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Éditorial/Editorial

Research indicates that the medications used to treat an HIV infection can also be used to prevent a person who has been exposed to HIV from seroconverting, i.e., from becoming HIV-positive. Because it takes 48 to 72 hours before HIV is detectable in a person's regional lymph nodes, the immediate period after HIV exposure constitutes an important window when these medications can be used for HIV post-exposure prophylaxis (henceforth referred to as HIV PEP). While the evidence about this prevention strategy is far from perfect, research involving occupational exposures to HIV (e.g., needle-stick injuries), animal model studies for sexual exposure to HIV, and case reports indicate that HIV PEP induces an 80% reduction in HIV seroconversion after exposure to HIV. Accordingly, international recommendations suggest the use of HIV PEP in all cases of exposure to HIV, whether the exposure occurred through sexual contact or otherwise. Guidelines to structure this intervention exist in the United States, the United Kingdom, and Austalia. In Canada, however, no such guidelines for HIV PEP exist.

Of even greater concern in the Canadian context is that HIV PEP is expensive, totalling approximately $1650CAD for the required 28-days of treatment. For individuals with private medical insurance that partially or completely covers pharmaceuticals, such costs are diminished. For example, a private insurance plan that covers 90% of medication costs still leaves a person paying $165CAD out-of-pocket. While this new figure is greatly improved, it may still constitute a significant enough barrier to prevent some persons who require HIV PEP from accessing a prevention strategy that will reduce their subsequent potential for HIV seroconversion.

To alleviate such financial barriers to HIV PEP, in some jurisdictions, these medications are publicly funded; e.g., after occupational exposures. Another situation where HIV PEP is often dispensed without charge is sexual assault. In these situations, the person who was sexually assaulted is typically offered and provided with HIV PEP medications at no cost to them.

However, unless it relates to a sexual assault, opportunities to obtain publicly funded HIV PEP are not afforded to gay, bisexual, and other men who have sex with men, notwithstanding the fact that, in Canada, nearly 50% of all new and previous HIV diagnoses involve a man who has sex with men. This situation constitutes not only an outright mismanagement of an effective HIV prevention strategy, but also it constitutes a blatant disregard for the health and wellbeing of gay, bisexual, and other men who have sex with men. Indeed, these highly expensive but efficacious medications are provided in many situations when HIV exposure is limited, but they are not subsidized in the more likely cases when a gay, bisexual, or man who have sex with men is potentially or actually exposed to HIV. Therefore, men who have sex with male partners who are serodiscordant—i.e., one partner is HIV-positive and the other is HIV-negative—are not granted this opportunity. Similarly, men who have had casual sex with a male partner of unknown HIV status are equally not given access to financially subsidized HIV PEP, even though they, again, are more likely than many other persons to be exposed to HIV.

An additional barrier to HIV PEP is that, almost everywhere in Canada, these medications can only be obtained by visiting a local emergency department, which involves a potential wait for access and the requirement to explain to an emergency room physician, registered nurse, or nurse practitioner the reason for requiring HIV PEP; i.e., a person needs to detail their HIV exposure. While an emergency room visit for an occupational exposure to HIV may not deter many persons from accessing HIV PEP, the situation is markedly different for sexual exposures to HIV. Research highlights that many persons avoid accessing HIV PEP due to fears, or previous experiences, of stigmatization by emergency room staff when they explain that their potential HIV exposure occurred through sexual contact. These concerns and experiences of stigmatization are exacerbated for persons who are non-heterosexual, thus exacerbating the inaccessibility of HIV PEP for many gay, bisexual, and other men who have sex with men.

In Canada, the outcome of the current situation surrounding HIV PEP is that these medications, which constitute an important and effective HIV prevention strategy, are otherwise inaccessible by some of the persons who require access to them most. Because gay, bisexual, and other men who have sex with men are most affected by HIV, and therefore are most likely to become infected with HIV based on enhanced exposure probabilities, it is important that HIV PEP becomes readily available. To accomplish such an undertaking, two changes are required. First, HIV PEP would need to be financially subsidized to ensure equal and equity access to these medications, and, second, the delivery of HIV PEP would need to become community-based. The latter modification to healthcare service delivery should diminish the deterrent effects that emergency rooms have on some gay, bisexual, and other men who have sex with men's willingness to access care. In the absence of these changes, the current healthcare system will remain biased against a subset of men who are unequally burdened by HIV in Canada.

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Abstract
Many ways of analyzing discourse based on the work of Michel Foucault have been developed. One way of organizing a discourse analysis is based on the work of Rawlinson.[1] An overview of the process of discourse analysis is presented and specific questions for each of the three parts of her proposed approach to discourse analysis are shown using the example of the discourse of advertising feminine hygiene products in women's magazines.

Key words discourse analysis, Michel Foucault, Mary Rawlinson

Rawlinson's Three Axes of Structural Analysis: A Useful Framework for a Foucauldian Discourse Analysis

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Introduction

A discourse is a systematic body of text, speech and action regarding a specific subject area in the realm of human experience that mobilizes power in the form of productive knowledge in the social world. A discourse forms its objects in order to create a unique domain in human experience or to redefine one that already exists. For example, the discourse of psychiatry creates and controls psychiatric conditions by defining and treating them. This further consolidates its power to do so.[2] Psychiatric knowledge thus relies on, and generates, power that undermines the ability of other discourses to speak the language, treat the patients, publish the research, join the associations, and have a voice in public policy. This does not mean that there are no other ways of speaking about human behaviours, but rather that there are dominant and resistance discourses locked in debate over definitions and authority. Discourses have a history, proceed in a systematic fashion, and serve to control a professional turf and defend it from other ways of having power in that realm of human experience.

Discourses co-exist in power-based relations that support particular ways of being and thinking about the world.[3] This makes any discourse a highly political entity. For example, punishment theories and medically-based physiological explanations for cancer exist at the same time.[4] In other words, there are dominant discourses and resistance discourses that co-exist within any field of study, such as medicine, history, physics, and education and they may conflict in their assumptions and implications. Discourses are always in flux, evolving and changing in response to internal and external pressure, thereby continuously producing effects on their discursive subjects and objects. Such effects are, in part, dependent on whether a particular discourse is dominant or marginalized in a given socio-political context.

Power, money and prestige are all involved in creating and managing discourses to control a realm of human experience. Various analytical approaches have been devised in order to understand the way discourses emerge and produce effects in relation to a given phenomenon, such as feminine hygiene. For example, the discourse of feminine hygiene products in women's magazines has changed the way human beings think and act with respect to menstruation, and, by extension, to feminine reproduction and hygiene.[5] What has come to be understood as "feminine hygiene", then, represents one particular discursive field that lends itself to discourse analysis. In this paper, I will discuss one approach to a Foucauldian discourse analysis using Mary Rawlinson's[1] work, and propose some lines of inquiry that would allow one to dissect the discursive processes involved with regards to feminine hygiene products.

Discourse analysis

There are many ways of analyzing a discourse for its effects on power relations among groups of people. Some discourse analysts use the philosophical approach of Michel Foucault as a theoretical framework for their work.[6-10] There are several variants of Foucauldian discourse analysis, but all include the following: (a) A review of the history of the discourse in what Foucault first called archaeology (and the modified later version, genealogy), (b) an analysis of how the discourse functions presently, and (c) an analysis of the effects of the discourse on power relations. Archaeology was the original term Foucault used to designate a method used to describe discursive formations as they exist at one point in time.[11] However, the method could not account for the manner in which discourses evolve. Therefore, Foucault[12] modified the method in his work, *Discipline and Punish: The Birth of the Prison* to include a way to analyze the way discourses emerge and change, and called it genealogy, following Nietzsche's[13] *On the Genealogy of Morals*. These two terms are sometimes mistakenly used interchangeably, when the proper term in a discourse analysis should be genealogy.[14]

These three parts of a discourse analysis can be presented together or separately. All three parts contribute to an understanding of *power*, and what Foucault referred to as the *power-knowledge dyad*. Discourse analysis is especially useful in examining the work of large institutions such as governments in soliciting, producing, supporting, sorting and applying productive knowledge to address particular issues in the administration of public life.[15]

There are many possible interpretations of existing power relations. Foucault refused to privilege one interpretation over another because he was suspicious of displacing one kind of domination and implementing another. In his opinion, the privileging of one form of interpretation necessarily led to the reproduction of power relationships when substituting the domination of one discourse over another. Yet, he also conceived of discourse analysis as a "tool for radical political action".[16 p5] Whatever the effect, many ways of performing a discourse analysis have been developed.[17-23] Foucault was well known for his reluctance to delineate a definitive analytical method of discursive analysis. Several authors have thus endeavoured to articulate one such method that remains true to Foucault's ideas. Mary Rawlinson[1] has suggested a fairly simple approach to a critical discourse analysis that is consistent with Foucault. In describing Foucault's philosophical approach to medicine, Rawlinson observed that he believed:

> truth is not so much discovered ... as [it is] produced according to regular and identifiable procedures that determine in any given historical situation what it is possible to say, who is authorized to speak, what can become an object of scientific inquiry, and how knowledge is to be tested, accumulated, and dispersed.[1 p373]

In analyzing Foucault's approach to discourse in medicine, Rawlinson sought to discern specific questions that could be asked by the discourse analyst. How did this discourse come to have the right to pronounce truth in some region of human experience? How does it function in the present? What power effects does it have? Following Rawlinson, useful questions can be generated to guide all three parts of the analysis. Not all questions will be relevant to all discourses under analysis, but most will be applicable to explaining their systematic functioning and their effects on power relations between people, and between people and institutions. As Rawlinson writes, "it can be determined how people came to think, talk and act in this way".[1 p376]

Terminology

Some definitions of relevant terms will support this discussion. The first part of a discourse analysis, the genealogy, explains the social circumstances of the origin of the discourse, the original power relations and how they were articulated or altered in order to consolidate a way of addressing some realm of human experience.

The second part of a discourse analysis, the structural analysis, identifies the internal rules of the present discourse that govern the operation of the discursive processes on objects to create *subjects*. The *objects* of a discourse are entities external to the discourse that serve as the targets for knowledge generation and intervention. The *objects* of a discourse are acted upon by discursive processes to form its subjects, the internal concepts of the discourse that are used in a proprietary manner to pronounce truth. The *styles of statements* in a discourse are the various forms that meaningful statements are allowed to take.[14] The *theoretical strategies* are the specifically defined processes of the discourse used on the *objects* to create *subjects* and produce knowledge/power.[24] The processes of the discourse have rules for the construction of *subjects* from *objects* by defining the evidence for what counts as an object or a subject and what can be said about them, by whom, and under what conditions these knowledge claims can be made.

The *theoretical strategies* of a discourse create the *subjects* of a discourse from its *objects* using *surfaces of emergence, authorities of delimitation, and grids of specification*.[11] A *surface of emergence* can be thought of as the edge of an existing discourse that allows related discourses to grow from it. For example, the discourse of medicine arose on the *surfaces of emergence* called natural science and philosophy, and the *styles of statements* in medicine were based on the rules of empirical science. *Theoretical strategies* in medicine follow the process of empirical science and require strict research protocols in order to be counted as true within the discourse of medicine. Descriptions of how the discourse arose in this manner can be found in the genealogy. Descriptions of how the discourse functions in this manner can be found in the structural analysis.

An *authority of delimitation* is a set of rules that identifies the manner in which a discourse can identify objects that are available to be acted upon to become subjects of the discourse. For instance, an *authority of delimitation* of prison discourse is the legal and court systems because it is through and by them that discourses of delinquency, criminalization, and incarceration identify the *objects* (e.g. people convicted of crimes) they use to create *subjects* (e.g. inmates) which are the bodies upon which a prison discourse can make claims of power/knowledge. For nursing, one particular authority of delimitation is medicine, because through discourses of medicine, human beings (*objects*) become designated as patients, the *subjects* of nursing (and medical) discourse. Nursing cannot in any official manner designate individuals as patients. This action is constrained by an authority of delimitation such as medicine. Once medicine has designated someone as a patient, then nursing discourse can act upon him or her.

A *grid of specification* is a systematic taxonomy of concepts constructed within the discourse that is used to place *objects* in an ordered hierarchy or table so they can become identified types of *subjects*. In psychiatry, a prominent example of a *grid of specification* is the DSM. This taxonomy orders the *subjects* of the discourse–in this case the physical and behavioural characteristics of human beings–into one category in the grid, say, depression or bipolar disorder. Individuals become discursive *subjects* constituted through and by an *authority of delimitation*. They can then be examined and, using *theoretical strategies*, be placed into one of the categories in the *grid of specification*. Now a person is a member of a discursive *subject category*, with a diagnosis, and may be treated by the correct authority in the correct manner, in the correct place. This identification and organization of bodies according to particular norms has given rise to numerous critiques in the way such processes perpetuate certain dominant discourses and disqualify others. In the fields of medicine and psychiatry, this process of categorization has been labelled the *medicalization* or *clinicalization* of social control because large scale social issues are transformed by well-established discourses into discipline-specific problems where discipline-specific terms such as *diagnosis*, *treatment*, and *expert* can be applied in discipline-specific locations such as hospitals or clinics. For example, it has been suggested that domestic violence should be a medical diagnosis so that it could be addressed by physicians.[25] Is domestic violence a social issue? A medical diagnosis? A moral issue? A psychiatric problem? What discipline will claim this issue as a disciplinary specialty? Are disciplines avoiding this issue? The process of defining social issues as belonging to a specific academic discipline works to co-opt the entire discussion of specific social questions and silence other ways of conceptualizing the situation. The resolution of the dispute over the "place" of domestic violence will determine its management or treatment: drugs, incarceration, counselling, visualizations, self-esteem or anger management workshops, and so on. The coexistence of conflicting discourses inevitably leads to tensions regarding grids of specification and authorities of delimitation. For instance, pharmaceutical discourse may propose one cause for anxiety, while social psychiatry proposes another. Tensions rise and fall continuously, sometimes creating new discourses.

The third part of a discourse analysis is the power analysis, in which the effects of the functioning of the discourse on power relations are analyzed. This differs from t genealogy in that the power analysis examines the functioning of the discourse on *present* power relations between populations, and between institutional structures and populations. Genealogy provides an analysis of the historical rise of the discourse and the power relations present at the development of the discourse, not the present version.

Now that terminology is briefly reviewed, we can move on the examination of methodological aspects of discourse analysis based on Rawlinson's work.[1]

Genealogy

The first part of this form of discourse analysis is genealogy, an analysis of the historical context and the development of a particular discourse over time. Genealogy includes a discussion of the interests of proponents and opponents of a given discourse, and the way consensus and disagreements have played out. Key concepts of the discourse sometimes have a significant social history and their origin is discussed. Genealogy provides a picture of the way a discourse emerged from a specific historical context and in the presence of other related discourses, so as to construct its place among ways of thinking about a given phenomenon. How does a discourse harness the power to be heard? Rawlinson describes Foucault's genealogical approach in this way:

> A genealogical analysis …reveals that the epistemological and the political, knowledge and power, are ineluctably intertwined, so that truth is not so much discovered — as if it lay ready-made in an objective reality patiently awaiting the articulate voice of science — as produced according to regular and identifiable procedures that determine in any given historical situation what it is possible to say, who is authorized to speak, what can become an object of scientific inquiry, and how knowledge is to be tested, accumulated, and dispersed.[1 p372]

In analyzing the discourse of advertising feminine hygiene products in women's magazines, genealogy would examine the following questions:

1.What other discourses and/or events provided models or ideas that influenced the functioning of the discourse under analysis and in what ways? For example, were there any discourses that were used as models for the discourse of feminine hygiene products in women's magazines?

2.What words in the discourse have a linguistic and social history that is significant for assessing the role of the discourse within current power relations? For example, words like *the curse, monthlies, crimson tide, menstruations, rags*, or *hygiene* carry particular meanings that mobilize certain understandings and behaviours in relation to feminine hygiene and associated products.

3.What historical context influenced the development of the discourse? What was happening at the time of the first discussions of feminine hygiene products that might have had an effect on the development of associated discourses?

4.What physical, bodily space was created by being described by the discursive practices of the discourse? For example, the space of the human vagina was suddenly available for description as never before.

5.What surfaces of emergence and conditions of possibility were acknowledged and appropriated and made visible by this discourse and by what means? Were there other discourses that were close to the discourse of feminine hygiene products that could have served as launching platforms for this kind of talk?

6.By what processes did the discourse construct the right to pronounce truth in some region of experience? How did the first instance of the discourse come about? Who performed this action? Why? What were some of the immediate consequences?

7.What other discourses were affected and how? What did the development of the discourse of feminine hygiene products do to the discussion in the letters to the editor section of magazines that carried the ads? Where else did discussion about the first ads take place?

8.What power struggles or turf battles occurred and what was the outcome? Was there competition among companies for control of the language of feminine hygiene products?

9.In whose interest was the social construction of this discourse? Who benefited from this discourse?

10.Whose interests were ignored and/or rejected? Who did not benefit from the discourse of feminine hygiene products?

Structural analysis

Following genealogy, the discourse analyst seeks to describe the current functioning of the discourse in a structural analysis. Rawlinson's approach is again very helpful by ordering the questions along three axes. She calls these axes *self-closed systems* because they are self-referential and presume exclusive structures for the functioning of the discourse. There are three axes along which to analyze the discourse; the axis of knowledge, the axis of authority, and the axis of value or justification.

The first axis is that of knowledge. This axis describes systems of concepts and rules for the formation of statements, what determines the difference between true and false, what can be spoken about, and the rules of evidence. Truth is the central tenet of this axis, therefore it involves epistemological considerations. The specific questions that draw out the knowledge dimension are:

1.What are the objects and subjects of the discourse? What strategies were women using for menstrual flow before a discourse of feminine hygiene products emerged, seized the subject, and described it and which (hygienic) strategies for its management are acceptable?

2.What processes differentiate the subjects and objects of the discourse? How did the discourse on feminine hygiene products colonize the space in women's magazines?

3.What is it that guides this discourse? Why was this discourse created in the first place?

4.What regularities can be discerned? Are there any discernible discursive patterns in women's magazines?

5.What processes produce the physical space, the meaning, and the assumed truths of this discourse? Was the process all done by advertisements? Were there articles, letters, pictures, studies, testimonials?

6.What does the discourse do to the resulting subjects? How does the discourse organize its words and expressions in order to create desired particular effect?

7.What grids of specification are there? Are there any graphs, or tables? I have seen tables that direct women to choose the right product for the right flow. I'm not sure if such tables were used at the beginning of the discourse.

8.In the rules for the formation of subjects from objects, what and where do individual differences, deviations, and complaints emerge? How did the type of product multiply from one to many, depending on many things that the consumer has to know about?

9.How is it specified that these subjects are to be used on pre-existing surfaces, constructed spaces, or bodies? How are you supposed to buy these products? How are you supposed to use them? How are you supposed to discuss them? When are you old enough to use them? How is this information disseminated to women – product inserts?

10.What authorities of delimitation exist? The discourse recommends, "See your doctor if..." under what circumstances?

11.What order governs the appearance, disappearance, replacement, and coexistence of the subjects, objects, concepts, styles of statements and theoretical strategies of the discourse? What associations are there for advertisers?? How do they share information?

12.What are the rules of evidence in the discourse? Where do the companies get their information? Studies? Customer feedback?

13.What order governs the multiplicity and diversity of the subjects, objects, concepts, styles of statements and theoretical strategies of the discourse?

Analysis in the second axis, that of authority, includes the rules for who is allowed to speak in this discourse, what systems are in place for education, reproduction and advancement of the discourse, and how the right to pronounce truth is managed internally. The questions answered on this axis are:

1.What are the rules for who is allowed to speak and who is not? Can anyone speak the language of feminine hygiene? Who is afforded legitimacy and authority, and on what grounds?

2.How is the discourse preserved, transmitted, disseminated? Are there industry standards for such advertisements?

3.What systems are allowed for education, association and advancement of members of the discourse? How do advertisers enforce their standards?

4.How is the right to pronounce truth preserved? How is the system of advertisers controlled?

5.What speaking positions are available to people within this discourse? What words can be used?

6.What speaking positions are not allowed? What words are not allowed?

Analysis in the third axis, that of value or justification includes the systems of regulation and the technologies of power, and how the deployment of the discourse on the bodies of actual human beings is justified. The questions answered on this axis are:

1.What social agents are mobilized in order to control the deployment of the discourse and how are they trained? How do advertisers train their ad writers?

2.How does the discourse justify the technologies of power that it constructs for its purposes? What do the advertisers say to justify the way they talk about vaginas?

3.How does the discourse justify suppressing other discourses that challenge its dominance in pronouncing truth? Do advertisers dominate other ways of talking?

4.What justification is provided for the punishment of participants? How are advertising standards enforced?

5.How is the suppression of competing discourses justified?

6.What is the justification provided by the discourse for its position as a pronouncer of truth?

The power analysis

In the third part of a discourse analysis, the power analysis, the current relations of power between groups of people are analysed for potential to perpetuate or extend situations of domination. Some relationships of power may be supported or resisted by the discourse. Within the discourse, there may be found dominant discourses and alternate discourses that resist them . Resistance discourses are alternative speaking positions that provide ways of acting and speaking that do not support the dominant way of thinking and of conceptualizing particular subjects.[26] In naming and describing resistance to power, a discourse analysis can uncover a process of co-optation by dominant discursive entities so as to govern the level of resistance among participants. Marginalized voices may be raised and then attenuated or even silenced. Discourse analysis produces one possible understanding of the dissemination of power and privilege. In this regard, along with Foucault, Rawlinson emphasizes that the power of a discourse is productive rather than repressive.[1]

In the power analysis, the following questions can be raised:

1.In whose interests is the continuation of this discourse? Who benefits from this discourse?

2.Whose autonomy and responsibility are enhanced by this discourse?

3.Whose autonomy and responsibility are reduced?

4.What dominations are established, perpetuated, or eliminated?

5.What sub-discourses of resistance are present within the discourse? Are there competing ways of talking about the subject of the discourse? What responses from readers were received?

6.What mechanisms are in place for systematic co-optation of resistance discourses?

7.Whose voice is being heard? Do women have input into how their bodies are discussed?

8.Whose voice is being left out?

9.Do individuals feel constraints against speaking?

10.Are all voices equally informed?

11.What power relations exist between this discourse and others?

Conclusion

Taken all together, the three parts of a discourse analysis using these questions can provide a close view of where and how a discourse comes forth, how it functions, and how it affects power relations. A discourse analysis concludes with interpretive claims about the observations made from the data. These claims might give insight into the discourse to those immersed in it and those outside the discourse, looking in. For example, there might be some key insights to be gained from conducting a discourse analysis of advertising for feminine hygiene products in women's magazines with respect to societal views of women's bodies and self-concept. The answers to the questions proposed here could contribute to the body of knowledge on women's movements. Discourse analyses may generate various understandings of contemporary phenomena. Other interpretations are therefore made possible, discourses may change, contexts change, and further discussion is enabled.

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2

Abstract
Population ageing is affecting all Western countries. In order to cope with this challenge, governments focus mainly on ageing in place. Detection of frail or vulnerable older people becomes essential in order to provide appropriate support and prevent adverse outcomes. In this article we review the main paradigms on detecting frail or vulnerable older people living in the community, examine the theoretical gaps and develop new research possibilities. While there is increasing literature on frailty and vulnerability in later life, both concepts are still developing. The key question is: to what extent the actual concepts of frailty or vulnerability are appropriate to detect frail/vulnerable community dwelling older persons? The different concepts trying to capture frailty and vulnerability are criticized. Conclusively, the article highlights the need for a new integrated conceptual model for detecting community dwelling frail or vulnerable older persons including physical, psychological, social and environmental variables.

Key words aging, detection, frailty, older people, vulnerability

A Theoretical Perspective on the Conceptualisation and Usefulness of Frailty and Vulnerability Measurements in Community Dwelling Older Persons

NICO DE WITTE, LIESBETH DE DONDER, SARAH DURY, TINE BUFFEL, DOMINIQUE VERTÉ, & JOS SCHOLS

Introduction

The proportion of older people is growing rapidly in all Western countries and increasing demands on health care with advanced aging can be expected. In order to cope with the challenges of an aging population, governments have changed their vision towards health care provision.[1] This change in vision is twofold. On the one hand, there is actually a prevailing belief among policymakers that an aging population inevitably means increasing demands on health care resources, social support, informal networks, etc.[2] On the other hand, academic research has demonstrated that older people themselves prefer 'aging in place'. They like to age in their own natural environment, often even if they are in need of long-term care, have economic difficulties or live in inadequate houses or deprived areas.[3,4] Ageing in place is chosen not only for economic, but also for social (e.g., neighbours) and contextual reasons (e.g., house, environment). Vulnerable older people are often reluctant to leave their community dwellings, even when it is difficult for them to manage the household chores, mostly because the familiar home environment provides them with a strong sense of meaning and belonging.[5]

In order to cope with the expected rise of financial demands and to meet the preferences of older people themselves, Belgium's policy has shifted towards deinstitutionalisation. Older people are invited to age in their own homes supported by formal and informal care. Institutionalisation in a nursing home will become restricted to situations where it is really necessary.

A policy with a focus mainly on ‘aging in place’ creates new challenges. A first challenge is the provision of adequate home care from both formal and informal sources.[1] Formal care in Belgium is, like in many other countries, threatened by staff shortages.[6] Informal care is jeopardised by a globalization process where for instance people no longer work in their place of birth. As a consequence, family and friends no longer live in close range of older relatives, thus forcing older individuals to confront the risks of aging alone. Consequently, growing old evolves to an individual rather than a collective experience.[7] As a consequence, a network of community care services, both public and private, is needed in order to provide necessary care and to support informal care.[8,9]

A second challenge is the early detection of frail or vulnerable older people so that appropriate support can be provided and unnecessary adverse outcomes may be prevented.

Indeed, aging in place confronts older people with the limits of their own resources; their informal and formal care framework and of their living environment. If there’s an imbalance between resources and demands, people can become frail or vulnerable.[10] In order to identify these limits and to ensure that adequate care is provided to the right persons in time, detection of these limits seems essential, but not obvious.

Research in Belgium, for instance, has demonstrated that despite Belgium’s well developed social security system, 6.4% of the community dwelling older people needing care do not receive any care at all.[11] This points to the fact that the actual detection mechanisms to identify frail or vulnerable older people only partly succeeds. In Belgium two measures are used: the KATZ-scale and BEL-scale.[12] The KATZ scale is a derivative of the original KATZ-scale developed by Katz and colleagues in 1963 and is used in both community and residential care to assess the dependency of patients and to determine the amount of care level one is entitled to receive.[13] The BEL-scale is used to determine if an individual is entitled to receive an allowance of long term care insurance. Although the use of both scales can be appreciated, they apparently fail to detect all the dependent, frail or vulnerable older persons.[12] Moreover, as both scales only focus on health and care, other needs are undetected and uncovered.

In this article we aim to review the main paradigms on detecting frail or vulnerable older people living in the community, to examine the theoretical gaps and to develop new possibilities for research in this area. From the literature, two applicable concepts can be retained: the concept of frailty, developed from within medical sciences and the concept of vulnerability, which originates from social sciences. The rationale to suggest these concepts is obvious. There is a wide agreement that old age involves a period of increased vulnerability.[10,14,15] As a consequence, identifying vulnerable older people and understanding the causes and consequences of their vulnerability is of human concern and an essential task of social policy.[14] While there is increasing literature on frailty and vulnerability in later life and both concepts have their merits in research, they are still developing. The key question of this contribution is: to what extent the actual concepts of frailty or vulnerability are appropriate to detect frail/vulnerable community dwelling older persons? This article consists of four sections. In a first section, four types of approaches regarding frailty in old age are provided. These frailty concepts are criticized in a second section. In a third section, the concepts of vulnerability are elaborated. The different concepts trying to capture vulnerability are criticized in section four. Conclusively, the article highlights the need for a new integrated conceptual model for detecting community dwelling frail or vulnerable older persons including physical, psychological, social and environmental variables.

Frailty and Vulnerability in older people

Frailty concepts, an overview

The word frailty is derived from the Latin word fragilitatem, which means frailness, weakness. Frailty is an often-used concept by clinicians to detect and classify elderly.[16,17] The term “frail elderly” has been a Medline MeSH-term since 1991 and is defined as “older adults or aged individuals who are lacking in general strength and are unusually susceptible to disease or to other infirmity.[18] In this section, without claiming completeness, we explore some historical and recent definitions and concepts of frailty.

The concept of frailty first emerged at the end of the seventies. In 1978 the Federal Council on Ageing (FCA) in the United States, introduced the term frail elderly to describe a specific segment of the older population. The FCA defines frail elderly as,

> “persons, usually but not always, over the age of 75, who because of an accumulation of various continuing problems often require one or several

> supportive services in order to cope with daily live". [19 p1]

In the 80s, frailty was associated with disability, the presence of chronic illness, old age and usage of geriatric services.[17] Later, more and more scholars became interested in the concept. Based on a review of Aminzadeh, Gobbens and colleagues found 17 different conceptual definitions of frailty.[19] According to Grenier[20] the way frailty is conceptualized and interpreted has profound implications for social responses, care practices and personal experiences of care. Moreover, researchers, policy makers, administrators and health care providers generally agree that frailty can have an important impact on affected individuals, their families (particularly those involved in care-giving), the health care system and society as a whole.[18] Karunanathan's[21] extensive literature review provided no signs of any consensus about the frailty concept. Moreover, roughly four types of conceptualizations of frailty can be distinguished: biomedical, bio-psychological, bio-psycho-sociological and integrative models. These four types will be explored in the next section.

A first conceptualisation of frailty is characterized by a purely biomedical approach. Frailty is seen as a collection of biomedical factors influencing an individual's physiological state and thereby reducing the individual's capacity to withstand environmental stress.[22] In this approach, frailty is measured by detecting physical problems. A wide range of physical problems have been linked to frailty: gait speed[23,24], a three meter walk test[25], a stand up test[24,25], endurance[26-28], weakness[26,27], reduced physical activity[26,27], weight loss[26,27], mobility[28], exhaustion[18], cardiac functioning[29], grip strength[25], balance[28], strength[28], slowness[18], neuromotor performance[28], sarcopenia[18,29], pulmonary peak flow[25] or lung functioning[29], renal and immune senescence[29].

Some scholars like Markle-Reid[30] and Hogan[17] criticized the lack of psychological or cognitive factors in assessing frailty. In order to meet these expectations, psychological or cognitive factors were added to the biomedical components.[31] These frailty models can be considered as bio-psychological. Puts and colleagues for example, measures the physical functioning but adds psychological markers such as cognition, mastery and depression in order to capture frailty.[32] Bravell and colleagues bring up anxiety, sadness, cognitive deficiency and management capacities as psychological variables besides the functional status of the individual.[33]

Besides the biomedical and bio-psychological, a third approach consists of the inclusion of social factors in addition to biomedical and psychological factors and thereby pointing to the interplay of bio-psycho-social factors in frailty.[34] The Edmonton Frailty Scale[35] for example uses social support besides cognition, general health status, functional independence, medication use, nutrition, mood, continence and functional performance in order to detect frail elderly.

At last, some conceptual models make an attempt to be integrative, as they aim to apprehend all four domains of functioning, i.q. physical, cognitive, social and psychological. The Groningen Frailty indicator[36] and the Tilburg Frailty indicator[37] can be classified among these models. The Groningen frailty indicator, consists of a physical (nine items), cognitive (one item), psychological (two items) and social (three items) dimension. The social dimension is measured by exploring respondents' experiences with emptiness, abandonment and missing people in their inner circle. The Tilburg Frailty Indicator[37] consists of eight physical measurements, four psychological components and three social components. The social component is captured by three questions: do you live alone, do you sometimes wish you had more people around you and do you receive enough support from other people.

Frailty: A critical insight

Although it's hard to deny that frailty research has it merits in research, there is still the emerging problem of a lack of consensus.[21] Moreover, the different approaches of frailty are criticized[20] as they are often based on a negative and stereotypical view of aging associated with becoming disabled[30], lack of hope[38] and loss or declining abilities[39]. Thereby they neglect the lived experiences of each individual[20], assuming that aging is a uniform process[39]. Walston recommends to go beyond the physical aspects of frailty[40] and according to Gobbens[41], addressing frailty exclusively on physical components jeopardises the attention for the individual as a whole.

Markle-Reid points to the fact that frailty is a multidimensional non age related concept that must consider the interplay of various physical, psychological, social and environmental factors. The fact that much biomedical research on frailty demonstrates great variations in frailty according to gender, socio-economic status, education, etc points to the social production of frailty.[30]

While some authors have elaborated their frailty instrument in an attempt to meet the aforementioned critiques (e.g., Groningen Frailty indicator, Tilburg Frailty Indicator), environmental aspects of frailty are still ignored. To our notice, only the operationalization of Nourhashémi[42] includes all domains as proposed by Markle-Reid[30]; a combination of biological, physiological social and environmental indicators. In such an approach, frailty shifts from a micro-level analysis focussing on the individual only to a macro-level analysis, where frailty is seen as a result of numerous intersecting factors, many of which are external to the individual. Additionally, some scholars[20] suggest to take the subjective perceptions of an individual into account, the so called lived experience. For example, social isolation, inadequate care and support[38] and living arrangements[43] are risks associated with aging, but all these factors can have both mutual and individual antecedents and are experienced in different ways.

Beside the criticism on the operational definition of frailty, some scholars expressed their concerns about the medicalization of aging due to the use of frailty measurements. For Robertson[44], the biomedicalization and gerontologization of old age is being reconceptualised as a new medical space requiring new supporting ideologies which protects the new created space, with over servicing as a consequence, and requiring new customers. As a consequence, the socially constructed dependency of older adults serves those structural interests.[44] Using functional and ill-health variables tends to a medical construction where older people are placed into classes (e.g. non frail, pre frail, frail, severely frail) and the distinction between normal and not normal is made. Those assigned with the status of frail become eligible for public and home-care services.[20] Not only does this approach overlook the social and emotional experiences, it also places elderly in competition with each other for the scarce resources.[39]

Kaufman[39] argues that frailty, constructed from within a health-care context, transforms the older people's lived and experienced problems to diagnosis, then to treatment plans and rules about what ought to be done, leading to negotiated compliance. This view ignores the role of the broader environment and neglects the cumulative disadvantages build up during the lifespan.[20] The implementation of frailty has no preventive aims, but corresponds with an increased professionalism and efforts to ration care and thereby neglecting government initiatives to include older people in the society. Problems of aging are reduced to an individual level, moving responsibility from the government to the individual.[45] As a consequence, the problem of frailty is depoliticized.

Frailty is a syndrome in older people which can be identified in clinical practice and in the community (46). However, only two instruments, the Tilburg Frailty Indicator[9,37] and the SHARE Frailty Index (26) are potentially suitable as screening instrument in primary health care but require validation in larger studies in primary health care settings.[47] In our opinion, broadening biomedical conceptual models with physical or social factors is a good attempt, but often ignores the preponderance of biomedical indicators. The reason for this dominancy lays in the medical origins of frailty. In developing the Clinical Global Impression of Change in Physical Frailty (CGIC-PF),[28] it was found that when clinicians were asked to rate the different factors of frailty, they rated mobility, stamina, and activities of daily living as most important and social and psycho-emotional factors as least important.

Some scholars point to the social construction of frailty (48). Therefore, in order to remain in the community, older individuals also rely on aspects in their social, psychological and physical resources. Consequently adjusting the frailty measures for home-care clients to a bio-psycho-social or more integrative approach may prove valuable (49). Furthermore, although social science literature acknowledges the merits of the frailty measurements in order to identify patient problems, it also points at a conflict between the biomedical conceptualisation and the older people's experiences. When older women were asked how they perceive frailty, most of the answers were not only linked to physical descriptions (being small, skinny, etc), but also to contextual, social and emotional problems, suggesting that elderly themselves have other definitions about frailty than clinicians (20).

Vulnerability

As mentioned in the previous section, the micro-level conceptualisation of frailty overlooks crucial aspects of lived-experiences when aging. These lived-experiences can only be understood by turning to other discourses then frailty.[20] Moreover, for each individual, the aging process takes place in a specific context, which is also ignored in frailty. In this section, we will elaborate on the concept of vulnerability, in order to determine whether it's a valuable alternative for frailty.

The word vulnerability is derived from the Latin word vulnerare, which means "to wound". In other words, vulnerability can be defined as "the capacity to be wounded". Vulnerability as a concept first emerged in the environmental sciences for the study of human impacts of natural disasters,[14] and several scholar have tried to define vulnerability. Chambers was the first to describe vulnerability as “the exposure to contingencies and stress, and difficulty coping with them”.[50 p1] Schröder-Butterfill describes vulnerability in old age as the interplay between biological and social threats, individual characteristics and resources, social relationships and wider economic, political and cultural structures, which are taking place on four domains; exposure (e.g. socio economic or marital status, region one lives in), threats (e.g. declining health, income loss), coping and outcomes.[14] Coping capacities are those individual capacities build up during the lifespan including wealth, social network and formal social protection which enables the older person to face the challenges. The outcomes are seen as the result of the whole process and include lack of healthcare, insecurity, social isolation, poverty, etc.

Grundy also points to coping in vulnerability and describes vulnerable elders as ”those whose reserve capacity falls below the threshold needed to cope successfully with the challenges that they face”.[10 p107] In this view, each individual ages with a build-up reserve capacity (income, material resources, family support, social support and health). If the challenges older people face exceeds these reserves, they become vulnerable. Crooks tries to capture both a lifespan and network approach by defining vulnerability as the end result of a cumulative process depending on the resources, including the networks older people have.[7] A lifespan approach is also found with Moser[51] as he describes labour, human capital/health, productive assets, household relations and social capital as assets against vulnerability.

Shi and Stevens’ model has three dimensions on both an individual and an ecological level.[52] On the individual level, the predisposing factors include age, gender and health. The enabling factors are socio-economic status, human capital and mediating factors like access to healthcare and social protection and needs are defined as illness, poverty, lack of income. On an ecological level, the predisposing factors include demographic components, location, political, legal and economic systems, the enabling socio-economic status of the community and quality of the environment. Ecological needs are described as trends in health care status, mortality rates and age discrimination. Important in this model is that all factors influence vulnerability by interaction or convergence. As a consequence, vulnerability does not only represent personal deficiency but is also a result of multiple risks. Although developed for natural hazard vulnerability, the model of Schneiderbauer and Ehrlich contains an interesting social perspective.[53] Social vulnerability is linked at different social levels: individual, household, administrative community, cultural community, national and regional. For each level, parameters were developed in order to measure the vulnerability at the different levels. This model emphasizes the complexity of social vulnerability by suggesting that vulnerability is multi-layered, but also potentially cumulative on different social levels.[53] In a more recent approach vulnerability is measured via communication with others, living situation, social support and social activities, leisure activities, personal perceptions, socioeconomic status and the use of Ryff scales.[54] Ryff scales measure multiple facts of psychological well-being like autonomy, environmental mastery, personal growth, positive relations with others, purpose of life and self-acceptance.[55]

Critique of the vulnerability models

Although the vulnerability concept has it merits in research, it also lacks a consensus as many authors are seeking an operational definition.[56]

Some models derived from hazard research and implemented in social sciences adequately describe the social oriented complexity of vulnerability by capturing it on different levels, demonstrating its potential cumulative character. In contrast, the practical use in order to detect community dwelling older individuals is questionable. Sometimes variables like age and gender are used in order to detect vulnerability. Scholars following this approach must be very cautious not to assess vulnerable older people from a stereotype point of view.

As some models include illness, disease and disability in order to measure vulnerability, they tend to frailty measurements from a biomedical point of view and to a normal not normal debate disregarding an individual’s coping capacities. For example, although an older person with a 20 year old paralysis of the right arm can be perceived as vulnerable by experts opinion, it’s is possible he managed to cope with this paralysis and the vulnerability becomes less evident. With this example we elaborate our fourth critique regarding the actual vulnerability approaches. In order to capture the lived experiences of older persons and their assets/coping strategies, some scholars introduce terms like human and social capital, which are all operationalised differently. One might wonder whether those operationalisations really enclose the lived experiences of older people. Fifth, to our notion, the psychological well-being of older persons which is reluctantly introduced in the frailty concept is underrepresented in most vulnerability approaches. Finally, some models try to capture the environmental living conditions. These measurements are often based on community, region or national level and thereby neglecting the lived-experiences of individuals in their environment. Moreover, the Belgian Ageing Studies[4] demonstrate that there are substantial differences, not only between individuals, but also between communities and regions. For example, De Witte et al.[11] demonstrated differences in the experienced care shortages between older persons living in rural regions or in cities. These findings suggest taking these individual, local and regional differences into account.

Discussion and conclusion

This paper examined frailty and vulnerability as approaches to detect older people in need. Based on the literature it can be concluded that both frailty and vulnerability have their merits in research. Because models of frailty and vulnerability are still in development and therefore incomplete, instruments based on these models only partly succeed in the detection of frail or vulnerable community dwelling older persons. On the one hand, the paper demonstrates that frailty is a concept dominated by medical science, disregarding the social and environmental context in which older people age. On the other hand, vulnerability tries to capture this context, but fails to do so on an individual level as environmental conditions are often measured on a regional level.

As a consequence, with population aging and aging in place as future challenges in mind, a new useful integral conceptual model for frail/vulnerable community dwelling older persons is needed and subsequently a related comprehensive and feasible instrument capable of detecting them.

First, this model must include all four domains of human functioning (i.e., physical, social and psychological functioning) and the quality of the broader environment in which this functioning takes place. In doing so, each domain should receive equivalent attention, thereby abandoning the prevailing preponderance of physical aspects. Second, it must acknowledge the complex interplay from both physical, psychological, social and environmental factors, thereby following Markle-Reid's point of view of the multidimensionality of frailty and vulnerability (30). As Schröder-Butterfill[14] stated, older people can currently be confronted with poor-quality housing and changing social networks on top of their health problems, which all can influence their well-being. As a consequence, the social network an elderly can rely on should be included as well, as suggested by Crooks.[7] Expanding the conceptual model beyond biomedical variables will withstand Robertson's remarks regarding medicalisation and gerontologisation of old age. Third, it is essential that the model comprises the lived experiences of the older persons themselves. As Kaufmann stated, the often reductionist and uni-dimensional view of clinicians may not be the true reflection of the lived experience and cannot capture the individual complexity of frailty.[39] As frailty may have a serious impact on ones quality of life,[57] it also requires taking the subjective perceptions of individuals into account. Fourth, the model necessitates rejecting the ubiquitous thought that frailty is age related[58] and approaching older persons as other individuals and not as dismantling human beings. Fifth, the new model must acknowledge that frailty can originate from life course determinants, which points to cumulative disadvantages build up during life. Finally, the conceptual model should clearly show the interactions within the domains of frailty as well as between frailty and other relevant factors.

On the basis of this conceptual model, an instrument can be developed for the broader detection of frailty in community dwelling older people. Using such an instrument will uncover the real needs of aging individuals on the different domains of human functioning and their environment instead of categorisation into frail-no-frail. This will, in our opinion, empower governments' policy of focussing on aging in place. Individuals are stimulated to age in their own environment, but they can be assured that if problems arise, these will be detected and remediated. Moreover, governments can gain a clear picture of what type of care or support is required and as a consequence, act upon adequately. In that way, successful aging in place can be optimised.

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3

Abstract
Drawing upon the developing literature on dispositive analysis, we examine the effects of pharmaceutical industry discourse on the subjectivities of nurse opinion leaders in the field of Multiple Sclerosis (MS) who have taken on the role of advocates of disease modifying therapy. Specifically, we draw attention to the '*technologies of the self*' MS nurse opinion leaders engage in as they promote the financial interests of the pharmaceutical industry. Accordingly, we demonstrate how the *ordering* of the management and treatment of people with MS regulates the time, activities, and actions of nurse opinion leaders to promote disease modifying therapy despite less than convincing evidence for its efficacy and cost-effectiveness. By focusing our description on the '*self-technologies*' nurse opinion leaders in the field of MS engage in, we problematize the relationship between the pharmaceutical industry and nursing.

Key Words instrumentality, knowledge (*savoir*), pharmaceutical industry, subjectivation, '*technologies of the self*'

'Technologies of the Self' as Instrumentality: Becoming Instruments of the Pharmaceutical Industry through Normative Practices

RUSLA ANNE SPRINGER & MICHAEL E. CLINTON

Introduction

The primary focus of this paper is on how the subjectivities of opinion leaders among Multiple Sclerosis (MS) nurses become ordered in regularities of time, activities and actions that promote the interests of the pharmaceutical industry through participation in discursive practices that assume uncritically the efficacy and cost-effectiveness of disease modifying therapies. The paper draws upon a Foucauldian dispositive analysis of the discursive effects of pharmaceutical industry discourse on nurse subjectivities which revealed the '*technologies of the self*' nurses engaged in to modify themselves to become both object and subject of the pharmaceutical industry.[1] Our starting point is the following quotation in which Foucault clarifies how we are to understand 'ordering':

> …an order reigns in the simple sense of a never ending, permanent regulation of time, activities, and actions: an order which surrounds, penetrates, and works on bodies, applies itself to their surfaces, but which equally imprints itself on the nerves, and what someone called the "soft fibers of the brain". An order, therefore, for which bodies are only surfaces to be penetrated and volumes to be worked on, an order which is like a great nervure of prescriptions, such that bodies are invaded and run through by order.[2 p2]

In the early 1990s three classes of interferons (Avonex, Betaseron and Rebif), and glatiramer-acetate (Copaxone), collectively known as the disease modifying therapies (DMTs), were heralded into the marketplace as new '*breakthrough*' therapies that claimed to alter the fundamental course of MS by reducing disease activity and burden. However, despite extraordinary cost and the elusiveness of long term protection from disability [3 - 13] the promulgation of the effectiveness of these therapies in the treatment of MS persists. Our empirical clarifications will bring out the relevance of Foucault's notion of order to demonstrate the subjectivation of MS nurse opinion leaders, and to reveal how they may be implicated in the drive of the pharmaceutical industry for evermore widespread use of DMTs. However, no grand narrative is intended, and we do not claim that every nurse opinion leader is subjectivized in the same way, or to the same extent. Rather, our more modest claim is that some opinion leaders among MS nurses are subjectivized in ways that perpetuate an unquestioned discourse about the advantages of DMT in the management and treatment of patients with MS.

We define MS nurse opinion leaders (NOLs) as those nurses in the field who are selected by the manufacturers of DMTs to play key roles at industry sponsored conferences and events and otherwise to engage in the education of MS nurses in the use of DMTs. Nurse opinion leaders are recruited following the direct observation of nurses who speak at company sponsored conferences and events about the treatment, care and monitoring of MS patients. Nurses who show sufficient affinity with DMT discourse are seduced into taking on leadership roles to facilitate a wide assortment of discursive mechanisms aimed at expanding the market for DMTs. For example, nurses may be approached and asked to speak at other conferences. They may also be asked to develop standard patient care plans and other similar materials for use by other MS nurses, or by patients. They might even be asked to host mini conferences or other educational events at their practice settings. Financial inducements in the form of honoraria are typically offered in return. Although the amounts involved are small in comparison to those paid to physicians, they are usually sufficient to encourage interest and maintain motivation.

Pharmaceutical company representatives are another source for the recruitment of NOLs. Nurses who are identified as suitable for further training and for taking on NOL roles are groomed by company representatives and encouraged to attend industry sponsored Speaker Training Bureaus and other like indoctrinating continuing education initiatives where further engagement of their interest can be developed. Although the NOLs actively engaged in promoting the interests of the manufacturers of DMTs are our main focus, we refer to MS nurses as well because they are the wider group from which NOLs are recruited by the pharmaceutical industry.

Theoretically speaking: Dispositive or apparatus?

Before continuing, we need to say something about our use of the term, dispositive analysis. What, it may be asked, is 'dispositive analysis'? And why do we prefer this formulation, which may at first sight seem somewhat idiomatic, to the more common translation of Foucault's 'dispositif' as 'apparatus'? We offer two points in our defense. First, far from being idiomatic the term 'dispositive analysis' is used increasingly in the secondary and tertiary literature on Foucault and discourse analysis. A simple Google search will return more than two million hits in a fraction of a second. A common characteristic of this literature is a preference for '*dispositive*' over 'apparatus' when translating the French, '*dispositif*' into English.

Our argument from common usage is sufficient for us to avoid accusations of idiomaticity. However, there is a more conceptual reason for our preference for 'dispositive'. Bussolini[14] has noticed that the appearance of new lectures by Foucault in translation has brought to attention a previously unnoticed conceptual distinction that has for the most part been passed over without comment in the secondary literature on Foucault's researches, writings and conversations. For Bussolini[14] there are strong reasons to favor the use of '*dispositive*' over 'apparatus' when translating the French '*dispositif*', or its Italian equivalent '*dispositivo*', into English. The problem with rendering '*dispositif*' as '*apparatus*' is that this translation collapses distinct etymological, and therefore conceptual lineages in French and Italian, thereby creating something of a false identity in English. Bussolini[14] points out that Foucault was careful to differentiate between '*appareil*' (*apparatus*) and '*dispositif*' (*dispositive*) when writing about power relations in *The History of Sexuality*. At this stage in his researches, Foucault used 'appareil' to refer to State and state affiliated power, and 'dispositif' to refer to the wider and changing relations of power that function beyond the State through normalization, law and control rather than punishment.[14] State systems and mechanisms of power conceived as 'appareil' are therefore a subset of wider relations among forces. In other words, to over simplify, to conflate '*appareil*'' with '*dispositive*' is to mistake a part for a whole, and to fix a conception of the wider relations, institutions, and practices of power in a less dynamic and strategic form than Foucault intended.[14]

Foucault's usage of '*dispositif*' in this sense was made clear in a conversation with Alain Grosrichard.[15] When asked specifically about the meaning or methodological function of the term '*dispositif*', inserted parenthetically immediately following the translators' "*apparatus*', Foucault replied:

> What I'm trying to pick out with this term is, firstly, a thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philosophical propositions – in short, the said as much as the unsaid.[15 p194]

Our dispositive analysis is therefore focused on bringing to the fore that heterogeneous ensemble that conditions DMT discourse, the institutions that produce it (science and scientific research, market economics, medical education, clinical practice, and consumer empowerment); and the organizations that are the sites for practice, (research laboratories, the pharmaceutical industry, medical and nursing schools, and sites of clinical practice). This focus on the non-discursive as well as the discursive permits us to bring to light the 'unsaid' in the management and treatment of people with MS. More particularly, our approach enables us to problematize the involvement of NOLs in promoting DMTs as an indispensable response to the urgent need to find more effective treatments for people with MS while serving the dominant strategic function of BigPharma profitability.

We use dispositive analysis, analysis of the dispositive; that is, our analysis of the wider formation that produces the discursive effects of pharmaceutical industry, to problematize the subjectivities of nurses engaged in uncritically promoting DMTs as effective in the management and treatment of MS.[1] Consequently, this paper unravels and reveals the '*technologies of the self*' NOLs as subjects engage in to modify themselves by what they know as they become both object and subject in DMT discourse. Using specific examples, the '*technologies of the self*'' nurses as subjects apply to themselves as they become '*expert thought leaders*' and '*key opinion leaders*'[16] for the pharmaceutical industry will be made visible. At the same time, and importantly, we examine what these nurses, as agents of the pharmaceutical industry, want to become as subjects in the sense of the kind of clinicians, professional leaders and patient advocates they aspire to be. By revealing the performances NOLs engage in to become objects and subjects of DMT discourse, we demonstrate how 'BigPharma' works towards the imposition of social uniformity on the practices of health providers to achieve its fiduciary goals.

Raising ethical questions about the omnipresence of 'BigPharma'

The concerns we advance about NOLs in the field of MS raise ethical questions about the increasing presence and influence of the pharmaceutical industry in healthcare practice generally, despite over a decade of radical criticisms of its omnipresence and questionable practices by ethicists[17-20], economists[21] healthcare providers[22-26] and a number of other social commentators[27-38]. Our intention is to raise awareness among MS nurses, and the profession of nursing as a whole about the insidious infiltration of the pharmaceutical industry into nursing practice.[39-42] Our paper is intended to break the conspicuous silence on this topic on the part of the profession of nursing[25] as is reflected in the dearth of nursing literature available on the relationship between the pharmaceutical industry and nursing. Of the literature that is available, there is very little expressing concern about the role the pharmaceutical industry plays in influencing nursing practice and nursing behavior.[39] However, as nurses increasingly acquire prescriptive authority in their expanding roles as nurse practitioners, a deeper understanding of nursing's relationship with the pharmaceutical industry, and the effects of those relationships on the subjectivities of nurses is required.

Uncritical acceptance

Based on the empirical work that is available on pharmaceutical industry's infiltration into the practice of nursing, it appears that nurses accept promotional material produced by the pharmaceutical industry, sometimes with the assistance of nurses, uncritically.[39] This disconcerting finding suggests that nurses are ill prepared to deal effectively with the tactics and strategies the pharmaceutical industry engages in to promote its products. This lack of insight into these seemingly benign strategies and tactics positions nurses as extremely vulnerable to exploitation. As Thomas Beauchamp and James Childress[43] argue, the pressure for drug companies to find positive results of new medicines positions nurses as particularly vulnerable when working in industry sponsored research environments. In situations such as these, much of nurses' vulnerability stems from their relative meager training in pharmacology, statistical inference, and critical appraisal.[39]

Of particular relevance is that nurses generally have a poor understanding of the marketing and persuasion strategies used by the pharmaceutical industry.[39] As such, this paper attempts to remedy these knowledge deficits by increasing nurses' awareness of the mechanisms of persuasion employed by the pharmaceutical industry to achieve its goals. Moreover, the paper also represents an attempt to prevent, or at a minimum, to disturb the imposition of social uniformity upon the human practice of nursing by opening up a much needed space for dialogue about the place wealth creation occupies in the delivery of human care.

What follows is an overview of Foucault's conceptualizations of '*the subject*' '*subject positions*', '*subjectivation*' and '*subjectivity*', which will serve to provide the necessary theoretical foundation for the exploration of the '*technologies of the self*' the subject applies to itself to become an instrument of the pharmaceutical industry. The review of these conceptualizations will also provide the foundation for the exploration of what subjects actually do to themselves in terms of the regulation of their time, their activities, and their actions as they shape themselves into objects of instrumentality for the pharmaceutical industry; and importantly, as they shape themselves into the subjects they wish to become. By demonstrating what subjects actually do to themselves to transform themselves into objects consistent with what the pharmaceutical industry requires it can be shown that an order, in Foucault's[2] sense, actually exits.[1] Moreover, it can also be shown that nurses' autonomy and authority in practice pales before the constraints of discursive determinism.[44]

The subject and subjectivity

To understand '*the subject*' from a Foucauldian perspective is to first understand that Foucault distinguishes between '*the subject*' and '*the individual*'. Foucault was not so much concerned with '*the individual*' as he was with the forms of power that transform the individual into '*a subject*'. From that perspective, '*the subject*' is to be understood as '*a form*', as opposed to '*a thing*'. Vital in understanding '*the subject*' as '*form*' rather than '*thing*' is to understand that '*the form*' ('*the subject*') is not constant even when attached to the same individual.[45] As Foucault explained, the subject is a form not primarily or always identical to itself.[45] To understand Foucault's conception of 'the subject' one has to be clear between the two different but interconnected meanings ascribed to '*the subject*'.[46] First, "human beings are made subjects",[46 p208] that is, they are made subject to. In other words, human beings are made to be subject to others by control and dependence. Second, the subjective identity of the subject, that is, who or what the subject understands itself to be is '*made*' or '*produced*' by being tied to a given identity through consciousness or self-knowledge.[46] However, notions of subjectivity arise through broad and complex social and historical contexts, the effects of which are unconscious. As Weedon[47] explains, conscious subjectivity, which is acquired through discourse, is inherently unstable inasmuch as subjectivity is constantly in process.

Subject positions and subjectivation

Subject positions can best be understood as ways of being within a particular social context, which call for different qualities or modes of being.[47] For example, one's subject position or way of being, as mother, father, child or sibling will be different from one's subject position as nurse, teacher, researcher, NOL, and so on for the myriad subject positions one subject occupies in any number of social contexts. Subject positions can also be understood as spaces from which one speaks and observes in a discursive formation.[48] A discursive formation is understood as occurring through the systems of thought and knowledge Foucault[38] argues operate beneath the consciousness of subjects. In other words, a discursive formation defines a system of conceptual possibilities that determines the boundaries of an individual's thought in a given domain or discipline.

Important in this understanding of a discursive formation as it relates to the treatment and care of individuals with MS is that it is precisely these discursive formations that constitute disciplines, and more importantly, it is these discursive formations that underpin the exercise of a discipline's techniques of control over individuals.[49] Put another way, subject positions have rules for the acceptance of certain individuals into those spaces from which one speaks (one's discipline). According to Akerstrom Andersen[48] these rules of acceptance also determine the situations in which the subject position can be used as a platform for speaking and observing, and they also determine the formation of statements once the subject has assumed a specific subject position.[48] Akerstrom Andersen[48] clarifies subject positions further by suggesting that subjecting arises when an individual or collective is proclaimed to be a subject within a specific discourse. As such, the individual or the collective is offered a particular position in the discourse from which they can speak and act in a meaningful way. On these basis subjecting signifies the space (the practice realm) in which the discursive individual (the nurse) receives itself as nurse, as expert, as key opinion leader, as collaborator, as partner, and so on.[48] Subjectivation on the other hand, occurs when individuals or groups are formed and transformed through discourse. Subjectivation must therefore be understood as occurring when the subject (individual or group) wishes to be that subject.[48]

As Akerstrom Anderson[48] points out, subjectivation signifies the space in which the individual gives itself to itself. Therefore, '*technologies of the self*' must be understood as the performances undertaken by individuals and groups within a particular space (the practice realm) to become what they want to become. Of significance to the context of MS treatment and care is that when a nurse accepts a particular subject position within the practice setting that nurse is transformed in such a way that he or she becomes a channel for the flow of power.[50]

'Technologies of the self' as instrumentality

'*Technologies of the self*' must be understood as arising through knowledge (*savoir*)[49] with '*savoir*' understood as the labour performed by the subject upon itself in order to know[49]. '*Technologies of the self*', as those have been described by Foucault[49], can therefore be understood as the performances the subject engages in to modify itself by what it knows. Put another way, '*technologies of the self*', are the modifications, formations and transformations that arise in the subject through unconscious ways of knowing. Indeed, it was this transformation that arose in the subject that was so striking to Foucault during his historical analysis of the discourses producing 'the criminal' and 'the prison'. So intrigued was Foucault by these transformations that demonstrating '*how*' human beings are made subjects,[50] became the very central focus of his corpus[49] as his response to questioning about his book '*Pierre Riviere*', clearly indicates:

> It's a totally strange story. It can however be said, and this is what struck me, that in such circumstances writing one's life story, one's recollections and experiences, was a practice found in a fair number of cases, and particularly in the prisons… one also finds judges and doctors doing this. It was the first great burst of curiosity about the individuals whom it was desired to transform and for the sake of whose transformation it was necessary to acquire a certain savoir, a certain technique.[49 p48-49]

Indeed, Foucault's purpose in writing '*Pierre Riviere*' was not at all to do with exposing the crime committed. Rather, it was to "render visible the medical and juridical mechanisms that surrounded the story".[49 p49] It was in this writing that Foucault made visible the '*mechanisms*' and '*techniques*' required to transform the subject into what the prison system required it to become (prisoner). According to Foucault[39] the visibility produced at that time left the experts of the day completely silent. Indeed rendering visible how human beings are transformed into required subjects in any number of contexts leaves the experts "equally dumb today".[50 p49] Foucault cautions "not to regard the point in time where we are now standing as the outcome of some teleological progression".[51 p49] Rather, he asks that we make inquiries regarding ourselves; that we inquire as to what we are here and now.[52] Thus, the inquiry we undertake asks critical questions about ourselves as nurses, and about our nursing knowledge relative to our engagements with the pharmaceutical industry.

Rendering the effects of power/knowledge visible

As the foregoing clearly demonstrates, power/knowledge produces effects; effects which are rendered visible by the '*technologies of the self*' or the '*self-technologies*' the subject applies to itself to transform itself by what it knows. In this sense, because activities are actions taken in pursuit of some objective,[53] and because actions consist of the activity or process of doing something to achieve an aim, in the context of MS treatment and care, activities and actions will be understood as the performances and practices carried out by MS nurses involved in pharmaceutical industry discourse as a direct result of their participation in that discourse. In other words, the activities and actions carried out by MS nurses engaged in relationships with pharmaceutical industry through direct contact with company representatives, through the conduct of sponsored research, through the writing of journal articles and research reports, through the facilitation of treatment decisions, and the further facilitation of compliance and adherence to treatment can all be understood as the '*technologies of the self*' MS nurses engage in to become what the pharmaceutical industry requires them to become (instruments of persuasion and surveillance); and importantly, what they themselves wish to become (expert thought leaders and key opinion leaders in their fields). While how an individual takes up a subject position is not observable, 'how' a discourse demands the individual take up a subject position is observable.[48] As such, the following explanation of self-technology analysis, along with the specific example of the '*technologies of the self*' MS nurses apply to themselves in the context of authorship will make visible and observable '*how*' discourse demands individuals take up particular subject positions.

Self-technology analysis

Self-technology analysis speaks to 'how' individuals manifest themselves as subjects. The approach concerns the analysis of the technologies available to an individual's manifestation of itself as subject, and how subject positions are created.[48] As previously discussed, within self-technology analysis the distinctions Foucault makes between subjection and subjectivation must be viewed as much more than theoretical distinctions. Recall that "subjection means that an individual or collective is proclaimed subject within a specific discourse. The individual, or collective, is offered a specific position in the discourse from which it can speak and act meaningfully".[48 p24] Subjectivation, on the other hand arises "when the individual or collective has not only been made the subject, but also wishes to be so".[48 p24] This important distinction lies between the two different demands made of individuals who are to become subjects, demands that arise through discourse.[1] In other words, the subject doesn't simply receive itself passively. On the contrary, the subject receives itself actively by giving itself to itself.[48] This active giving of oneself to oneself is to be understood as not only a mode of subjecting, it is also to be understood as a mode of transformation.[49] Thus, in the context of MS treatment and care, in addition to the demands nursing discourses make of its subjects, the strategies and tactics the pharmaceutical industry employs cannot be underestimated.[1] As Rose reminds us, in analyzing relations between 'the self' and power, "it is not a matter of lamenting the ways in which our autonomy is suppressed… but in investigating the ways in which subjectivity has become an essential object and target of certain strategies, tactics and procedures of regulation".[54 p152]

As previously pointed out, subjectivities are both constituted and constrained through what Foucault calls the "great nervure of prescriptions" that arise in discourse.[55 p304] Important in the analysis of '*self-technology*' is to understand that utterances arising within specific discourses are never value free; they are always based on certain rules of acceptability. As Foucault argues, these rules of acceptability "run through individual oeuvres, sometimes govern them entirely, and dominate them to such an extent that nothing eludes them".[56 p139] Discourses are therefore much more than what can be said and thought; discourses are also about who can speak, when, and with what authority.[49] As such not just anyone can speak about any subject. Only those possessing the qualifications, prestige and status to speak are afforded authority within a given discourse.[56] Due to the status the medical professions enjoy in modern society, all are afforded a certain status and therefore positioned as '*expert authorities*',[1] all with the privilege to speak based on their credentials and the status they enjoy within the hierarchy of those professions. Indeed, the pharmaceutical industry has come to appreciate the marketing value of engaging the medical professions in their marketing activities.[29] As Angell[22] argues, the price of medicines is determined by their value in preventing and treating disease, and it is the physician (and increasingly the nurse) who plays a central role in determining what that value will be. Thus, return on investment for the pharmaceutical industry has been contingent upon the prescribing behaviours of physicians,[22] and will increasingly become contingent upon the prescribing behaviours of advanced practice nurse practitioners and other health professions achieving prescriptive authority.

Self-work

We have mentioned several times NOLs as the subjects and objects of DMT discourse. Subjectivity, in this sense, involves the discourses NOLs participate in as a result of their involvement in promoting the interests of the pharmaceutical industry. Such involvement is not confined to those occasions when NOLs speak in favor of the advantages of DMTs; it is a consistent part of everyday practice in clinical settings. This is because the discourses a subject engages are biased in favor of the practices typically participated in by the subject.[1] In other words, those discourses that relate directly to current practice are the most influential on current practice. In the practice of nursing, discourses of science and medicine play a pivotal role.

However, there are any number of discourses that govern and influence the individual subjectivity of NOLs. The discourses in which they participate as they practice resonate with "personal history and biography; formal training and education; professional identity; practice relevant experiences; and with participation in the relevant plurality of the social apparatus"[1 p226-227], to which they belong. All of which contribute to what Springer[1,25] describes as the heterodiscursive space of subjectivity. Therefore, when determining the various '*self-technologies*', or the '*self-work*' that NOLs engage in, one must not fail to consider the heterodiscursive space of subjectivity; the relevant plurality of the social apparatus; the dispositive. The forms of consciousness NOLs engage in within the heterodiscursive space we have referred to can be made visible by attending to how NOLs act on themselves as objects from the subjectivity of the heterodiscursive space they occupy; that is, by attending to the '*self-work*' NOLs engage in. While there are any number of possibilities, our concern is with those '*technologies of the self*' that operate in favor of the pharmaceutical industry via '*self-work'* by acting on human vulnerabilities and professional and personal identities, such as those governed by aspirations for status, recognition, prestige and authority.

Technologies of the self and nursing subjectivities

When NOLs participate in DMT discourse their subjectivities are doubly impacted. As subjects, NOLs express subjectivities governed by the requirements of clinical practice in all its heterodiscursive complexity. In the following statement, Costello and Halper[57] link commitment to the importance of a 'trusting nurse-patient relationship', a central tenet of professional nursing discourse, and 'long-term adherence; a clinical prerequisite for remission in DMT discourse, and a pharmaceutical industry imperative linked in part to financial interests:

> An open, trusting nurse-patient relationship is critical to long-term adherence. Recent anecdotal evidence from the pharmaceutical industry supports the importance of nursing education and sustained nurse-patient relationships to patients receiving self-injected therapies.[57 p18]

Here the NOLs Costello and Halper instruct other MS nurses within the normative expectations of MS clinical practice to achieve the goal of 'long-term adherence' through the means of a 'trusting nurse-patient relationship. Such exhortations reinforce professional values understood from within subjectivities that leave DMT discourse unquestioned, while urging MS nurses to work at developing nurse-patient relationships of the trusting kind. In other words, the MS nurse is prompted to strive for, to work at, to apply '*technologies of the self*' that will cultivate a persona of trustworthiness consistent with the interests of not just the person with MS, the explicit focus of the statement, but also in the interests of the pharmaceutical industry that speak loudly from what is not and cannot be said. Such trustworthiness requires the application of '*self-technologies*' that allow the MS nurse to manage personal time to be wherever possible always available for unscheduled drop in visits or telephone contact so that any problem or concern the patient may have can be addressed without delay, thereby eliminating any resistance to treatment.[1] Such foundations of trustworthiness involve a transformation in clinical practice whereby surveillance[58] of treated patients takes precedence over other important care practices the patient may require.

The point to be taken from this example is that '*technologies of the self*' are the means MS nurses adopt as they strive to meet the expectations set out for them in the dominant discourses of practice in which they participate. As such, MS nurses apply myriad '*self-technologies*' as they strive to practice in accordance with DMT discourse in those settings where it dominates clinical practice.

Thus, this unraveling of the '*technologies of the self*' MS nurses apply to themselves; can be taken as but one example of how the pharmaceutical industry inserts itself into nursing practice. Irrespective of context, when nurses consciously attend to the requirements of practice germane to medication, they develop expertise required of them by their professional subjectivity, while transforming themselves at the same time into instruments of the pharmaceutical industry; unless, in the absence of evidence, they bring a healthy skepticism to the unsubstantiated claims made for the benefits of DMT products. It is important to understand that in the '*self-technologies*' nurses apply, be it as authors, as experts, as NOLs, as relational and knowledgeable partners in decision-making, as enthusiastic, hopeful, empathetic, friendly and responsive supporters,[1] that without insight into the forms of subjectivation and instrumentality the pharmaceutical industry engages in, nurses believe they are being faithful in their practice to only their understanding of nursing. Fundamental to such beliefs is the commitment to actions that are in the best interest of the patient.[1,25] However, without suspicion, nurses will not realize that they may be unwittingly exploiting the fears and hopes of their patients as they (nurses) take up their subject positions as 'channels for the flow of power' from the pharmaceutical industry. Indeed, it is the '*ordering*' of the work nurses perform in their everyday clinical practice settings, as well as the work they perform upon themselves as they conform to the expectations of their discipline, as well as the expectations of the heterodiscursive spaces within which they work, that their subjectivities are formed and transformed.[1,25]

Discussion

There are frameworks other than dispositive analysis that we could have used in preference to finding insights and directions for inquiry from Foucault's problematizations and researches. Therefore an obvious question is why did we opt to conduct our studies of DMT discourse within a distinctly Foucauldian conceptualization. The strong reasons we have for our approach are motivated by two concerns. The first as already mentioned is to explore DMT discourse within a broad framework of the unsaid: the institutions, practices, and networks of changing an interactive relationship that influences conceptions of the management and treatment of people with MS. As we have mentioned, the notion of 'dispositif' (dispositive) we find in Foucault's researches and conversations provides a sufficiently challenging and enlightening framework in which to investigate our interest in the current dominance of DMT discourse in managing and treating MS. We deliberately exclude our usual formulation of people with MS here because we want to draw attention to the influences that impact MS patients as they participate in DMT discourse as the recipients of a relevant treatment regimen. However, we want as well to link our understanding of the conceptual contribution of the 'dispositif' with an exploration of how politics of the 'self' constitute a distinctive subjectivity among physicians, among nurses; and among MS patients who serve as extensions of the pharmaceutical industry within the changing dynamics of conditioning institutions, organizations, practices and discourses.

Our interest in the distinctive subjectivities to which we have drawn attention raises the challenging question of the relationship between our use of Foucault's concept, '*technologies of the self*' to his distinctly ethical concerns, especially those he researched in *The History of Sexuality*. What, it may be asked, links our account of DMT discourse within a dispositive to the sort of ethics that interested Foucault? The short answer in one word; freedom. We will explain.

Let us take it that what Foucault means by '*technologies of the self*' is essentially self-constitution through practices of freedom. We now have two things to reconcile, what we might call the techniques of domination, the strategies and tactics of the 'dispositif' that provides the historical and immanent context for understanding the '*how*' and '*why*' of DMT discourse; and the practices of freedom we refer to as 'technologies of the self' that have a positive influence on promoting the interests of the pharmaceutical industry. The '*technologies of the self*' we refer to are in a sense practices of freedom, but at the same time they involve self-transformation into the subjectivities we have described. With this, we arrive at a Foucauldian paradox. For Foucault, the self is not an objective entity standing outside the discourses in which it is constituted, but a political and therefore ethical entity. Therefore, those we have called NOLs are engaged in activities and practices that are conditioned by the power relations and much else that are the elements of the *dispositif* that produces, reproduces, develops, regulates, advances and promotes DMT discourse.

However, the subjectivities to which we refer, following Foucault's later work, involve a notion of the subject that is capable of self-transformation. The paradox we engage with therefore is that of accepting that strategies and tactics of domination that are entirely compatible with a self that has the capacity for self-transformation. This works to the advantage of the pharmaceutical companies to the extent that the subjectivities of nurses, as well as physicians and people with MS are constituted by DMT discourse, but this also leaves open the potential for commitments, actions and consequences that will provide alternative forms of self-transformation. In his later writings, Foucault takes us some way towards overcoming the paradox of domination with freedom, but we still have conceptual work to do to reconcile his archeological and genealogical studies with his ethics.

We claim that Foucault's notions of '*dispositif*' and 'technologies of the self' give us indispensable conceptual, political and ethical resources in which to research what would be unsaid about the contemporary management and treatment of people with MS. Foucault stimulates us to research neurological, nursing, and self-care practices to begin to understand how and where the ideas come from that support the ascendancy and dominance of DMT discourse. We claim no privilege for our perspective. We steer clear of any totalizing notions. We have no grand narrative to relate, no definitive answers to the problematizations we have drawn attention to; rather we seek to understand what we have described. We problematize the subjectivities MS nurses and MS NOLs, as well as the subjectivities of physicians and MS patients. We encourage an agenda of seeking out the values, interests, organizations and institutions that intertwine in the domination and control of an important field of clinical practice.

We therefore propose a double reading of our final quotation from Foucault; a reading consistent with our usage of '*technologies of the self*' in the sense of self-transformation in accordance with the interests of the pharmaceutical industry, and the more positive ethical meaning Foucault intended:

> The task of testing oneself, examining oneself, monitoring oneself in a series of clearly defined exercises, makes the question of truth – the truth concerning what one is, what one does, and what one is capable of doing – central to the formation of the ethical subject.[59 p68]

We arrive at our double reading from what we have called the Foucauldian paradox, by reading the subjectivities of physicians, nurses and people with MS as objects, but also as subjects.

Conclusion

This demonstration of what MS nurses who become influential advocates and the first line contact with MS patients do to themselves in response to the knowledge generated by pharmaceutical industry presence and influence, and which in turn transforms them into instruments of persuasion and surveillance, demonstrates the forms of power involved in transforming nursing subjectivities into objects and instruments of the pharmaceutical industry. Not only do such transformations risk distorting the practice of nursing itself, it transforms nurses into allies, agents and marketers for the pharmaceutical industry. The result of that transformation raises patient motivation, compliance and adherence to the status of a nursing imperative and displaces the caring practices of nursing.

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Résumé
Une étude portant sur l'expérience de la souffrance existentielle a été conduite auprès de personnes atteintes d'une maladie grave. L'un des objectifs visait à explorer ce phénomène à partir d'une approche qualitative qui privilégie l'expérience de personnes atteintes de maladies graves. À l'aide d'entrevues non structurées, 14 personnes ont été rencontrées. L'analyse des résultats a conduit à deux grandes thématiques. La première thématique renvoie à une situation de crise et de bouleversements. Elle se décline en divers effets que provoquent les maladies graves dans l'existence. La seconde thématique est intrinsèque à la première et regroupe des énoncés qui font voir un questionnement excessif qui porte sur plusieurs dimensions de l'existence. Finalement, la souffrance est plutôt comprise comme un passage qu'il faut traverser, comme une quête de connaissances et comme une réalité à habiter et à rendre familière. Elle n'est pas forcément négative.

Mots clés crise, expériences de maladie grave, hyperquestionnement, souffrance existentielle

Souffrance existentielle : de la crise à l'hyperquestionnement

DANIELLE BLONDEAU, NICOLAS VONARX & LOUIS ROY

Introduction

De façon générale, pour les philosophes hellénistiques, la souffrance et la mort relèvent de la contingence et, par conséquent, n'ont qu'une valeur mitigée. Pour les surmonter, le sage doit apprendre par son activité intellective (le *logos*) à se hisser hors du monde de la contingence. Il doit s'élever au-dessus du monde sensible en faisant usage de la raison. De la sorte, il ne les subit plus comme un pathos, mais parvient à les maîtriser. Et s'il peut y arriver, c'est que la souffrance (comme tout objet) n'a pas de valeur en soi, qu'on la détermine et lui donne un statut dans notre histoire et notre expérience. Plus près de nous, pour Nietzche qui s'est inspiré des philosophes de l'Antiquité grecque, la souffrance fait partie de la vie. Elle n'est pas un obstacle pour le surhomme, mais une résistance au travers de laquelle il doit passer pour affirmer sa surhumanité. C'est dans le dépassement de la souffrance que l'homme se surmonte. Comme le souligne l'auteur : «Par-là, il ne nie pas l'existence, il affirme au contraire son existence à lui, et *seulement* son existence».[1] Et Lavelle[2] d'ajouter sur ce thème qu'on peut tirer un avantage de la souffrance, qu'on peut lui donner du sens. Il serait alors aussi question d'attitude au sens d'une attitude intellectuelle par laquelle on peut avoir un certain pouvoir sur la souffrance. En effet, elle montre en filigrane la vie et la valeur que nous lui attribuons. Lavelle ajoute : «La possibilité de souffrir mesure en un certain sens la puissance d'ascension dont chaque être est capable.[2 p31]

Ricoeur, philosophe contemporain, s'est intéressé à la question. Il faut noter qu'il distingue la douleur de la souffrance. Il définit la douleur comme «des affects ressentis et localisés dans des organes particuliers du corps ou dans le corps tout entier».[3 p59] Quant à la souffrance, elle fait référence à «des affects ouverts sur la réflexivité, le langage, le rapport à soi, le rapport au sens, au questionnement».[3 p59]

Sous le premier axe, la souffrance se présente comme un paradoxe : par la souffrance, je prends conscience de ma vie, mais c'est une vie diminuée dans ce qu'elle a de plus vivant qui apparaît. «Réduit au soi souffrant, je suis plaie vive» précise-t-il.[3 p60] L'expression est intéressante puisque c'est dans la plaie qu'apparaît la vie, sa valeur et son sens. La souffrance n'est donc pas un objet extérieur que la faculté de connaissance peut s'approprier.

Ricoeur termine avec le questionnement que pose la souffrance et qui prend la forme de «pourquoi?» : pourquoi moi, pourquoi ici, pourquoi maintenant? Voilà pourquoi, écrit Ricoeur, «la souffrance interroge» à la recherche de sens.[3 p67] Mais la souffrance échappe à cette tentative de compréhension et d'objectivation par le sujet précisément parce qu'elle est sans objet ni pourquoi. Elle est toujours «un excès; souffrir c'est souffrir trop», elle existe «dans la 'nature' sans avoir de justification dans l'ordre moral».[3 p68]

Bref, tous ces philosophes nous enseignent que la souffrance est une donnée ontologique. Ce constat ne renferme pas une apologie de la souffrance. Il signifie simplement que la souffrance fait partie de la condition humaine. Elle est une caractéristique de l'humanité même. Vergely ajoute à ce titre qu' «Un mort ne souffre pas. Un vivant souffre. C'est là le signe de son identité de vivant sensible et charnel».[4 p267]

Dans un ordre d'idées plus attentif à un arrimage entre la souffrance, la société et les réponses pratiques qu'on lui donne, un courant interprétatif en anthropologie de la santé nous livre une distinction entre la souffrance et la douleur, tout comme elle le fait à propos de la maladie qu'elle décline en réalité biologique, réalité signifiée et réalité socialisée. Dans cette perspective, et comme objet de la médecine scientifique, la douleur renvoie le plus souvent à une affection somatique, à un rapport au corps extrêmement réduit, qui tient notamment dans sa version sensorielle. Comme événement embrassant la totalité d'un être, la souffrance ne peut s'y réduire. La souffrance évoque plutôt des « affects ouverts sur la réflexivité, le langage, le rapport à soi, le rapport à autrui, le rapport au sens, au questionnement ».[5] La souffrance déborde ainsi et englobe des phénomènes physiques. Elle tient dans les significations d'une existence[6] et l'on ne saurait s'y adresser sans aborder le sens d'un Mal lors de certaines occasions où l'existence est bouleversée. Des auteurs l'entendent bien ainsi quand ils présentent la souffrance comme un problème d'ancrage et d'appui qui découle d'un manque de sens,[7] comme un non-sens ou des conditions habituelles de construction du sens qui font défaut.[8]

La souffrance serait donc une expérience subjective et vécue qui ne se laisserait pas prendre aisément dans des lectures réductionnistes, sommatives et objectives qui conduisent à des interventions mécaniques éloignées des significations véhiculées par les personnes aux prises avec un événement. La souffrance est plus, et dépasse encore une dimension personnelle, puisqu'elle est aussi une trame de sens dont la structure et le contenu sont produites socialement, culturellement et historiquement : trame de sens qui conduit par ailleurs à l'incarner, à se la représenter, la faire voir et la partager d'une certaine manière.

Qu'il soit question de lectures anthropologique ou philosophique, la souffrance est existentielle, entendu ici, et selon Tillich, qu'elle renvoie au fait «de participer à une situation, en particulier à un acte de connaissance, avec la totalité de notre existence, ce qui implique des conditions temporelles, spatiales, historiques, psychologiques, sociologiques et biologiques».[9] Elle semble devoir être associée au sujet du sens ou à une question de significations. Convoquer des lectures anthropologiques et philosophiques pour l'aborder et la comprendre nous apparaît donc incontournable. C'est tout particulièrement le cas quand on crée des dispositifs d'actions et de gestion en vue de lutter contre, de la contrecarrer, de la maîtriser et de la contrôler. C'est le cas au sein des sciences de la santé qui véhiculent parfaitement ces intentions, et dans lesquelles on ne s'embarrasse pas toujours d'un temps d'arrêt conceptuel. Aller souvent droit au but en engageant des interventions à l'endroit de catégories diagnostiques savantes très précises et prédéfinies apparaît souvent ici plus prioritaire.

Nous l'avons remarqué à travers les usages multiples du terme de souffrance dans le domaine de la santé. Là, on la matérialise, l'objective, cherche à la mesurer, et la confond avec la douleur et la détresse, la dit parfois psychologique, existentielle, morale, totale ou encore spirituelle. Certains tentent d'y faire correspondre des gestes ou des interventions, tels des psychologues à travers la « thérapie de la dignité »,[10] le « recadrage de l'espoir : le soin centré sur le sens »,[11] et, enfin, le « faire du sens et l'ajustement psychologique ».[12] On retrouve encore cet intérêt pragmatique dans la littérature en sciences infirmières où l'on tente de définir et de caractériser des soins spirituels sous une forme et en regard d'une lecture très réductrice de la souffrance et des sujets qui l'éprouvent.[13]

Au-delà de leur approche respective, du bien-fondé ou des dérapages dont il peut être question dans les approches précédentes, il faut mentionner l'absence d'un questionnement sur la nature ontologique de la souffrance existentielle vécue par les personnes malades. Si on accepte pourtant qu'il est nécessaire d'élargir l'expertise des professionnels face à la question existentielle[14] et si « des recherches ultérieures sont encouragées pour établir une thérapie standard pour la souffrance existentielle»,[15] il faut poursuivre la recherche sur la souffrance existentielle pour définir clairement ce concept. La littérature spécifique sur la nature de la souffrance existentielle dans le contexte de soins palliatifs est tout particulièrement limitée,[16] alors que c'est précisément dans cette discipline de la pratique médicale et sur ce terrain, qu'il est question d'une grande préoccupation à l'endroit de cette souffrance aux multiples qualificatifs. C'est encore plus nécessaire de s'engager dans cette quête de savoir quand on sait que ces carences ont des effets sur les pratiques. Morita et ses collègues l'ont bien constaté en soulignant que : « Une raison pour laquelle on assiste à un pauvre développement du soin spirituel dans notre pays est que le concept de souffrance existentielle n'est pas bien établi et qu'aucun instrument d'évaluation n'a été validé ».[15]

C'est en regard de ces préoccupations que nous avons conduit une étude exploratoire portant sur l'expérience de la souffrance existentielle auprès de personnes atteintes d'une maladie grave et de professionnels de la santé travaillant en soins palliatifs. Le but de l'étude visait à mieux comprendre l'expérience de la souffrance existentielle en accueillant des catégories d'interprétation issues de discours de personnes atteintes de maladies graves et de professionnels qui les côtoient de près. À partir de notre lecture critique de la littérature, une conceptualisation de la souffrance devait être avant tout enracinée dans des données empiriques et ne pas répondre d'emblée à des termes spécifiques aux sciences de la santé et à des catégories de lecture professionnelles. Nous avons alors adopté une posture plutôt phénoménologique en mettant entre parenthèses des a priori théoriques et en étant sensibles à des formes perçues et vécues de la souffrance. En d'autres mots, il fallait laisser venir à nous cette lecture à partir des principaux acteurs concernés et la saisir dans un contenu et une forme entièrement subjective et relative aux répondants.

Méthode

Les personnes qui ont participé à cette étude qualitative habitaient la région de Québec. Certaines avaient vécu ou vivaient encore une maladie grave, et d'autres étaient des professionnels de la santé qui travaillaient en soins palliatifs. Au total, 14 personnes atteintes de maladies graves ont participé à l'étude. Neuf d'entre elles étaient de sexe féminin et cinq de sexe masculin. La répartition de l'âge se situe entre 28 à 77 ans. Sept personnes étaient atteintes de cancer, quatre de sclérose en plaques et trois personnes avaient subi une greffe de foie, de rein ou de cœur. Quant au groupe de professionnels de la santé, il était composé de trois médecins, de sept infirmières, de trois intervenants en soins spirituels et de trois travailleurs sociaux. Les participants ont été recrutés auprès d'organismes communautaires et d'associations de personnes malades de Québec comme la Fondation québécoise du cancer ou la Fondation canadienne de la fibrose kystique. Les professionnels de la santé ont été recrutés à travers le Réseau de soins palliatifs du Québec via le Bulletin de l'association.

Les données ont été recueillies sous la forme d'entrevues individuelles non structurées et d'entrevues collectives semi-structurées. Les premières ont été conduites auprès des personnes atteintes de maladies graves. Les échanges portaient sur leur expérience, notamment sur l'histoire et l'expérience de la maladie, et leur souffrance, etc. Dans ces entretiens, nous leur demandions simplement de nous raconter cette expérience et de nous livrer des contenus relatifs à leur souffrance. Quant aux entrevues collectives, elles étaient conduites avec les professionnels de la santé invités à échanger sur leur expérience en tant que témoins de la souffrance d'autrui. Cette forme d'entretien avait été choisie pour permettre aux professionnels de partager leurs pratiques de terrain et de faire émerger collectivement une lecture de la souffrance en fonction d'expériences d'accompagnement vécues. Durant ces entretiens, nous leur demandions d'aborder les manifestations de la souffrance, ses causes, sa progression durant les épisodes de maladie et les interventions professionnelles qui lui étaient adressées.

Tous nos échanges ont été enregistrés et ont été retranscrits sous la forme de verbatim. L'analyse thématique de leur contenu a été faite à l'aide du logiciel N'Vivo 8. Cette analyse consistait à identifier des thèmes et des sous-thèmes récurrents au-delà de la singularité des expériences, à les repérer sous forme de catégories et de sous-catégories de sens pour les interpréter ensuite. Dans ce texte, nous présentons les catégories et les sous-catégories les plus évoquées par la plupart des participants à nos enquêtes sans nuancer nos résultats en fonction de leur âge, de leur sexe ou d'autres variables. De là, nous proposons de comprendre la souffrance sous la forme d'un processus marqué par des situations de crise et par un hyper-questionnement qui sont, tous les deux, inter-reliés.

Résultats

L'analyse des résultats obtenus dans le cadre des entretiens nous ont conduits à deux grandes thématiques sous lesquelles se retrouvent un certain nombre d'énoncés relatifs à l'expérience et à l'expression de la souffrance. La première thématique renvoie à une situation de crise et de bouleversements. Elle se décline en divers effets que provoquent les maladies graves dans l'existence et en un ensemble d'aspects de la vie qui étaient jusque-là inconnus et inattendus. La seconde thématique est intrinsèque de la première et regroupe des énoncés qui font voir un questionnement excessif qui porte sur plusieurs dimensions de l'existence.

L'annonce et le développement de la maladie : situation de crise dans l'existence

Tout d'abord, rappelons que l'annonce du diagnostic d'une maladie à caractère potentiellement mortel induit une situation de crise, vécue sous la forme d'une rupture brutale avec le cours des choses jusque-là connues, prévues et anticipées. Soudainement et avec brutalité, la maladie impose un nouvel ordre de réalité à la personne qu'elle affecte. La vie vient en quelque sorte de basculer, dans le sens où la maladie et ce qui l'accompagne dominent la scène et deviennent les mots-clefs qui dictent les scénarios de la vie quotidienne. Parfois, il se peut même que toute l'existence se réduise à la maladie. Les propos suivants obtenus dans le cadre de l'étude l'indiquent très bien:

> Tu t'aperçois que ta vie, c'est la maladie. […] J'avais l'impression que ma vie tournait autour de la maladie. […] Je ne serais plus jamais comme avant. […] Il y a quelque temps, j'ai pris conscience qu'il m'est possible d'être en forme, mais je n'aurai jamais la santé. Cette prise de conscience a été un choc, parce qu'être greffé, c'est avoir une vie médicalisée. (Femme, 35 ans, maladie congénitale; greffe du coeur)
>
> Les maladies graves, […] même quand tu guéris, ça demeure en toi pour la vie. Ça reste dans le plus profond de ton être. Tu n'as plus la même façon d'aborder la vie, d'aborder toutes les situations qui te sont données. […] On est marqué au fer rouge, ça reste tout le temps. (Homme, 57 ans, maladie congénitale rare; greffe cœur et foie)

Dans tous les cas, l'ordre de réalité dans lequel les participants sont plongés ne va pas de soi, puisque l'ordre qui dominait jusque-là était celui qui organise la vie de bien-portants. Tout reste donc à découvrir et cette découverte se déploie sous le signe de la perte et de l'épreuve à l'endroit de ce qui s'impose comme nouveau et d'indésirable. Les participants nous l'ont partagé en abordant notamment les sujets des relations qu'ils entretenaient avec les autres, des activités de la vie quotidienne, de leur corps, et de leur horizon temporel.

•Le sujet des relations aux autres

Les énoncés des répondants nous renvoient à des changements dans la forme et la qualité des relations qu'ils entretenaient avec les autres. À ce titre, certains soulignaient davantage des éloignements ou la perte d'amis en raison de la maladie :

> Il existe des gens qui ont peur de la maladie, d'autres perdent des amis parce… qu'ils ont peur de la maladie ou parce qu'ils sont mal à l'aise et qu'ils ne sont plus capables de nous voir ainsi, car ils affirment, que c'est douloureux de nous voir dans cet état. Les malades le sentent. Les malades affirment qu'ils perdent des amis parce qu'ils ne sont plus en mesure de leur parler… de plus certains affirment qu'il est drôle de réaliser que ceux qui ont gardé contact ne sont pas ceux que j'aurais pensé. Les plus proches sont partis parce qu'ils ont plus de difficulté à vivre ça. (entrevue de groupe infirmières cadre)
>
> Lorsque tu as un cancer… C'est le monde qui te fuit, parce qu'ils ont l'impression que tu es contagieuse. […] C'est sûr que certains vont s'éloigner parce qu'ils ne pourront plus te voir ou diront, je ne suis plus capable de la voir depuis qu'elle a le cancer, de plus je sais qu'elle va mourir. (entrevue individuelle. Femme, 52 ans, cancer avec métastases au foie)
>
> Tu n'oses pas le dire parce que le monde te fuit. Les personnes, quand elles savent que tu as un cancer, elles ne veulent pas te rencontrer. […] Elles ne te posent pas de questions, elles ne veulent pas que tu en parles, elles ont peur. On est leur miroir. C'est compromettant de t'intéresser à cette personne-là, tu as pas d'espace pour parler de ce que tu es en train de vivre. (entrevue de groupe agents de pastorale)

D'autres répondants rapportaient leur inquiétude en regard d'une relation avec leurs enfants qui allait prendre fin à la suite de leur décès. Les propos suivants illustrent bien cet aspect:

> Je pensais à mes enfants, parce que je les laissais, je les abandonnais. …Je suis préoccupée pour mes enfants. Je me demande s'ils pourraient avoir besoin de moi après la mort. […] Mon fils pourrait avoir besoin de se confier sur ce qu'il vit. Ma fille est souvent malade, elle a une santé frêle. […]Plus ça avance, plus ça me fait penser, plus j'ai mal de laisser la terre, de laisser mes enfants. (entrevue individuelle. Femme, 53 ans, cancer du sein avec métastases aux poumons)
>
> Quand ils me l'ont annoncé, c'est ça qui est venu me chercher. J'ai dit « je verrai jamais mes enfants plus

> vieux, je n'aurais pas le temps de connaître tous mes petits-enfants ». Ça c'est une douleur intérieure qui va te chercher. Moi, c'est ça qui vient me chercher le plus,…c'est de laisser mes enfants et mes petits-enfants. (Femme, 52 ans, cancer avec métastases au foie)

En bref, ces verbatim rendent compte d'un renouveau relationnel obligé auquel doivent faire face les personnes atteintes de maladies graves.

•Changements dans les activités de la vie quotidienne

Au même titre que les relations, ce qui ne posait vraisemblablement aucune inquiétude dans la vie quotidienne avant la maladie est devenu un enjeu de taille. L'inscription de la personne dans le quotidien est tout autant marquée par de la nouveauté. Elle prend des formes jusque-là méconnues. Par exemple, certains gestes essentiels disparaissent et imposent de fait une certaine composition pour pouvoir suivre le cours de la vie. De la même manière, la durée et les formes dans lesquelles se réalisent les gestes ne sont plus les mêmes. Sur ce point, les répondants soulignaient différentes situations:

> J'allais au centre d'achat et je n'étais pas capable de marcher longtemps, j'étais fatiguée, j'étais toujours fatiguée. Je disais à mon conjoint « va dans un autre magasin, je vais m'asseoir ici, je vais prendre un café ». Je m'assoyais puis je repartais et je faisais un autre bout. (Femme, 62 ans, sclérose en plaques)

> Avant, je faisais le ménage de l'appartement, en deux heures. Sans problème, était correcte pour la semaine, tout est correct. Maintenant, pour cinq pièces, je fais le ménage en sept jours. Je fais une pièce par jour, puis le lavage dans une journée. (Femme, 37 ans, sclérose en plaques)

> Il y a un deuil, une rupture à faire. C'est de quitter ses habitudes de vie, qui peut être de quitter un travail professionnel, de quitter les siens, de quitter la vie, même, tu sais. (entrevue de groupe agents de pastorale)

Comme le précise bien un agent de pastorale dans l'extrait précédent, les changements dans le déroulement de la vie quotidienne obligent à des deuils. Les deuils sont à comprendre ici comme des pertes qui donnent lieu à de nouvelles manières d'entreprendre les actes du quotidien au gré de la maladie, de son évolution et de ce qui l'accompagne sur le plan physique.

•Des nouveautés et des imprévus dans la manière de faire usage de son corps, de le considérer, de l'habiter, de l'apprécier

Le sujet du corps était encore significatif chez les répondants quand il s'agissait d'échanger sur la souffrance. Ce sujet n'était pas spécifiquement abordé pour partager les effets somatiques de la maladie. C'est plutôt sous l'angle des capacités du corps, de son usage et tout particulièrement sous l'angle de l'image qu'on en a et que les autres s'en font que le corps est apparu dans les discussions. Les propos suivants nous donnent un bon aperçu de ces préoccupations à l'endroit des usages du corps et de son image:

> Des sports physiques, qui demandent des efforts, j'ai de la difficulté. […] Je suis capable de rien faire côté sportif, c'est très, très difficile pour moi. Je n'aime pas me sentir inférieure, dans le sport, dans n'importe quoi. […] C'est peut-être pour ça que je ne sors pas, je fais rien… tant qu'à aller me faire mal, je n'y vais pas. (Femme, 62 ans, sclérose en plaques)

> Je me reconnaissais plus. Mentalement, physiquement, je me reconnaissais plus du tout. Tu te regardes puis tu as la face large comme ça, j'aimais plus la vie. […] Le soir, je me couchais et je pleurais tous les soirs. C'était dur. […] J'étais gênée parce que… moi, j'étais une fille qui avait fait attention à moi toute ma vie, puis là, je me ramassais avec 25 livres … On aurait dit que je venais d'accoucher. J'avais une bedaine. (Femme, 35 ans, maladie congénitale; greffe du coeur)

> Je me rappelle quelqu'un qui nous avait demandé d'enlever de sa chambre tous les miroirs parce qu'il était devenu incapable de voir son corps dans l'état où il était. (entrevue de groupe agents de pastorale)

> Avec la chimio, je suis devenu chauve et imberbe. Ça a été quelque chose. […] Je trouvais que je ressemblais à un martien, il ne me manquait plus qu'une paire d'antennes. […] J'avais les cheveux longs. […] Des beaux cheveux naturels, pas colorés, rien. C'est ce que j'avais de plus beau, mes cheveux. (Femme, 46 ans, cancer d'origine X; métastases au foie et aux os)

•Transformations sur l'horizon temporel

Enfin, un dernier thème tout aussi important dans les entretiens renvoie à des bouleversements provoqués sur la ligne du temps où chacun situe des perspectives de vie et des projets. À ce titre, plusieurs répondants nous l'ont indiqué :

> Quand je travaillais comme fleuriste, au début, ça allait bien, car j'étais capable de travailler 40 heures par semaine. Mais après, c'était quand même bon. Finalement, mon neurologue m'a diminué à une trentaine d'heures par semaine puis les derniers mois, je faisais 20 heures par semaine. J'ai vraiment beaucoup diminué … ce n'est pas évident parce que

> c'est un métier que j'aimais beaucoup. […] C'est vraiment un gros deuil encore. (Femme, 37 ans, sclérose en plaques)

> Souvent, à cause de la maladie, leur rôle change, leur rôle social peut changer. […] De quitter leur emploi parce qu'ils sont obligés de s'ajuster à beaucoup de choses, car à un moment donné, la reconnaissance du titre personnel, c'est ton emploi, lorsque tu le perds et que tu es malade, ça devient difficile à vivre. (entrevue de groupe infirmières cadres)

Mais en plus, des projets et un avenir qui leur paraissait certains sont devenus flous ou se sont carrément effacés. Ces « à venir » concernaient des projets professionnels, des étapes de vie clairement indiquées (le moment de la mort y compris), des projets de couple ou simplement des voyages et des loisirs qui agrémentent la vie. Les répondants l'exprimaient très bien dans les extraits de verbatim qui suivent :

> Quand on travaille, on se dit je vais pouvoir arrêter à tel âge, on pense à notre retraite, mais moi, c'était pas prévu que je prendrais une retraite forcée à 50 ans. (Femme, 54 ans, sclérose en plaques)

> Je prive ma femme de tout. […] On avait l'habitude de voyager, on voyage plus. Ça fait 5 ans qu'on sort plus à cause de ça. […] Le pire, c'est de faire perdre la vie aux autres. Elle a sa vie, elle pourrait voyager. […] Elle ne veut pas. Ça serait bon qu'elle se change les idées pendant qu'elle est capable. … c'est là qu'est mon gros problème. Ce n'est pas… évident du tout. (Homme, 77 ans, sclérose latérale amyotrophique)

> Est-ce que ça va être demain, c'est ça le facteur temps. […] Si tu me disais, dans 10 ans, tu vas mourir, je dirai, j'ai le temps de faire plein de choses. […] Voir vieillir mes enfants puis mes petits-enfants. […] Si ça arrive, ça arrivera. On n'a pas de temps. C'est le temps qu'on n'a pas, c'est ça la souffrance, une partie de la souffrance. […] La souffrance intérieure. […] Tu ne peux pas prévoir l'avenir. (Femme, 52 ans, cancer avec métastases au foie)

La maladie évoque ainsi une méconnaissance et une incertitude suite à la perte de ses repères habituels. Elle signifie également d'être dans l'attente, comme si la vie s'arrêtait. La personne ne s'inscrit plus dans son monde habituel et se retrouve, en quelque sorte, privée de son inscription sociale usuelle. L'annonce de la maladie, c'est parfois aussi devoir vivre l'hospitalisation ce qui a pour conséquence d'être retiré de son lieu habituel. La personne doit se plier à la logique du système de soins comme, par exemple, vivre l'hospitalisation ou se présenter quotidiennement à des traitements et abandonner ainsi toutes ou quelques-unes de ses activités quotidiennes.

Les pertes, les chamboulements et les transformations dans la réalité des personnes atteintes de maladies graves ont été inévitablement accompagnés de manifestations psychologiques et émotionnelles. Passer du monde des bien-portants à celui des personnes malades, faire les frais des changements illustrés plus haut rebondit chez la plupart sous la forme de pleurs, de peurs, d'anxiétés ou d'autres manifestations du même genre. Toute une gamme d'émotions ou de réactions allant de l'état de choc, du comportement de fuite, de l'insécurité, de l'incapacité de penser, jusqu'à l'impossibilité de croire ce qui arrive accompagne ainsi le moment de crise. La brutalité de la rupture est viscéralement ressentie. Les expressions suivantes livrées par les répondants témoignent très bien de la brutalité de l'événement : «coup de masse» (Homme, 69 ans, cancer du poumon), «marquée au fer rouge» (Homme, 57 ans, maladie congénitale rare; greffe cœur et foie), «coup de poignard» (Femme, 52 ans, cancer avec métastases au foie), «virée à l'envers» (Femme, 54 ans, sclérose en plaques).

La spirale du questionnement ou l'hyper-questionnement

Ce passage et ce plongeon dans une réalité pleine de nouveautés provoquent encore un questionnement intense. Cette fois, la maladie invite à porter un jugement sur ce qui se présente dorénavant. Des entretiens réalisés, on constate que les personnes atteintes de maladies graves sont confrontées à un questionnement tout azimut. Ce questionnement est d'ailleurs un élément clef de la souffrance éprouvée, tout particulièrement quand la personne qui questionne et veut savoir ne reçoit pas forcément de réponses certaines.

On constate effectivement un hyper-questionnement dans l'histoire des participants comme si la crise déclenchait une quête excessive de réponses afin de trouver du sens, de comprendre, d'organiser ou de réorganiser la logique de la vie. Surgissent ainsi de nombreuses questions au sujet de réalités existentielles rarement interrogées jusque-là. Cet aspect est largement constaté par les professionnels quand ils énoncent que les personnes atteintes de maladies graves sont confrontées à un non-sens ou à une perte de sens. Entendons ici qu'il s'agit d'une absence de réponses significatives comme en témoignent les propos suivants :

> La souffrance existentielle, je la vois de façon plus spécifique quand la personne est en fin de vie ou elle n'a plus de sens à sa fin de vie. […] Peut-être qu'il y a des souffrances autres, mais on dirait que la souffrance existentielle est plus forte que toute, quand il n'y a plus rien qui a de sens. (entrevue de groupe avec agents de pastorale)

> Peut-être que la souffrance existentielle, c'est quand la personne ne trouve plus de sens à ce qui lui arrive, ou à ce qui lui est arrivé, ou à ce qui va lui arriver.

> (entrevue de groupe médecins)
>
> Je pense que les personnes en fin de vie sont face à l'inconnu, sont face au questionnement. […] plus les gens prennent conscience que la fin approche plus les gens approchent des questions vraiment profondes et comme, par exemple, les regrets, les choses qu'ils auraient voulu faire, le sens de la vie […]ils ont beaucoup de questions, qu'est-ce que je vais devenir, pourquoi j'ai existé sur la terre, quel a été le sens de ma vie. (entrevue de groupe travailleurs sociaux)
>
> Il y a la question existentielle. Quand ils commencent à poser beaucoup de questions. Pourquoi moi? […] Ils font beaucoup de remise en question, tout le temps. […] Tout le long du trajet, du début à la fin. (entrevue de groupe infirmières cadres)

Pour mieux nous en rendre compte et le dire dans les termes des répondants la part de cet hyper-questionnement dans leur épisode de maladie, voyons sur quoi portaient leurs questions et comment elles étaient éprouvées.

•Les causes de la maladie et pourquoi moi ?

Un des questionnements portait sur la maladie en tant qu'événement qui survient dans une histoire de vie. Son apparition requiert une explication ou une recherche de significations où se discutent la cause du mal et la part de responsabilité de celui qui en fait les frais. Les réponses données sont évidemment propres à chacun. Mais au-delà des réponses (satisfaisantes ou non pour la personne comme pour les soignants), les questions sont récurrentes et lourdes de conséquences. Elles véhiculent tantôt une part de responsabilité, tantôt une forme d'accusation de soi, un constat d'injustice ou de mérite comme le soulignent les extraits suivants :

> Je ne trouvais pas ça juste. […] J'ai toujours fait du sport, de l'entraînement, je m'entraînais beaucoup. Je mangeais bien, je n'ai jamais fumé, je n'ai jamais fait d'excès. Il est donc certain que tu te demandes : pourquoi moi? J'ai tout fait pour être correcte, pour être en santé. […] Le monde qui est malade et qui peut faire quelque chose pour changer, le monde qui mange mal, qui a des problèmes de cholestérol et qui veut pas arrêter, je ne comprends pas ça. (Femme, 35 ans, maladie congénitale; greffe du coeur)
>
> Souvent, les gens pensent qu'ils ont le cancer parce qu'ils se sont mal alimentés ou qu'ils n'ont pas fait telle chose, ou qu'ils ont fait telle chose. Ça occasionne beaucoup de détresse ... . (entrevue de groupe infirmières cadres)
>
> Des gens qui sont très âgés et qui disent, je suis trop jeune, j'avais encore plein de projets, il existe une espèce de détresse par rapport à l'impression de vivre une injustice,… c'est souvent mentionné par les patients, parfois aussi par les familles. Il y a toute la notion d'injustice car il ne méritait pas ce qui lui arrive. (entrevue de groupe médecins)

•Questionner l'évolution de la maladie et le mourir

Le questionnement porte aussi sur la finitude et la fin de la vie qui apparaissent le plus souvent éloignées des préoccupations quotidiennes des bien-portants. Cette fois, c'est la progression de la maladie, ses effets redoutés, la forme qu'elle va donner au quotidien et la manière dont la fin de la vie va se présenter, et quand elle va se présenter, qui font office de questionnements et de préoccupations. Des questions se posent à nouveau sans qu'on puisse véritablement anticiper justement ce qui va véritablement advenir. Les propos suivants illustrent, par exemple, un questionnement sur l'évolution de la maladie et ce qu'elle peut faire de la personne malade :

> Quand t'apprends […] que tu as quelque chose, tu te dis, il m'en reste pour comment de temps et que va-t-il m'arriver? De plus, ils ne disent rien parce que c'est une maladie… qui n'a jamais été diagnostiquée, cette malformation. Le temps que ça se passe, tu digères le tout et pendant quelques mois on se demande qu'est-ce qu'on… on a peur. (Homme, 57 ans, maladie congénitale rare; greffe cœur et foie)
>
> La sclérose en plaques, on ne sait jamais où on est touché et la prochaine poussée se présentera dans comment de temps […] Tu entres et tu vois plein de chaises roulantes en ligne, à l'entrée. Tu viens le cœur… le cœur te fait mal, et on a toutes la même réaction parce que… peut-être qu'un jour je vais être rendue à la chaise roulante. (Femme, 54 ans, sclérose en plaques)

Enfin, des énoncés évoquent clairement des interrogations à l'endroit de la mort dont ils se prêtaient parfois à imaginer la plus funeste des issues :

> Tu vis une insécurité tout le temps. […] Il me reste combien de temps? Est-ce que ça va être demain, c'est ça le facteur temps. […] Si tu me disais, dans 10 ans, tu vas mourir, je dirai, j'ai le temps de faire plein de choses. […] Voir vieillir mes enfants puis mes petits-enfants. […] Si ça arrive, ça arrivera. On n'a pas de temps. C'est le temps qu'on n'a pas, c'est ça la souffrance, une partie de la souffrance. […]. La souffrance intérieure. […] Tu ne peux pas prévoir l'avenir. (Femme, 52 ans, cancer avec métastases au foie)
>
> Ma peur, c'est que ça dure trop longtemps. Quelques-uns supposément qui se sont rendus à 10 ans, j'ai dit au médecin il me reste encore 3 ans. Il me reste encore 2 ans… dans 2 ans, je vais être là ? (Homme, 77 ans, sclérose latérale amyotrophique)
>
> Donc, je trouve que les souffrances sont davantage de l'ordre d'un sens, d'inquiétude, de peur aussi, …

> la peur d'être… de mourir seul, la peur de mourir souffrant, la peur de mourir étouffé. (entrevue de groupe infirmières de chevet)

•Des décisions à prendre

Les décisions concernent notamment l'hospitalisation, les traitements ou la gestion d'affaires qu'il faut régler du temps de son vivant. Les extraits suivants nous donnent à ce sujet quelques exemples :

> Ils pensent beaucoup à […] répartir leurs biens à chaque enfant, ça leur occasionne beaucoup de soucis … quand ils entrent en hébergement, ils commencent déjà à penser à ça. Leur testament et si tout sera bien équilibré … ça leur cause de la souffrance parce qu'ils se demandent tout le temps s'ils en ont laissé assez à un, puis l'autre. (entrevue de groupe infirmières cadre)

> Dans les souffrances, moi, j'inclurais les décisions à prendre […] Ils se font encore offrir de la chimio et qu'est-ce que je fais avec ça? Est-ce que je manque de courage? Ou si je dis non, est-ce que je prive les miens de bons moments avec moi? Mais en même temps, je n'en veux plus, je suis brûlé, je suis empoisonné. D'avoir à porter la décision de cesser ou de ne pas initier de la chimio, c'est une souffrance […]. (groupe de discussion des agents de pastorale)

Ces questions illustrent bien comment souffrir s'arriment avec des incertitudes, des quêtes de certitudes et des incompréhensions. Dans une recherche de significations et d'informations, les personnes atteintes de maladies graves sont prises dans une quête d'intelligibilité en regard de la maladie et ce dans quoi elle les plonge. Elles ont en quelque sorte à rendre clair et compréhensible cet événement dont elles ne soupçonnaient en rien le vécu et la réalité pratique.

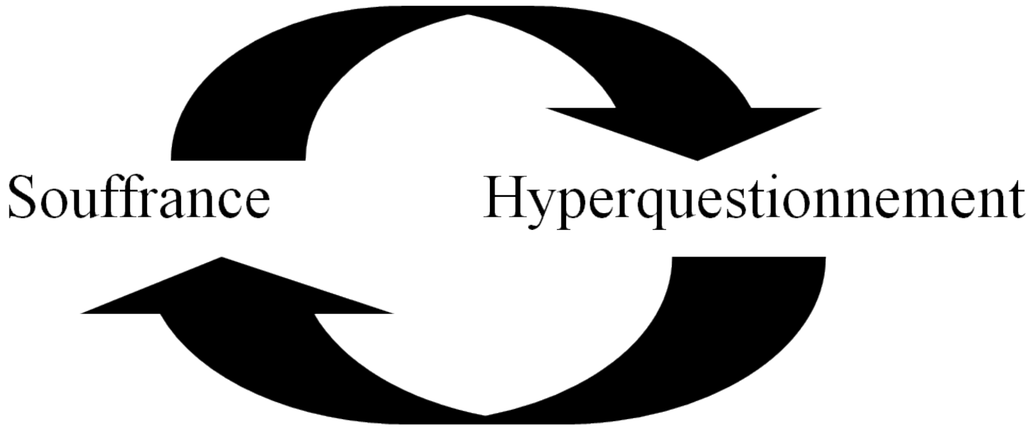
Discussion

Les résultats de cette étude nous conduisent d'abord à penser la souffrance à partir de cette idée de crise induite par des changements brutaux occasionnés par la maladie à l'endroit du corps, de ses usages et de son appréciation, à l'endroit des relations aux autres et des projections de soi dans le temps. Cassell a bien évoqué que la plus grande souffrance est associée aux événements qui menacent l'intégrité d'une personne.[17 p31] Boston et al.[18] qui ont conduit une revue de littérature sur le thème de la souffrance existentielle, à partir de 156 articles, retrace cette notion de crise, particulièrement en évoquant la perte de sens. La crise renvoie bien ici au mot grec Krisis qui signifie un moment charnière où l'on doit prendre une décision et trancher. En d'autres mots, la crise est une fracture de vie où les repères habituels disparaissent. L'idée du moment charnière indique un mouvement de bascule. La bascule se fait d'un ordre de réalité vers un autre ordre de réalité, une fois que la maladie est installée et que ses effets sont ressentis. C'est pourquoi la crise est un moment de décalage par rapport à une réalité habituellement éprouvée et par rapport à une manière d'habiter cette réalité qui est devenue au fil du temps un schème d'existence pratique et un cadre de significations. Ce cadre et ce schème volent alors « en éclat », conduisant inévitablement à une méconnaissance et incompréhension de ce qui s'installe dorénavant. Même s'il s'agit d'un contexte quelque peu différent, cette idée rejoint bien les résultats d'une recherche conduite auprès de patients ayant subi une chirurgie cardiaque. En effet, les répondants expriment leur souffrance à travers la tristesse de ne plus former un «tout intégré».[19 p536] D'autres évoquent l'idée d'une «déconnection de soi».[20 p381]

Cette idée rejoint bien celle de Kierkegaard dans son Traité du désespoir[21] lorsqu'il indique que la souffrance découle de l'écart à soi, qu'il s'agit de souffrir de ne pas être moi. Le symptôme de ce décalage à soi est le désespoir. L'homme ne possède pas la possibilité de s'identifier à lui-même, donc il souffre, et il en est désespéré. Si le moi souffre ainsi, c'est qu'il n'arrive pas à faire un avec son soi. Essentiellement, il se situe dans un entre-deux : « L'homme est une synthèse d'infini et de fini, de temporel et d'éternel, de liberté et de nécessité, bref une synthèse. Une synthèse est le rapport de deux termes. De ce point de vue, le moi n'existe pas encore ».[21 p75] Cette discordance à soi dont le moi souffre prend forme dans le désespoir. L'écart à soi qui cause le désespoir est en même temps la cause de la souffrance.

S'appuyant sur Kierkegaard, Ginvert explique encore que : « La souffrance est l'intimité du moi, déchiré d'avec soi ».[22] Elle correspond à cette idée de dissolution du vivant que l'on retrouve chez Prost.[23] Ainsi, on comprend mieux les enjeux auxquels sont confrontées les personnes gravement malades et la quête dans laquelle elles se trouvent. La mise en suspension de la vie telle qu'elle se déroulait et de tous les allants-de-soi pratiques et théoriques qui l'accompagnaient, les conduit vers le projet d'être à nouveau et de se débarrasser du fardeau de ne pas être pour reprendre ici les termes de Tillich.[9] En d'autres mots, il est question de reprendre le cours de la vie avec une certaine maîtrise et surtout de s'y repérer pour s'y inscrire à nouveau.

Présenté comme un second aspect de la souffrance largement évoqué dans les entretiens, l'hyper-questionnement annonce en quelque sorte cette recherche de repères et de significations. Cette caractéristique a aussi été évoquée dans la littérature du domaine de la santé. Par exemple, Mount,



en faisant référence à la spiritualité, évoque la question suivante : «Est-ce que ma vie a un sens et un but?».[24 p41] C'est bien ce qu'évoque Ricoeur quand il écrit que «la souffrance interroge» à la recherche de sens.[3 p67]

L'hyperquestionnement témoigne bien de l'importance de s'inscrire dans une forme d'agir à travers les questions qui portent sur l'administration et la gestion de ses affaires, et de ces biens par exemple. Il rend bien compte d'un intérêt exacerbé de connaître l'événement (questions sur les raisons d'être de la maladie), d'identifier des panneaux indicateurs qui se trouvent sur le chemin emprunté (question sur l'évolution de la maladie) et de juger des formes possibles de cheminement (questions sur l'espérance de vie et la fin de vie). En d'autres mots, l'hyper-questionnement est une manière de se familiariser avec une incontournable réalité, de s'y retrouver et d'y jouer à nouveau un rôle. C'est certainement pour cette raison que des professionnels de la santé nous ont indiqué que les personnes atteintes de maladies graves semblaient vivre une souffrance plus forte en début d'épisode de maladie grave, et qu'elles semblaient moins souffrantes aux moments d'une mort proche :

> … Pour l'avoir vécu dans ma famille, toute la période de la chimiothérapie, de la radiothérapie, est-ce qu'on en prend, est-ce qu'on n'en prend pas, en plus les effets secondaires, c'est atroce. On dirait que vers la fin, il existe une espèce de résignation qui s'empare des gens. […] Plus la fin de vie approche, souvent, la souffrance, en quelque sorte, s'atténue, il y a un lâcher-prise. (entrevue de groupe agents de pastorale)
>
> Habituellement, les premières étapes sont plus difficiles que la fin. C'est paradoxal, mais… même avec cette détérioration physique, on dirait qu'il s'installe une paix. (entrevue de groupe infirmières)

Finalement, l'hyper-questionnement ne serait plus d'actualité quand la réalité est devenue suffisamment familière au cours du temps. L'expérience de la souffrance se déploie alors dans le passage obligé entre deux univers, qui envenime l'existence.

Conclusion

Sans avoir suivi et analysé l'entièreté d'une expérience de maladie qui se vit dans la durée pour apprécier pleinement le vécu d'une souffrance, notre recherche compréhensive nous a quand même permis d'identifier des éléments clefs et récurrents qui caractérise la souffrance. Nous avons appris que la souffrance des personnes atteintes de maladies graves ne se confondait pas forcément avec ses sources (pertes et changements psychosociaux par exemple), avec les thèmes des questionnements (philosophiques, spirituels et religieux), et ne se confondait pas non plus avec ses expressions morales et émotionnelles. La souffrance est plutôt comprise comme un passage qu'il faut traverser, comme une quête de connaissances et comme une réalité à habiter et à rendre familière. De fait, la souffrance n'est pas forcément négative en soi.

Une pathologisation de la souffrance semble alors ne pas convenir, tout comme les interventions qui visent à la prévenir ou à s'y adresser de front. D'ailleurs les professionnels interrogés dans notre recherche nous ont bien indiqué à propos des interventions, qu'il s'agissait simplement de prendre le temps de fournir des informations et d'être francs, d'être suffisamment présents pour créer une relation où l'on peut être à l'écoute et être attentif à la quête qui se présente, ou de fournir encore à des personnes des lieux d'expression artistique capable d'asseoir cette quête. En d'autres termes, penser la souffrance dans les termes de ce texte consiste avant tout à accompagner un cheminement avec une certaine humilité et avec le sentiment que la souffrance ne se prête à aucune maîtrise. Elle ne se prête donc pas du tout à des formes de catégorisation objective. Elle relève constamment d'une incertitude dans la manière dont une personne chemine pour sortir d'un moment où il n'est plus, et habiter de nouveau le monde de la vie : en étant cette fois gravement malade.

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