This research realised by M Cognet, E Adam-Vezina, and S Bascougnano was financed by the DREES-MiRe (Direction de la recherche, des études, de l’évaluation et des statistiques, Mission de la recherche) and took place into the research program ‘Production et traitement des discriminations : nouvelles approches.’


4 We chose the term ‘compliance’ and not adherence because it translates better the term used in France which is ‘observance.’ ‘Adherence’ in English refers to ‘adhésion’ in French and the term is not used in the French health sector.

5 The French born individuals in a territory or French overseas departments or of parents been born themselves in these regions are excluded here. These individuals are not very numerous in our sample (1%). However, we tested effects in different statistical counting by agglomerating them either with other born French, or with natives of the countries of sub-Saharan Africa and the Caribbean. This different counting tried to prove effect of the colour of skin on nationality. At any rate, though by considering the weakness of their
numerical part, the natives of the Caribbean appeared to us more follow similar therapeutic trajectories to those of the natives of sub-Saharan Africa.


8. For Sub-Saharan Africa or the Caribbean, the odds value R=58.753 and p=0.004; for those from North Africa the odds value is R=16.110 and p=0.055.

9. In the modelling relationships within the data (regression), ‘aggravated stage’ was the main reference category.

10. The French men are many to enter protocols (27 on our total sample of 38 French men) and among those who are included, 85% (23 on 27) have a recorded contagion by homosexual contacts.

11. On 17 women registered in protocols, only 2 women are European (born in France).

12. Only 3 African patients are included in protocols on the Africans’ total sample of our study that amounts to 16 but none of the inclusive patients has a mode of homosexual contacts. On our total sample, appear to us however 2 Africans whose mode of recorded contagion is homosexual contacts.

13. At the men native of the Maghreb, nobody participates in a study. We have however in our total sample, 4 men from the Maghreb whose recorded mode of contagion is homosexual contacts.

14. 81% of ‘black’ men and 90% of patients from North African (merged men and women) participate in no study.

Bibliography


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Global Rhetoric, Local Actors: Community Health Workers and the Concept of Participation in Rwanda

David MacDonald Matthews

Abstract
This chapter explores the role of community health workers in generating community participation in health in rural Rwanda. In particular, it focuses on the enduring conflict between empowerment and utilitarian models of participation, drawing on fieldwork carried out in Mayange, Rwanda, where the Millennium Villages Project is located. While undertaking the community health worker role has clear advantages for individuals in terms of training, political prestige and access to economic opportunities, the Rwandan government’s refusal to provide regular monetary compensation neglects the significant time commitment demanded by the position. Community health workers must also negotiate conflicts between the biomedical interventions they are meant to advocate, and traditional healing practices in their villages. With renewed emphasis on primary health care and community participation as a means of achieving the Millennium Development Goals, it is more important than ever to consider the ways in which such programs may both empower and exploit local actors at the community level.

Key Words: Community health workers, community participation, primary health care, Rwanda.

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1. Introduction
Since the beginning of the primary health care movement in the 1970s, medical anthropologists have taken an interest in the symbols of community participation in health. The primary health care movement has been characterised as an effort by public health officials to reverse the control of doctors and public health authorities over health and medicine, giving back this responsibility for maintaining health to ordinary citizens. In the early days, proponents of community participation envisioned self-motivated communities working alongside the state to design their own programs to improve health and development. Not surprisingly, this vision has been difficult to achieve. Throughout the development of primary health care, anthropologists have attempted to develop a critical approach to community participation, framing the concept not only as a means of empowerment and community engagement, but also as a mechanism for exploiting local resources and extending state control.
While the rhetoric and practice of participation have been fully integrated into mainstream health and development discourse, key ideological divisions persist between utilitarian and empowerment models. The utilitarian model sees participation as an effort by governments and donors to use community resources, such as land, labour and money, to offset the costs of providing services. In contrast, the empowerment model defines participation as a tool through which local communities take responsibility for diagnosing and working to solve their own health and development problems. While the utilitarian model sees participation as a means, the empowerment model portrays participation as an end. Given its dualistic nature, Stone has characterised community participation as a ‘double-edged sword’ in that it calls for the empowerment of the poor while simultaneously deflecting responsibility away from those who truly have power.

According to the Alma-Ata model of primary health care, locally recruited community health workers were to play a key role in extending basic health care services to underserved populations. While community health worker programs were very popular during the height of the primary health care movement in the late 1970s and early 1980s, enthusiasm diminished significantly in the 1990s. This decline in enthusiasm was attributed in part to the challenges of scaling up programs in a sustainable fashion, as well as the perceived success of ‘vertical’ programs that focused on individual diseases. Recently, there has been a renewed interest in the role of community health workers in the public health literature, particularly in their contribution to child survival. There has also been a renewed focus on primary health care as a means of achieving the Millennium Development Goals. Within this context, policy makers have recommended the ‘massive training of community-based workers’ as a ‘quick win’ for achieving the Millennium Development Goals.

The case of Rwanda provides a particularly striking example of this renewed focus on community health workers as agents of community participation in health. In its efforts to rebuild the health system following the civil war and genocide of the early 1990s, the Rwandan government has placed increasing emphasis on community participation as a means of improving rural health services. The government’s conception of ‘participation’ involves both material contributions on the part of communities, in the form of a community-based health insurance scheme known as ‘Mutuelles,’ and the use of a cadre of volunteer community health workers to extend health care services to rural areas. The National Community Health Policy, which was released in 2008, emphasises, thirty years later, a renewed commitment to the values of primary health care, as articulated in the Alma-Ata Declaration of 1978, with a goal of ‘bringing health care as close as possible to where people live and work.’ While these policies espouse rhetoric of empowerment and community
engagement, their underlying aims are clearly utilitarian. Although the health insurance scheme has increased access to health care, it has also been a means to solicit resources from the community in support of their own care. In a similar manner, while the policy of community health workers aims to bring health services closer to the community and empower a cadre of local health workers to reorient themselves towards cosmopolitan values, it also fills the utilitarian need for additional health service providers and allows for greater surveillance and the enforcement of health norms in remote rural areas.

Here I discuss some of the key findings from my fieldwork in Mayange, Rwanda, drawing on work carried out for my master’s thesis. The case of Mayange provides a clear illustration of the tensions involved in creating community health worker programs. In Mayange, the notion of ‘community’ is still being renegotiated as Rwandans attempt to rebuild their lives following the devastation of the 1990s. Mayange is also becoming increasingly connected to the global rhetoric of development through the work of the Millennium Villages Project, a multi-country development program intended to demonstrate that the Millennium Development Goals can be achieved in sub-Saharan Africa through targeted, multi-sectoral investments in rural communities. Overall, the Rwandan case demonstrates that tensions between the empowerment and utilitarian functions of community health workers programs, both at the level of individual health workers and at the community level, where the relationship between biomedicine and traditional healing practices continues to generate tension.

2. Methodology

My data are based on two and a half months of fieldwork carried out between July and September 2008 as well as an extensive review of the ethnographic literature on Rwanda. During my fieldwork, I was based in the Mayange Sector, which is home to the Millennium Villages Project. Over the course of my fieldwork, I carried out observations at the health centre, assisted with training and outreach activities for community health workers and conducted semi-structured interviews with 32 of the 70 community health workers in Mayange. These interviews were conducted in Kinyarwanda and translated with the help of a field assistant. Interviewees included 15 women and 17 men. They had from 2 months to 14 years of experience as community health workers, although the majority had been recruited in early 2007. I also conducted interviews with many of the health centre staff and project staff, both Rwandan and expatriate.

3. History of Mayange

The Mayange Sector has a population of approximately 25,000 residents, and is located about 40 km south of the capital, Kigali. Though
much of Rwanda is characterized by fertile green hills, the landscape of Bugesera district is more arid and less hilly than most of the country. As in much of Rwanda, nearly all arable land is under cultivation, with cassava, beans, maize, sorghum, potatoes, sweet potatoes and bananas forming the staple crops. The region receives relatively little rainfall and is subject to periodic drought. As a result, residents often complain of *inzara tiewenizuba*, meaning ‘sunshine’ or ‘drought,’ as a major health problem for the village. Because of the poor farming conditions, the area was relatively underpopulated for much of Rwanda’s history; however the government began to encourage settlement following independence in 1962. A large number of Tutsi sought refuge from ethnic violence by settling in the region in the 1960s. This was later followed by a wave of Hutu resettlement from the northwest as part of *paysannats*, government policies that encouraged the resettlement of land-poor peasants from over-populated regions of the country. Because of its large Tutsi population, nearly 50%, compared to the national average of 15%, and its proximity to the capital and the Burundian border, the area was hit particularly hard by the genocide of 1994. It is estimated that nearly 50% of the population was killed, both Tutsi and ‘moderate’ Hutu, with large numbers of the surviving population displaced.

The community has undergone profound social and physical changes in the years since the genocide. Villagisation policies have radically altered the physical arrangement of Mayange, and the majority of residents now live in clusters of mud-brick homes, known as *imidugudu* (singular *umudugudu*), as opposed to the dispersed homesteads that previously characterised rural Rwanda. *Imidugudu*, which typically consist of 80-140 homes, have become the lowest level of political organisation in Rwanda and there are 35 *imidugudu* in the Mayange Sector. Mayange is a designated resettlement area, with many genocide survivors, ‘old’ and ‘new’ caseload returnees, and released *genocidaires* returning to live there. As a result, the landscape is dotted with new homes under construction to house returnees and survivors. In terms of infrastructure, Mayange is reasonably well served. The sector has five primary schools, one secondary school and one vocational school. As per government policy, there is a single health centre, although the Millennium Villages Project has recently opened three additional health posts in more remote parts of the sector. While physical infrastructure is in place, the provision of services has continued to be a challenge.

4. **Community Health Workers in Mayange**

Community health workers have existed in various forms in Mayange since 1996, when an initial group of volunteer health workers was recruited to provide emotional support for traumatised individuals in the wake of the genocide. During the late 1990s, their role gradually expanded to include basic preventive and promotive services; however, they received little
training or support from the health centre. The development of the National Community Health Policy and arrival of the Millennium Villages Project in 2005 led to renewed interest in establishing a formalised community health worker program for Mayange and the project hired a Director of Community Health in early 2007 to support the health centre in re-invigorating its community health programs. She describes her role as ‘supplementing and improving upon’ the government guidelines, rather than adapting these guidelines to the policies of the Millennium Villages, emphasising the ‘need to respect government policy without forgetting that there are things to improve.’

In early 2007, the project and health centre engaged in a major recruitment campaign for community health workers. Elections were held at the umudugudu level and one male and one female health worker were selected for each of the 35 imidugudu, for a total of 70 community health workers. Prior to the elections, the health centre drew up a list of criteria for the health workers and ‘sensitised’ the community to these criteria. Local authorities ran the elections, but the project staff helped to ‘facilitate’ the selection, encouraging appropriate candidates to come forward. Candidates had to be between the ages of 21 and 49 and know how to read, write and speak Kinyarwanda. There were also a number of social criteria, including being ‘respected by the community,’ ‘motivated by a spirit of volunteerism and humanitarianism,’ ‘respecting human rights,’ ‘having well behaved children’ and ‘not being polygamist.’ In keeping with government policy, the project staff opted to support a cadre of unpaid, volunteer community health workers as opposed to a group of paid, professionalised village health workers, as called for in Millennium Villages Project policy documents.

According to the job description, responsibilities of the community health workers include the planning and implementation of outreach activities, the gathering of epidemiological data and the submission of monthly reports. They are also responsible for sensitising community members on child health, family planning, nutrition, hygiene, and various diseases at monthly umudugudu meetings. Community health workers are expected to make regular home visits, identifying illnesses requiring professional treatment, providing support to those with HIV/AIDS, and encouraging women to give birth at the health centre. Although tuberculosis rates are low, some community health workers provided directly observed therapy to those suffering from TB, supervising the delivery of medicines on a daily basis. In general, community health workers are expected ‘to take initiative and innovate within their community to improve the health status of the population.’
5. **Conflicting Roles of Community Health Workers**

The work of community health workers in Mayange involves several key tensions. At the individual level, there is tension between the empowering benefits of becoming a community health worker and the costs of undertaking the role as a volunteer. While becoming a community health worker can have many benefits for individuals, both in terms of social and political prestige, and access to training and economic opportunities, there is a perceived need amongst health workers for adequate monetary compensation in recognition of their work. The tasks assigned to community health workers are ever-increasing, taking time away from their responsibilities as farmers and family members, and health workers repeatedly stressed the need for compensation in recognition of their many responsibilities. At the community level, there is conflict between traditional healing practices and the biomedical interventions advocated by community health workers. Community health workers are explicitly required to create linkages between their local communities and biomedical practices, and many serve as advocates for biomedical interventions. However, they are still held accountable to the social systems of their village, and must find ways to balance this dual role. In the conclusion, I discuss the ways in which these tensions are mirrored at the policy level, where there continues to be a divide between a rhetoric that seeks community empowerment and policies that are fundamentally utilitarian in practice.

In interviews, community health workers expressed a number of benefits of being selected for the job. In particular, they spoke of the social and political prestige of assuming an elected position within their village, as well as the educational opportunities afforded to them through training in health prevention and promotion. Although a few had attended secondary school, most health workers had only completed their primary education. As such, becoming a community health worker provided significant opportunities for educational advancement. Although often not explicitly mentioned, it was clear that health workers also benefited from the economic opportunities provided by the position, as well as the prestige of distributing medications and participating in health centre activities.

Despite the many benefits of undertaking the job, community health workers consistently expressed a desire for regular monetary compensation. The requirements of the position were constantly increasing and, for many, it had become a near full-time commitment, distracting them from their farming and family obligations. While it is likely that such responses were due, at least in part, to the fact that my informants perceived me as having influence with the project, there is general consensus in the literature that community health workers must be paid if programs are to be sustainable in the long run and not be diminished by volunteer fatigue. Consistent with the Rwandan government’s program of community performance-based
financing, community health workers in Mayange are not remunerated on an individual level. Instead, the workers are required to form a business cooperative and engage in collective profit-making activities. The cooperative received 1,000,000 RWF (approx. 2,000 USD) from the project in December 2007 and used the money to purchase a field, where they plan to cultivate cassava. The health workers are also planning to open a boutique to sell food and other goods to staff and patients at the health centre. While many health workers are enthusiastic about this new form of economic engagement, they note that they do not expect to receive any profits for quite some time. Even if the field or boutique manages to turn a profit, it will have to be divided seventy ways. In addition, this system of compensation obliges health workers to spend additional time on profit-generating activities outside of the health centre, increasing rather than decreasing the time commitment of their role. In the meantime, the project provided health workers with bicycles and mobile phones as a form of compensation in kind. While this appears to have increased motivation, it remains unclear how such one-off rewards will sustain and encourage community health worker engagement in the long run.

One of the most challenging aspects of the role of community health workers is their position at the interface of traditional care practices in their villages and biomedical interventions advocated by health professionals and government. In interviews, health workers often described the challenge of being accountable to both systems. They also spoke of difficulties in establishing their credibility to deliver preventive and promotive health messages when speaking at umudugudu meetings or making home visits. Community health workers were required to assert their biomedical knowledge in contrast to local care practices, and often seemed to take an antagonistic, rather than holistic, approach towards traditional medical beliefs. This dialectic was expressed in a number of different ways, although it was difficult to get a clear sense as to what extent restrictions against traditional medicines were strictly enforced. One community health worker described calling the ambulance in secret after someone had insisted on seeking traditional rather than biomedical care. The health worker then ordered the patient to enter the vehicle and sent her to the hospital. Another health worker mentioned that people could be ‘punished’ for going to see traditional healers and suggested that women who drank traditional remedies during pregnancy were often fined by the health centre. While it was difficult to verify these claims, most health workers tended to speak in more general terms about the difficulties of integrating traditional and biomedical practices and cited villagers’ ‘capacity of understanding’ as an obstacle to delivering health education messages.
6. Conclusion

The rhetoric of international health policy has a tendency of repeating and reinventing itself. Thirty years after the declaration of Alma-Ata, calls for a renewed focus on primary health care are as strong as ever. While many of the naïve assumptions about the empowerment functions of participatory health policies and communities’ capacity for self-reliance have been replaced by a much more utilitarian approach to primary care, the conflict between empowerment and utilitarian approaches continues to pervade health policy and practice. The Rwandan case shows that, more than ever, there is a need to account for the ways in which policies of participation may both empower and exploit local actors. A focus on the technical outcomes of participatory policies has often neglected the fact that primary health care is, and always has been, political. Any attempt to reconfigure the relationship between health care systems and communities will inherently involve a renegotiation of the power structures at a local level, and primary health care remains a powerful political symbol both in rhetoric and in practice. Participatory policies have enduring appeal because they are inherently aspirational. In order to fully understand them, we must move beyond the rhetorical level to observe how they are realised in the social practices of local actors within defined communities.

Notes

1 Although the terms ‘primary health care’, ‘community participation in health’ and ‘community health workers’ are interrelated and used somewhat interchangeably, they refer to different levels of public health strategy. ‘Primary health care’ refers to an overall model for organising health care systems and services. In contrast, ‘community participation in health’ is an approach used to implement primary health care services. ‘Community health workers’ are individual community members, enlisted as part of community participation programs to deliver primary health care services at the local level.


14 Quote from the community health worker job description, unpublished.

Bibliography


David MacDonald Matthews recently completed an MPhil in Medical Anthropology at the University of Oxford.
Rural Community Leaders’ Perceptions of Healthy Leisure: Resources, Needs and Constraints

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Abstract
Chronic diseases are prevalent and costly health problems that affect children and adults of all ages. Additionally, rural communities are more likely to have chronic diseases due to lack of physical activity and poor diet. Promoting healthy leisure lifestyles through low-cost, community programs can help improve health and wellbeing. However, community participation is necessary to effect sustainable community change. The purpose of this study was to understand how community leaders in a rural town viewed resources, needs and constraints associated with leisure-based self-care. We conducted semi-structured interviews with 24 community leaders from diverse organizations in an impoverished, racially diverse rural community. Resources identified included leisure programs for youth and adults, an outdoor track open for public use, and free lunchtime meals for seniors. Needs identified included educational programs on healthy eating and/or physical activity, chronic illness prevention, and leisure alternatives to crime, drugs and teenage pregnancy for youth. Constraints included lack of resources and infrastructure, inaccessible and unaffordable facilities/sites, lack of low-cost leisure, and lack of culturally sensitive programs. We discuss our findings in relation to previous research and in regard to future steps toward implementing a healthy recreation program in the community.

Key Words: Leisure-based self-care, recreation, racial health disparities, rural health.

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1. Background and Significance
A. Chronic Diseases Are Prevalent, Costly and Debilitating
Overall, the health of the U.S. population has improved markedly over the past century. However, there remain persistent health problems that challenge individual health outcomes as well as our societal values. Chronic diseases are both prevalent and costly health problems that are also leading causes of death in the U.S. During 2001, more than 30,000 people died from heart disease and over 2.1 million people had arthritis in Illinois. Chronic diseases also cause disruptions in work, family, and leisure and are associated with diminished physical health and psychological well-being.
B. Rural and Racial/Ethnic Minority Health Disparities Persist

Rural communities and racial/ethnic minorities tend to have higher rates of many chronic diseases, with rural racial/ethnic minorities the most understudied and underserved of all. Rural areas rank poorly in 21 of 23 selected health indicators, including healthy self-care behaviors such as exercising. For racial/ethnic minorities, environmental issues and poverty are consistently observed in chronic disease rates. Factors such as these contribute to higher cancer and diabetes rates in the African American population as compared to Whites. Add to that, rural minorities generally have even worse health and less access to health care than minorities in urban areas. According to Hartley, the elimination of health disparities among racially diverse rural populations requires a community approach that is sensitive to local variations in personal, social, environmental and cultural realities. We tend to agree and thus have utilized a community-based participatory research approach in the current study.

C. What Do U.S. Health Leaders Advocate to Improve Health?

According to Healthy People 2010, lowering the incidence of chronic diseases and addressing health disparities through public education and health promotion programs are two important public health goals. Promoting healthy leisure lifestyles through low cost, highly accessible community-based programs can help achieve these public health goals. Prior to implementing any community-based participatory program, it is pivotal that we gain thorough knowledge of the community’s resources, needs, and cultural environment, as well as develop relationships with community leaders and organizational representatives to achieve participation through meaningful partnerships.

D. Study Objectives

We utilized multiple phases using mixed methods (interviews, focus groups, surveys, and a town hall meeting) to address the overarching objective of understanding leisure-based self-care in a racially diverse rural town. The primary objectives of the interview phase (Phase 1), which are the focus of the present chapter, were to understand resources and needs for healthy leisure opportunities as well as constraints to participation. We chose this town because it is one of only a few rural communities in Illinois that has a substantial African American subpopulation (11.8%) and, compared statewide, it has higher poverty rates and fewer residents with health insurance.
2. Literature Review

A. Leisure-Based Self-Care Practices

Self-care practices are broadly defined as activities performed by individuals, groups, and communities with the intention to enhance health, prevent diseases, limit illness, and restore health. Self-care includes lifestyle practices to maintain and improve health and to prevent disease, such as eating healthy foods, not smoking and engaging in healthy leisure activities. In this study, we are interested specifically in ‘healthy’ leisure activities freely chosen during one’s free time outside of work, which we refer to as leisure-based self-care practices. Leisure-based self-care practices include leisure-time physical activity, social leisure, and spiritual leisure. There is preliminary evidence that people intentionally participate in these leisure practices to maintain and improve their health and well-being.

Leisure-time physical activity (e.g., walking, swimming, gardening) is linked to several health indicators, including longevity and independence, physical health, mental health, and cognitive functioning. In addition, leisure-time physical activity reduces distress and improves well-being in the midst of stressful life circumstances. An array of social leisure activities, such as social outings to movies and sports events, companion travel, playing cards and bingo, and social group activities, are also associated with lower mortality risk as well as maintenance of functional status and improved recovery from disability. Social support, which often is procured through social leisure engagements, is associated with better physical health and lower obesity levels as well as improved psychological well-being. Spiritual leisure (e.g., praying, attending church) is also positively associated with physical health, social support, coping, and managing chronic illness and disability among racially diverse groups. It appears that people intentionally choose leisure settings to nurture the spiritual dimension of their lives.

An overview of the health benefits of leisure-based self-care practices reveals that often leisure-time physical activity, social leisure and spiritual leisure are interrelated. For example, participation in leisure-time physical activity may have a strong social dimension and, for some individuals, outdoor leisure has a meaningful spiritual dimension. Son and Hutchinson found that physical activities had an important social dimension for some rural American Indian elders. In addition, spiritual leisure, particularly through Native American church, provided opportunities for social engagement. Other than their study, there has been no comprehensive attempt to examine rural minorities’ resources, needs and practices for leisure-based self-care.

There are some studies on the leisure-time physical activity of racial/ethnic populations and with rural populations. However, attention to the relationship between other types of leisure-based self-care
practices (i.e., social and spiritual leisure) and the health of racially diverse rural communities is limited.51

B. Utilizing Social Cognitive Theory to Understand Leisure-Based Self-Care

There may be resources for leisure-based self-care but constraints to participation. Constraint negotiation theory52 indicates that people perceive intrapersonal, interpersonal and structural constraints (i.e., obstacles and barriers) to leisure, negotiate strategies to overcome them, and have personal expectations about the benefits of leisure. Recently, researchers have recommended that perceived cultural constraints be added to the constraint construct.53 For instance, cultural constraints related to perceived discomfort, lack of appeal and lack of perceived appropriateness of leisure activities54, 55, 56 may limit racial/ethnic minorities’ participation in healthy leisure activities. Some research57, 58, 59 has suggested that leisure creates racial/ethnic alienation. Therefore, just as important as understanding the resources for leisure-based self-care are identifying underutilized resources, possible constraints underlying this underutilization, and community needs.

3. Methods

A. Overview of Data Collection Process

This community-based participatory research project used mixed methods with four phases of data collection, with the perspectives revealed in each phase informing the next phases of the project. In Phase 1, we conducted semi-structured interviews with community leaders and organizational representatives; in Phase 2, we conducted focus groups with residents from diverse cross-sections of the community (African American, low income, older adults, and hospital staff); in Phase 3, we conducted a survey with residents on behavioral aspects of leisure-based self-care; and in Phase 4, we invited all study participants to a town hall meeting to discuss the findings as well as to brainstorm ideas on ways we could work together to address the issues. This chapter focuses on the results from Phase 1 of the study, in which we interviewed 24 community leaders and organizational representatives, oversampling African American leadership through a snowball sampling strategy, which resulted in 5 interviewees (approximately 20%). The semi-structured interview guide included questions about resources and needs for, and constraints to, leisure-based self-care in the community as a whole as well as for racial/ethnic minorities.

B. Data Analysis Strategy

We utilized Huberman and Miles60 as a guide to code transcripts. More specifically, one member of the research team chose four diverse interview transcripts to develop an initial codebook. Then, another member
of the research team coded all of the transcripts, adding, merging and refining the codes as themes emerged from the data.

4. Results
A. Community Resources to Promote Leisure-Based Self-Care

According to the community leaders we interviewed, there are many resources to promote leisure-based self-care already available in this rural town, including (in alphabetical order): city parks, a community center, a cultural center, churches, a senior center, the recreation department, and a nonprofit recreation facility, just to name some of them. Additionally, there are outdoor recreation areas nearby such as a foundation-funded park, and the old public high school track is open for public use. However, there may be underutilization of some of these resources. For instance, one leader said,

I think as a whole we don’t take advantage of the resources that we have, particularly the free resources. We have the two park systems, Foundation Park and Fairview Park that are available. There are a lot of activities in the community such as Balloon Fest … We have, I think, a really pretty good option here as far as recreation. We have the Cultural Society and the events that they put on.

Accessibility may explain some of the underutilization, as many residents do not own a vehicle or forgo attendance to special events due to entrance fees. However, accessibility does not explain all underutilization, as some nonprofit organizations are located within walking distance from key constituents: ‘… The Youth Center is utilized more by the minority part of our town because that is where it’s centralized at, try to give them more of a local ability to be involved in sports.’ This quote also highlights the race and class segregation of this rural town that may also contribute to underutilization of resources.

B. Community Needs for Healthy Leisure Opportunities

Some needs that were identified by community leaders included: a) educational programs on healthy eating, cooking, food options, b) educational campaign on physical activity opportunities, c) chronic illness prevention (e.g., diabetes, stroke, heart disease), d) leisure alternatives to crime, drugs, teenage pregnancy, etc., e) exposure to other ways of life, f) social opportunities, g) something sustained over time. Some leaders also recognize the importance of going to where people work and live rather than expecting them to come to their organization: ‘I think we need to … make things available where people are rather than looking for them to come to us or come on campus or whatever it may be.’ Most leaders also recognize how
busy people are, indicating that many residents juggle multiple jobs to earn a living wage. Therefore, having a program that requires little time is essential to getting people to participate: ‘You know something that’s easy for people who work, you know, because that’s the ones who really have the most trouble with it, trying to fit that into their schedule and all that.’

Leaders also mentioned the importance of programs and resources for children and adults across the lifespan. Some leaders indicated that there were many resources for children whereas others thought more were needed. This pattern occurred with older adults, too. Some participants indicated that there were many opportunities for older adults whereas others thought much more was needed. Similarly, some participants expressed that there were different needs and/or preferences for leisure programming for African Americans (‘there’s nowhere to go’) and others expressed the belief that the issues were similar across race (e.g., programs that address chronic health conditions are needed for all races). Overall, health education and job education were mentioned frequently as important needs. In regard to education on healthy recreation opportunities, one leader said,

> Probably educating the public about what is available, particularly for free because we have such a large percentage of our population that is low-income. And along with that, what are the benefits—the potential health benefits—for people if they do participate in those kinds of activities.

C. Constraints to Participation in Leisure-Based Self-Care

According to community leaders, there are many constraints that limit residents’ participation in leisure-based self-care, such as (not in any particular order): lack of time, especially for people who work multiple jobs; inadequate transportation; lack of low-cost facilities; cost of healthy foods, especially for residents on a tight budget; lack of culturally sensitive options; being overweight/out of shape; lack of motivation; and family/friend disinterest and/or schedules. Leaders attributed constraints to the individual (i.e., motivation), to interpersonal relationships (‘my family won’t eat healthy foods if I make them’), and to environmental constraints (accessibility, infrastructure). In regard to inadequate transportation, one leader who works at a nonprofit organization for low-income individuals commented:

> I think for our clientele in large part transportation is problematic. There is public transportation available but it does have a small fee. Our individuals are mostly on very, very limited income so then even paying a small fee a few times a week would add up for them and make it difficult
for them even to maybe get to some of these resources that are available.

This quote reflects a common theme. Poverty was mentioned by several leaders in regard to a wide range of constraints to participation. For example, in regard to physical activity, one leader indicated, ‘When you don’t have a job and [sic] you don’t know how your bills are going to be paid, you’re not really worried about a gym membership. You know I think a lot of that comes to the incomes and the high unemployment in [town].’

In regard to lack of time, one leader said, ‘I think most people would like to make the time but feel other things take priority. I think it’s because of the stress of work and family.’ Another leader echoed this perspective, saying,

I think so often people say ‘I’m so busy,’ I think they make physical activity the last priority. It’s the last thing on the list. You know, there are so many things you have to do. You have to go to work and you have to take care of your family, and you have to be at this meeting or that. And then when the day gets down to the last hour it’s time to wash a load of laundry or some other small minute thing that we can think of that we could be exercising instead of and we don’t necessarily have to go to the track to walk. You can walk around the block of your house, you know?

5. Discussion

When referencing resources in the community as a whole, every community leader identified multiple resources that contribute to the health and well-being of residents. Almost all leaders identified recreation departments and/or non-profit facilities and parks as important sites for leisure-based self-care, particularly leisure-time physical activity. Leaders also mentioned a diverse array of other resources for leisure-based self-care, including social and spiritual resources as well as educational opportunities, such as social organizations, non-profit health organizations, churches, the public library and the community college. However, when speaking about healthy leisure resources in the community for racial minorities in particular, except for African American leaders, most leaders struggled to identify any unique resources. Those who could not determine unique resources tended to downplay their importance, usually by saying that everyone can utilize the same resources. However, leaders working in the African American community indicated that, aside from church, available resources do not support the types of activities in which African Americans are interested in participating. Instead, African American leaders indicated that most African
American residents have to travel to the nearest city (which is 45 minutes away) to attend culturally relevant programs, services and events. However, African American leaders also underscored that only those with higher incomes can afford to travel to the city. This issue highlights the class-based differences that are also prevalent in this rural community.

There were some similarities across community leaders on the need for healthy leisure opportunities, with leaders naming healthy diet and physical activity the most frequently. Some leaders referred to these needs in terms of prevalent chronic health conditions such as heart disease and diabetes. Unlike with resources, in which most leaders readily named off several resources for leisure-based self-care, most leaders only identified one or two healthy leisure needs. Perhaps this finding suggests that there are only a few prevalent needs for healthy leisure within the community; namely, programs to address weight control and weight management through diet and exercise. There were also contradictions between leaders on which specific populations need healthy leisure opportunities. Some leaders identified youth as the high need population, indicating that older adults have plenty of programs and services; however, other leaders described the opposite scenario, in which older adults are in high need with many programs for youth. In this way, leaders highlighted the needs of the population that they tend to serve through their organizational role to the neglect of others. In this way, leaders are stakeholders within the community vying on behalf of their constituents for a piece of the proverbial pie.

Similar to previous research, leaders identified intrapersonal constraints, interpersonal constraints, and structural constraints to participation in leisure-based self-care. Of particular note, leaders described diverse viewpoints about the constraints residents face to participation in healthy leisure opportunities. For instance, some leaders underscored intrapersonal constraints such as lack of motivation, lack of knowledge, and a general negative attitude toward healthy leisure. Other leaders highlighted structural constraints, such as a lack of resources and infrastructure, inaccessibility of facilities and amenities, and the high cost of facilities and healthy food options. A few leaders also mentioned the role of interpersonal constraints, which tended to be linked to family/friend lack of interest and/or others’ time constraints. Several of the constraints mentioned (e.g., inadequate transportation, time pressures) relate to the fact that many residents are low-income and/or work multiple jobs. Additionally, African American leaders identified cultural constraints to participation, such as a lack of culturally relevant opportunities and traditionally unhealthy food choices. The former constraint may suggest that there is race-based leisure alienation in this community. The latter constraint indicates that choosing healthy food options may be particularly difficult for African Americans because these food selections are rooted in social traditions.
Our long-term goal is to develop a project with several community partners to utilize existing resources to address constraints to leisure-based self-care. Therefore, using strategies to bring community leaders together toward a common goal for healthy recreation will be an important next step toward the successful development and implementation of a leisure-based health promotion program.

Notes

6 CDC, 2009, op. cit.
10 Eberhardt et al., 2001, op. cit.
13 Probst et al., 2004, op. cit.
Rural Community Leaders’ Perception of Healthy Leisure

16 Godbey et al., 2005, op. cit.
17 Israel et al., 1998, op. cit.
23 Ibid.
31 C F Mendes de Leon, T A Glass, L A Beckett, D A Evans, & L F Berkman, ‘Social Networks and Disability Transitions Across Eight Intervals


35 Son & Hutchinson, in press, op. cit.


44 Heintzman, 2000, op. cit.

45 Son & Hutchinson, in press, op. cit.
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45 Son & Hutchinson, in press, op. cit.
Bibliography


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Their Natures are Similar, Their Habits Make Them Different: The Cross-cultural Challenges for Chronic Disease Primary Prevention in Canada and the World

Zhenyi Li

Abstract
Population-wide primary prevention through modifiable risk factors such as smoking, physical inactivity, and unhealthy dietary practices, has been proposed as a proactive, efficient and cost-effective method for reducing the economic burden of chronic disease worldwide. Identification of a target population’s knowledge, behaviours, and beliefs related to chronic diseases is essential for effective and appropriate chronic disease prevention. This chapter examines the findings from three research projects focusing on the cross-cultural distinction between East Indian-Canadian, Chinese-Canadian, and Mainland Chinese populations on their knowledge, behaviours, and beliefs related to ischemic heart disease or stroke. Cross-sectional descriptive comparative quantitative data analyses reveal that different mechanisms of knowledge acquisition, behaviour change, and belief transformation form the barriers to realize actual changes in those populations when primary prevention educational programs originally designed for European-Canadians were delivered without any change. Confucian teaching on the commonality of human nature and the distinction of their habits, which includes their knowledge, behaviours, and beliefs towards health, illness and disease, is reflected in the conclusion of this chapter.

Key Words: Intercultural health communication, chronic disease primary prevention, behaviour change.

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Chronic disease prevention is a proactive approach that aims to ease the economic burden in health care systems. In stark contrast to expensive last-phase aggressive biomedical intervention on individual patients, population-wide chronic disease primary prevention is regarded as an efficient, cost-effective, user-oriented and friendly method. The heart of such a notion is that many risk factors leading to chronic diseases are modifiable so that many chronic diseases can be prevented. Those preventable and modifiable risk factors include unhealthy dietary practices, physical inactivity, excessive alcohol consumption, smoking, and many other ‘habits.’ These habits, also known as behavioural patterns, facilitated by
socio-economic policies, regulations, and public health education, are often believed to be changeable.

As a result, public health advocates promote healthier lifestyles, present chronic disease risk factors to different communities, and advance certain legislation changes through educational institutions, mass media, lobbying, public events, and other communication channels. Tobacco advertising, for example, is now one of the most highly-regulated forms of marketing. Some or all forms of tobacco advertising are banned in many countries. In the United States smoking rates shrank by nearly half from the mid-1960s to mid-1990s when strict regulations were launched. In British Columbia, Canada, smoking prevalence rate has fallen by 58% since 1985. Notwithstanding the tobacco advertising regulation, the number of the smoking population in China is, regrettably, still increasing. Researchers found that the development of tobacco control policies in China did not affect tobacco consumption and second-hand smoke exposure. Apparently similar preventive strategies could result in different outcomes.

Different results from similar strategies might not be strange to Confucius. This Chinese philosopher did not study modern biomedicine or public health, but he pointed out a crucial fact that medical and health care professionals nowadays could easily neglect: 'human natures are similar, their habits make them different.' Habit changing cannot be viewed the same as biomedical intervention by modifying genetic factors in human bodies, which are mostly universal across ethnicity and nations. Habits are behavioural patterns formatted by cultures, which an individual has been immersed in and has acquired from. Each culture presents reward or punishment to people when they select to internalise or reject certain values, attitudes, and beliefs from that particular culture. Smoking is a culture-coded behaviour. There are different values, attitudes, and beliefs attached to smoking in different cultures. Through advertising, tobacco firms try to link smoking with athletic prowess, sexual attractiveness, career success, adult sophistication, adventure and self-fulfilment. In China, smoking is commonly believed as an important social and cultural interaction medium. In Canada, smoking is viewed as a private activity so that even smokers agreed that there should be some sort of restriction on smoking in restaurants or other public buildings. Therefore, smoking prevention efforts will have to address and counter prevailing beliefs, values, and attitudes surround smoking in each culture respectively.

Habit changing propaganda can hardly be standardized across cultures. Smoking, drug addiction, and excessive alcohol consumption might have been viewed negatively as ‘unhealthy’ by people from many different cultures. Hence, public health professionals may still launch similar prevention and habit-change projects across cultures. By comparison, to convince people to become physically more active could have been a difficult
and different story. For example, sedentary jobs are more valued than physical labour in many cultures. Confucius taught his students to keep a steady and leisurely pace since they were well-educated gentlemen and senior governors. This tradition has been respected and passed on over centuries until it bumped into an English gentleman, Mr. Boris Johnson, Mayor of London, who put on casual clothes and walked fast in the Beijing National Stadium in 2008 to take over the Olympic flag for the London 2012 Summer Games. No Chinese officials could act as he did in Beijing or ride a bicycle to work in London. The Chinese governors would argue that they know how important it is to be physically active and keep fit. Otherwise, Beijing might not be so interested in hosting the Olympic Games. But their culture just discouraged them to move in a fast pace after they have reached a high-ranking position. One can imagine how hard it could be to create persuasive messages for the Chinese people to become more physically active.

Another ‘mission impossible’ is to provide advice on diet. A healthier diet, based on modern nutritional science might not be culturally appreciated and accepted. Gourmets, gastrologers, epicures, and gluttons have taste buds and stomachs designed by their cultures. Nutritionists have no seat in a party or festival just because nutrient contributions seldom make sense to the mind, satisfy the body, or integrate well with the atmosphere. Canada’s Food Guide to Healthy Eating published in 2007 was evolved from the original 1942 Canada’s Official Food Rules. The same intent underlies all of the guides between 1942 and 2007: guiding food selection to promote the nutritional health of Canadians. But the language softened: ‘Official Rules’ became ‘Guide’ in the title. Food choices, broadened to include diverse preferences and traditions of Canadian aboriginals and immigrants, have been added. Scientists gradually learned that food and eating are more cultural than natural when they revised the ‘Guide’ in the past six decades. In 2008, the ‘Guide’ has been translated into French, Arabic, Chinese, Farsi, Korean, Punjabi, Russian, Spanish, Tagalog, Tamil, and Urdu. Unfortunately, these publications were basically a literal translation. The pictures, examples, and recommendations were exactly the same as those in the English version. Bagel, pork, yogurt, cheese, and many other ‘common’ foods are used as ‘standard’ examples in the ‘Guide’ in 12 different languages. There was no consideration if a Chinese had ever known about bagels, or if a Muslim would consider pork for dinner. This example just reminds us how difficult it could be to create an interculturally appropriate and effective message related to ‘healthier diet.’

Habits are not universal but cultural. Yet they are much more real to a person than scientific rationality. Behaviour change advice based on assumptions such as how health risks could be perceived, understood, and accepted by people from different cultural backgrounds is blind to the contexts within which individual health experiences are located. Some
scholars, therefore, propose a ‘culture-centred’ approach to health communication that is grounded in interaction and consultation with community members. This suggestion emphasizes the vital role of culture in health communication. Nevertheless, should culture be centred? Where is medicine in health communication then? Or shall we have culture positioned as it should be in the realm of health communication but not necessarily centred? Have we measured how critical culture impacts on health behaviour changes? Do we know how culture may facilitate knowledge acquisition, behaviour change, and belief transformation? Furthermore, are there differences among people from the same culture but with different international and intercultural experiences? This chapter presents three research projects that attempt to position the role of culture properly and utilize culture effectively in health communication.

All three projects focus on knowledge, behaviours, and beliefs related to chronic diseases. In particular, ischemic heart disease (IHD) and cerebrovascular disease (stroke) are selected because they related more to habits like physical inactivity and biased dietary choices often viewed as less harmful or deeply rooted in some cultures. The first project compares East Indian-Canadians (N=102) and European-Canadians’ (N=102) knowledge, behaviours, and beliefs related to IHD. The second and third projects look at knowledge, behaviours, and beliefs related to stroke. The second one compares the differences between Chinese Canadians (N=103) and European-Canadians (N=103). The third project examines whether there are internal differences among Mainland Chinese (N=835).

These three projects adopted similar questionnaires primarily based on closed-ended questions from established tools and consisted of four parts: IHD or stroke related knowledge, health behaviours, health beliefs, and demographic information. The back-translation method was used to translate the questionnaire into Punjabi or Chinese. The questionnaire was pre-tested on a convenience sample of seven individuals and modified to enhance clarity of certain items.

The questionnaire assessed knowledge, behaviours, and beliefs related to IHD or stroke. Knowledge of IHD or stroke factors was assessed by asking subjects to respond ‘true’ or ‘false’ to the statements related to IHD or stroke risk factors documented in the literature. Five health-related behaviours related to IHD or stroke risk were assessed: physical activity, dietary intake, smoking, alcohol consumption, and stress management with a modified questionnaire used to measure dietary behaviour. Health beliefs related to IHD or stroke were assessed using the Health Belief Model (HBM). The model hypothesized that individuals will undertake a positive health action if they perceive the disease to be threatening (perceived susceptibility), if they believe it to have potentially serious consequences (perceived seriousness), if they believe the recommended action to be
efficacious (perceived benefits), and if they find barriers to practise the particular health behaviour (perceived barriers) to be minimal. In the questionnaire, nine subscales measured the following constructs: perceived susceptibility to develop IHD or stroke, perceived seriousness of IHD or stroke, perceived benefits about following a healthful low-fat diet (dietary benefits), perceived barriers to following a healthful low-fat diet (dietary barriers), perceived benefits of exercising (exercise benefits), perceived barriers to exercising (exercising barriers), general tendency to engage in health behaviours (health motivations), perceived self-efficacy about following a healthful low-fat diet (dietary self-efficacy), and perceived self-efficacy about exercising regularly (exercise self-efficacy). Items had a five-point response format with anchors at 1 (strongly disagree) and 5 (strongly agree).

Statistical Package for the Social Sciences (SPSS) version 11.0 software was used for data analysis. Descriptive statistics (frequencies, percentages, means, and standard deviations) were used to describe subject characteristics and knowledge, beliefs, and behaviours related to IHD or stroke. Results were analysed to distinguish differences among the East Indian-Canadians, Chinese Canadians, European-Canadians, and Mainland Chinese.

Cross-sectional descriptive comparative quantitative data analyses reveal that different mechanisms of knowledge acquisition, behaviour change, and belief transformation form the barriers to realize actual changes in those populations when primary prevention educational programs originally designed for European-Canadians were delivered without any change.

Acquisition of knowledge is different between European-Canadians and people of Asian ancestry. For example, primary sources of general information about stroke for Mainland Chinese were family and friends (33.5%), television (30.3%), and newspaper (27.8%). Better educated Mainland Chinese also read books and use the Internet to search stroke-related information. Doctors were ranked not as primary source (11%). This finding reveals the collectivist inclination in Chinese society, in which people are integrated into strong, cohesive groups and become interdependent to each other. Mass media, which are not usually viewed as trustworthy resources by European Canadians, are regarded as reliable knowledge sources in China.

Some behaviour is hard to change. The research projects found that East Indian-Canadians were less likely to modify their cooking style and their traditional dietary practices that encourage the consumption of foods high in fat. Such dietary acculturation difficulties were found by other researchers in Canada. Chinese respondents liked to add more salt or sugar than recommended in their dishes, which is another dietary habit hard to modify.
However, we also found that East Indian-Canadian women were more likely to have healthy dietary practices compared with men. Similarly, Chinese women were more apt to report diet and weight to be very important in health than men. This can be viewed as a key to promote healthier diet since many women are in charge of grocery shopping and cooking at home in those communities.

The mechanism to change behaviours is different. On the one hand, European-Canadians surveyed in these projects were more likely to identify factors related to an individual person such as a lack of self-discipline or a diagnosis with heart disease, to influence their participation in positive health behaviours. East Indian-Canadians, on the other hand, tended to identify factors related to their environment like the weather conditions. They expected their social support system such as family and religious leaders to influence their health behaviours. Dependence on familial support and religious faith in matters related to health and illness have been reported previously in South Asian groups. The tendency to rely on changes starting from externalities is also found in the Chinese community. The majority of Mainland Chinese respondents (53.9%) reported better living conditions as a way to reduce life stress, followed by better relationships with the family / at work (46.2%) and more money (32.7%).

Religion plays an essential role in shaping an individual’s health beliefs and these beliefs influence one’s likelihood of engaging in health promoting activities. Fatalistic attitudes toward disease causation in some groups of Indians makes them less inclined to alter their behaviours by effecting positive health changes in response to a diagnosis with heart disease in that they are less concerned with controlling their ‘fate’ compared with European-Canadians. They reported lower health motivation. This corroborates a previous report. A poor understanding of IHD risk factors may perpetuate a sense of helplessness and lack of perceived control over one’s health in this population.

Years in Canada appear to make little difference on stroke-related knowledge, behaviours, and beliefs when comparing new and old Chinese immigrants to Canada. International experiences have little impact among Chinese-Canadians and Mainland Chinese. This indicates that traditional Chinese culture dominates health knowledge, behaviours, and beliefs.

From intercultural perspective, these barriers and facilitating factors for positive health behaviour changes parallel the collectivistic cultural orientation suggested by Hofstede. To pursue a change in a collectivistic community, social support should be drawn on. Mass media can be used to provide knowledge. Key members of the household and religious leaders are the first to endorse health promotion activities to encourage participation in these behaviours. Familial and social obligations are the major factors to
empower individuals with Asian ancestry to pursue behaviour changes and belief transformation.\textsuperscript{34}

Lupton argued that efforts of Western health promotion are typically based on the universal logic of scientific rationality, draw upon individualistic assumptions about the constitution of health risks and hence are ignorant of cultural contexts, and are unresponsive to the socio-cultural-economic contexts within which health experiences are located.\textsuperscript{35} Neglecting collectivism, the current health education practice in Canada addressing self-efficacy may not function well in communities emphasizing collectivistic interests and harmony.

The general tendency found in the three projects, namely that Asians attribute their stress to environment and look for a cure from balancing good and evil forces, also reminds us of the importance of holistic health care. Holistic health care emphasizes health practices such as spirituality and patient-provider interaction. In other words, it calls attention to the human side of medicine where therapeutic process could be a dialogue wherein the doctor and patient ‘create the illness, its meaning, and the solutions’ together.\textsuperscript{36} Currently the inflexible and static disciplinary hierarchies, organizational structures, and day-to-day communication practices in Canada and other Western health care systems based on an acute disease care model ignore important relationship between health and relationship, environment, and supernatural wellness. Ellingson argued that the U.S. medical system is ‘neither natural nor neutral’, which serves ‘neither patients nor health-care providers effectively.’\textsuperscript{37} Recognition of cultural impact on health communication is apparently necessary to fix this shortcoming, though it shall not be exaggerated as the core of a cure. The respondents all liked to have their cultures be respected, considered, and integrated in health care procedures. But they did not see culture as a substitute for medicine.

The findings in diverse communities in Canada are valuable for other countries since Canada is probably one of the most ideal settings to examine intercultural health care. Canada presents pre-eminent characteristics of globalisation and subsequent challenges in modern health care.\textsuperscript{38} New immigrants keep on filling the Canadian health care system with different perspectives, expectations, and preferences. Different from those of a century or more ago, these new immigrants’ countries-of-origin have developed health care services and facilities now. China, for example, has hospitals practicing both Western and traditional Chinese medicine. These immigrants have convenient and frequent connections with their native cultures via modern communication and transportation technologies, which make them less willing to depend on, accept or trust what Canada can offer in health-related knowledge, behaviours, and beliefs. They have choices. They can shop around. Medical tourism can be viewed as a silent complaint. Primary prevention in the globalisation era is not to ‘standardize habits.’
Quite the opposite, it is to understand different habits and utilize their cultures to motivate habit changes.

Confucian teaching on the commonality of human nature and the distinction of their habits asks practitioners in health education and disease prevention not simply to distribute biomedical information. To design a persuasive message on habit changing requires examination of the individual and his or her community. One commonality of the surveyed communities with Asian ancestry in the three projects reported here is that the mechanism of change relies on collectivistic influence. Individuals in those communities will change their behaviours only after they obtain the knowledge from their families, friends, or mass media, see the behaviour changes in their communities, and follow the belief transformation of opinion leaders. Empowerment requires more than just information delivery and diffusion of technical innovations. Effective primary prevention is to work with individuals and communities at the grassroots pursuing intercultural understanding and knowledge exchange.

In conclusion, knowledge and beliefs about what constitutes important health practices may not necessarily translate into actual behaviours among people from different cultures. Simplistic messages emphasizing the benefits of positive health behaviours may be less effective in facilitating behavioural change in this group. Strategies such as targeting nutritional education toward the women and including specific advice for substituting traditional ingredients, modifying recipes, and changing food preparation methods, should be combined with risk factor education and strategies to enhance health motivation and accountability.

Notes

2 ibid.
5 ibid.
8 Ma, op. cit.
19 P Wang, op. cit.
20 G Rodrigues, op. cit.
22 P Wang, op. cit.
23 Rodrigues, op. cit.
24 P Wang, op. cit.
25 Rodrigues, op. cit.
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27 P Wang, op. cit.
29 Rodrigues, op. cit.
32 S Wang, op. cit.
33 S Wang, op. cit.; P Wang, op. cit.

Bibliography


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Section 2

The Power Struggle
The Military Metaphors of Modern Medicine

Abraham Fuks

Abstract
Medical discourse is replete with the language of war and such phrases as ‘the war on cancer,’ ‘magic bullets,’ ‘silver bullets,’ ‘the therapeutic armamentarium,’ ‘agents of disease,’ ‘the body’s defences,’ and ‘doctor’s orders’ are deeply engrained in our medical rhetoric. The mindset engendered by this discourse of war renders the patient as a battlefield upon which the doctor-combatant defeats the arch-enemy, disease. The reified disease becomes the object of the physician’s attention, displacing the patient as the interlocutor in the doctor-patient relationship. This shift of attention is exacerbated by contemporary imaging methodologies, and patients, who in Foucault’s clinic became open to the medical gaze, are rendered totally transparent, perhaps virtual. Diagnostics becomes centred on the putative agent and therapeutics revolves around extirpation and conquest. Arguably, the most important effect of this framing of medicine is the eradication of the patient’s voice from the narrative of illness. The dialogic construction of the narrative of illness is supplanted by the physician’s case record of his search for the physical seat of disease and the healing effected through the development of meaning falls victim to a militarized discourse. The military metaphors that pervade medicine undermine the ability of physicians and society to deal with the burgeoning burden of chronic illness.

Key Words: Metaphors, medical language, war, military discourse, narratives, doctor-patient relationship.

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1. Introduction
Modern medicine has achieved stellar successes in dealing with acute infectious diseases and modern surgery has developed remarkable tools for repairing and replacing many organs and parts of the body. Despite these accomplishments, the public arena is filled with discussions about the ‘crisis in medicine.’ Indeed, health care is a major topic of political debate and a recurring feature of public policy forums in Canada, the United States and the United Kingdom. Physicians complain about third party interference in medical decision-making and young graduates, concerned with the quality of their own lives, choose non-traditional modes of practice in clinics with fixed hours and interchangeable doctors. Patients are concerned with flexible and easy access to their physicians, continuity of care, and, most of all, seek a physician who will listen to their needs and concerns. Perversely, the length
of the typical medical interaction has shortened substantially and the patient community has increasingly turned its attention to ‘alternative’ healers - at a time when medicine can actually provide greater benefits than ever before. These social, economic and political forces have resulted in enormous strains in the doctor-patient relationship, the arena for diagnostic and therapeutic interventions, and have cannibalized the medical interview, and perhaps the clinical relationship, without which medicine devolves to a mechanical and technical pursuit within a chaotic system of care delivery.

How can one understand this paradox? What might explain the dissonance between the daily evidences of success, for example, hip replacements, cataract surgery, cardiac angioplasties and renal dialysis, on the one hand, and the common complaints by patients that doctors fail to listen to their concerns? Why is contemporary practice stroboscopic in character, with physicians interrupting their patients’ narratives within seconds of the beginning of their stories of illness? This chapter intends to make the case that the language and metaphors of contemporary medical discourse express and reflect the stresses in the doctor-patient relationship and, more importantly, that this discourse is, at least in part, responsible for shaping the behaviours that characterize the practice of medicine today.

The language of medicine, both lay and professional, is thoroughly infused with the language of war. Kathleen Sebelius, the newly sworn-in Secretary of Health and Human Services in the United States announced in her first press conference, ‘We’re determined to fight this outbreak,’ referring of course to the swine flu, ‘and do everything we can to protect the health of every American.’ The World Health Organization raises the alert levels for epidemics as the Pentagon does for a terrorist attack. We speak of the ‘magic bullets,’ and ‘silver bullets’ of ‘the therapeutic armamentarium’ targeted to destroy the ‘agents of disease.’ Presidents and prime ministers announce ‘global combats against malaria’ and ‘wars on cancer,’ the latter propounded by President Nixon in 1970. We are told to eat well to strengthen ‘the body’s defenses,’ in preparation for ‘the battle against infections,’ and to avert ‘heart attacks’ and sidestep ‘killer T cells.’ Little wonder that oncologists fight ‘fire with fire’ as tumours are ‘locally invasive,’ ‘aggressive,’ ‘silent’ and ‘widespread’ or ‘under control,’ precisely consonant with an imperialist, militarized view of malignancy. Of course, the ‘battle’ cannot be won without following ‘doctors orders.’ The war metaphor is so familiar and commonplace in our medical rhetoric that we easily lose sight of its militaristic origins and significance.

Though some have attributed this metaphoric stance to the advent of the germ theory of illness of the late 19th century, such language can found as early as in the works of Thomas Sydenham in England in the mid 17th century. Sydenham noted a physician to be one is who is well equipped, thus, ‘In eradicating a chronic disease therefore, whoever is possessed of a
medicine, powerful enough to destroy the species of it, justly deserves the appellation of a physician.\textsuperscript{13} He described his system of therapeutics as follows, ‘Meanwhile I attack the enemy within by means of cathartics and refrigerants, and by means of a diet of the kind described;\textsuperscript{14} and the difficulties of clinical work by noting, ‘A murderous array of disease has to be fought against, and the battle is not a battle for the sluggard.’\textsuperscript{15} Finally, this physician, known as the Hippocrates of England, depicted the work of the practitioner with this phrase, ‘I steadily investigate the disease, I comprehend its character, and I proceed straight ahead, and in full confidence, towards its annihilation.’\textsuperscript{16}

Published almost three hundred years later, the following three book titles illustrate the continuing persistence and pervasiveness of the military in medical discourse, both in the formal medical literature and the public press: Robert N. Proctor, \textit{Cancer Wars: How Politics Shapes What We Know and Don’t Know About Cancer}\textsuperscript{17}; Karen Stabiner, \textit{To Dance with the Devil: The New War on Breast Cancer}\textsuperscript{18}; and Roberta Altman, \textit{Waking Up, Fighting Back: The Politics of Breast Cancer}.\textsuperscript{19}

2. \textbf{Reification of Disease}

This military metaphoric language reflects and parallels a centuries-long cultural process of the reification of disease, starting with Sydenham, who saw diseases as distinct entities and species and undertook their classification much as Linnaeus had organized the flora and fauna in biology. Sydenham’s intent was to achieve a classification by criteria that could then lead to clear therapeutic choices in purging, bleeding and the like in releasing the ‘morbific matter’\textsuperscript{20} and restoring the balances of the humours. Nonetheless, the ontologization of illnesses as independently recognizable disease entities represents the first stage of the shift of attention of the physician from the patient to the disease entity. This redirected medical gaze was later focussed by the early pathologists on the morphologic evidence of disease within the body, and, with the introduction of the microscope, on increasingly smaller portions of the patient. The pioneers of the Parisian school of clinical medicine laid the foundations of the modern clinical method by developing methods for ascertaining the presence of disease by external clinical examination, and made the embodied disease visible to the medical gaze, as described by Foucault.\textsuperscript{21} I would argue that the biochemical and molecular understanding of disease characteristic of the 20\textsuperscript{th} century has pushed this trend along its vector of reification and reduction to the point that a genetic disease may be thought to reside in a misshapen molecule due to an error in DNA orthography. The patient’s body has become superfluous to the molecular physician; now not simply open to the medical gaze, but rather completely transparent to it. Magnetic resonance imaging aims to visualize pure disease, untainted by the patient or his body, and tissues are merely
ghosts on the computer screens of the MRI output. The psyche, totally invisible and ephemeral from the stance of radiologists and molecular pathologists, has been left behind on the analyst’s couch.

The earliest examples of this reification of the patient’s illness into the physician’s disease, to use a distinction proposed by Arthur Kleinman, use the word ‘conquer’ to indicate a battle between ‘nature’ and the disease in which the protagonist is the ameliorative power of nature that leads to the resolution of the illness with little or no physician intervention. However, should this natural process not have proven sufficient to the task, the protagonist becomes the combatant physician battling the enemy, the disease. There are no instances of the patient taking up the fight, as it were. Contemporary uses of the metaphor treat the enemy as the disease but one can again distinguish two subtypes, one in which the patient is the fighter, and another in which the doctor is cast as the disease slayer. The latter is the more common of the two, though the website of the Canadian Cancer Society envisages a partnership with its French slogan: ‘le cancer: une lutte à finir’ and that of its American counterpart in the US asks us to ‘Join the Fight Against Cancer.’ The British analogue, Cancer Research UK, issues its own invitation with the pronouncement, ‘Together we will beat cancer.’

Far more common in the modern discourse of medicine is the physician taking up therapeutic arms against the enemy, disease, towards its eradication. Though attractive at first glance, for who could gainsay the eradication of smallpox as an epidemic illness, the consequences of this metaphoric stance are broad and perverse. First and foremost, the reified disease has not only become the focus of the physician’s attention, it has become the interlocutor in the relationship, supplanting the patient. That individual in turn, has been relegated to the passive status of battlefield, in keeping with the state entailed by the term, patient. Thus, the interface between physician and patient, the central arena for the development of trust, meaning and healing, disappears as the medical gaze shifts to the disease, and, as noted previously, is increasingly removed almost in stepwise fashion, from the sickroom of the 18th century, to the pathologist’s bench of the 19th century, the imaging room of the 20th, and the DNA sequencer’s computer screen of the 21st.

Diagnoses

The shifts of locale for the diagnostic act are the result of increasing technological sophistication from the stethoscope to the MRI machine and the human genome project. This development reinforces what Charles Rosenberg has called the ‘tyranny of diagnosis,’ once again putting the doctor’s desire for diagnostic clarity ahead of the patient’s need for relief of suffering. In fact, while the surgical hero is the one who removes a tumour or repairs a coronary artery, the physician’s hero is the Sherlockian or Oslerian
diagnostician. While the relief of uncertainty that attends an accurate diagnosis can be helpful for the patient, it can hardly substitute for the development of personalized meaning relevant to the particular patient and his unique variant of the illness in question. The quest for diagnosis pins a label on the enemy and provides a target for the therapeutic attack; it is also a taxonomic act that erases the messy individuality of the particular patient. Thus, while illnesses are unique, diseases are abstracted archetypes relevant to the physician and, perhaps as important, to the modern hospital administrator and insurance provider who rely on diagnostic categories for their spreadsheets and payment schemes. Within the prevailing metaphoric framework, therapeutics becomes a final act of conquest, whether by purging, by drugs or by the fleam. All revolves around elimination and extirpation with little contribution from the passive patient. In this reified construction, preventive medicine is assigned to develop a security cordon to thwart an attack by an enemy invader, reflected in the recent discourse around the flu pandemic. In the case of non-infectious diseases, preventive medicine has been transformed into a search for disease at its preclinical stages, and thus, readily susceptible to conquest. Again, this strategy is reminiscent of the early warning systems of anti-missile defences.

Most exemplars of the military metaphors cast the physician in heroic terms, in many instances as the individual responsible for identifying the reified disease resident in the patient’s body, naming it and arranging for the means of extirpation or elimination. Modern medicine’s chemotherapy, whether antimicrobial or antitumour, is the analogue of Sydenham’s ‘medicine, powerful enough to destroy the species of it [disease].’7 The self-evident successes in treating bacterial infections have served to entrench this construct and reinforced the positioning of disease as the physician’s natural enemy, leaving the patient as a bystander and spectator to the fray. In order to understand why this displacement is so important, one must examine its impact.

4. The Patient’s Voice

As disease became ontologized, the patient’s voice began to disappear from the chronicle of illness. Mary Fissell has described that in the mid 18th century, a physician’s notes quote the patient’s own words.28 By the end of century however, the narrative is in the words of the doctor and the patient’s voice is gone from the casebook. At the outset of the century, the narrative was constructed by the patient as a historical and idiosyncratic explanation of causality and meaning rooted in her own individual history and experience. The physician often recorded and accepted these models, basing his diagnosis and treatment upon them. The physician was also keen to serve the patient well as a continuing source of his livelihood. With the shift to the hospital and the clinic, the agent with greater autonomy is
increasingly the physician rather than the patient. Moreover, with the
growing impact of scientific technologies, reified diseases become known to
the clinician (and pathologist) through a series of abstractions increasingly
removed from the patient. These were first seen as physical signs, moving to
x-ray and MRI images and arriving at molecules in this century. The
casebook now reveals only medical jargon and the physician’s words,
however sparse—the doctor has abducted the narrative and transformed it into
a genre not recognizable by patients. As Fissell describes, in England in the
1770’s, 70 percent of all diagnoses were in English, and 19 percent in Latin.
A mere three decades later, 79 percent of all diagnoses were in Latin; only 1
percent were still in English.” An instruction to a medical student of that era
quoted by Fissell aptly captures the transition: ‘give early Relief to your
Patient and it will be a means of gaining his confidence and esteem, then
attack the Disease more radically.”

The loss of the first person story is emblematic of the transformation
of the patient from author and owner of the narrative, whose very uniqueness
served as a means of explicating the mysteries of illness, to a passive,
generic, and often solitary observer of care. The patient’s story, especially
when validated by the attendant physician, aided in the reduction of
uncertainty and served in the construction of meaning without which the
experience of illness is fraught with fear and anxiety. All reflexive
descriptions of illness, including those by physicians of their own
experiences, describe the loss of control and the disorientation that
accompany the inability to participate in the affairs of daily living and the
uncertainty that attends the sudden, unexpected onset of illness. In those
instances where we also expect the patient to be a ‘fighter’ who must ‘resist’
being ill, the state of sickness can be complicated by a feeling of having
failed to achieve the suitable level of the ‘desire to win.” Thus, we
compound the injury of disease with the social insult of failure.

5. From the Battlefield to Eden

The ability of the physician to help patients while working within
the current reified model depends in part on the nature of the illness for
which the patient seeks help. That is, the construct of eradication may not be
counterproductive where the illness is one in which a clear and rapid
diagnosis can be made and is generally susceptible to cure. But, anything
short of ‘complete victory’ will not suffice. In disease, as in war, partial
victories are more like unsatisfactory stalemates rather than welcomed
successes - in any event, they are most appreciated by those who leave the
field early, when winning is a declared fiction rather than reality. No matter
what one calls it, the battlefield remains occupied and the patient’s suffering
remains unknown to all but the patient. Yet, few illnesses fit this clear-cut
mold any longer. Many patients are afflicted by maladies that have no name,
yet whose suffering is real. Further, the major disease burden in this new century is chronic illnesses that can be greatly improved but hardly cured. Amongst others in this group are cardiac disease, chronic inflammatory conditions of the joints, connective tissues, lungs and bowels, diabetes mellitus, mental illness and increasingly, malignancy. Add to these the incurable ailments of aging, and we are dealing with a vast battery of illnesses for which medicine offers few cures but, by contrast, very powerful means of ameliorative care. Hence, modern illnesses do not lend themselves to rapid cures and cannot be extirpated. Hypertension cannot be cut out, nor can diabetes mellitus be destroyed. Thus, military metaphors undermine the ability of physicians and society to deal thoughtfully and effectively with the growing prevalence of chronic illnesses. In fact, there are hints of new metaphors of renewal, springtime and blooms that accompany discussions of regenerative medicine and stem cell therapies. We may yet witness a shift from warlike eradictions to edenic fountains of youth.

6. **The Paradox**

The contemporary paradox is thus not simply a result of nostalgia for the good old days of kindly physicians. It reflects the outstanding capacity of a highly technical medicine to work wonders for those diseases that capture the attention of physicians while its practitioners fail to recognize and acknowledge the sufferers that sit patiently while the doctor addresses the ubiquitous computer screen. Given that declarations of war are limited in their capacity to support a conversation, the arena of the sickroom and clinic are bereft of a language that can be shared by patients and their physicians. The healing capacity of the listener needs a phenomenological fusion of horizons with the speaker, or at a minimum, shared goals and the acknowledgement thereof. Given the powerful guiding force of a metaphor that redirects the physician’s attention and intent, it is not surprising that patients continue to search for an interlocutor who has long since left the clinical arena.32

The capacity to listen attentively and actively is a skill necessary to the proper practice of medicine and an integral part of the clinical method. In this context, the clinician’s capacities and habits, call them art or science, are crucial to curing, caring and healing. These are not the add-ons of a medical finishing school that provide a veneer of communication skills to make patients ‘feel good.’ The personhood of the physician is intrinsic and foundational to his capacity to relieve suffering. Lifelong learning is effectively the continual becoming and development of those clinical skills and not simply the accumulation of new knowledge. These needed skills are closer to the evolution of wisdom, or more properly perhaps, Aristotelian *phronesis*.33 It is through the deepening of the physician-patient relationship that the skills become rooted in the morality of medicine. It is through the
recognition of the patient as a significant other, an alterity that has a natural right to respect and one whose personhood is at once at stake and the focal point of the obligations and duties of the doctor, that we finally discover the moral grounding of the profession.

Lastly, it is not simply for patients that medicine must create new metaphors. What is also at stake is the very persona of the physician whose own identity cannot be rooted in warfare and assaults. When physicians forget how to listen to their patients, they also become deaf to their own souls.

Notes

Abraham Fuks

16 Ibid., p. 33.
20 Sydenham, 1848, op.cit., p.112
27 Sydenham, 1788, op. cit., p. xlv.
The Military Metaphors of Modern Medicine

29 ibid., p. 103.
30 ibid., p. 95.

Bibliography


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Construction of a Non-medical Point of View Regarding Medicine and Health: An Example of Self-injury Internet Forums

Baptiste Brossard

Abstract
In the last decade, growing areas of expression on the Internet that deal with health raise the question of the perception of medicine and health by individuals. Based on a qualitative sociological survey conducted since 2006 on forums devoted to self-injury behaviours and its members, we show the impact of these forums on ways of thinking about this problem and its medical treatment. Possibilities of discussions between individuals who suffer from the same ‘mental disorder’ – which is ‘taboo’ in other scenes of social life – create for each member an extended network of acquaintances and, therefore, occasions to discuss relationships among patients and psychiatrists, medicines, viability of diagnoses and therapies. How does this change the choice modalities of psychiatrists by these potential patients and affect their trust in treatments? Through a precise focus on forums where self-injury behaviour is discussed, we bring to light the concrete logics of the construction of these points of view on self-injury and psychiatry, through relationships between forum members, which will lead us to discuss the potential impact of these forums.

Key Words: Self-injury, self-harm, forums, internet, psychiatry, mental health.

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In this text, I ask how the Internet is changing the relationship between its users and their mental health problems. Starting from this general question, I will focus on self-injury behaviours, and Francophone forums that deal with them. How do these spaces lead people’s ideas of their mental health? Do these forums influence the choice of medical treatment, and do they orient the patient/psychiatrist relationship?

To give a quick definition of self-injury, this is the voluntary, regular practice of self-harming. It is done without any will to die, provides neither aesthetic value nor sexual pleasure, but is motivated by an overwhelming angst, a ‘mental’ suffering. More specifically, the practice consists in the cutting, burning, and hitting of oneself. It often starts to develop during adolescence, amongst girls, but it could begin before or after
adolescence, from the age of twelve to thirty, as well as amongst men and boys.

Although this behaviour is of a solitary and intimate nature, there are currently four Francophone forums that are devoted to self-injury behaviour. The mission statement of these communication spaces is to provide ‘mutual aid,’ through the establishment of collective debates, an exchange of experiences, or a search for help or attention. The very existence of these forums leads to a conclusion in itself: self-injury behaviour is considered as ‘taboo,’ but the Internet gives a collective sharing of these intimate practices.

My work is based on a sociological survey, which has been in progress since 2006, on these forums: I proceed with the observation of forums and with focused interviews with about fifty members. I also conducted a quantitative study regarding public opinion within the forums about psychiatry: all messages that give an opinion on psychiatrists, or relate consultation experiences and care trajectories, have been assembled into a corpus. This corpus has been analyzed by ALCESTE 4.5 (Analyse Lexicale par Contexte d’un Ensemble de Segment de Texte), textual statistical software.

Concerning the research literature on this topic, three kinds of publications can be found:

1. Health sociologists have noticed that an increasing number of individuals have access to medical information. The Parsonian model, which considers the patient as a passive actor, is being abandoned in favour of a more interactive approach: the relationship between doctors and patients doesn’t seem to be as asymmetrical as it first appeared, and we can talk about a ‘new figure of a rational, informed and active health consumer.’

2. Further findings have led authors to account for interactional and contextual aspects in the study of medical categories, as shown, for instance, in the inclusion of the effects of post-traumatic disorder into the Diagnostic and Statistical Manual (DSM) after pressure from Vietnam war veterans.

3. Patient associations are not a new phenomenon (they emerged in France after the First World War), and research on the internet shows how these previously evoked trends are reinforced by new communication technologies. For example, Cécile Méadel has demonstrated how the Internet is for parents of autistic children a way of broadcasting their opinions on
psychiatry, and of discrediting psychoanalytic theories regarding autism. In Globally, the Internet is an increasingly powerful information tool and has made academic knowledge more accessible to the layperson. In 2006, 50% of the Internet users used the internet to search for information regarding health, sometimes to confirm professional views and diagnoses.

3 Sociologists who specialize in youth studies are interested in the internet as a new common way of sociability, integrated to daily life, and favouring intimate talks: a tendency that is correlated with the individualization of access to the Internet in families.

On this basis, it can be stated that the general population, but in particular the younger generation, is increasingly using the internet for information concerning health issues. I will look at this process, taking self-injury as a particular case study because it is still considered to be such a ‘taboo’, and has not yet been properly categorized into the medical world. However, before dealing with this, I will focus on the operations of the chosen forums.

1. Internet Forums: Sociologically and Historically Contextualized Spaces

Although we often consider the internet as a unified medium, I prefer to conceive forums as differentiated, socially and historically contextualized spaces. To make a sociological comment on the internet forums, we must abandon the idea that these ‘virtual’ spaces are totally free, totally unstable, and totally without any past. Although people can connect to others and write on the message boards in a seemingly free and limitless way, without any material or physical engagement, this is not to say that permanent forms of organization and social relations do not exist.

A. History of Forums

As regards Francophone forums that are dedicated to the self-injury issue, observations and interviews with forum members that have been carried out since 2006, show how forums have developed over the years. So we are able to assemble a history of their existence that defines the identities of these forums. This history, in turn, provokes and encourages discussion. Several things occurred:

Before 2000, no forums about self-injury existed. Internet users interested in this subject went to other sites: more generalist Francophone
sites or specialist Anglophone sites. This step is important because many rules and ideas of current forums derived from this.

Later, one site monopolized the studied space for four years, from 2000 until 2004: AM.org. Because of its success, which led to a very high volume of visits, it led the way with a harmful example of the pattern that should be followed for shared, collective experiences: impersonal, and with a lack of moderators. This partly explains the strictness of the rules currently applied in the forums that are now ruled by older members. The forum Secret Harms, created in 2004, is very strict for precisely this reason: describing injuries is forbidden, and its members have to try to analyze their experiences. Its creator has stated openly that she chose these rules in direct contradistinction to those followed by AM.org.

When AM.org lost its momentum, many new forums emerged, but they did not last a long time. Only Secret Harms still survives. Indeed, since 2006, a new structuring has taken over, because other forums have begun to stabilize: Secret Harms, Solidarity AM, which are the strictest, and two other forums. It should be noted that, members who are afraid of the strict rules of the two first forums often migrate to the latter two, which were created by younger people who never knew AM.org.

This brief overview is intended to show a form of historicity on the internet, that may be taken into account in the analysis of what is said in these forums, according to different kind of configurations: no sites, monopoly, more or less structuring.

B. Explicit and Implicit Rules

Rules are an important question in forums, and especially as concerns self-injury: ‘misbehaviour’ can easily happen, as can suicide threats, harmful blackmail and false information. How can forums be made more stable and longer lasting in this unstable material framework? This question needs to be contextualized in these terms: What degree of injury description should be allowed? Should photographs of injuries be authorized? What other rules should be established to prevent misbehaviour?

In addition to formal rules, which can consist in prohibited descriptions, emotional blackmail and quantitative descriptions (size and depth of cuts for instance) to avoid any form of ‘competition’ between members, there are also some informal rules, which play a fundamental role. First, as in all social groups, there is a form of social control: responses and collective attention to messages define, more or less tacitly, the legitimacy of what is written. To successfully participate in these forums, a newcomer has implicitly to apply this norms, for instance there is a certain way of talking about self-injury, being careful to spell correctly, and so on.

Second, there is evidence of a self-selection of the public forum, which filters members according to their adherence to rules and
‘atmospheres.’ In other words, this is a kind of self-selection by the ‘taste,’ which targets the sociological profile of potential newcomers.

C. Two Examples

For instance, in Secret Harms [‘Blessures secrètes’], the aesthetics of the site gives a serious impression: the header is very simple, the colours are plain, and there are no images. The title of the site appears in a minimalist format, with a medical edge to it. The seriousness of the forum is also apparent too from the body of the page: white as the dominant colour, no animation, and so on.

![Welcome Page of the Web Site Automutilation: Blessures secrètes (Secret Harms)](image)

We’ll Get By [‘On va s’en sortir’], in contrast, displays a series of the various stages of suffering, using juvenile graphics. Light colours, and happy icons are intended to evoke the wallpaper in a child’s bedroom. This atmosphere ultimately reaches out to sympathy and warmth. Sentences are encouraging, ‘you won’t be judged,’ and there are spelling mistakes, which contrasts with the sobriety of Secret Harms.
It is not surprising, therefore, that the members of Secret Harms are, typically, older and better educated than those of We’ll Get By, though it must be acknowledged that the information given by members is often unreliable, so it is difficult to obtain accurate information about the social profiles of members.

D. The Internet as a Differentiated Space

This introduction serves to demonstrate that each social space in the Internet is governed by rules and standards: if some general conclusions can be reached regarding the use of the internet and its influence on different elements, it cannot yet be regarded as a unified entity. Rather, it seems appropriate to replace each finding in its historical and sociological context of studied spaces. It is important to keep in mind that historically, implicit and explicit rules lead to an orientation of social characteristics of the public that can be informally accepted in each space.

Whilst these arguments may seem like trivial details, it is noticeable that more and more journalists and psychiatrists base their articles on the study of messages found in forums. In France, journalism and scholarly articles on self-injury are, most of the time, based on interviews with
members of forums. These interviewees then become representative, without meaning to, of self-injurers, for the viewers and readers of these reports. But the speech they present is previously constructed by socialization on forums.

2. **The Construction of a Category and Its Consequences**

These points of view are even more interesting because the category ‘self-injury’ has not yet been fully recognized in the medical world. According to psychiatrists and forum members, self-harming is not a recognized disorder in itself but is considered as a symptom. How does the act of frequenting these forums affect people’s conception of self-injury?

A. The Term *Automutilation*

The French word ‘automutilation’ [literally ‘self-mutilation’], which is often translated by ‘self-injury,’ is the most frequently used word by the internet users, sometimes shortened to the initials AM. Forums are named according to this appellation. But more and more psychiatrists disagree with using this term because of the lack of specificity: ‘automutilation’ can refer to the mutilation of a body part. They prefer instead ‘blessures auto-infligées’: ‘self inflicted harm’ or ‘scarifications.’

For some members, the very existence of a word has created a rediscovery of their practice. Some respondents say they did not know before looking at these forums that there was a term to define such a practice. In fact, some of them had never imagined that other people might also be injuring themselves voluntarily. At least two types of reactions can be observed:

1. strengthening the awareness of having a ‘pathology’: ‘If a word exists and is discussed in forums and by psychiatrists, my behaviour is, in fact, the symptom of a real mental disorder.’

2. relief that they are not alone: ‘Others do it, so I’m not crazy.’

B. Self-definition and Consequences on ‘Real Life’

It is particularly interesting to look at messages from newcomers. They often begin their participation in forums by asking those who have been members for longer time periods if their practice - for example excessive nail biting, cuts up to any degree, hitting the wall - can really be defined as self-injury.

But psychiatrists themselves have not yet reached consensus on the definition of self-injury behaviour. And the most influential members of
forums try to define it in a way like that of the psychiatric point of view, which is paradoxical. The common opinion in forums, under the guise of some psychiatric notion, consequently constitutes the principal way of describing self-injury ‘well.’ This has led to a general attitude, namely that psychiatrists who do not have the same definition are ‘bad’ psychiatrists. Thus a judgement of psychiatry is made without any initial will of activism.

This mechanism of definition - or rather self-definition - has many repercussions in the non-virtual life: it is used as a way of communicating to others, gaining trust, and judging the seriousness of the practice, because this practice can be contextualized within other real life stories. Being able to position one’s behaviour within a pre-defined range of degrees, and to understand self-injury more generally, makes it easier to explain the problem to one’s friends: contrary to usual belief, the frequenting of forums actually seems to encourage dialogue ‘in real life.’

3. Postures Toward Psychiatry

Psychiatry is obviously a common topic of conversation in forums, because relationships with therapists appear to be essential in the daily lives of members who consult, as well as for those considering a psychiatric follow-up. Message boards can deal with individual practical advice or personal stories. They can begin too from larger questions such as ‘What do you think of psychologists?’ There are also messages that concern certain medications.

After study of the corpus of all the messages about relationships with psychiatry in the four forums, I now describe and analyse how frequenting forums orients the conception of psychiatric care.

A. ‘These People who Look at You Without Saying Anything’ - The Mystery of Psychiatry

The most striking aspect of the corpus is a great misunderstanding that clearly exists amongst the members of the forums. Psychiatry is viewed as a kind of strange and incomprehensible profession, and consultation with psychiatrists as some kind of mysterious moment.

Forum users often feel they have missed the point, especially at the end of consultations: ‘These people who look at you without saying anything’ is a representative expression of this misunderstanding. Silent moments seem to be the most terrifying part of consultations. Another source of surprise is the frequent prescription of drugs after very short consultations. Concerning differences among psychologists, psychiatrists, psychotherapists, and so on, there is also a certain degree of confusion and a large number of errors in their definitions.

In addition to the mystery that surrounds the psychiatric consultations, the effects of the therapies are also mysterious. As another
member said, ‘I have been seeing a psychiatrist since late January 2008 and it is going very well, but paradoxically, I am not any better.’ Psychiatrists are actually seen as a confidante, sometimes making the sufferer feel slightly better, and who could be said to be almost as important as a boyfriend or girlfriend: ‘I looked for a psychologist for 6 months […]. It helped me in so far as she partially restored my self-confidence. I think she has targeted a part of my problem, and since it is better (but meeting up with my boyfriend is at least twice as effective).’

B. Talking about Psychiatrists

An analysis by the textual statistical software ALCESTE 4.5 breaks down three kinds of lexical structures in discourse about psychiatrists. The first category is a narrative one, within specific vocabulary: appointments at the psychiatrist, consultations, prescriptions, money, time expressions, and so forth.

The second one is devoted to the hesitations in reaching decisions about whether or not a follow-up consultation is necessary. Words that appear frequently include: ‘to help,’ ‘to speak,’ ‘to change,’ ‘to understand,’ ‘parents,’ ‘to say,’ ‘to desire,’ ‘to try,’ ‘useful,’ ‘courage.’ The word ‘fear’ is often employed too, to describe apprehension about consultations. There are also many verbs associated with relationships, which are closely linked to the usual way of talking about psychiatry.

The last category is the most interesting because the lexical composition is more complex. By reading messages in this category, one can draw out their normative goal; this includes all debates regarding what makes a good psychiatrist. Two types of vocabulary are present here. On the one hand, there are some technical words: ‘situation,’ ‘relation,’ ‘to act,’ ‘patient,’ ‘to control.’ On the other, a very sensitive lexical field is mobilized: ‘to cry,’ ‘feeling,’ ‘pain,’ ‘painful,’ ‘tears.’ Debates are made up of two types of arguments, some of them using a professional lexicon, some a highly personal and emotional one.

C. Criteria That Make ‘A Good Shrink’

By looking more qualitatively at these messages, we can see that these forums gradually create a set of criteria that describe what makes a good or a bad psychiatrist. Indeed, to disqualify a psychiatrist, professional arguments are employed: someone is incompetent or does not know how to do his or her job. Professional mistakes are raised too: confidentiality, discretion, and then the time accorded to consultation – in relation to the price of a consultation.

However, to judge the positive value of a psychiatrist, more personal qualifiers are usually employed, and this explains the differentiation of vocabulary previously mentioned. To give a representative example, one
member says: ‘I have already consulted a psychiatrist, but he was incompetent. [...] One day I got so tired, so I changed to an adorable psychologist.’ Incompetence is opposable to adorable. ‘Mine is very nice and loves me a lot I think ... she tells me a lot of compliments.’

A common thread on all four forums is that it is really necessary to change one’s psychiatrist until one who fits is found. The very emotional vocabulary used for them is similar to the language of romantic relationships, at least expressions that are literally the same in French: ‘find the good one,’ ‘this is not the one that you need,’ and so on.

D. Opinions on Psychiatry and the Internal Organization of Forums

Expressed opinions towards psychiatry depend on one’s role in the forums. ‘New members’ are more radical in their messages; some of them ‘burn psychiatrists at the stake,’ while others, in contrast, give a very favourable view of psychiatry.

More experienced influential members show more moderate opinions. But it does not mean that they are more moderate since those members who hate psychiatrists do not bother to enter into discussions on them. This aspect is probably explicable by the respect in the forums for moderate behaviour. Influential members who want to be respected have to rely on their personal opinion and experience to give the most moderate council to newcomers.

Further we can find in each forum some ‘pro-psychiatry’ moral entrepreneurs (in the sense of Howard Becker’s use of the term). They are influential members, often psychology students, sometimes sons or daughters of psychologists, who promote the benefits of psychotherapy. These members intervene in every message that is about relationships with psychiatrists, to emphasize the positive aspects of therapy. As influential members who are sceptical towards psychiatry refrain from comment, these moral entrepreneurs play an important role because they are often the only influential members to guide newcomers on these issues.

Finally, even if in forums there is evidence to suggest that the majority of the members are very sceptical about psychiatry, they still tend to encourage consultations, which allow forum administrators to disengage themselves from the total responsibility of members’ actions. I collected many stories where people decided to see a therapist, under pressure from members of the forum, when they had reached a dead-end.

5. Conclusion

We can synthesize the findings of this report into three main ideas:

1. It is important to link the organization of forums with the ideas that they diffuse.
Some dominant opinions regarding self-injury and psychiatry emerge from forums, but they are definitely opinions rather than open claims.

Surprisingly, the frequenting of forums seems to lead to an opening up of its members to their friends, and to psychiatric follow-up.

Notes

Bibliography


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The Legitimacy of Alternative Medicine: A Question of Science or Social Ethics and Cultural Politics?

Archie Graham

Abstract
The present chapter addresses the critical issue of scientific validity in the current debate between mainstream medicine and alternative health and wellness practice, particularly the critique by advocates of conventional biomedicine that alternative practices are irrational and unscientific. This debate is not merely about science or just about different technical approaches to the treatment of disease. Other forms of medicine like Chinese herbalism, Indian Ayurveda, European homeopathy and aboriginal practices, are marginalised by the dogmatic vocabulary of dismissal as unscientific, superstitious, or worse, as metaphysically inspired quackery, even though those who make these statements usually have little or no knowledge of the cultural foundations of the methodology they are condemning. The debate is more about conflicting metaphysics and belief systems, ethical principles, and cultural politics, all of which are promulgated through widely recognised instruments of medical power and authority for establishing the legitimacy of how illness should be treated and what counts as treatment. A question never asked: if science is the measure of the validity of medical methodological and even epistemological integrity, how is science itself validated?

Key Words: Medical heresy, fallacy of defamatory association, rhetoric of denigration, methodological bias, systemic misreporting, nature's creative ecology, science's hidden metaphysics, boundary questions, missionary politics, medical colonialism.

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1. Introduction
On the one hand, I am coming at this issue from the outside, as a philosopher. On the other hand, I am coming at it very much from the inside, as a patient. Like many others, I arrived at alternative medicine because I suffered from a stubborn chronic condition that my family doctor, bless her heart, could not deal with alone. At first, she sent me to one specialist after another, allergists, GI specialists, and infectious disease experts. I was subjected to a battery of tests, and received some help along the way, but no sure diagnosis and little lasting relief. In the end, it was my family doctor who, by virtue of her first-class diagnostic skills and refusal to capitulate to the parameters imposed on her practice by her profession, helped me to take the first steps towards discovering the underlying medical problems. At my
request, she agreed to run a blood test for heavy metals, even though she had no clinical evidence at the time that this could be a factor in any known disease, and she discovered that I had unusually high levels of mercury in my blood. I had become aware of this issue after reading a book on the dangers associated with dental amalgams, the fillings that include mercury. As an inveterate teeth-grinder, I had ground my amalgams until they released mercury into my mouth and blood stream. Subsequent to this I consulted with multiple medical and non-medical naturopaths, most of whom were, at that time, being subjected to harassment by the Ontario College of Physicians and Surgeons. With their help, however, and my own research I found a way to eliminate the mercury from my blood. It was only after this had been achieved, that I started to develop the capacity to manage the numerous health conditions I was suffering from. Today, I still consult the same family doctor, but I also regularly see a naturopath, making use of each one when the need arises in the ongoing management of my health. Both my doctors are MDs, although both are atypical in that the one is open to cooperating with alternative practitioners, while the other has developed his own independent naturopathic practice, one of the best known in Canada. Both have endured periods of intense pressure from established medical authorities to toe the line.

While there is an increasing number of individual MDs all across Canada, the United States, and Britain, those breaking rank and migrating towards a practice which is more inclusive of alternative therapies increasingly known as complementary medicine, there is still fierce resistance from the conventional medical profession, from its established institutions, and medical associations. Without any intent to minimise the significance of the multiple issues involved in the debate, I am going to focus on the critical issue of scientific validity, on the critique by advocates of conventional medicine that alternative practices are irrational and unscientific, by which they mean that these practices have little or no theoretical or methodological integrity, and are unsupported by valid research or convincing evidence. I will address the philosophical substance of this critique by attempting to show that the arguments do not demonstrate what they claim, and that their proponents are themselves, ironically, often guilty of the very infraction they accuse others of committing. I will argue further that the appeal to science here is beleaguered by unacknowledged issues about the basic concepts and theories of science, and by a lack of recognition of questions raised by this appeal, ones which highlight the limitations of its theoretical and methodological powers, I will argue that the debate is more about conflicting metaphysics, belief systems, philosophical perspectives, ethical principles, and cultural values.
2. The Heresy of Alternative Medicine

The charge that alternative medicine is unscientific and antagonistic to reason is often expressed in a thoroughly unscientific and irrational way. It is frequently treated as if it were a form of heresy, which is sometimes subjected to what might be called the fallacy of defamatory association, and generally to the rhetoric of denigration. While it is clear that the medical establishments have shifted ground in the last twenty years, this rhetoric has not really disappeared. Recent critics have connected alternative medicine with paranormal energy fields, and a belief in aliens and unidentified flying objects, referring to it as a new-age religion masquerading as medicine, or as quackery, animistic idolatrty, astrology, and witchcraft. Its practitioners are thought to dismiss rational assessments of their practices, opposing scientific investigation, and attacking reason itself because they believe in what is claimed to be a ‘magical view of nature and mind and a mystical conception of knowledge.’ In particular alternative medicine is found wanting in its refusal to be open to criticism, in particular to the kind of self-corrective critical scrutiny that is invoked through argumentation, theoretical analysis, and clinical trials. What is most remarkable about this scurrilous commentary is that it is presented in the name of science, as if it were thoughtful, well-founded, rigorously deduced, and rationally conclusive, when in reality it is frequently a function of close-mindedness: refusing to accept the rational possibility of new (or old but non-Western) paradigms of practice, theoretical models and methodologies; restricting the range of inquiry into the development of disease; and demonstrating little or no understanding of the ‘alien’ forms of knowledge it refers to. This kind of criticism is often based simply on assumptions and presumptions about other cultural concepts of nature that are, as such, unsupported, unwarranted, and either inaccurate or false.

3. The Cult of the Double-Blind

If the charge of irrationality is not enough to dispel the allure of alternative medicine, its unscientific nature is said to be demonstrated by its failure to meet and develop what is considered to be the gold standard of all tests in scientific medicine, double-blind, randomised, controlled clinical trials or RCT. This is what the BMA designates as the standard that will have to be met by alternative practices seeking legitimacy. It is the RCT that provides what is broadly referred to as convincing evidence. But how rational and scientific is the RCT itself, and just how convincing is the evidence it adduces?

While it is clear that the RCT, as one among other methods of health research can and does provide useful. If limited results, its privileged status as the gold standard that determines the validity of all medical knowledge and practice is such that other forms of knowledge and practice are
marginalised, devalued or dismissed out of hand. This marginalisation is effected by means of a built-in methodological bias in the RCT itself, and manifested in an unrealistic and inflated perception of the real value of the RCT. The first produces a predisposition against the independent evaluation of alternative practices and treatments. The second can issue in the misinterpretation and the oversight of the glaringly problematic reality of clinical trial processes and results, and seriously distorted reporting of medical reviews on the other.

A. The Methodological Bias and the Question of Evidence

The built-in methodological bias of the RCT is largely a function of the fact that the dictum of 19th century mathematical physicist Lord Kelvin, to measure is to know, is taken as an ultimate imperative in clinical trials. This bias is revealed most saliently, perhaps, in terms of two key problems, the definition of evidence, and the definition of causality in the search for the origins of disease.

What, then, is convincing evidence? It is reproducible laboratory results, mathematically quantified in terms of objective data that can be replicated in the settings of other experimental labs. This is what is generally referred to as ‘proven’ results, ones that can be detected and measured in physiological, biological, and biochemical terms. The reliance on this conception of evidence is so universal in the medical world that the rule seems be consonant with the claim of 19th century mathematician William Clifford who wrote that ‘it is wrong always, everywhere, and for anyone, to believe anything upon insufficient evidence.’

This conception of evidence involves the search for a cure for disease in terms of micro-causes, rather than the broader range of research to preserve health and prevent illness by looking not merely at micro but also macro-causes. Scientific medicine is driven by the need to identify disease as an isolated pathological condition for which there is a single cause, or at best a small group of closely related causes that are localised most often now in microscopic areas of the body, ones that can be detected by scientific instruments, and that will respond to a particular therapeutic tool or pharmacological treatment.

The RCT, based on this conception of causality and the mechanistic/materialistic notion of nature that goes along with it, automatically marginalises, precludes consideration of, fails to do justice to, and cannot properly evaluate practices like Ayurveda and Chinese herbalism which are based on an entirely different view of causality derived from the traditional philosophies of Asia, one which can only be understood in relation to the concept of nature as it is understood in that context, a concept at odds with the traditional Western view (although one that we are beginning to see reflected in recent research in quantum physics on the one hand and the
environment on the other). Nature in Hinduism, Buddhism and Taoism, broadly speaking, is explained as having a metaphysical origin in a mystery that lies beyond human cognition. It is nevertheless a veritable confluence of real, inter-related, symbiotic processes, which is inclusive of human beings as miniature exemplifications of these processes. Nature is a creative ecology of being which generates the limitless capacity for novelty and diversity in its emerging forms of life. Every one of these forms of life is a cause and an effect, the cause of an ultimately indefinable plurality of effects while at the same time itself an effect of an ultimately indefinable multiplicity of causes, each chain of causes and effects operating in multiple directions.

In the context of medical practice based on this concept of nature, good health is understood as a dynamic balance of all the inter-related factors involved in the causal lineage of the development of any given creature. Disease emerges not merely from one cause alone, but from multiple causes radiating around the victim, some of which are known, others not--biological, physiological, psychological, social, spiritual, and environmental causes. Thus in Ayurveda health is maintained by attending to carefully considered dietary practices, daily and seasonal routines, and a lifestyle that involves modulation of material and spiritual needs, while disease is caused by imbalances within each of these categories and among them. In other words, the conditions of good health and the causes of disease are as much psychological, social, and cultural as they are biological or physiological.

B. The Problematic Reality of the RCT and the Systemic Misreporting of Medical Reviews

The professional bias around the RCT seems to be a function of the methodological successes, real or perceived, which have resulted in the privileged status of this method as the gold standard of all medical research. This bias is, ironically, the function of an attempt to eliminate or at least functionally minimise the irritating hindrance of a more general human bias in the conduct of research by developing what is sometimes considered to be an almost perfect instrument for achieving near-certain results understood in the sense of mathematically formulated and purportedly objective data. The result is a vision of the RCT that is decidedly out of touch with the problematic reality of the actual practice of clinical trials, and the exertion of laboratory control, over the research environment may end up producing results that are not necessarily congruent with what happens in the uncontrolled environment of the real world.

This view is articulated most pointedly by respected members of the medical community. I rely here on accounts mainly from mainstream medical publications. British medical researchers Ellis and Adams, for example, in the *British Journal of Clinical Practice*, document the wide range of issues connected with this point. Patients, for example, are carefully pre-selected,
which may mean that the results of any given trial apply only to the limited group studied, and not to the general population where there are a vast variety of differences that have not been factored in. Completed trials, which produce negative results, are less likely to be published, which gives a distorted impression in medical journals of the overall results of certain kinds of research. Statistics can be misused or even develop into outright fraud, not so much by the manufacture of results as the ‘cleaning up of data’ and ‘the exclusion of cases from a trial on the grounds that they are atypical biases the result.’ In addition, ‘the double-blind, placebo-controlled trial is only as good as its blinding,’ and if the blinding is faulty bias can of course occur. The authors lament the fact that so little reporting of the success of blinding is done. Ellis and Adams tell us, finally, that RCTs can be skewed by asking the wrong questions, which can lead to the use of the wrong controls and, of course, misleading results. Add to all this the fact that as US MD Ray Strand points out, another much bigger, profoundly un-clinical trial of medications takes place after the formal trials have ended, and we can understand not only how imperfect our gold standard is but also how dangerous. I am referring to the fact that drugs are released into the market and consumed by people suffering from multiple medical conditions, or taking a variety of other drugs, who then have adverse reactions. None of this is, or perhaps even can be, properly monitored or controlled.

The professional bias around the RCT can be additionally illustrated in relation to reviews of medical literature, some of which become thoroughly unreliable when they involve interpretation and reporting of the clinical success or failure of alternative therapies. Let me refer to Barker Bausell who in his *Snake Oil Science*, a virulent critique of alternative practice as unscientific, gives us a particularly useful example of this. Bausell cites a series of reviews from the Cochrane Collaboration, a research institution devoted to producing high-quality, unbiased reviews, which he thinks avoid the criticism of being unfavourable to CAM therapies. He cites the conclusions, mostly one-sentence statements, of some 98 reviews of what he calls ‘high-quality systematic reviews’ of clinical trials of alternative or CAM treatments. He claims that this survey shows only a positive rate of 5%.

If we examine all of the reviews, however, we find numerous reasons for declaring the bankruptcy of Bausell’s report. Firstly, roughly 69% are completely neutral or vaguely positive in terms of what they conclude a little fact that this statistician neglects to mention. Secondly, the only instances in which the author adds his own comment to qualify the conclusions being reported are the positive ones, and this comment in every case downplays the positive result by suggesting some flaw in the RCT, in spite of his earlier insistence that these are all high-quality systematic reviews. Thirdly, the only cases where the author gives us more than a one-
sentence conclusion are ones that involve a critique of a study that showed positive results, which in some cases simply produces nothing less than sheer equivocation. Fourthly, nowhere in this discussion are we given any indication of how carefully these trials were done, whether those who carried them out understood the importance of calibrating proper doses of herbs, for example, whether they carried out the research under adequate time conditions, how much or what other medication patients were taking, etc., in other words, whether the conditions under which the research was carried out were suited to the therapies under scrutiny. Fifthly, the author admits that this review does not include consideration of non-Cochrane–based CAM reviews because he tells us candidly that he is predisposed against them.\textsuperscript{13}

It may be imagined that the RCT is fine in itself, and that these are only logistical or human error problems associated with its execution. But it is practically inconceivable that clinical trials could be devised let alone implemented to successfully address, let alone resolve, issues like the ones discussed here and achieve anything close to the elimination of human interference or error. The result is that the general public, as Strand suggests, is always going to be part of the trial outside of the laboratory, and the clinical results can never be completely assessed in this context. The problem lies more with the RCT itself. It is an icon placed on a pedestal that serves as a kind of shrine for what has been called a veritable ‘cult’ that ‘produces orthodoxy narrowing the choices for patients and doctors.’\textsuperscript{14} It belittles other forms of information and disenfranchises other kinds of knowledge, such as the experience-based knowledge of the individual doctor or alternative practitioner. It does so by generating the impression that an explanation of cause in mathematically quantified, biochemically precise terms is the most advanced kind of evidence. This has the effect of disavowing the ability of physicians to make decisions on the basis of what they are so often faced with, so-called ‘insufficient evidence with multiple variables at play whose interaction may well be non-linear.’\textsuperscript{15}

The notion that alternative practice is unscientific because it does not generate convincing empirical evidence in the sense discussed here is based on the profoundly narrow view of empiricism and evidence that is associated with this conception of the RCT. The reason why empirical evidence of alternative forms of medicine, such as Ayurveda and Chinese herbalism, among others, is found wanting in the setting of clinical trials, is that the RCT is designed in such a way as to discount it. That notion of empirical evidence is defined not in terms of explanations of biochemical results replicated in an artificial environment, but in terms of distinct and unique conditions of patients observed in their own concrete, lived experience. Treatments are developed from close observation of the specific needs, case studies of the patient’s total experience, medical, biological, physiological, emotional, nutritional, spiritual, and environmental factors.
This means respecting the integrity of his *anecdotal testimony*, not because it is replicable, but for what it is in its *uniqueness and distinctness*. The doctor engages in a *trial and error* administration of remedies in dosages calibrated to individual needs, in a process of piecemeal adjustment over time, to address the astonishing diversity of multiple symptoms and root causes of illness in the *living laboratory of everyday human experience*. This approach is premised on the development of *experiential wisdom* of both the practitioner and the patient. On the one hand, the practitioner’s wisdom consists of the savvy that comes from a *first-hand encounter with a broad range of variables and uncertainties* supplemented by an *awareness of the layered complexity of unique individual case studies*, and it may be unmatched by any acquired knowledge of clinical trials. On the other hand, the individual patient’s potential wisdom is understood as one that may be cultivated with the help of the practitioner to approach the ideal of the process of healing by *realizing through internal empirical observation*, the dynamic *changes of subtle energy* inside the body and how to balance these in such a way as to preserve and restore the homeostasis that is the foundation of good health. This is radical empiricism and arguably more rigorous than the medical version.

4. **The Hidden Metaphysics & Belief System in the Scientific Project**

The critique that alternative medicine is unscientific is ultimately premised on the view that conventional medicine, in contrast to alternative, is not just an art but one which is firmly based on science, and that it is irrational not to accept this science or worse to attack it. The science implied in this critique is conceived as a completely self-contained child of a pure reason unsullied by social, political, and religious attachments and therefore free from the biases associated with those attachments.\(^\text{16}\) While it is grudgingly admitted that medical practice does involve ‘intuition, guesswork, and gut feeling’ with ‘room for a hunch’,\(^\text{17}\) it is nevertheless grounded in a rational, ‘internally consistent theory’ which is in keeping with ‘the definition of natural laws as fundamental as that of gravity,’ and issues in objectively valid knowledge of illness and disease.\(^\text{18}\) The power of scientific medicine lies in the power of science itself, the power of explanation. Only that which can be explained in rational terms is acceptable and eligible for consideration as objectively true. And only those explanations that have been subjected to critical scrutiny and confirmation by systematic observation, measurement, and testing of the natural phenomena they refer to are candidates for producing principles to be considered as natural laws.\(^\text{19}\) Science in this sense, as one, which aspires to objective near-certainty of the material conditions of life and death, often proclaims itself antithetical to, and liberated from metaphysics, faith and belief. But, in real terms, how different is science in
respect to its reliance on metaphysics, faith and belief than Ayurveda or Chinese herbalism, and how irrational is it to question it?

A close analysis of Stephen Hawking’s theoretical physics in *A Brief History of Time*, however, reveals a picture of science that does not accord with the above view. We are presented with an account of the universe, which is said to have begun with the big bang, a fireball which erupted at the beginning of space-time and subsequently cooled as it expanded, that its most basic ingredients consist of subatomic particles the latest of which are called quarks and best understood in terms of string theory, that stars, which reach the end of their lifetime collapse into black holes that become colossal vacuum cleaners sucking all surrounding matter into them to disappear for ever.

To summarise all to briefly in the interests of time, I will say only that Hawking expresses serious doubts about all of these matters, about the big bang because it involves the breakdown of all known scientific laws and can never be confirmed, about atomic particles because scientists keep on discovering more and more minute particles, and about black holes because since they emit no light and can never be observed.

So uncertainty haunts the scientific project in general and mitigates its claims of near-certainty, accuracy and predictability. This uncertainty takes the form of what Hawking considers a basic law of nature, Heisenberg’s Uncertainty Principle, according to which the behaviour of material objects cannot be predicted with complete accuracy since the observation of such events requires the presence of light which changes the position and velocity of the objects under scrutiny. This is not to say the big bang, atoms, or black holes don’t exist, only that whether they do or not, or that whatever they are or are not, is always open to question, and that asking such a question, is a fundamentally rational exercise, whereas accepting these without taking seriously the uncertainty surrounding them, is decidedly irrational.

While there is no question that the development of scientific knowledge enables us to survive, develop our lives in ways that would not have been possible otherwise, and to do so by exercising limited control over our lives, the permutations of all the possible combinations of natural processes are, perhaps, infinite, such that we are incapable of measuring and predicting all of the patterns they are likely to form. Nature inside the body and outside it, in its parts and in whole, is always in process, always in transition, and always escaping our efforts to completely understand its laws or harness its powers. So the aspiration of the RCT to mathematically exact data, predictive near-certainty, and control of disease, seems outlandishly unrealistic and effectively misleading in the midst of this reality.

This conception of science and its implications for the RCT seems largely lost on the self-appointed defenders of scientific medicine. In
contrast, they appear to be trapped in a positivistic time warp in respect to the conception of science implied in much of their criticism of alternative medicine. As such, they fail to recognise with sufficient emphasis the profound uncertainty within the study of science itself. This in turn, means that they do not acknowledge the limitations of their own enterprise, questions about which have lurked beneath the surface of this entire discussion. For example, if we take the word of the scientific critics of alternative medicine that detectability is to be taken as the ultimate standard for deciding between sound scientific results and unsound ones, we can rightly ask how we detect detectability. If, to take another example, we align ourselves with the British Medical Association in its apparent commitment to Lord Kelvin’s dictum that measurement is knowledge, how then do we measure the status of measurement? If, to consider yet another example, we can say that the view of evidence in clinical trials implies that it is always wrong to believe anything upon insufficient evidence, how could it ever be possible to adduce evidence for this claim, since to do so would require us to take the position of an eternal observer? These questions are no mere intellectual tricks that you might expect from a philosopher, but questions that go to the roots of science itself, and to our confidence in its presumed unassailable reliability. Their significance is highlighted by one over-riding question: if science validates all knowledge, what validates science?

All of these questions are boundary questions that effectively draw attention to the limitations of scientific rationality and its theoretical materialism, since any attempt to scientifically reason towards their resolution would either be circular or require us to step outside the boundaries of science as we have traditionally understood it. I would go further and say that they involve the recognition of the necessity of an article of faith (in the sense of an act of acceptance which is not in itself rational) and a belief system to complement it. It is worthy of note that although Stephen Hawking does not ask such questions, he seems to be aware of the problem they lead to when he posits the following as the ground of his own scientific project: a belief that the universe is orderly, governed by laws and not arbitrary, an assumption that we are rational beings who are free to observe the universe and arrive at our own conclusions, and a craving to understand and explain the whole of nature.20 Some of us may be forgiven if we think this seems more like metaphysics and religion than the science implied in the world of medicine.

In any event, one thing is patently clear from this little survey of the scientific project: the claims of the biomedical critics that raising questions about the integrity of science constitutes an attack on reason itself, is nothing less than a desperate appeal to the spirit of dogma, an obstinate refusal to engage in a reasonable dialogue, and an antipathy towards what in fact is the
most fundamental exercise of rational enquiry, asking questions and addressing doubts.

5. **The Missionary Politics of Medical Colonialism**

The reality is that the dismissal of alternative practices like Ayurveda and Chinese herbalism as unscientific cannot be understood without situating these practices in the broader context of European colonial history and its political ethics (even though, strictly speaking, China was not colonised by Europe). Science, historically, was one of the key factors in the development of the cultural imperialism reflected in the concept of civilization, and the correlative differentiation of our culture from others which were considered to be the opposite. Scientific medicine in this context took ownership of an esoteric understanding of disease to create an orthodoxy that then served to marginalise all other forms of medical practice from elsewhere in the colonised world. This medical colonization was invoked, for example, in 1833 by the British East India Company when it closed ‘virtually all the existing Ayurvedic training centres and schools,’ although it is worth noting that the Indian Government has since re-established and recognised both Ayurveda and homeopathy as part of its integrated health system. The colonial character of medicine is not something only of the distant past but is often reflected in the language of more recent representatives of the tradition of scientific medicine. Skrabanek refers to the ‘mystique’ around Chinese medicine, of ‘ancient Oriental ritual,’ and ‘the magic of model manikins and golden needles’ as the ‘trappings’ of the ‘veil of mystery’ which when lifted will relegate acupuncture to ‘its original place among counter-irritants’ and destroy its power over the ‘minds of the gullible.’

This is hardly a scientific but a crude ethical judgment with distinctly racial overtones, one based on standards of good and bad originating in collective or even national self-interest, and used to differentiate the orthodox from the deviant, the superior from the inferior, the civilized from the primitive, us from them-- the alien others. If the Western medical system is in a position of dominance, not only here in Europe and North America, this is in part the result of our colonial history, and its ideological ethics, political devaluation, and ethnic and racial demarcation of people and practices. The public expression of this politicised ethics takes the form of a defence in the name of ‘the integrity of medical science … professional honour in the face of charlatanry, and … the public welfare.’ But this is probably more correctly understood if we think of it as a contemporary version of what Foucault, when referring to European health practices in the 18th century, called a politics of health which was devised to take control of the well-being of the social body as a whole and the individual body in particular, for economic and political reasons. If it is, then it is a
politics which makes use of the machinery of power to engage in the practice of population control and to generate a system of medical knowledge as the basis for an ideologically directed economy.\textsuperscript{25}

The social entrenchment of this system of operational power in medical institutions and professional bodies establishes a basis for the preservation of the dominance of the methodology through the exercise of authority over individual members of the profession by requiring their compliance or by inflicting punishment on those who fail to comply. The victims of this system of medical dominance are not only the many doctors I spoke of at the outset of this chapter, but the millions of patients who are treated within it.

\textbf{Notes}

9 Ellis and Adams, 38.
Bibliography


Haahr, M. T., and Hrobjartsson, A., ‘Who is Blinded in Randomized Clinical Trials? A Study of 200 Trials and a Survey of Authors,’ in *Clinical Trials*, vol.3 No. 4, 2006.


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Assessment of Capacity, the Person and Ethical Questions

Sandip Talukdar

Abstract

This chapter utilise case examples to illustrate certain ancillary issues concerning the assessment of capacity of patients, subsequent to the enforcement of the Mental Capacity Act 2005 in Britain. The primary purpose of this act is to provide a legal framework for acting and making decisions on behalf of individuals who lack the capacity to make healthcare, residential, and financial management decisions by themselves. Close examination suggests that this act has the potential to influence several other aspects of the person’s life, if his/her choice is not deemed ‘appropriate’ by the professionals. Various studies have demonstrated that there is poor correlation between capacity and the degree of cognitive deficits in the elderly population. Capacity may be considered to be as personal to the individual as any other aspect of their health, individuality, and personality, including attitudes and beliefs that he or she may hold. It is a debatable point as to what extent, if at all; it is pertinent for others to probe the person’s capacity without adequate reason, and to make a judgment concerning the same.

Key Words: Capacity, law, England, assessment, ethics, Mental Capacity Act.

1. Introduction

The Mental Capacity Act came into effect from October 2007 in England and Wales. This act was designed to provide a legal framework for actions and decisions being made on behalf of persons who are unable to do so. Major decisions for such persons may pertain to healthcare, independent living, and financial management; as well as to consenting for treatment, testamentary capacity, research, voting, sexual activity, and driving. The healthcare and social service workers are usually the professionals involved in decisions involving capacity for clients who may be elderly and vulnerable.

To possess ‘capacity’ regarding the ability to make a decision, the individual must be able to comprehend the relevant information pertaining to the decision; retain it for a sufficient length of time; consider this information along with his pre-existing beliefs, wishes and choices; and come to a decision for himself. He should then be able to communicate by any means.
The act also states that all reasonable help and support must be provided to the individual for making the decisions.

Capacity may be impaired by any neurological disease (temporary or permanent) afflicting the cognitive functions. The correlation of capacity to the progress of disorders like Alzheimer’s disease may be quite variable. Capacity is also deemed to be decision and time specific for purpose, and a person may lack capacity to decide on comparatively complex topics like financial management; while retaining capacity to decide on matters like independent living.

It is important to note that the Mental Capacity Act cannot be used in its present form to treat a person against his will; neither can it be used to force an individual lacking capacity to live in a stipulated place against his wishes. An addendum named the Deprivation of Liberty Safeguards was introduced in 2008 to enable such a decision to be made the person’s behalf, in his best interest, to restrict his liberty for an appropriate reason in such situations.

The issue of capacity in the elderly is ‘dominated by a fundamental tension between two core ethical principles: autonomy and protection. I argue that the new act has the potential to influence several aspects of a person’s life apart from the major ones of residential and financial decisions. There are innumerable factors and choices, which influence the well being of persons and the diagnosis of a medical condition, can be construed as the former being vulnerable to risk from any activity that other professionals may deem to be unwise. All of these may further interact to produce ethical dilemmas and challenges in addressing the care of the individual.

I will use a few case examples of individuals with diagnosed mental disorders to illustrate these points. The personal details described in these cases are fictitious, but they serve to highlight the real issues which I have come across while working as a psychiatrist for older adults; and which may presumably be faced by other health or social welfare workers elsewhere in this country.

2. The Case of Mr. B.

Mr. B. is a gentleman in his mid-seventies, retired and a lifelong bachelor. He was referred to the psychiatric services by his General Practitioner for failing memory. Mr. B. was investigated, and a diagnosis of Alzheimer’s dementia was made. He fulfilled the guidelines for treatment as recommended by the National Institute of Clinical Excellence, and was commenced on a medication. He responded well, and there was an initial improvement in his cognitive function detected by formal testing. He agreed to stop driving, and assessments at home did not reveal any domestic risks.

Six months later his community psychiatric nurse received a phone call from the social worker, who stated that Mr. B. had applied for a licence
for salmon fishing. The social worker requested an assessment of whether Mr. Bright had the ‘capacity to indulge in salmon fishing.’

3. Discussion on Mr. B.

This issue deals with whether Mr. B. has the capacity to make an informed decision to purchase a salmon fishing licence while being aware of all related regulations. But more importantly, the question arises as to how strong is the right of the professionals to involve them in the situation with an automatic assumption, that activities unfamiliar to them must be potentially dangerous. Mr. B. may argue that he is not indulging in anything that poses threat to others. It may be an activity that he has indulged in previously. Is there indeed such a serious threat to Mr B’s well-being that the authorities can justifiably impose their opinion to supersede that of an innocent individual in this instance?

From a consequentialist point of view, it may be argued that the process is aimed at ensuring the safety and well being of Mr. B. In this context, the information provided by the social worker does need to be considered as a potential risk factor. But from a deontological perspective, it is difficult to perceive the justification with which the person’s individual interest can be impeded with a paternalistic attitude, further bolstered by reference to the newly introduced law.

It is also a moot point as to why the psychiatric doctor should receive such a request, rather the patient’s primary care physician, or any other trained official of the social services. There may be additional problems for active efforts being made to encourage the individual to reconsider the wisdom of his decision, which may produce further moral dilemmas for the healthcare professional. Mr. B. does reserve the right to ask the question as to why should a psychiatrist suddenly visit him at home and ask him rather strange questions about whether he feels safe when fishing, or whether he is fully aware of the new changes to fishing regulations that have only recently come into effect. Mr. B. is well within his rights not to answer any of these, and even to demand that the interviewer leave his premises.

While discussing the concept of ‘persons’, Harris has defined a person as ‘any being who is capable of valuing its own existence’. In this example, Mr B certainly does so, and he wishes to enjoy his own existence. Interfering with his individual choice on grounds of risk to his own self demonstrates a discounting of his worth as a moral agent. A person living an independent life with support in the community may expect that he continues to have the right to indulge in activities he considers safe, and which does not interfere with the lives of other people.

I wish to provide an alternative scenario here. Let us assume that Mr. B. was not in contact with psychiatric services, and had not been given a formal diagnosis, though he still had the same cognitive defects. In such a
situation, no questions would have been asked about his capacity to indulge in salmon fishing. The difference solely results from the fact that he is formally diagnosed to be suffering from a mental illness.

It may be commented that the society presumes Mr. B. to be fulfilling the characteristics of the sick role with its rights and obligations. His disease and ‘sick role’ are thus taken to be the permission for the authorities to act with the assumption of him not fulfilling the characteristics of a moral agent at this time, irrespective of the severity of the illness. In contrast with diseases from which patients can to make a full recovery, dementia is progressive and incurable. While current modes of management are directed at enabling the patients live as wholesome and satisfying a life as possible in their own environment; this is always done with a strong emphasis on the risks, which are integrated into an individualised care plan. But, I argue, the approach puts a greater emphasis on the concern expressed by others than that of the patient himself.

The counterargument is that the entire process is designed to serve another moral principle of beneficence. But one might as to whether it is the beneficence of Mr. B. or that of the professionals and agencies who wish to make sure that he comes to no harm, since their action (or inaction) will definitely be open to scrutiny and possible retribution ‘if anything happens.’

The risk-dominated approach to management dictates that Mr. B.’s ‘protection from harm’ is considered the primary goal; and it is the ultimate responsibility of the doctors to make the decision to restrict his liberty. It is a different issue that in real life it would be extremely difficult to physically prevent Mr. B. from indulging in his hobby if he wishes to. Although ‘capacity’ is the new hot topic of the day in social and healthcare, the Mental Capacity Act does not permit the restriction of Mr. B’s liberty in the situation I have hypothesised. There are indeed certain instances where a decision involving a healthcare intervention may be taken in the best interests of a patient who lacks capacity, for example, providing flu vaccination to a person with advanced dementia. But a vast number of day to day decisions may well fall into a gray area, though all of them could theoretically be associated with potential risks. Thus in practicality, virtually anyone connected with Mr. B.’s well-being (or related to him in any way) could believe that a particular facet of his lifestyle is dangerous to him, and ‘something should be done about it.’

It is acceptable that in a welfare state, such an attitude about the well-being of others should prevail. But, as I have already argued, had Mr. B. not been ‘labelled’ with a psychiatric diagnosis, none of the current concerns would have been expressed. The state and the society thus assume him to be a sick individual for all purposes and, I argue, there is an almost automatic assumption that all his decisions must be tinged with the fact that he suffers from dementia.
From pragmatic points, it is difficult to see how in Mr. B.’s case, his capacity can be assessed in a manner similar to, for example, assessments concerning road safety made for driving. Even if he demonstrates that he understands the basic concepts and is able to make an informed decision, the critical and concerned ‘others’ may want to know as to whether Mr. B. is able to recall every detail of the current fishing bye laws to indulge in his activity.

The slippery slope argument may become prominent here: should we continue to assess his fishing skills in a practical field, and if his skills and risk appreciation are found lacking, should he be challenged with the fact? To consider another hypothetical example: what would the outcome be if Mr. B.’s hobby was not fishing but fell walking in the Cumbria countryside? Would the state be justified in restricting his liberty if it was felt that he had an increased chance of getting lost in the fells when out on his own? Would it be justifiable to restrict his liberty against his will, or perhaps more drastically, force him to be subjected to electronic tagging in such situations?

Several other pertinent questions can be asked about the issue. Some of them will also be evident in the next example, which follows.

4. The Case of Mrs. H.

Mrs. H. is a seventy six year old lady who is restricted to wheelchair following a cerebral stroke. She has a degree of memory impairment, and has been diagnosed to be suffering from mild vascular dementia. She is a widow and has three children, all living long distances away. She has carers and home support organised by social services. She has sufficient funds and properties to fund her own care. She has not made a will, and is still able to manage her finances with minimal support.

A friend of her husband has recently moved into the locality, and he comes around regularly to see her. He also arranges for her trips to day centres, doctor’s appointments, and shopping. Mrs. H. knew this gentleman well from past, and welcomes him. He himself is widowed and has no near relatives. Recently, Mrs. H. has contacted her solicitor saying that she would like to draw out a lasting power of attorney (LPA), making this gentleman the done. The solicitor asks her to see a psychiatrist to determine if she fulfils the criteria for drawing out an LPA. The doctor who sees her is satisfied that she is indeed able to do so. But when she informs her social worker of her wish, the latter suggests that she should tell her children about her decision, which Mrs. H. agrees to do.

A fortnight later, the children of Mrs. H. send an angry letter to the solicitor, the social services, and the psychiatrist concerned. They believe their mother has been forced into making this decision, and it would not have gone ahead had any of them been present. They also ask as to why she is deemed of having capacity in this matter when it has been diagnosed that she is suffering from dementia. They believe that her friend is planning on
moving into the same house as her, and staying as a ‘common-law couple’,
which will give him full rights over her property after six months. They
believe that their mother has been let down severely by the services who
failed to protect her from financial abuse.

The social worker contacts the healthcare team, and a joint
assessment reveals that Mrs. H. has indeed asked her gentleman friend to
move in. She does not object to her children being informed about this. The
children ask the psychiatrist if this can be prevented under the Mental
Capacity Act.

5. Discussion on Mrs. H.

The Mental Capacity Act clearly mentions certain decisions, which
are exceedingly personal, can never be made on behalf of other people, and
this includes marriage and relationships. But a salient point here is the
query of the children questioning their mother’s decision regarding whom to
entrust with looking after her money. The family in a sense is asking as to
‘how can she have the capacity to make a decision which we deem as unwise,
considering that she has a mental illness?’ While the professionals are trained
at an initial stage to appreciate that people may continue to make unwise but
informed choices in spite of having a mental illness; the existence of the
Mental Capacity Act may give the notion to the lay public that unwise
decisions can be overridden if necessary.

It is also worth examining if a person’s capacity can and should be
explored whenever others express concern of any sort regarding their well-
being. Can it be deemed ethical to examine a person’s capacity without
informing him or her of the procedure, the need, and the outcome, as well as
having a justifiable reason that the interviewer finds satisfactory? This is an
important topic because there does not appear to be any clear guideline as to
how the scene should be set for the meeting or the questions, and it is often
down to the individual’s style of questioning.

Personally, I consider it appropriate and essential to explain to the
patient as to why I am seeing her, and also that an opinion has been sought
from me regarding their capacity on a particular topic. It may be
acknowledged that such explanation may in itself result in an emotional
response on behalf of the patient; and may also contribute to further antipathy
in her mind directed against the healthcare and social welfare professionals.
But I argue that there cannot be any justification for failing to inform the
patient the reason for the assessment. Neglecting to do so would fall foul of
one of the basic tenets of medical ethics, namely, the respect for the patient’s
autonomy.

To use a common analogy, it is not appropriate to take a blood
sample for a liver or renal function test from a conscious and coherent patient
without explaining the reason thereof and obtaining her consent. Similarly, I
argue, it cannot be ‘right’ to probe someone’s innermost feelings and wishes without explaining in a simple manner as to why such questions were being asked in the first place. Any instance of probing of capacity without due explanation of the reason would be treating the person simply as the ‘means’ to obtain an end result of ‘does he have the capacity or not?’ and neglect to confer the dignity on the patient which he or she deserves. The benefits of such action in both the above cases described above are not clear from a consequentialist view, and are certainly contrary to the Kantian principles.

I agree that taking the patient into confidence may not be possible on all occasions; for example, if the person has a severe dementia and is unable to comprehend basic information. But there are several instances where the situation falls between the extremes. I will provide another brief example at this point.

6. The Young Inpatient

A 24-year-old male patient with schizophrenia has been admitted to an inpatient psychiatric unit. He has no objections to the admission, and has at least partial insight, knowing that he needs to take medications and take part in a therapeutic programme for rehabilitation. However, he occasionally refuses to take some of his tablets. The registrar on the ward has directed that every time he refuses to take any medication, or refuses to participate in any programme (like group therapy or outdoor activities); his capacity to make such a decision must be assessed. He also tells the junior doctors that this now a legal requirement with the enforcement of the Mental Capacity Act and everyone will be acting illegally if they fail to assess his capacity.

7. Discussion on the Directive

Irrespective of whether the patient has the capacity to take his tablets or not, he cannot be legally forced to take the medications against his will under the said act. The patient will need to be detained under one of the sections of the Mental Health Act 1983 for this purpose; and force feeding of medications is not generally considered to be a pragmatic option. It is difficult to imagine exactly which purpose would be served by assessing his capacity on each occasion; as compared to observations and assessments of his presentation, which is ongoing in any case. The directive that his capacity must be assessed each time his decision is perceived unwise makes one wonder as to whether this is the beginning of another slippery slope, which assumes that sick individuals can make no independent decisions unless it conforms to that of the specialists.

We appear to be faced with a major ethical challenge at this juncture. The legal framework has been developed to ensure that the patient is protected from harm. But this needs balancing with a questioning of whether such an approach centred squarely on risk may interfere with the
autonomy of the individual on grounds unrelated to the disease. This may vary from the example of Mr B mentioned earlier, to more common and mundane day to day decisions of the individuals. Utilitarian arguments from the principle of beneficence may not fully suffice in several situations against arguments that the new act is leading to an increased propensity for patient’s individual preferences and choices being questioned and probed.

8. Conclusion

The Mental Capacity Act in England has the potential to induce a greater number of everyday decisions of Mental Health service users to be scrutinised for elements of risk and the person’s wisdom in coming to a choice deemed unwise by others. While a word of defence needs to be put in favour of the healthcare and welfare professionals, who are entrusted by the family and state with the expectation of caring for the unwell person; there appears to be a potential for any activity on behalf of the patient being ‘put under the microscope’ by any individual entrusted with their well-being. It is to be hoped that capacity continues to be regarded as an intimate attribute of the person, and its assessment is done only when appropriate, and when such assessment is able to contribute positively to the management plan and well-being of the person.

Notes

7 J Harris, The Value of Life, Routledge, New York, 1985, p 18
9 T L Beauchamp and J F Childress, The Principles of Biomedical Ethics, Oxford University Press, New York, 2009, p 197


Bibliography


**Sandip Talukdar** is a specialty doctor in Old Age Psychiatry working for the National Health Service in Cumbria, England. His interests lie in the ethics of psychiatric practice and management in the community of behavioural problems associated with dementia.
Section 3

The Contextual Approach
Integrative Approach for Estimation and Correction of Human Psychophysiological State

Larisa Kruglova

Abstract
Therapy by means of colour and music measured by computerised BIOL system for human psychophysiological state (PPS) rehabilitation based on person’s IR radiation is introduced in this chapter. The result of the investigation highlights the necessity for integrated healing approach by means of physical factors like medicamentous or physiotherapeutic and the correction of the subject’s PPS. The correction procedure of the subject’s PPS includes stages of adaptation, estimation of a current psychological person’s state by means of psychological tests, automatic definition of the character of demanded musical influence depending on the results of testing, colour-music biological feedback, the period of a relaxation, final psychological testing. BIOL system has many advantages, including contactless, non-invasion, automatic operation, and individual approach to correcting factors. The important feature of the system is its operation applying the principle of ‘diagnostics during the moment of treatment.’ This system was used in different establishments, medical included, and the testing of the system application showed its aesthetic attraction, reliability, efficiency.

Key Words: Integrated approach, person’s infra-red radiation, colour-music therapy.

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1. Basic Principles of Estimation and Correction of Human’s Psychophysiological State

The human being is a complex integrated system and to maintain his health the person should keep in order not only his physical body, but also his thoughts, emotions, feelings, intentions.

There are various means to keep the healthy person’s state: medicamentous therapy, physiotherapy, psychotherapy. The means applied should be effective, safe, impact both physical and psychoemotional states of the person. Colour and music meet these requirements.

Light is a major factor life existence on the Earth. Colour is defined by the length of wave of electromagnetic radiation and is a major factor defining viability of biological objects. Light of different wavelengths affects differently the organs and systems of an organism and the organism as a whole (tab. 1). Colour can be perceived not only by the cells of the retina of an eye,
but also by the skin surface where biologically active points are located, through these points the impact is transferred to the organs and systems of the organism connected with them.

Colour application for the therapeutic purposes has been known for a long time. Already Avicenna prescribed a bath with tinted water to his patients, also to use clothes of certain colours and decorate the interior depending on their state. In 19th century French scientist Augustus Pleasanton discovered the medical effect of colour influence: blue and violet rays rendered soothing effect on patients. Now colour therapy is used both in medicine for state improvement of people with various diseases, and for the creation of adequate emotional-psychological conditions in industry, transport, business, etc.

<table>
<thead>
<tr>
<th>Colour</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Red</td>
<td>Making active, resilient, dynamical, intensive.</td>
</tr>
<tr>
<td>Orange</td>
<td>Restoring, recovering, warming, stimulating.</td>
</tr>
<tr>
<td>Yellow</td>
<td>Strengthening, toning up, recovering.</td>
</tr>
<tr>
<td>Green</td>
<td>Compensates power losses, weakens pressure, calms.</td>
</tr>
<tr>
<td>Dark blue</td>
<td>Calming, constraining, concentrating, cooling emotions.</td>
</tr>
<tr>
<td>Violet</td>
<td>Inspiring, removing pressure.</td>
</tr>
</tbody>
</table>

The sound is the other factor of action. The sound reflects the processes of formation, transformation of a substance, movement of objects in the world around. According to the antique scientists the sound in the form of music is the reflection of the world’s harmony. Music creates vibrations to harmonise the person with the world around. The effect of musical influence can be explained by the fact that music is capable of causing certain mental images, associations accompanied by respective alterations in physiological processes (tab. 2). Music is used with success in modern medicine in obstetric practice, in posttraumatic states, for pain removal.

<table>
<thead>
<tr>
<th>Musical style</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Gregorian church chanting</td>
<td>Spatial slackness. For meditations, silent activities, can lower stress.</td>
</tr>
<tr>
<td>Slow baroque music (Bach, Handel Vivaldi, Corelli)</td>
<td>Gives the feeling of stability, order, safety. Creates stimulating environment suitable for activity or work.</td>
</tr>
<tr>
<td>Classical music (Haydn, Mozart)</td>
<td>Capable of raising concentration, memory, spatial perception.</td>
</tr>
<tr>
<td>Music of romanticism</td>
<td>Emphasises expressiveness and sensuality. Wakens individualism, mysticism. Used for activization of</td>
</tr>
<tr>
<td>Genre</td>
<td>Effect</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>(Schubert, Schuman, Tchaikovsky, Chopin, List)</td>
<td>sympathy, passion, love.</td>
</tr>
<tr>
<td>Music of impressionists (Debussy, Fore, Ravel)</td>
<td>Based on free-moving moods and impressions. Causes pleasant images, as in dreams.</td>
</tr>
<tr>
<td>Jazz, blues, reggae</td>
<td>Cheer up, inspire, give pleasure, disseminate grief, aggravate humour and irony, raise sociability.</td>
</tr>
<tr>
<td>Rumba, macarena</td>
<td>Raise palpitation, do breath more frequent and deep, force all body to move.</td>
</tr>
<tr>
<td>Pop, national melodies</td>
<td>Provoke motion, create sensation of well-being.</td>
</tr>
<tr>
<td>Rock music</td>
<td>Wakens feelings, stimulates active movements, removes pressure, weakens pain. Also creates pressure, causes discord stress and pain in the organism.</td>
</tr>
<tr>
<td>Music in punk, rap, hip-hop, grunge style</td>
<td>Drive over, raises activity.</td>
</tr>
</tbody>
</table>

As colour and music render complex effect on psychoemotional and physiological spheres of the person, they can be successfully used as influencing factors for person’s psychophysiological state correction.

To increase the efficiency of influence it is important that correcting factors correspond to a person’s current state and vary depending on the state change during the correction in a feedback mode. There are various feedback systems including those intended for correction of the state. In many cases such systems are used to get rid of physical and/or psychoemotional pressure, to reach a certain mode of functioning of organs or organism system, to help an individual to develop skills to control the psychophysiological state. The signals received from any organ or parts of the body are transformed into various forms: sound, waves, values, etc. and are presented to the subject in order to control the organ functioning.

The estimation of the person’s state can be made on different parameters: the electrocardiogram, EEG, Galvanic Skin Response (GSR), etc. Convenience, availability, opportunity of application both in clinical, and in off clinical conditions determine the choice of a parameter under control. Parameters of human’s own fields and radiations of various natures - biofields are the integrated parameter reflecting current physical, psychoemotional state of a person representatively. The most convenient supervision by modern
technical means is the person’s own infrared radiation in wavelengths range of 8-14 microns.

**BIOL** system to correct psychophysiological state (PPS) by means of colour and music, based on use IR components of person’s biofield has been developed in Moscow Design Department ‘Electron’ by the group of scientists under direction of I.M. Kogan. This system consist of a personal computer and a radiometer in wavelength range from 8 to 14 microns connected to it.

2. **Correction of the Person’s Psychophysiological State by Means of Biofield Colourmusic Human-Machine System BIOL**

   It is desirable to implement the correction procedure in the room for relaxation with the corresponding interior, light, sound and visual technical equipment. During the correction procedure a patient is sitting in front of the monitor screen or the projective screen with his hand on the radiometer. The software of the system carries out the automatic correction procedure through the following algorithm.

   In the beginning of a session the biofield parameter value of a person’s palm, brightness temperature (BT), is registered in the background mode.

   Then the estimation of the person’s current psychophysiological state is done by means of the reduced Lusher test. This test consists in a consecutive choice of the most preferable colour from 8 ones offered. The sequence of the chosen colours reflects the subject’s current psychophysiological state, its formalised analysis being expressed in the form of the reaction coefficient (RC). After the comparison of the received reaction coefficient with the rating value, the conclusion about person’s state is done: if it is excited or calmed, after that the music of corresponding character: calming or exciting, automatically switches on.

   To provide such colour influence the colour scale corresponding to the subject’s psychophysiological state as well as the colour scale matching the range of brightness temperatures expected variations are to be worked out. This problem solution is as follows. The change of biofield parameter dynamics varies with different people and depends on their psychophysiological features, current PPS, external influences of the various nature. The musical images used in BIOL system cause individual variations of brightness temperatures. To evaluate these variations the time test musical influence interval to define the value of brightness temperatures change is appointed.

   The scale initial colour is set due to this change and in case of the biofield parameter dynamics trend preservation the most part of the scale is to correspond to the nature of musical influence.

   According to the established parameters, the system works in an automatic mode with colour-music biological feedback (CMBF), when colour
and musical images affect the person and cause his biofield parameters changes which, in its turn, lead to the change of colours on the screen.

Upon termination of CMBF value of brightness temperatures in a relaxation mode is registered.

At the end of the session repeated estimation of individual’s psychophysiological state by means of the reduced Lusher test is made. According to the change of reaction coefficient, the conclusion about efficiency of the correction procedure of subject’s PPS is done.

BT values during the session are written into the file, then with these values applied, the graph of brightness temperatures dynamics - thermogram is drawn.

3. Use of BIOL System for Estimation and Correction of Individual’s Psychophysiological State

The BIOL system is multipurpose, and can be used for both rehabilitation of the person, and monitoring of individuals’s state at various kinds of influences. Numerous researches by means of BIOL system have been carried out in various establishments.

For example, researches of stability of flying staff to thermal loads have been carried out in the State Research Experimental Institute of Aviation and Space Medicine (Moscow).¹

The examinee was placed in the thermal chamber and was kept there about 1 hour at temperature of about 50°C.² Such influence led to significant change of the person’s state with the respective change of physiological parameters values, such as: arterial pressure, frequency of intimate reductions, frequency of breath, weight of the body. Measurement of biofield parameter in a background mode was carried out before thermal load and after the action the session of rehabilitation by means of BIOL system was done. Change of the parameters of IR radiation before and after thermal loading correlating with changes of the basic physiological parameters has been stated (fig. 1). After a series of thermal influences training in a sauna during 2 weeks re-testing on thermal stability has been carried out, results of measurements of biofield parameter in these tests have shown training effect and increases of stability of flying staff to thermal loads (fig. 2).
4. Conclusion

In BIOL system there are many interconnected aspects, which are related to physical, intellectual, emotional spheres of a human being.
The first aspect is a phenomenon of human own fields and radiations – a biofield, which is researched and widely used for diagnostics and therapy of person’s state.

The second aspect. BIOL system is the human-machine system using modern computer engineering and technologies.

The third aspect which has the direct attitude to a theme of the present conference, – therapy by means of colour and music – the major factors of the physical, mental, spiritual worlds.

BIOL system has a number of features, characteristic for biofield systems: contactlessness, noninvasive, safety. The important feature of the system is overlapping in real time both diagnostics and the therapy adequate to a current individual’s state.

The system for rehabilitations of a person’s psychophysiological state reflects modern approach to treatment, which includes harmonizing influences not only on physiological processes and organic structures, but also on psychoemotional state of human.

Such system has a wide area of application and can be used both in medical practice for monitoring, diagnostics and correction of the person’s state, and in ordinary conditions for preventive maintenance of consequences of stressful influences.

Notes

1 <http:ww/toolsforwellness.com/biofeedback.html>
2 ibid.

Bibliography


<http://www.toolsforwellness.com/biofeedback.html>

Larisa Kruglova graduated from the Moscow State Technical University in 1987. Since 1994 she has been engaged in the research of human radiation. Her professional research interests are: biofield, colourmusic therapy, information technologies.
Cracking Up and Back Again: Transformation Through Music and Poetry

Diane Leslie Kaufman and Karen Deborah Goodman

Abstract
This chapter describes the transdisciplinary use of poetry therapy and music therapy in a substance abuse setting in a women’s group over eight sessions. An introductory literature review informs the reader that this use of poetry therapy and music therapy is unique. The authors describe the use of a poetry book, written by Dr. Diane Kaufman, a Psychiatrist who uses poetry in therapy, composed to reflect themes in suffering and healing as well as suggestions for reflections on these themes. Through the reading of these poems, the women in substance abuse recovery become motivated to write their own personal poems, weaving together not only their stories through poetry but also their spirits in changing group dynamics. Music therapy is offered as a means of deepening the emotional content of the poetry. Professor Karen Goodman, Music Therapist, along with her students at Montclair State University, improvise to each poem as requested and directed by each woman in the group. By the end of the eight sessions, the women have extended more involvement in the level of music making, suggesting a continuum of levels in this process. Questions for future consideration in the music therapy/poetry therapy process are posed.

Key Words: Creative arts therapy, music therapy, poetry therapy, substance abuse treatment, transdisciplinary.

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Poetry encompasses all human experience and offers recognition, welcome and solace to the outcast and isolated. As such, it can be especially therapeutic in the recovery from substance abuse addiction. Poetry enlarges the capacity for living through exploring, integrating and accepting paradox. In giving voice to anguish, poetry allows for mourning, thereby creating psychological space and hope for re-birth of a renewed self. Poetry’s ability to both contain and express deeply felt emotion produces catharsis by means of carefully chosen word, symbol, and metaphor made memorable through richness of imagery and musicality of rhythm and sound. The non-judgmental witnessing of self, which is seen and heard through its spoken words, is validating and nurturing. By evoking empathy, poetry helps heal the wounded self. Poetry therapy, utilizing poetry as a therapeutic tool, builds on cultivating the inner capacity for continued psycho-spiritual growth through
all of life’s challenges\(^7\) while it empowers and transforms the self through the creative power of words.\(^8,\,9\) By granting permission to shamed, disowned, and silenced aspects of the inner self to speak, a vital liberation occurs.\(^10\)

This article tells the story of the link between poetry and music, the subsequent link between poetry therapy and music therapy, and the realization of a transdisciplinary approach between two professionals who meet to work through the healing arts with women in substance abuse recovery.

1. **The Link Between Poetry and Music**
   Poetry and music, often thought of as separate entities, have a history, in antiquity, of being linked together. The root of the Greek word ‘melody,’ for example, signifies both poem and music, emphasizing a fundamental unity in their existence. In the ancient past, poems, sung through variance in their pitch suggested a musical language, a language possibly connected to mankind’s original speech.\(^11\) It is therefore quite logical to think of poetry and music in the same breath… and, quite possibly, poetry therapy and music therapy in the same breath.

2. **Music Therapy and Poetry Therapy**
   Although music therapy and poetry therapy have reportedly been used with women and adolescents with chemical addictions and poetry is mentioned as a spontaneous tool within the context of various case studies in music therapy,\(^12,\,13,\,14,\,15\) the interrelationship of poetry and music therapy has yet to be explored as a transdisciplinary process.

   In their evolving work in the spring of 2009, Kaufman and Goodman begin to form transdisciplinary collaboration for the use of music therapy and poetry therapy with substance abuse clients in an outpatient treatment center. Further, Kaufman and Goodman consider the interrelationship of poetry and music therapy in terms of the following: 1- levels of structure in introducing poetry and music therapy experiences to clients; 2- levels of affective exploration within the context of poetry and music therapy experiences; 3- the possibilities for a poetry therapist and a music therapist to work together.

3. **The Discovery of Collaboration: Poetry and Music Therapy**
   In presenting a joint poetry therapy/music therapy experience over eight two hour-long sessions with a group of women with chemical addictions, Kaufman and Goodman explore possible ways of cooperative work. The idea for integration of poetry and music therapies begins with an initial connection at the University of Medicine and Dentistry of New Jersey (Newark) where Goodman is an invited guest lecturer on music therapy for the University at large. The possibility for synergistic work to deepen the
therapeutic experience results in ongoing conversations on how to best integrate their respective expressive arts. Kaufman is invited to present on poetry therapy at Montclair State University for Goodman’s music therapy students who are then introduced to *Cracking Up and Back Again: Transformation Through Poetry*, a workbook developed for recovery in substance abuse outpatient programs. During the presentation at the university, students spontaneously decide to improvise music to one of Dr. Kaufman’s poems. It is such a successful experiment that it leads to further conversations regarding the possibility of the music students contributing to a poetry therapy and music therapy project as part of a community service project. Permission for this community service project is obtained from Integrity House, a residential drug treatment program in Newark, New Jersey, where Kaufman is facilitating poetry workshops in order to pilot a ‘poetry and music’ group experience for selected female residents. Three undergraduate students and three graduate students studying music therapy join Kaufman and Goodman as music therapy assistants in these sessions. They are ready to extend the work introduced to them through *Cracking Up and Back Again*. They will extend poetry through the use of improvised music.

4. **Cracking Up and Back Again Inspires Themes of Recovery**

*The Cracking Up and Back Again* poetry text, comprised of fifteen poems with an accompanying written reflection on the poem, provides questions for the reader to inspire a personal written response. All the poems, written by Kaufman, represent part of her own life journey towards healing. The poems, though personal, also speak to universal themes that all of us may encounter in suffering and healing. The text begins as follows:

Poetic Medicine

There’s always a big black pot
Simmering
Bubbling
Boiling over with troubles
Scalded air rising hot
Burning eyes and skin
A big wooden spoon
Hands spellbound
Can’t release the grip
Stirring wildly
Stirring non-stopping
And it’s always darkest night
The brew gets thicker and thicker
As more troubles keep piling in
You ask yourself, ‘Oh! When will it ever end?
A whisper replies, ‘Pour out the pot and start all over again!’

The written reflection includes ‘The ‘pot’ which is our own vessel of being will surely break as in ‘breakdown’ or ‘crackpot’ unless we do something about ‘it’ and ourselves …When one person breaks silence all of us gains strength…. Are you ready to take your poetic medicine? How sick do you have to make yourself in order to get well?’ The poem is an honest expression of hopelessness, but also speaks to hope and necessary courage for transformation can occur.

The fifteen poems travel a journey from despair to recovery including fear of losing one’s mind, shame, co-dependency, impact of violence, guilt, yearning for forgiveness, feelings of sexuality, and the wish to be dead which become poetically transformed into humility, acceptance, personal responsibility, gratitude, wanting to live, and dedication to making a positive difference. All of these themes are relevant for recovery in a substance abuse outpatient setting. The final poem entitled, ‘Yesterday My Heart Cracked Open’ includes these lines:

Friend
I pray for you
Your heart to crack
Wide open
Be not afraid
Be free instead

Spirituality is part of this poetic journey. As such, the text in its entirety is congruent with principles of the Twelve Steps of Alcohol Anonymous. The poems exemplify a living process of recovery. The reader, by means of a parallel process, begins to experience a felt sense of a personal recovery journey through reading, writing, and reflecting on Cracking Up and Back Again and creating their own life generating poems. Personal poems are like messengers, bringing back gifts from the symbolic world, revealing hidden truths and helping us to better let go and live.

5. The Poetry Therapy Process Begins
As a step toward stimulating the creative poetry process in the clients, Kaufman presents each poem as a model for reflection and discussion. As such, focused attention is given to the poem and to the person who wrote it. Poems written in the prior session have been typed by Kaufman and are returned. The clients read these poems aloud, sometimes to the
spontaneous applause by the other group members. After reading and discussing new poems, the clients write their own poems and take the opportunity to read these aloud to each other. This structure provides continuity and containment as well as modeling respectful caring for each other’s words, voice and personhood, which foster the creation of a safe and nurturing group dynamic.

The group reads two or three poems in sequential order from the text at each session. Different clients volunteer to read aloud so that different voices can be heard. A discussion ensues about the poems, often bringing the women to share how addiction impacts and has impacted their lives. Following this, the women are invited to write a poem inspired by the *Cracking Up and Back Again* poem, certain lines of the poem, the reflection comments and questions, or anything else they would like to write about. The one rule is to be respectful of their own and each other’s process to courageously look within, create, and share with others. The women are told that at the end of the eight sessions, they will each be given their own copy of the *Cracking Up and Back Again* book. The reason for this is to encourage the group to travel together from poem to poem in order to reach the final ending of poetry and transformation. The women appear to understand the value of this, and no one objects.

Poetry therapy techniques also include writing a collaborative group poem with lines taken from the women’s own poetry. This exercise takes place spontaneously with inspiration and energy generated from reactions to the poetry of *Cracking Up and Back Again*. The following poem first originated as individual poems written in response to Kaufman’s poems ‘The Place of Forgiveness’ and ‘I Am This.’ With assistance by Kaufman as facilitator, the women worked together to compose a group poem:

```
I am weak
I am not strong
Some may say this is wrong
I am learning to be just me and
I’m sorry drugs had a hold on me
Yes drugs had a hold on me to a big degree
They held me hostage and I couldn’t be free
I am alive within this body
Just to get one more buzz
I hurt everyone I love
I am right but also wrong
What is the melody to this sad song?
I looked in the mirror and what did I see
All I know it was just me
I am true but I am a liar
```
My soul is dangerously on fire

Expressive Arts for Recovery Group Poem
April 28, 2009


After clients take the time to create their own poems stemming from their initial processing of Kaufman’s thematic poetry, they are asked if they want to have their poem set to music. Some eagerly comply; others apprehensively say ‘not yet’, possibly linked to resistance to deeper emotional impact of their words.

The responsibility for setting the poem to music, in these cases, falls to the music therapist and therefore can be viewed as a Level One or beginning level of songwriting. What other possibilities might exist other than having the music therapist interpret the mood of the poem, the appropriate musical structure, harmony and melody for a song?

Subsequently other levels of structure, referred to here as Levels Two, and Three emerge in the last session of eight. The last session of the group includes a Level Two structure, intermediate level where clients became involved in their own music making by initiating suggestions for the style of the song (i.e. waltz, march, Latin, rock, etc), the tempo of the song, the type of instrument (including the vocal voicing) for their accompaniment and, finally, the mood of the song, which can result in predictable harmonies associated with varying degrees of happiness or unhappiness. Another technique used in Level Two suggests that the therapist ask the client to rhythmically repeat the words to a poem, inviting a ‘sprech stimme’ or speech song intonation that could lead into suggestion of a melodic line. Level 3, Intermediate/Advanced level, including Level 2 techniques supplemented by the client actually joining in a musical dialogue with the therapist, including antiphonal or echo singing, are also present in the last session. Although a Level 4 structure, Advanced, does not take place in this group, it conceivably could take place if the group continues. This level would involve preliminary training in song writing, sufficient for the client to create their own song structure for their poem and accompany and/or solo sing their work.

7. Case Example

One specific example of poetry (by Lorena L.) set to music occurs in the last session and thematically describes the inner struggle of the substance abuser … ‘a storm of thoughts… of using in my mind …blood pressure boiling hot, burning heart and soul, tear filled eyes’ and the need to ‘clear your mind and start all over again.’ Goodman begins the song on the keyboard with a driving rock tempo in minor key, creating a vocal line to
complement the key and the mood of the song. The woman contributing this poem abruptly stops Goodman whereupon she is encouraged by both Kaufman and Goodman to provide more structure. The woman requests the use of the guitar rather than the keyboard and asks for more ‘quiet.’ The new musical interpretation of the song is more melodically lyrical and, in a sense, sentimental, perhaps inviting more reflective feelings. The woman is satisfied.

These ideas suggest levels of music making initiated by the client in response to one’s own poetry and apparently represent new methods in songwriting as, more typically, clients compose lyrics to pre-existing melodies.22, 23

8. Levels of Affective Exploration within the Context of Poetry and Music Therapy

Themes explored in the poetry of the women in the substance abuse group include the following: loss, fear, death, and hope. Some of these themes are related in the context of spirituality, family, separation and reattachment, love and persistence to change and heal. For example, the following poem reawakens the sense of determination or hope that the client wishes to find:

Need to be more awake
Don’t make another mistake
Try to look at something new
Try to do it from another view
Change the thoughts that are in my head
Enough already, enough’s been said
Brand new views that I must see
Truth hurts, but it will set me free

Sara S.
Expressive Arts for Recovery
April 19, 2009

Perhaps the most vital questions concerning levels of affective exploration within the context of poetry and music therapy experiences touch on the deepening of emotional exploration through the process of the poem being set to music, music not only triggering the neurological capacity of music to simultaneously engage the mind and body but music providing a tool for more in-depth emotional experience that a client might resist: ‘I don’t want you to set my poem to music… because that will make the words real.’

The impetus of more defined rhythm, harmonic mood setting and the tension and subsequent relief of the melody further stimulate the poem,
initially serving, as a container for thoughts and feelings. As the women in the group state, ‘you made it real for me.’ Indeed the women who resist having their poems set to music confirm that the emotionality of the music is not ‘something I am ready for yet.’ Despite this self-protectiveness, the ability of the music therapist to musically invite participation and the building cohesiveness of the group members to model for each other leads to all the women singing the closing poem with the therapist as well as a jokingly sung round of ‘You can’t make me sing. No, I won’t do it.’

9. Reflections on Changing Group Dynamics

Music and poetry therapies are known to enhance group cohesion and group therapeutic work. These therapies can also exert real yet subtle influences on the experience of time to the benefit of clients who are burdened with a past they cannot escape, a present, which feels frightening and unbearable, and a future, which seems impossible to reach. The eight-session music and therapy experience show the women to be increasingly comfortable with sharing their feelings in response to poems read and poems written. They do not rush through writing their poems and are most often respectful in keeping silent while the other women are still writing. The women remember each other’s poems and encourage each other’s creative process in writing and in making music. There is a feeling of pride in the room… that in this group the women are not labeled as addicts but are known within themselves and by us as poets who have something meaningful to express in word and music. When one woman courageously describes experiences of sexual abuse through her poem, the group reaches out to her gently and with compassion.

A turning point in the group is in the fifth session when the women write the collaborative group poem and then participate in its creation into music, suggesting it be done first as ballad and then as scat. There is amazement and joy shared by all group members over the poem, the music, and most of all, the creative process that makes something beautiful out of so much pain.

One woman (Sara S.) in particular seems to blossom through the group sessions, increasingly finding her voice and opening up in sharing her past full of pain and regrets, now hoping for a better life. The other women in the group joke aloud with her in a caring way, about how much she has begun to speak up in the music and poetry group in comparison with how shy and withdrawn she is in other settings. Sara smiles in agreement with their observations. Sara’s feedback on the group is ‘You opened up my heart to writing again! I loved the music and instruments. Your classes really lifted my spirits.’

Additional comments from the women include: ‘You’ve influenced not just me but my whole life – forever.’ ‘I love this workshop…I love the
music and the way it was put to the songs. It gave me some peace to my pain and trials. Thank you.’ ‘The music also intensified the feeling and brought out many suppressed feelings I kept locked away. Through my experience with this workshop I am going to continue writing poetry to express my feelings.’ ‘I loved every moment of this class. Music made it real, alive and fun. I could relate to everyone’s poem and feel connected to each person in some way.’

10. Closing Thoughts: Possibilities for a Poetry Therapist and a Music Therapist to Work Together

In a preliminary series of sessions, Kaufman and Goodman are successful in stimulating the clients of this substance abuse music therapy/poetry therapy group to accept their thoughts and express their feelings through artistic process. Further exploration of the process of a poetry therapist and music therapist working together would involve discussion and ongoing resolution of several issues:

- What comes first, the poem or the music?
- Who handles the verbal processing of the poetry? of the music?
- What transferences and counter transferences may interface between the clients and the therapists? Between therapist and therapist?
- What devices exist in structuring both the poem and the song?
- How might additional understanding of each other’s craft expedite the process further?

Notes

5 Akhtar, op.cit., p. 235.
6 C Steele, We Heal from Memory: Sexton, Lorde, Anzaldua and the Poetry of Witness, Palgrave, New York, 2000, p. 4.


Kaufman, op.cit., p. 1

Kaufman, op.cit., p. 2

Kaufman, op.cit., p. 61


Bibliography


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**From Sponge to Source: Health Information in the Lives of Gay Men Living with HIV**

*Joel Minion, Peter Bath, Kendra Albright*

**Abstract**
Existing research into the information activities of people living with HIV has typically focused on issues of where individuals look and how they search. Little attention has been directed to understanding the meaning health information carries for those who use it or how information practices are contextualised within the social experience of living with a chronic condition. This chapter explores how biomedical and experiential health information co-mediate the lives of gay men living with HIV. The discussion is based on a qualitative study of the information experiences of 24 HIV+ gay men living in the north of England. Ethnographic data were collected using unstructured interviews, health questionnaires, home mapping and photography. The findings indicate that the men’s information practices parallel the distinction drawn between disease-as-pathology and illness-as-social-experience. Participants typically passed through a limited period (not always immediately upon diagnosis) in which they became ‘sponges’ for biomedical knowledge about the virus and its treatment. The information collected was regarded as essential to understanding and managing the physical effects of HIV, with specialist doctors playing a central role in the learning process. Over the longer term, however, disease information proved secondary to illness or experiential information collected either directly from a man’s own history or from that of others like him. This second type of health information helped men inform their everyday lives while dealing with the uncertainty of their long term prognosis. Charitable HIV support agencies, in particular, served as a key information ground in which experiential knowledge was exchanged, a process that then facilitated the emergence of men regarding themselves as valuable sources (i.e. creators and disseminators) of essential health information rather than simply consumers.

**Key Words:** HIV/AIDS, gay men, health information, information practices.

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1. **Introduction**
   Living with HIV brings with it a host of information-related challenges. From a clinical perspective, rapid advancements in research and treatment can make staying well informed difficult and complex. In practical terms, the chronic and oftentimes unpredictable nature of HIV alongside changes to life circumstances mean people’s information needs can vary
tremendously over time. This chapter discusses a selection of findings from a larger study into the information world of HIV+ gay men. The aim of the research has been to understand how information practices among these men are influenced by the social context of being both positive and gay. The present discussion focuses specifically on the ways in which biomedical information practices differ from and yet complement their experiential counterparts.

This study builds on three propositions in the existing literature. First, people will avoid information they perceive as too costly in social terms to access. They will also ignore information so long as their world can be made to function without it. Second, understanding the world view of an information user is vital to understanding his/her everyday information practices. As a result, information must be defined as anything the user finds informing. Finally, disease and illness must be distinguished conceptually, with disease referring to pathologies of the body and illness to the social experience of ill health. Information science research seldom draws this distinction, with health information implicitly associated with biomedical knowledge. The information users collect from personal experience in an effort to understand their health is seldom regarded as comparable in importance.

2. Related Work

Research into the information activities of people living with HIV (PLWH) is not extensive and must be referenced cautiously. Much of the research has been conducted in the United States, the only major Western country without universal public healthcare and one still characterised to varying degrees by the so-called ‘culture war’ around issues such as sexual orientation. Furthermore, the patterns of information behaviour among PLWH likely changed, perhaps significantly, after the mid-1990s as effective treatment transitioned HIV infection from a terminal to a chronic condition. As a result, research conducted before this period may be of limited applicability. Finally, many studies did not restrict their samples to gay men or did not identify sexual orientation as a variable for analysis. As a result, information practices specific to men who self-identify as gay often cannot be identified.

These weaknesses noted, it is known that people diagnosed with HIV typically learn about their condition from four sources: healthcare professionals, social support networks, the media and Internet, and others with the virus. Access to information is no longer considered a problem by most PLWH. The Internet alone is generally not considered a primary source, although white gay men with a higher education who used the Internet had an appreciably better understanding of HIV.
also appears to allow HIV+ individuals to cope with their infection by exchanging information with one another.\textsuperscript{13} People with HIV search with greatest frequency for drug, medical and treatment information, followed by information about general wellness, relationships, and legal issues.\textsuperscript{14} They consider themselves more hopeful about their future as a result of what they find.\textsuperscript{15} White, gay men show some preference over other social groups for information taken from newsletters, educational forums and peers.\textsuperscript{16} Gay men also inform their decision about antiretroviral therapy (ART) more on the experience of friends rather than by accessing biomedical sources.\textsuperscript{17} Once on treatment, PLWH with report a high degree of satisfaction with their knowledge of medications, though finding information relevant to one’s personal circumstances remains a problem.\textsuperscript{18}

3. Methodology

Three selection criteria were used to recruit participants into the study. Men were required: (1) to be at least 18 years of age; (2) to self-identify as gay; and, (3) to have lived with a diagnosis of HIV for a minimum of two years. An ethnographic approach was then used to elicit narratives about past efforts to become informed about first being gay and then being HIV+. Ethnographic methods are particularly suitable to this type of research because they are characteristically more emergent than pre-structured\textsuperscript{19} and can detail ‘the routine, daily lives of people.’\textsuperscript{20} They are also able produce ‘thick descriptions, contextual understandings and fine-grained analyses about the influence of social structures on men’s health and illness behaviours.’\textsuperscript{21} Within the ethnographic approach, interpretive interactionism was used to understand how key life experiences (coming out, testing positive, disclosing one’s status, initiating treatment) shaped the meanings given to the health information accessed.\textsuperscript{22}

Data were collected during single meetings in the home. The average meeting lasted just under three hours and began with completion of a brief health questionnaire. Next, each participant was asked sketch the floor plan of his home and indicate on it anything in his home solely because he was positive. Photographs were later taken of these items in order to identify possible sources of information in the home such as HIV-related publications and health journals. The main part of each meeting was given to conducting an unstructured interview addressing each man’s experiences growing up gay, testing for HIV, and becoming informed post-diagnosis. Finally, fieldnotes were written immediately following a meeting, while the interviews were transcribed by a professional service.

A majority of the participants were recruited with the assistance of four charitable HIV agencies in the north of England. The remainder were enrolled by word of mouth. Due to a slow initial uptake and on the
recommendation of one of the agencies, an inducement was introduced retroactively following the first three meetings. Participants were offered a £10 grocery voucher, with an additional £10 being donated on their behalf to the agency through which they were recruited or to the HIV charity of their choice. The meetings were conducted between October 2007 and August 2008, with most taking place from April 2008 onwards.

4. Analysis

In keeping with the centrality of biographical and historical context in interpretive interactionism, the first stage of data analysis involved writing a short biography for each man, outlining his experience of key transitional events. These included coming out to family members, developing an awareness of HIV, negotiating safer sex practices, testing for the virus, and developing a ‘stock of knowledge’ following diagnosis. These personal histories helped identify essential structures and patterns in how men sought, used and shared health information. Two distinct types of information became evident as a result: information needed to understand the pathology and treatment of HIV infection, and information needed to live with HIV on a daily basis.

Biomedical and experiential information were then each considered with respect to how the men sought and used health information. Sources of the former included healthcare professionals (primarily HIV specialist doctors), charitable support agencies, the Internet, and print materials. Not surprisingly, experiential information was collected from past personal health experiences as well as from the experiences of other HIV+ gay men, typically in the mediated setting offered by charitable HIV support agencies. NVivo software was used to classify systematically all relevant portions of the transcripts and field notes into the information typology devised. The results were then reviewed for consistency in theme, with the men’s experiences summarised and key quotes identified.

5. Results

The participants: the average age of the 24 men who took part in the study was 41.9 years (range: 26.4 to 57.6 years). All of the participants identified themselves ethnically as either White British (n=22) or White European (n=2). Two reported having been raised outside the United Kingdom (one in Europe and one in Africa), while two others had lived most of their adult life overseas, returning to the UK only recently for health reasons. At the time of our meeting, the majority of the men lived either alone (n=11, 46%) or with a male partner (n=10, 42%).

With respect to education, two men (8%) had left school without any formal qualifications, six (25%) had achieved at least one O Level or equivalent, three (13%) had achieved at least one A Level or equivalent, three
(13%) had earned a certificate or diploma, seven (29%) held at least one undergraduate degree, and three men (13%) had earned postgraduate degrees. All of the men had been working or at university at the time of their diagnosis. Seven (29%) were presently in full time employment, three (13%) part time, and fourteen (58%) were living on a government disability allowance. Two of the men on benefits were also enrolled part time as students.

The average age at diagnosis had been 32.2 years (range: 23.8 to 50.1 years), with the average length of time since diagnosis 9.8 years (range: 2.3 to 21.9 years). Most men had been diagnosed in either their 20s (n=11, 46%) or their 30s (n=10, 42%). Eight (33%) had tested positive in or before 1996, the year the efficacy of combination antiretroviral therapy was announced publicly. Four men (including all three participants in their 20s) had yet to initiate treatment.

Information as sourced: all of the men except for one individual diagnosed in 1986 reported being aware of HIV prior to the point at which they believed they became infected. Their level of awareness varied considerably, although all of them knew that condom use during anal intercourse prevented viral transmission. Participants were asked via the questionnaire to identify their main source(s) of information about HIV in the weeks following diagnosis and then again at present. Their responses were sorted into six categories for analysis:

Table 1: Main source of information

<table>
<thead>
<tr>
<th>Information Source</th>
<th>At Diagnosis</th>
<th>At Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare Provider (HCP)</td>
<td>13 (54%)</td>
<td>6 (25%)</td>
</tr>
<tr>
<td>Support Agency</td>
<td>4 (17%)</td>
<td>12 (50%)</td>
</tr>
<tr>
<td>Print Source</td>
<td>1 (4%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Internet</td>
<td>6 (25%)</td>
<td>10 (42%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (8%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>None</td>
<td>1 (4%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Total Responses *</td>
<td>27</td>
<td>35</td>
</tr>
</tbody>
</table>

HCP = HIV doctor, GP, nurse practitioner, nurse, social worker, counsellor
Support Agency = Staff/volunteers at charitable agencies supporting PLWH
Other = friends, partner, television
* Multiple responses result in percentages totalling more than 100%

The sources used by the men following diagnosis and at present reiterated the findings of past research, namely a preference for information...
accessed directly from individuals viewed as knowledgeable about HIV rather than through print or electronic sources. The present data did indicate, however, a sizeable shift in the men’s source preferences over time. Not only did their reliance on healthcare providers decrease, but they turned in increasing numbers to charitable HIV support agencies for their information. This transition was studied in greater detail by reviewing interview transcripts and field notes for stories in which the men spoke more about the types of information they searched for, as well as when and where. Emergent patterns indicated that the men established a very different relationship over time with information about the disease of HIV than with information that allowed a man to live with infection on an everyday basis. The remainder of this discussion focuses on this distinction.

6. Biomedical Information

Biomedical information was defined in this study as anything that informed a participant about the pathology and treatment of HIV infection. In practice, biomedical information helped participants meet two principal needs. First, it supported a man’s ability to make sense of CD4 and viral load test results. Respectively, these clinical markers are used to assess immune system functioning (ART is generally started when CD4 counts fall below 350 cells/mm³) and the amount of virus in the bloodstream (ideally, viral load should be undetectable while on ART). Most of the men were being tested every two to four months regardless of whether they had initiated treatment. Understanding these numbers offered many men the comfort of a quantifiable representation of their health.

Biomedical information was also valuable in understanding ART. All of the men were aware that antiretroviral medications prevented HIV infection from becoming a terminal condition. But ART, which aims to raise CD4 levels and drop viral loads, can be complex and must be tailored to the individual. Common challenges faced by patients include side-effects, issues of adherence, and the threat of developing drug resistance. While a few men had been living successfully on one combination of medication for multiple years, almost all had needed to change combinations, many within the 12 months leading up to our meeting. The four men not on treatment had each begun investigating what was involved in anticipation of the need to make informed decisions in the short to medium term.

Beyond these two needs, all of the men had urgently sought biomedical information at some point in an attempt to answer the highly personal question, am I going to die? This search, however, was almost never long term and seldom took place more than once. Rather, men experienced a single period lasting a few weeks to a few months during which they intensively added to their stock of biomedical knowledge. Outside of this period, disease related information, such as that needed to
understand and address changes in CD4 counts and viral levels, was gathered
but in a considerably less directed fashion and with far less exigency.

The men conducted the threat-of-death search at different points in
time. Some did so immediately following their diagnosis. Owen (age 38,
diagnosed in 2002) described himself as being like a sponge during this
period, remarking how ‘no information was too small.’ Others, by contrast,
waited up to several years before taking steps to learn more about the threat
posed by HIV. Stephen (age 38, diagnosed in 1996) did so only after a near-
death experience in 2006. The issue for men such as him was never one of
denying their original diagnosis; in fact, they had all been exposed
continuously to biomedical information during regular medical visits. They
simply made little effort to become informed at a more in-depth level. The
reasons given were varied: some men felt fine and had no HIV-related
symptoms; others were too ill and lacked the energy to search; while a small
number spoke of being in denial of the potential long term impact of HIV on
their body.

HIV specialist doctors were the default source of biomedical
information in the first instance. Many men spoke highly of their doctor’s
wealth of knowledge and authority in treating HIV, with a few having
developed relationships with particular consultants over many years. A more
detailed reading of the transcript data, however, revealed that most specific
comments about biomedical information sourced from specialist doctors
emphasised their role in understanding test results and initiating ART.
Questions about concerns such as mental health issues, drug side effects,
nutrition, and even drug therapies in development were often cited as being
inadequately or poorly addressed. A third of the men also spoke about
problems in accessing HIV care that in turn limited the availability of
biomedical information from this source. These included overly brief
appointments and a failure to see the same doctor in consecutive visits.

Charitable HIV support agencies provided the main alternate source
of biomedical information. Such agencies were often seen as being more
comprehensive, personally relevant, and accessible. As Jon (age 35,
diagnosed in 1996) stated succinctly, ‘If the medical system typically
provides a leaflet, HIV agencies offer a book.’ Within the agencies,
biomedical information was sought mainly from trained staff, including
visiting or part time lay HIV educators (often positive themselves). Julian
(age 56) reflected on the value of one such educator, stating:

If you talk to Terrence, he will go into great detail and it’s
more sort of comfortable because he will explain
everything because he will take the time. Whereas when
you go to the [doctor], like I say, it’s quite technical and
it’s quite a lot of jargon which I sometimes don’t understand.

As in the case of doctors, men expressly sought biomedical information through agencies only for a limited period of time, even though they frequently maintained longer associations with the groups as service users in other areas.

While approximately half the men regarded the Internet as an important, if secondary, source of biomedical information, many also viewed it with some scepticism. A key problem was the issue of overload. The sheer volume of information available was variously described by men as mind boggling, bamboozling and ‘too much and too deep’. Stephen recalled how ‘in the early days when I did use the Internet a lot, I found out too much information and didn’t understand it all so it didn’t paint a bright picture. It kind of overloaded me and I couldn’t just see the bits that I needed to.’ Andrew (age 35, diagnosed in 1999), moreover, found easy access to biomedical information on a multitude of high quality sites meant unintended exposure to things he would rather have not known: ‘What I don’t like about [the Internet] is the fact that it’s more negative information as in another thing to worry about.’

By comparison, print publications were viewed much more positively by the men. Two frequently mentioned glossy magazines provided readers with regular overviews of specific medications and announcements of new therapies or research advances. ‘I like [Positive Nation] because there are some interesting articles in there about new things which I don’t really get to know unless I start really researching – and at the moment I don’t have the time’ (Jon, age 35, diagnosed in 1996). These publications also benefited from being physically tangible as well: ‘They just seem more real than looking online’ (Adam, age 27, diagnosed in 2005). In addition, two national HIV organisations published free monthly newsletters distributed by post (as well as downloadable online) covering similar topics. Unlike the magazines, however, only one of the newsletters was aimed exclusively at PLWH; the other was written for medical professionals as well. Of it, Owen commented, ‘I can understand it, but for other people who have got no idea what blind studies mean – placebos and stuff like that – it’s very in-depth.’

7. **Experiential Information**

In contrast to biomedical information, the men in this study appeared to attach greater value to personal experience. If blood tests and ART kept a man alive, the ability to live productively on a daily basis underscored the need to informed by experience. In practical terms, experiential information was effectively impossible to avoid. Jerome (age 44, diagnosed 1999) summed up the reality of accumulating self-knowledge by
stating, ‘You are living with your condition 24 hours a day, 7 days a week, 365 days of the year for a number of years, so that makes you knowledgeable.’ While none of the participants kept health journals, all of them called upon personal past experience and spoke about the process by which they re-established a sense of equilibrium around their health at some point following their diagnosis. For many, there was an initial ‘propensity to get flustered and worried at the first ache, the first pain, the first niggling headache that just doesn’t seem to want to go away with an aspirin’ (James, age 45, diagnosed in 2000). But even experiential information could become overwhelming: ‘It is very difficult to monitor yourself constantly without becoming a hypochondriac’ (Pieter, age 46, diagnosed in 1989).

Experiential information underscored the importance in the men’s lives of self-management rather than the development of expertise. Participants’ focus appeared to be on striking a balance between being informed about one’s own body and getting on with life. ‘I try and put the illness to the back of my mind and get on with what I want to do. There is absolutely no point in swallowing all these tablets and going to the hospital to all these clinics if you are going to let the illness rule your life’ (Gordon, age 42, diagnosed in 1993). In this respect, living with HIV often left limited space for an ongoing influx of large amounts of biomedical information in particular.

Participants did, however, often rely significantly on the experiences of other HIV+ gay men. In some cases friends served this function, but mostly they used charitable HIV support agencies to serve as information grounds or public places where experiential information could be exchanged, often serendipitously while accessing other services such as psychotherapy, massage sessions and hot meals. But as with biomedical information practices, the use of HIV agencies to access experiential information was not necessarily most intense following diagnosis. It took Andrew, a nurse, seven years to establish contact. During this time, he had become well informed biomedically but had not discussed his experience with other HIV+ gay men:

The impact of talking to Anthony [a positive staff member] was profound. He had similar experiences, similar worries, similar anxieties. Just being able to communicate with another person that was HIV+, that had similar experiences, was just so powerful. I can’t put it into words, really, the impact it had on me. A positive impact, you know? He is a lot older than me so there is an element of seeing into the future, which is a bit scary.

Jerome, on the other hand, worked for one such agency. During a longer discussion on the purpose of the group, he said:
I think when you bring a group of people together with a multitude of conditions and you sit down and you start talking, you ask people to share their experiences, you know - the things like fatigue, depression, lethargicness that everybody experiences at some time – I think it actually helps switch the light on for quite a few people.

Although HIV agencies were typically used as information grounds for longer periods than men sought biomedical information, involvement generally did taper off. A small number of individuals shifted into volunteer roles but most maintained only limited links to an agency through occasional visits or via mail outs of newsletters. Men accounted for this distancing in a variety of ways. Liam (age 39, diagnosed in 1999) said, ‘I am not getting out of it as much as I used to. It’s a little bit negative. I am not negative anymore. I’m just getting on with it now.’ Damian (age 38, diagnosed in 2001) found too many service users took more than they gave: ‘They just want to talk about themselves so I never get a chance to relate it to me.’ And Owen captured the dependency that sometimes developed when men spent extended periods of time in agency offices. In full time employment himself, he remarked, ‘I can’t get my head around why can they not pull themselves away from it? Why do they want to live in this HIV world seven days a week?’

Ultimately, it was experiential information that allowed men to attach social value to their personal histories with HIV, therein becoming sources of information themselves. Gary (age 52, diagnosed in 1986) was the longest surviving participant in the study.

I am not banging my own drum and I am not a bigheaded person. But because I have been 22 years with HIV, I have seen some differences and I have listened to people and I know a lot. And I can pass that on to someone, you know what I mean?

Unlike other men, Gary still attended a support group on a semi-regular basis because it offered him a sense of purpose and personal fulfillment. Jack (age 36), who tested positive in 2004 after working for more than a decade as an HIV educator, had supplemented his encyclopaedic knowledge of HIV with personal experience of his own infection and antiretroviral regimens in order to offer something he could not have done prior to diagnosis: ‘I think my job now is to just help people to relegate HIV to a place at the back of their mind once they are convinced they are actually okay.’

Viewed from this perspective, experiential information flowed in a ‘pay it forward’ fashion, moving slowly from longer-term survivors to the
more newly diagnosed. Stephen (diagnosed in 1996) spoke of having arrived at a time in his life where he could now offer a shoulder to cry on only because of those who had been there for him. Outside of support groups and moments of crisis (such as a friend testing positive), however, experiential information was shared quite informally and sporadically. It tended to slip into discussions around matters unrelated to HIV. Even at the agencies, ‘we don’t sit around and talk about AIDS a great deal’ (George, age 47, diagnosed in 1990).

8. Discussion

The aim of this study was to understand the information practices of HIV+ gay men within the context of their social experience of sexual experience and being positive. Given the existing research into the information activities of PLWH, it was not surprising that participants turned primarily to healthcare professionals (notably HIV doctors) and charitable agencies for many of their information needs. The impetus behind specific information practices, however, and the manner in which they went about informing themselves both highlighted the degree to which health information cannot be approached as a homogenous entity. Rather, different types of information served distinct purposes at different points in time.

Biomedical information had meaning in large measure because it addressed the central concern of staying alive. With HIV having become a chronic and largely manageable disease, the issue of dying was more readily muted by the men than it would likely have been in the past. Once a man was able and willing to inform himself through an authoritative source that his infection was controllable, his urgent need for biomedical information was minimised. Specialist doctors were a preferred source for this purpose, but support agencies offered biomedical information that was more comprehensible and comprehensive. As a result of these information practices, most men felt that developing an overly extensive biomedical stock of knowledge offered only a quantified assessment of their state of their health that did not translate sufficiently into successfully living life on a daily basis.

Experiential information, on the other hand, gave the men a better idea of what to expect in their future. The development of a personal history with the virus brought a deeper sense of meaning about the impact HIV would have on how they lived their lives. Participants added to their stock of experiential knowledge by interacting with other HIV+ gay men and hearing their stories. The value to experiential information lay not in its clinical accuracy, but in its affirmative and even predictive potential. Biomedical information, by contrast, was unable to address a man’s life concerns, issues that included such things as whether he was going to become progressively
incapacitated or whether HIV would prove an insurmountable barrier to achieving a long-term relationship.

Within the information world the men constructed, it was experiential information in particular that allowed many men to add value to their lives by being able to inform others. This transition marked an ability to move beyond being simply a consumer of health information and services. As Jerome remarked, ‘I still like it when I have been able to help somebody understand, help them come to terms with their not being punished because they are HIV+. They are just, you know, they are not alone.’

Considered jointly from around the time of diagnosis, biomedical and experiential information performed overlapping and complementary functions in the men’s lives with HIV. Regardless of whether testing positive had been a surprise or a confirmation, the news set in motion a pattern of information practices aimed at reconciling oneself with one’s viral status. And where biomedical information was sought and used to re-establish a sense of control, experiential information addressed social issues such as isolation and stigma. The former was a means of keeping HIV in check; the latter, a means of developing a social context in which to live with HIV. Both types of information attended to different aspects of the men’s efforts to ‘make peace’ with their health.

The advantage of using a research approach focused more on life history was that it allowed for the identification of an arc along which the men used information to propel themselves from one understanding of their health to next. If there was an endpoint, it was achieving a set of life circumstances where the inflow of health information began to be balanced by an outflow, and where there was an overall decreased urgency (though not altogether elimination) to become still further informed about HIV. In other words, the men reached a point where their lives were again functioning with less information rather than more.

Notes


12 Hogan & Palmer, p. 435.


14 J T Huber & JM Cruz, p. 44.

15 ibid., p. 46.

16 Hogan & Palmer, p. 435.

17 R S Gold & D T Ridge, ‘“I will start treatment when I think the time is right”: HIV-positive Gay Men Talk about their Decision Not to Access Antiretroviral Therapy’. *AIDS Care*, vol. 13, no. 6, 2001, p. 705.


While the importance of the Internet appeared to increase markedly the longer men lived with HIV, analysis of its use as a source of health information was complicated by the fact many of the men were diagnosed prior to ready online accessibility in British homes. Only one of the thirteen men diagnosed prior to 2000 reported the Internet as a main initial source. Interestingly, even among the eleven participants diagnosed in 2000 or later, under half (n=5) reported using the Internet as a primary source of information, including two who ranked the Internet alongside a healthcare provider.

**Bibliography**


Gold, R. S., & Ridge, D.T., ‘‘I will start treatment when I think the time is right’: HIV-positive Gay Men Talk about their Decision Not to Access Antiretroviral Therapy’. *AIDS Care*, vol. 13, no. 6, 2001, pp. 693-708.


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AIDS and the Paradigms of Dissent

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Abstract
Health care standards are based on a negotiation of consent or consensus, a paradigm of scientific knowledge. Scientific revolutions in virology, immunology, and HIV/AIDS exemplify both consent and dissent. A medical consensus coalesced around a viral agent (HIV) as the cause of AIDS. A health practices consensus formed around a binarism of ‘safe’ and ‘unsafe’ sex practices. A social consensus eventually developed around a meaning of the HIV-infected as the sentimentalised victims of disease. However, the emergence of two opposing political and social ideologies in the United States in the 1980s, the Religious Right and the gay rights movement, delineated a discursive field in which competing representations of the medical and social meanings of the disease were contested. This chapter examines three paradigms of dissent. First, the American HIV-denialist John Lauritsen, who rejects the HIV consensus, exemplifies ‘gnostic’ dissent. Second, the narrative representations of HIV in fiction by the African-American fantasy writer Samuel R. Delany, who has rejected the binarism of ‘safe’ and ‘unsafe’ sex practices, exemplifies sceptical dissent. Third, alternatives to mainstream sentimentalized views of ‘AIDS victims’, which were created by AIDS ‘zines (underground self-published magazines) such as Diseased Pariah News and Infected Faggot Perspectives, exemplify cultural dissent.

Key Words: AIDS, dissent, epidemiology, disease prevention, culture, literature, media.

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1. Introduction
Making sense of health, illness and disease entails making sense of the processes by which both dissent and consensus operate within epidemiological, evidence-base, and cultural discourses. Speaking here today about AIDS dissent, I am struck by an intriguing personal coincidence: I have left my home in Mansfield, Connecticut, a town founded by religious dissenters, chiefly Congregationalists, in the eighteenth century, coming to Mansfield College, Oxford, a college founded by religious dissenters, chiefly Congregationalists, in the nineteenth century. Dissent often has a paradoxical and symbiotic relationship with consensus and the status quo. To use one of the preeminent tropes of our age, dissent often ‘goes viral’ and becomes a new consensus.
The discourses of medical science are based on the rhetorical and epistemological development of consensus about what Thomas Kuhn famously called a paradigm of scientific knowledge. The late-twentieth-century scientific revolutions (to use Kuhn’s term) in virology, immunology, and HIV/AIDS medical treatment exemplify both consensus and dissent. The mainstream medical consensus, for example, quickly coalesced around a viral agent (HIV) as the cause of AIDS. The mainstream health practice consensus initially formed around a clearly defined binarism of ‘safe’ and ‘unsafe’ sex practices that would prevent or promote HIV transmission and encouraged a rigid adherence to that prevention regimen. The mainstream cultural consensus eventually developed around a meaning of the HIV-infected person or AIDS-affected patient either as normal (in a mass marketed stereotype of the mainstream ‘normal’) or as the sentimentalized victims of disease. Paradigms of dissent, however, also developed around the medical, health practice, and cultural meanings of HIV/AIDS.

This chapter will focus on three paradigms of dissent. First, the American HIV-dissenter John Lauritsen has persisted in rejecting HIV as the cause of AIDS. I will characterize Lauritsen’s epidemiological dissent as a gnostic paradigm. Second, the narrative representations of AIDS in fiction by the African-American fantasy writer Samuel R. Delany in the 1980s and early 90s rejected the rigid binarism of ‘safe’ and ‘unsafe’ sex practices. I will characterize Delany’s evidence-based health-practices dissent as a sceptical paradigm. Third, alternatives to the mainstream normalized or sentimentalized view of ‘AIDS victims’ (highly marketed in mass media) were created by AIDS ‘zines (non-commercial, underground self-published periodicals) such as Diseased Pariah News and Infected Faggot Perspectives. I will characterize the dissent of AIDS ‘zines as a cultural paradigm.

2. Crisis of Legitimation

In the post-World War II United States, a social, cultural, and political consensus developed around medical science in general and the figures of the medical researcher and physician in particular. The development of new vaccines (the Salk and Sabin vaccines against polio for example), the invention of an array of antibiotics, and the creation of contraceptive devices and pharmaceuticals, all served to endow enormous symbolic and cultural capital in the health sciences and their practitioners. In popular culture the physician was both skilled technician and wise sage (as well as being white and male), represented on television in such programs as General Hospital, Dr. Kildare, Ben Casey, MD and Marcus Welby, MD. Physicians, or white lab-coated actors appearing as though they were physicians, were employed as endorsements in print and television advertising, including, infamously, for tobacco products. However, several factors contributed to the eventual legitimation crisis surrounding medical
science. First, the optimistic prospects of technology, including medical technology, encountered the realities of the Law of Unintended Consequences. Citizens in the West eventually recognized industrial environmental pollution as a by-product of progress, and the side effects of pharmaceuticals and medical devices were eventually publicized. The Counter Culture of the 1960s and 70s, with its back-to-nature ethos, was suspicious of technology, including medical and pharmaceutical technology. Women and minorities discovered that they had not always been well served by a dominantly white, male medical establishment. The Boston Women’s Health Book Collective, for example, assembled the ground breaking book Our Bodies, Ourselves in 1971, with its frequent emphasis on healthy lifestyles and natural health treatments in lieu of technical interventions. The dissemination of Holocaust documentary evidence including the exposure of the Nazi’s pernicious medical ‘experiments’, which might have been ‘quarantined’ by simplistically categorizing the Nazis as anomalous monsters, was eventually followed by revelations of the Tuskegee longitudinal study in the Southern United States, where poor African-American men with syphilis were left untreated (despite the eventual availability of penicillin) in order to study the disease’s stages of development. In the 1980s the emergence of two opposing political and social ideologies, the Religious Right and the gay rights movement, delineated a discursive field in which competing representations of the medical, health care, and social meanings of sexuality and of AIDS were contested. Only a decade before, gay activists had successfully engaged in a struggle to have homosexuality removed from the Diagnostic and Statistical Manual (the DSM) used by medical psychiatrists in their diagnoses of mental illness, but right-wing figures countered with discredited social science, like the work of Paul Cameron, and with dubious medical data in their opposition to gay social equality. Eventually among the most visibly HIV/AIDS-affected communities, namely gay / bisexual / transgendered / queer populations, resistance to the mainstream consensus and development of alternative paradigms of dissent occurred.

3. Paradigms

By framing my analysis here as ‘paradigms of dissent’, I am cautiously using Thomas Kuhn’s now overused term, ‘paradigm’. His 1962 book (enlarged in a second revised edition in 1970), The Structure of Scientific Revolutions, has itself become paradigmatic. Indeed, it reminds me of Harold Bloom’s comment about Americans and the Bible: It’s the book they believe in but haven’t actually read. Kuhn anatomised the complex recursive processes whereby an existing consensus may be called into question, dissenting models compete, and the existing paradigm even replaced by a new consensus. Moreover, an established scientific paradigm
provides the framework for the initiation and enculturation of scientists-in-
training and for the establishment of the rules of research within the field
circumscribed by that paradigm, defining the methods, instruments, and
forms of scholarly dissemination. When a body of new evidence accumulates
sufficiently to call into question an existing paradigm, this epistemological
crisis may precede a scientific revolution in which a new paradigm is formed.
What Kuhn described, in other words, was not a simple linear process but a
complex social, cultural, epistemological, disciplinary and discursive
ecosystem. In a later essay, ‘Objectivity, Value Judgment, and ‘Theory
Choice’, Kuhn addressed his critics, who in the years since the publication of
The Structure of Scientific Revolutions had characterized his views as
‘irrationalist,’ ‘subjective,’ or even ‘mystical’. In turn now I will look at
John Lauritsen’s epidemiological dissent, Samuel R. Delany’s health-
practices dissent, and the representational dissent of AIDS ‘zines.

4. Lauritsen’s Gnostic Epidemiological Dissent

John Lauritsen is a gay activist whom my colleague at the
University of Connecticut, professor of social psychology Seth Kalichman,
has characterized as an ‘AIDS denialist’, along with other controversial
figures such as the virologist Dr. Peter Duesberg and the former South
African president Thabo Mbeki. Kalichman offers a psychosocial analysis of
this ‘dissent’ (a term that Kalichman rejects, however, as legitimizing the
phenomenon), situating it near but also distinguishing it from Holocaust
denial and 9/11 denial. Lauritsen is the author of several books and
numerous articles on gay liberation, AIDS, and other topics, mostly self-
published by the Pagan Press that he founded. Like some other medical
dissenters, Lauritsen rejects the epidemiological consensus that HIV causes
AIDS, asserts that pharmaceutical companies have conspired to sell drugs
that are toxic, and projects a coherent pattern of meaning onto the health
crisis by attributing as its cause unhealthy behaviours among gay men,
including recreational drug use and overuse of antibiotics. Lauritsen has been
vigorous and prolific in his writing about AIDS. In a slender book published
in 1986, Death Rush: Poppers & AIDS, co-authored with Hank Wilson,
Lauritsen critiqued many urban gay men’s use of inhaled amyl nitrate as a
club drug and sexual stimulant and attributed its immune suppressive and
mutagenic side effects as the cause of AIDS. In The AIDS War (published in
1993), Lauritsen collected his previously published periodical articles on the
(published in 1997 and co-edited with Ian Young), Lauritsen gathered essays
from several authors, critical of the scientific consensus about HIV infection
and of the economic power of pharmaceutical companies. Dissent from the
received view, moreover, seems to be a discursive habitus (to use Bourdieu’s
term) with Lauritsen. His most recent foray into dissent from scholarly
consensus has been his 2007 *The Man Who Wrote Frankenstein*, which asserts that Percy Bysshe Shelley, not Mary Godwin Shelley, was the actual author of the gothic classic and that the book is a coded celebration of male love. According to Lauritsen, Mary Shelley’s authorship was initially concocted by her father and more recently supported by a conspiring consensus of feminist academics (against whom Lauritsen explicitly pits himself). On his Web site he describes himself as ‘an antiwar activist, a gay liberationist, an AIDS dissident, a publisher, and an all-around freethinker’ who has ‘exposed fraud, punctured group fantasies, and blasphemed against the prevailing superstitions’. I characterize the dissent of Lauritsen (and other AIDS dissenters or HIV denialists) as a gnostic paradigm. Gnosticism is the name we give to a variety of philosophical traditions and mystery religions of late antiquity related to neo-Platonism and also associated with early heterodox Christianity in which the material world is imagined as the site of contending forces of good and evil, where a vast evil conspiracy subjugates the masses who have been deluded into believing the conspirators’ illusory version of reality, and in which a few *illuminati*, who have somehow learned the esoteric or secret knowledge, struggle to save the benighted. Or to put it in vernacular pop-culture terms, *The Matrix* meets *Angels and Demons*. On a variety of topics, Lauritsen views himself as an enlightened man struggling against a conspiracy that uses human ignorance and passivity to keep the rest of us in our place. The fact that he (and often other denialists) has no technical training or credentials in the fields in which he writes and the fact that he and most denialists (even those, like Peter Duesberg, who have technical expertise) do not publish peer-reviewed articles in respected journals is a point of pride. In other words, he has not been initiated into the secret societies of professional expertise that are nothing more than co-conspirators in a plot to harm or control the masses.

5. **Delany’s Sceptical Evidence-Base Dissent**

Now I turn to the sceptical paradigm of Samuel R. Delany. Writing during the darkest years of the AIDS epidemic among urban gay men in the United States (with mounting fatality and declining hope for a cure), the African-American fantasy and science fiction writer Samuel R. Delany strategically embedded consensus HIV science into some of his narratives while simultaneously dissenting from the health crisis’s emergency practices of prevention, particularly the strict binary opposition of safe-sex/unsafe-sex (i.e. ‘on me, not in me’, in the popular formulation of the day). Throughout his career Delany has dissented from the mainstream code of sexual reticence in favour of a superfluous excess of explicit language about body functions and pleasures, including the sexual, particularly in two of his works, the shorter narrative ‘The Tale of Plagues and Carnivals,’ and the long novel *The Mad Man*. For Delany, discursive reticence in the age of AIDS is unethical,
so his explicit language is not meant merely to be sensational but salutary. To both of these fictional narratives, Delany attached a non-fiction appendix. In the first instance, ‘The Tale of Plagues and Carnivals’, Delany provided a discussion of the state of epidemiology and the disease-prevention evidence base when the tale was first published in 1985 (revised and updated when the work was republished in 1994). In the second instance, the novel *The Mad Man*, at the end of the novel Delany appended verbatim the article ‘Risk Factors for Seroconversion to Human Immunodeficiency Virus Among Male Homosexuals’, a 1987 research article from the British medical journal *The Lancet*, which suggested that oral sex might not be a probable vector of transmission of HIV. Delany was quick to point out that he had had countless oral sexual contacts with other men for decades, a practice that he did not discontinue with the onset of AIDS, presuming, like many of New York’s gay men, that he was already infected. In fact, however, he has repeatedly been tested with a negative result each time; this anecdotal evidence and that of others suggested to him that much AIDS-prevention education at the time was simply erotophobic, overly rigid, and not evidence based. As he concluded in the appendix to ‘The Tale of Plagues and Carnivals’:

> At this point in time, any talk of ‘possibilities of AIDS transmission’ is talk of superstition. (Anal receptive sex is no longer a ‘possible rout of sexual transmission’; it is the overwhelmingly probable rout of sexual transmission, homosexual and heterosexual.) Superstitions sometimes turn out to have a basis in fact. But again, we need hard-edged and repeatedly supported information about probabilities.

In Delany’s sceptical view of the evidence base, AIDS educators’ listing of oral sex as ‘unsafe,’ although well intentioned and not utterly illogical, was not supported by medical research at the time, or by his own and other gay men’s experiences, their anecdotal evidence base.

6. AIDS ‘Zines’ Cultural Dissent

Finally, the paradigm of cultural dissent: AIDS ‘zines. A ‘zine is a self-published non-commercial fan magazine devoted to a particular cultural phenomenon (originally appearing in the late 1940s among fans of science fiction), which, as I have suggested in a previously published article, requires a continuous recalibration of the rhetoric of transgression and dissent. In the 1980s and 90s AIDS ‘zines provided self-representations that dissented from two cultural paradigms of the AIDS patient. In the early years of the epidemic in the United States, AIDS was horrifying. In addition to exotic
opportunistic infections, the syndrome often created emaciated and disfigured bodies of patients. AIDS patients were therefore sensationalized in the tabloid press, and barely less so in the mainstream media, which thrives on terror and anxiety to garner audiences. Eventually, however, two alternative stereotypes developed that initially seemed more benign. The first stereotype was the person living with AIDS as ‘disease victim’, a sentimentalized view derived from nineteenth-century fiction and melodrama and from twentieth-century television and cinema. (Think of America’s favourite actor, Tom Hanks, in the AIDS-themed film Philadelphia.) The second stereotype was the person living with AIDS as utterly normal and otherwise healthy, an image that was largely a product of pharmaceutical advertising but also reproduced to some extent in such magazines as Poz or Art and Understanding. However, for many people living with AIDS, these stereotypes were equally objectionable because their queer bodies would not or could not conform. By their very ‘zine titles, the creators of Diseased Pariah News or Infected Faggot Perspectives or Piss Elegant or Death Camp or The Daily Plague were dissenting from a normalized or sentimentalized consensus, creating in the process what Daniel Brouwer has called ‘counterpublics.’

7. Conclusion

These three instances of dissent (Lauritsen’s gnostic epidemiological dissent, Delany’s sceptical evidence base health practice dissent, and the AIDS ‘zines’ cultural and representational dissent) remind us that disease is not simply an empirical epidemiological event but is imbedded in social imagination and relationships: how we imagine ourselves, how we imagine others, and how we imagine ourselves in relationship to others. However, I am not equating the ethical implications of the three paradigms of dissent. Lauritsen’s denial of HIV as the infectious agent causing AIDS has life-threatening implications when employed in public policy, such as in the South African government’s initial refusal of antiretroviral treatment to prevent mother-to-child HIV transmission. Nonetheless, in each instance, I
see the effects of paradigmatic crisis, which in the case of HIV/AIDS has also produced what Paula Treichler aptly called this ‘epidemic of signification’.19 In Lauritsen’s gnostic language, occult demonic forces (Big Pharma) enslave the masses who must be freed by the illuminati (people like him). In contrast, Delany, accepting the epidemiological consensus, nonetheless employed a sceptical paradigm and used language to illuminate the gaps in medical evidence and evidence-based practice. Finally, the dissent by the creators of AIDS ‘zines from mainstream cultural stereotypes, stereotypes that may comfort the comfortable but can afflict the afflicted, creates a cultural antibody to resist the West’s infectious sentimentality.

Notes

2 For a discussion of the concept of crisis of legitimation, see J Habermas, Legitimation Crisis, T McCarthy (trans), Beacon Press, Boston, 1975.
4 Although Nazi medical abuses were substantially documented in the Nuremberg Trials immediately following World War II, they were not widely known in North America until the publication of W L Shirer, The Rise and Fall of the Third Reich, Simon and Schuster, New York, 1960. A complete history of the Tuskegee experiment was published in the same year that the gay-related immune disorder (later to be called AIDS) was first reported in mass media, JH Jones, Bad Blood: The Tuskegee Experiment, Free Press, New York, 1981.

9 For a discussion of the linguistic *habitus* and the related bodily *hexis*, see P Bourdieu, *op cit*, pp. 81-89.


**Bibliography**


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