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Éditorial/Editorial

In 1998, the Supreme Court of Canada ruled in *R. v. Cuerrier* that a person living with HIV must disclosure his/her HIV-positive status in situations where there is what the court called a "significant risk" for HIV transmission. Problematically, the threshold of "significant risk"—i.e., the measure of sexual or other practices that were deemed "significantly risky"— was never clarified in the *Cuerrier* ruling. This left the subsequent and often varying interpretation of this legal precedent to trial judges across the country. On the whole, the outcome of these ensuing criminal proceedings was a relatively stable legal interpretation which appeared to suggest that either proper condom use or an undetectable HIV viral load, which is a serological measure of the number of copies of HIV in a person's blood, would sufficiently negate the possibility of HIV transmission to such a degree that, from a legal perspective, the potential for transmission was below the threshold of "significant risk". In such cases, a person was therefore not criminally obliged to disclose his/her HIV-positive status before sexual activity.

Fourteen years later, the Supreme Court examined two subsequent cases on HIV-positive status nondisclosure (*R. v. Mabior* and *R. v. D.C.*), thus offering the criminal justice system an opportunity to clarify ambiguous case law. On Friday, October 5th, 2012, the Supreme Court of Canada released its updated ruling about HIV-status disclosure, and identified that a person does not need to disclose his or her HIV-positive status provided that he/she uses condoms and has what the court called a "low", not "undetectable", viral load. In all other situations, HIV-positive status nondisclosure constitutes a criminal offence.

At first glance, this ruling appears to amend previous flaws in the *R. v. Cuerrier* decision. There is now greater clarity about the "significant risk" threshold: Anything less than both condom use and a low viral load is above this legal measure, and thereby warrants criminal repercussions Upon further inspection, however, it is evident that the *Mabior* decision is actually more severe than the previous *Cuerrier* ruling. While trial judges had previously accepted that condom use OR an undetectable viral load—defined by the Supreme Court as an HIV viral load that is less than 50 copies per milliliter of blood—would push the potential of HIV transmission during sexual contact below the "significant risk" threshold, now a person living with HIV must both use condoms AND have a "low viral load" for a sexual contact not to pose a "significant risk" for HIV transmission. Setting aside the legal issues that relate to this ruling, such as, what evidence is required to demonstrate a "low viral load", which was defined as fewer than 1500 copies per millilitre, further examination of this precedent uncovers some potential complications for public health, HIV prevention, and the provision of care for persons living with HIV.

For one, this ruling ignored the extant empirical evidence which suggests that nondisclosure prosecutions could negatively affect both public health HIV prevention efforts and clinical care for people living with HIV. More specifically, the *R. v. Mabior* ruling rejected the research findings which suggested (a) that the ambiguity of the criminal law has caused nurses and other health professionals to negate decades of scientific literature about the differing degrees of probability for HIV prevention and instead classify all possibilities of HIV transmission as identical (e.g., Myhkalovskiy and colleagues); (b) that some persons living with HIV feel unsafe speaking candidly with health professionals, and, consequently, are unable to seek help for HIV-related problems, including symptom management and safer sex practices (e.g., O'Byrne and colleagues); (c) that nondisclosure prosecutions permit persons who believe they are HIV-negative to blame others for HIV transmission, and, accordingly, shirk any sense of personal responsibility regarding HIV acquisition (e.g., Dodds and colleagues); and (d) that disclosing one's HIV-positive status involves psychosocial costs, such as, potential rejection, violence, depreciation, or hostility (e.g., Adam and colleagues).

From a health care perspective, another issue with the *R. v. Mabior* decision is that it does not promote, or at least afford any protection to, HIV prevention work in clinical practice. Indeed, while, on the one hand, the decision accepted a "low viral load" and condoms as the conditions of a valid defence against nondisclosure prosecutions, on the other hand, it failed to include any protection of the information that patients reveal to their health professionals on either of these matters. In other words, the court did not offer any protection to persons who openly and honestly discusses issues, concerns, or problems they might be having with condom use and/or with HIV medications. It is, therefore, possible that anything a person living with HIV says to his or her health professional could be used as evidence against him or her in the criminal justice system if this person living with HIV were to be prosecuted for HIV-positive status nondisclosure. Problematically for both persons living with HIV and overall HIV prevention efforts, people's potential reticence to raise their concerns about condoms or medication use with nurses or other health professionals constitutes a disconcerting barrier to clinical care for persons living with HIV, and a potential hurdle for effective HIV prevention work.

Lastly, the *R. v. Mabior* decision relied on a Cochrane Library systematic review about the effectiveness of condoms to reduce HIV transmission, which suggested that condoms reduce

HIV transmission by 80%. While one could uncritically accept the findings of this review, assuming falsely that the Cochrane Library suggests proper rigour, understanding, or valid outcomes, a review of this Cochrane document uncovered a series of major errors in the authors' understanding of HIV transmission. In fact, it was quite clear that, while the authors understood the principles of a systematic review, they did not have a solid appreciation of the dynamics and mechanisms of HIV transmission. For example, confounding factors that would affect HIV transmission—such as, circumcision, the presence of secondary sexually transmitted infections (STIs), spermicide use, and the occurrence of other types of sexual contact without condoms (e.g., oral and/or anal sex)—were simply listed as "notes" in the review document. Notwithstanding the fact that each of the foregoing factors has been established in the literature to independently correspond with an increased probability of HIV transmission, for some unstated reason, the authors of this Cochrane review did not consider these items in their analysis or conclusions. Instead, without acknowledging the variability that the aforementioned items induce in HIV transmission, they stated that condoms are 80% effective. While this oversight should render the findings of this Cochrane review invalid, this methodologically proper, but content deficient, document was nevertheless used to guide the *R. v. Mabior* decision.

In closing, the recent Canadian legal decision on HIV-positive status disclosure, which could have both greatly clarified the law and aligned more precisely with the extant scientific literature about HIV prevention and HIV transmission, has left persons living with HIV and health professionals with no more guidance than they had with the previous *R. v. Cuerrier* decision. Furthermore, the Supreme Court of Canada accepted the current practice of using patients' health records against them in nondisclosure prosecutions, which could undermine the abilities of health professionals to provide appropriate care and undertake person-specific HIV prevention initiatives for persons living with HIV. Based on such a conclusion by the court system, should Canadian health professionals introduce themselves in a fashion similar to police? Should they inform patients that anything they do or say in the presence of health professionals, could potentially be used against them in a court of law in the future? If this is the case, did the Supreme Court of Canada just formally and publicly acknowledge that health professionals are, as Foucault argued, agents of the state who not only provide health care services, but also discipline bodies and exact compliance and adherence? If this is the case, then the "care" in health care has yet again been further compromised.

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Abstract
Internet research methods in nursing science are less developed than in other sciences. We choose to present an approach to conducting nursing research on an internet-based forum. This paper presents LiLEDDA, a six-step forum-based netnographic research method for nursing science. The steps consist of: 1. Literature review and identification of the research question(s); 2. Locating the field(s) online; 3. Ethical considerations; 4. Data gathering; 5. Data analysis and interpretation; and 6. Abstractions and trustworthiness. Traditional research approaches are limiting when studying non-normative and non-mainstream life-worlds and their cultures. We argue that it is timely to develop more up-to-date research methods and study designs applicable to nursing science that reflect social developments and human living conditions that tend to be increasingly online-based.

Key words anthropology, Internet, methods, nursing, qualitative research

LiLEDDA: A Six-Step Forum-Based Netnographic Research Method for Nursing Science

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Introduction

Social arenas have previously been limited geographically. However, with the Internet the boundaries of social arenas are being redrawn. One such social arena are virtual communities or, as we call them, (Internet) forums. In this study we adhere to Ridings', Gefen's and Arinze's definition of a virtual community as "groups of people with common interests and practices that communicate regularly and for some duration in an organized way over the Internet through a common location or mechanism".[1 p273] The scientific community to consider this development and to take it into account when social groups are studied. Many types of interest groups and micro-cultures that were previously studied on the spot are now found online, largely only in the form of Internet forums. These forums are shaped around the interests and needs of like-minded people and center on more or less specialized areas of interest. Some of the many areas these forums address are politics, sex, family life, music and health. According to Ridings and Gefen[2] people use virtual communities differently depending on the community type, but the main reasons are to exchange information, friendship and social support. We have chosen to study two micro-cultures, namely women with a common interest in discussing breast augmentation[3], and a micro-culture of men discussing the life turning event of becoming a father.[4] Through our practice of trial and error in online research we have developed a methodology for nursing science. Throughout this article we will use examples from our research experience to illustrate the use of this methodology.

Background: movements in anthropology

Since the early days of cultural and social anthropology, ethnographic fieldwork has been central to collecting data when studying cultures. For example, in the 1920s, Malinowski[5] published his famous work from living with Trobriands in Papua New Guinea. During the 20th century, a shift took place in anthropology and researchers started to conduct ethnographic studies 'at home'.[6] Karra and Phillips[7] argue that the shift implied many advantages, including easier access to study sites and the need for fewer resources, as well as making translation easier. However, they also point out disadvantages such as the lack of critical distance, conflicts of roles, and a limited serendipity. A further milestone in the development of ethnography was Goffman's[8] work of describing the social situation for patients in asylums. In the 1970's, Spradley introduced an alternative way of working with ethnographic data, illustrated in his ethnography of the culture of tramps[9] and study of culture in a college bar.[10] Leininger and McFarland[11] developed the ethnonursing research method to study transcultural care within the nursing discipline. Nowadays, ethnography has become a well-established research method in several widespread nursing contexts, such as, patient council[12], nursing on an acute stroke unit[13], privacy and dignity of cancer patients[14], nursing in a paediatric intensive care unit[15], and psychiatric intensive care[16,17]. Following the anthropological movement to bring studies 'back home', the next wave began several years ago when ethnographic research began to be applied to virtual cultures. As Wolcott states, "One can do ethnography anywhere, anytime, and of virtually anything, as long as human social behavior is involved (or was involved […]".[18 p68]

Ethnography becomes netnography

In general, there are many different methods for conducting research using the Internet; including quantitative methods such as surveys and intervention designs, as well as the use of virtual focus groups.[19] Use of the Internet as a source for gathering research data has been a fact for the past 20 years in interdisciplinary research fields. In consumer research, Granitz and Ward[20] studied communication within a virtual discussion group for coffee drinkers, while Werry[21] studied communication in an Internet Relay Chat (IRC) from a linguistic perspective. In sociology, Williams and Copes[22] used qualitative methods to explore the complex process of identity-making in subcultures in cyberspace. Further examples can be found in tourism research where Lee and Hu[23] studied online complaint records from hotel evaluations.

In our own discipline of nursing, the use of the Internet as a resource for data collection has been less extensive but a literature review reveals a few examples. Enqvist and colleagues[24] used a narrative design to focus on women's experiences of postpartum psychosis, while Fox, Ward and O'Rourke[25] studied supportive interactions between patients using the same weight-loss drug; and in mid-wife research, Kouri and colleauges[26] studied family life through conversations regarding experiences of pregnancy.

It has taken years to develop guidelines and research procedures for this new world of opportunities; however, the debate on how to approach the Internet as a research site is still far from reaching a consensus. In the field of nursing research the use of this resource has been rarely discussed[27] and methodological concerns and guidelines have not yet been fully standardized. Directions in the use of the Internet are to guide nursing research in the future. Through developing methods and approaches in this area, we can help equip nursing researchers to elaborate upon new practices in relation to the caring practices taking place over the net. Earlier studies demonstrate that the advice and communication that is expressed through Internet forums dissolves the limitations and boundaries of different professions or real life power structures. Internet forums seem to give those seeking health-care advice and nursing competence an opportunity to reorganize their social relations and status in relation to health care professionals.[3,4] As such nursing researchers need to closely monitor and elaborate on this new practice as it develops, and grows in importance. The challenge is therefore that nursing researchers need to both methodologically and conceptually grasp this new challenge while also establishing an ontological coherence with the established values of the caring and nursing paradigm. In this article we present a six step method for a forum-based netnographic approach for nursing science to establish standards. In the first and original work of Im and Che[27] directions to protect human subjects in Internet research are proposed. The authors list five issues that researchers need to consider when conducting investigations using the net. In later work, Im and Che[28] discuss methodological issues for recruitment on the net. Because of the risk of bias in gaining access to informants they suggest "quota sampling", which means deliberately choosing informants with different socioeconomic and geographic backgrounds, as a way to balance groups of ethnic minorities in Internet research. Following this, two additional articles[29,30] present methodological guidelines for using online forums and Internet communities as sources for gathering qualitative data. Over the last decade, Internet usage has expanded by nearly 500%.[31] With this rapid expansion, people have come to use the Internet for different purposes; for example, shopping[32], gaming[33], dating[34], and other forms of computer mediated communications (CMC) like chatting, e-mailing and instant messaging[35]. Now that people tend to use the Internet more on a daily basis despite geographical distances, opportunities to find people with similar interests, values and goals have expanded. Since much of social interaction has moved to an online existence, social researchers are obliged to investigate these arenas along with researching off-line realities. Research interests within nursing science are wide-ranged and extend from abstracted ontological issues to very practically-oriented problems. Examples include the study of what it is to be human and the study of human life-worlds, human health and suffering. Also, nursing research investigates issues related to the nurse-as-professional; asking how-questions. Regardless of whether the research question is more philosophic or practical in nature, it is often from the standpoint as a human being. Sometimes such perspective is almost impossible to achieve using traditional study designs, for example when studying deviant behavior and taboos. Based on the authors' ex post facto experiences and engagement in ethnography and netnography, we have retrospectively synthesized our previous work in the area to present a systematic six step research method suited to post-modern nursing research. The steps consist of: 1. Literature review and identification of the research question(s); 2. Locating the field(s) online; 3. Ethical considerations; 4. Data gathering; 5. Data analysis and interpretation; and 6. Abstractions and trustworthiness. The first letters of the steps together build the name of the method, we it LiLEDDA.

LiLEDDA – A six-step forum-based netnographic research method for nursing science

In this article we present a six step forum-based netnographic method for nursing science which we call LiLEDDA, an acronym derived from the steps in the process (see Table 1). This presentation summarizes and describes our own experiences and knowledge gained through conducting ethnographic research online, using Spradley's[36] structured ethnographic method in combination with Kozinets's[37] methodology, adopted to the field of Nursing and Health Science. We will guide the reader through all these steps and provide examples of applications using data we have gathered in a study exploring women's thoughts, feelings and shared values, as expressed in a breast enlargement forum.[3]

1. Literature review and identifying the research question(s)

As with most research methods, the researcher must conduct an extensive literature review of the topic of interest. It is advisable to use widely used databases relevant keywords. We will not elaborate in detail on how to conduct a literature review here, but refer instead to other researchers' descriptions of this step.[i.e., 38] The two central purposes of the literature review are to first understand what knowledge already exists and second, to identify what is lacking in the theoretical body of knowledge. While evaluating the research problem it is advisable to adhere to its significance, researchability and feasibility.[39] The researcher should then, based upon the existing knowledge and gap in knowledge, formulate a research question or questions that are pertinent to the present study to thereby provide complementary theoretical knowledge.

Summary of considerations: 1) Selecting databases, 2) Evaluating the research questions.

2. Locating the field(s) online

The second phase focuses on locating an online forum where the topic of research is discussed collectively by engaged people. It is advisable to use large search engines to locate the forums, for example www.google.com or www.yahoo.

Table 1: Overview of the six steps in LiLEDDA
1. Literature review and identifying the research question(s) 2. Locating the field(s) online 3. Ethical considerations 4. Data gathering 5. Data analysis and interpretation 6. Abstraction and trustworthiness

com. It is also relevant at this stage to decide whether the forum should be written in the researchers' native language or second or even third language. According to the Internet World Stat from June 2010,[31] English is number one among ten top spoken languages on the Internet (536,6 million users), followed by Chinese (444,9 million users) and Spanish (153,3 million). Given these statistics, the first step is to determine which language the forum should be written in. It is also likely that more forums and more postings are available in English than in, for example, smaller language groups such as Swedish or Norwegian, if the topic is not of local interest only. One benefit of choosing an English speaking forum is that it is easier to protect the anonymity of those posting, because it can be harder to locate the source among the many possible forums. If the researchers choose to use a non-English forum, for example an Icelandic forum, perhaps because this is the native language of the researcher, this limits the diversity of forums that can be found but enriches the analytic process, as it will be easier to understand and interpret nuances in the dialogue. Given the linguistic connections between culture and language, this becomes highly relevant in LiLEDDA. Another advantage to using non-English forums is that posting-excerpts presented in the published work are often translated to English since English is the most accepted publishing language and this further protects the identity of the posters. However, we recognize that translated data can be potentially problematic for analysis for other reasons. Second, it is important that the forum is highly relevant to the research question, meaning that the main topic of the forum should be relevant to the research question. For example, in one of our studies, we elaborated on plastic surgery. In that study we located an online forum where we believed the (cultural) members were likely to have an insider perspective on our research topic. The third consideration is that the forum should be a public website, meaning that no registration is necessary to access the postings. Choosing a non-public website requires that the researchers obtain permission from the system operator and the members/posters. The choice of cloaking level is further addressed below under ethical considerations. Fourth, the researchers must decide upon which characteristics the forum should demonstrate. This is based on three variables: A) The frequency of the postings, which is set as a minimum of 100 postings per quarter (the frequency might be too high to be measured accurately on a daily or weekly basis). The frequency determines the forum's level of activity and whether it is a living culture where people interact through postings; or stated in Spradley's[36] words, their current involvement. B) The variation in data. As the researcher engages deeply with the data, different types of posters emerge that represent a wide range of social roles. Our own research has shown that some posters are newbies while others are insiders. Forums are also likely to adopt a large number of unrecorded lurkers, based on their electronic shadows as readers-only (cf. 37). While newbies, with a passing interest in the forum, often initiate postings with a question, insiders answer on the basis of their own experience by offering concrete advice, and demonstrate strong social ties to the online forum. We hold that this dialectical movement in the communication strengthens the dynamics of communication among the forum members and leads to variation in the data. C) The amount of data, which is set as a minimum of 100 postings in total to provide enough raw data for analysis. Looking to similar guidelines, Spradley[36] holds that an ethnographic scholarly study requires a minimum of six one-hour interviews, although many ethnographic works include about 30-40 interviews.[41] Our values are partly set on the basis of our own experience of scanning different forums with varying levels of activity and our experience of conducting traditional ethnographic work. Spradley[36] further states that good informants should be thoroughly encultured and be currently involved in the culture. If the forum has a low level of activity, then it is difficult to analyze basic ethnographic questions such as 'what is happening here?'. We adhere to the position that even if a minority of posters may contribute to a majority of posts with a low frequency of postings, the data might be useful. For example, in one of our studies[42] we describe the intricate power relations between the minority of experienced posters and how they backed up each other's statements in relation to the less experienced posters entering the forum. This kind of discourse analysis is possible to conduct even in forums where a minority of posters may contribute to a majority of posts. However, we do suggest using an active forum with a variety of posters interacting in discussions. Forums that do not meet these criterion will likely fail to produce a ″living and active culture″ and might be excluded from further consideration. One possible methodological limitation is that it is impossible to fully describe or provide a sociodemographic overview of the posters. However, by looking for demographic and social markers in the postings and signatures, the researcher can make a fair estimation of the posters' sociodemographic representation. Fifth, several forums that might meet the inclusion criteria and thereafter determine whether to include one or several forums and which, for example on the basis of random selection or convenience sampling. In our studies, we used the criterion as described above and in the final selection we used convenience sampling as it made data selection understandable. Finally, after making a selection, the researchers must become familiar with the construction of the forum. This stage involves scanning the site, understanding how the threads and postings are organized and reading the frequently asked questions, also called FAQs, carefully.

Summary of considerations: 1) Forum language, 2) Relevance of the forum; 3) Public or closed forum; 4) Forum characteristics; 5) Selection; 6) Familiarization.

3. *Ethical considerations*

An early step in the netnographic method we propose is to discuss ethical considerations. There are several ethical decisions to make. First, researchers must determine whether the study and the data collection should be treated as human subject research or not. A collective perception among Internet research scholars is that Internet pages that are free to access without a password should be considered as public, and therefore research conducted using them should not be considered as human subject research.[43-48] According to Kozinets, when the researcher participates over time with forum members and/or conducts interviews online, this is clearly human subject research, whereas "[…] conversations, if gathered in a publicly accessible venue, is not human subject research […]".[37 p141] We argue that a LiLEDDA-study, which is strictly archival and cross-section observational without any intervention or interaction with the posters, is in line with these collective perceptions, and is therefore not human subject research. However we acknowledge that there is literature arguing to the contrary.[49-51] We further acknowledge that ethics review boards may have a different perspective. Therefore it must be stressed that ethical considerations depend largely on the topic of research and how the data is to be used, since there is no set of guidelines that is adapted to all online research. Second, a review of other netnographic studies indicates that researchers vary in the extent to which they act overtly or covertly in the data collection process. For instance, Blevin's and Holt's[52] netnography explored beliefs and attitudes among heterosexual men about prostitutes. To collect such data they covertly downloaded posts from public forums. Another group of researchers conducted a netnographic study based on a forum for people suffering from bipolar illnesses.[53] The researchers tried to maximize the posters' awareness of their presence by first seeking permission from the forum operator and further by posting announcements. Kafai[54] was even more overt in her netnography of game culture among teens playing Whyville; she recruited Whyville players via an announcement and further asked for written consent and parental consent. Kafai's approach demonstrates that for some netnography research there is a benefit to inviting the posters to participate in the research. Similarly, this might be beneficial in nursing and health oriented netnography, for example, when organizing research on hospitals or controlled self-directed educational programs for patients and relatives over the net, this participative design might be useful.

In our netnography we chose to remain covert, reducing the risk of contaminating the field (cf. 55). LiLEDDA does not advise the researcher to be covert in principal or automatically. Rather, this stance must be evaluated and discussed with colleagues in each individual research project. However, we do argue that there are potential advantages of using the covert strategy since knowledge can be gained in a way that would not be possible otherwise. Also, in accordance with a well-known anthropological rule, it is important not to contaminate the field to avoid disadvantaging future research. Third, even though the netnography study[3] we referred to earlier was not human subject research and data were collected covertly, the demand to consider the ethics of the study was still highly prioritized as our intention was to use the results to provide guidance to researchers who would use LiLEDDA in the future. Nevertheless, the third ethical issue concerns the integrity of the posters and their postings. Kozinetz[37] thoroughly describes four levels of disguise in netnographic studies. Uncloaked, minimum cloaked, medium cloaked, and maximum cloaked. We argue for a high level of cloaking when conducting a LiLEDDA study in nursing science because postings can disclose highly private information, unlike other less personal postings in, for example, an online forum describing the coffee culture.[56] The highest level of cloaking provides maximum security for the posters; researchers are advised to avoid real nicknames/handles or direct quotes that can be traced using a search engine. Fourthly, researchers are advised to use colleagues, both inside and outside the project, to calculate the potential risks versus advantages with respect to the level of cloaking and whether the study is a human subject research or not. For example, it might be wise to discuss the research design and at what level interaction between the researchers and the posters might take place. Fifthly, in human subject research, the researcher is obliged to critically reflect on the risks versus benefits of the study. Even though a study is not concerned with human subject research, it is still necessary to carry out this exercise to fully consider the ethics of analyzing the postings. We advise researchers to explicitly reflect on this in a separate sheet using headings such as “Risks for the posters in the forum”, “Benefits for the posters in the forum”, and further ”Evaluation of the risks and benefits in a wider perspective”. Finally, it is also relevant to reflect on the volume of data the study must include. The sample size should be calculated carefully such that the minimum amount of postings are included to assure that the research question can be answered, but it is also important not to include far more postings than necessary.

Summary of considerations: 1) Human subject research or not, 2) Overt or covert; 3) Concealment of the posters; 4) Discuss with colleagues; 5) Evaluate risks versus benefits for the study group; 6) Volume of data.

4. Data gathering

This phase of the research process is one of the most critical since systematic work is important for assuring the rigor and trustworthiness of the study as a whole. After locating the field and thoroughly evaluating ethical considerations, it is time to collect data. Many forum platforms, such as vBulletin, phbb, and mybb, are similar to each other in the way threads are structured. There are different ways to collect data from a forum. One way is the “sequential-top-down posting”; which means that data is gathered from the top thread and down, working backward.[sf.3] Other ways are also applicable, for example, systematic random assignment.[39] No matter which method is chosen, this stage is called gathering posts. In several of the forum platforms it is possible to use some sort of printer friendly view or pure HTML view. This is preferable to use to exclude banners and other unnecessary graphics. All the text is simply marked and then copied and further pasted into an empty text document. If data are gathered by more than one researcher, this should be done simultaneously to prevent mashing threads as new threads can be created by the posters at any time. One strategic way of collecting data is that one researcher gathers threads from odd pages in the forum, while a second researcher gathers threads from even pages. If posters create new topic during the data collection process, this bumps the last thread on an odd page to the following page which is a risk during this phase. There are two ways to minimize the risks after the data gathering session, depending on the character of the forum. The researchers may double check that no additional threads were created during the session and pay attention to this during the raw-peeling so the data does not appear twice. If the forum is highly active and new topics are created constantly, it is possible to choose a time of day when the activity is at a minimum or have a single researcher collect the data. The latter solution would double the time necessary to gather data but reduce the risk of mashing data to a minimum.

Data in the forum should be of an archival type; as the data is published in an online forum, the researcher thereafter dumps data. This means that data are copy/pasted from the screen to a text file. The forum used in our example of an LiLEDDA-study[3] had a printer-friendly function which reduced the amount of irrelevant information. The dumping procedure was made cross-sectional from the forum’s first posting to the last and was carried out in five hours. The data collection yielded about 720 threads, 5400 postings and 2046 pages written in 10 point text, single spaced. Depending on the forum, there might be non-text based data (i.e., pictures, and movie clips). These are sometimes accessible but not always for unregistered visitors. In several threads, the posters advertised external web pages (such as blogs or surgical clinics web pages). We strongly recommend excluding information such as external links because it is easy to become led away from the main data. Therefore, we argue for adherence to stringent inclusion and exclusion criterion and systematic rigor. However, pictures can be useful artefacts, though we chose to exclude pictures. During data gathering and the data analysis, field notes were also written down and were treated as data. To enhance rigor, protocols were made. To make the process as systematic as possible to maintain control over the data, a protocol was created using an excel document with six columns, that included: 1. Forum page; 2. Dumped (the dumper signed this box after dumping the forum page); 3. Comments / Initial analytic notes; 4. Number of pages in the text document; 5. Number of pages in the text document after raw peeling (explained in the data analysis section); 6. Percentage of data loss after raw peeling.

Summary of considerations: 1) Gathering posts; 2) Dumping; 3) Writing data protocol.

5. Data analysis

An early step in the analysis procedure is the writing of memos which is a particular ethnographic tradition that helps the researcher to maintain a reflexive approach.[57] Aktinson[58] writes that “Memos bring analytic focus to data collection and to the researcher’s ideas”.[58 p167] We recommend including activities like writing analytic and methodological memos. Analytic craftsmanship involves several steps. First, the text document with pasted raw data should be processed. Even though text is copied/pasted data from a printer friendly view, some debris often remains. By deleting such debris, that is the forum logotype, parent thread labels and quotes from earlier postings, the text documents are "raw-peeled". Like the dumping procedure, this is a repetitive activity, but it enables the researcher to begin honing in on the data and to record further memos. In our study[3], the data was reduced from 2064 to 1479 pages, by raw peeling, with a range of 16-44% debris reduction and a mean value of a 28% reduction. The remaining 1479 pages net for analysis were considered sufficient for carrying out a qualitative study. Second, the researcher must skim the data. Through this activity local knowledge of the language in the postings and identification of culturally specific recurrent terms is obtained. We identified terms such as "cc:s" (size of implants), "rippling" (wrinkles on the implants), "DB" or "double bubble" (deformity of an implant) and an analytical memo concerned posters supporting each other. Third, it is preferable that two or more researchers skim the data separately, such that the results can be compared and discussed; focusing on what paths, clues and traces are relevant for deeper analyses and interpretation in relation to the aim of the study. This process is called "sorting data". Fourth, the research must carry out an in-depth analysis, engaging with the data on a deeper level. This can be done both quantitatively and qualitatively. In our study, we considered qualitative in-depth analysis to be the most appropriate in relation to the study aim, which focused on peoples' shared values, feelings and thoughts. However, in general LiLEDDA should not be considered to be limited to qualitative in-depth analysis as different research questions might be best answered by using other methods, for example parametric statistics (cf. 59). The interpretation of the data involves the researcher merging the initial and superficial thoughts that were generated from skimming and analytic memos. It is then possible to sort out different cultural domains; that is, a collection of different items which relate to each other, fit together, and are the same kind of thing. A cultural domain might be the 'implants' and 'post-operative complications' when studying the culture of women who undergo breast augmentation. In this analysis a netnography should ideally include a consideration of the context for the forum talk, how people come to the forum, how they post, and how the researcher integrates (or not) with the forum. For example, we found that there were differences between those who were planning to undergo a breast augmentation and those who had undergone the procedure years before.[3] We were inspired by Spradley's[36] approach to analyzing ethnographic data to initially reveal cultural domains. Specifically, we applied Spradley's structure for analyzing data, and asked descriptive, structural and contrast questions. During the initial phase of the analysis, it was obvious that the artefact, "the implants", was central in the culture. When the analyst has identified such a central artifact or domain in the culture, it must be deeply analyzed; how it is used in the language and which attributes are associated with it. In our case, the implants had several parameters, such as size, shape, material, and so forth and were frequently discussed. The implant played an important role when having a breast augmentation. Questions were asked, including "When are these parameters discussed?" In line with Atkinson[58] we analytically assumed there was a difference between posters who had already undergone the operation and those who had not yet done so. Further questions needed to be asked, such as "What are all the differences between discussing the implants' parameter before and after the operation?" Prior to the operation, the posters were expressing strong emotional feelings (again we operationalized all kinds of feelings by posing descriptive questions). We also analyzed other posters' reactions to posts about feelings that were expressed prior to the operation and concluded that women who had undergone a breast augmentation earlier cared for those who had not come so far in the process. By analyzing cultural domains in this way, categories and themes crystallized according to differences and levels of abstraction. This resulted from traversing between immersing ourselves in data and temporarily breaking from this to reflect.

Summary of steps: 1) Raw-peeling; 2) Skimming; 3) Sorting data; 4) In-depth analysis.

6. Abstractions and trustworthiness

The last step in LiLEDDA is to discuss the results and argue for the trustworthiness of the study. First it needs to be stated that trustworthiness depends on the epistemological position of the researcher. Since this is a fundamental question related to the aim and claims of the researcher and the research conducted it will not be covered here. However, we acknowledge that there are many existing assumptions about epistemological positions in ethnographic research (cf., 9,11). We suggest that a discussion written following a LiLEDDA analysis should follow the same conventions as other academic writing based on other scientific methods. We do recommend reviewing well-acclaimed methodological books on this step. Here we can briefly recommend some very general guidelines. First, state the major findings; then further discuss how they are related to earlier research and theories. One might also consider whether it would be useful to extract one or two concepts from the findings and further discuss these in a wider context. Finally, one should highlight any implications the findings have in a wider context. In our study of a breast augmentation forum, we found that the women used the forum to educate one another and provide support; these are two central ingredients in nursing. We used Orem's[60] self care theory to discuss how the women cared for each other over the Internet and the concepts "cyber nursing" and "torrenting" were coined. In this abstraction process it is important to not only grasp the methodological principles presented in this article. Considerable in this step is to grasp the conceptual and theoretical levels of nursing knowledge to preserve the ontological coherence of nursing research even as new methodological approaches are introduced to study a new field of reality. We will return to this important topic of epistemological interest for nursing research in the discussion section below.

Achieving trustworthiness in a qualitative study is heavily debated in scholarly literature.[61-64] More specifically it is also debated in the literature on ethnography.[57,65] Kozinetz[37] focuses on member check as a way to achieve credibility in a netnographic study. We do not recommend member check as epistemologically it is highly contradictory to qualitative (nursing) research (cf. 66,63). The basis of epistemology in nursing research is to adhere to multi-perspective truths, in line with the life-world theory presented by Dahlberg, Drew and Nyström.[67] Seeking validation from the cultural members would imply that the cultural members express a greater truth, or an absolute truth that the researcher can validate independently. This kind of validation tends to mirror the findings toward the cultural member's own self picture rather than lending trustworthiness to the researchers' interpretation. Along with this argument it is important to clarify that the researchers' truth is not to be considered as more truthful or more accurate than that of the cultural members'. Although in a netnographic research project, the voice of the researcher is given precedence as being the one holding an outside perspective whose task is to channel a description of the culture through a netnographic lens and present it in a wider perspective. Furthermore, according to Schien[68], a culture is ordinated by several levels, yet members are not conscious of the most profound levels of a culture's structure. Following this, only the more superficial levels of a culture would be subject to validation. We propose that researchers using LiLEDDA adopt other values to increase the trustworthiness of their study.

First, we would argue that the data is trustworthy because it was not intended for research. Several researchers within suicide research[69-71] argue that the subjects' personal diaries, daily notes, reflections and personal notes are regarded as the most trustworthy data in answering the question of why people commit suicide. This is because the data was never intended for public consumption. However, even if some methodological considerations and limitations associated with suicide research differ from those of netnographic research, the validation of data as shared without the intention of scrutiny and or having been constructed for research intentions might be regarded as the same.

Second, netnography is sometimes criticized for being a lazy research method, and is sometimes referred to as speed or armchair ethnography because the researcher does not physically go out into the field and metaphorically "get their hands dirty". Netnography is, of course, hugely time saving in contrast to traditional ethnography; for example, the researcher can copy/paste activity from an Internet forum rather than carry out interviews. Nevertheless, the other methodological steps are just as demanding as in traditional ethnographic studies. Moreover, in the study we refer to as an example above[3] we gathered almost 1500 pages of qualitative data, which is far more than would normally be collated in most qualitative studies; it is a highly demanding effort to read and become familiar with such a volume of data. In comparison, Mason[41] concluded that the mean number of interviews in qualitative studies from a sample of 560 PhD studies was 31 interviews. In ethnographic studies, the mean was 37 interviews. Based on our experience of transcribing qualitative interviews, one-hour of audio typically amounts to about 20-25 pages of text. This means that the data in our study is equal to about 75-100 qualitative interviews.

Third, trustworthiness is interconnected with how the findings are presented. We hold that in a forum-based netnography data must be presented in such way that it makes sense to an outside reader but is still a description of the raw data originating from the culture studied and has not been culturally translated - we call this "releasing findings". We can provide an example of releasing findings from our netnographic study of a breast augmentation forum culture.[3] In this study, we used Orem's[60] self care theory to describe the forum culture and held that the posters were both the agent of action (the one acting) and the object of action (the one acted on) as they supported each other and performed "cyber nursing". This theoretical reasoning was further illuminated in the finding, for example, as we released a conversation between three posters. One of these expressed her problem of having a hunchback after the operation, while two other posters gave support and offered advice on what might be helpful. Releasing findings in this way is rather similar to Geertz's[72] concept of "thick description" in anthropology.

Finally, we argue that trustworthiness in a LiLEDDA study is linked to the serendipity of the findings. Serendipity means “A chance and unexpected discovery during data collection, often by searching for something else”.[73 p368] We would like to explain how serendipity is linked to trustworthiness with an example from our study of breast augmentation.[3] Before conducting the study, we thought that we would produce an index of posters and the reasons they gave for undergoing breast augmentation. However, we clearly discovered something quite different as a result of our deeply engaged analysis. Through in-depth qualitative research we adopted an emic perspective and began to “sense the communion” among the posters and to understand the posters’ shared values, feelings and thoughts within the culture of breast enlargement Internet forums among women undergoing aesthetic plastic surgery. We argue that serendipity also reflects important aspects of trustworthiness in a LiLEDDA study.

Summary of sources of trustworthiness: 1) Non-research-produced-data; 2) Extension of data; 3) Releasing findings; 4) Serendipity.

Discussion

In this article we have presented LiLEDDA, a six-step forum-based netnographic research method for nursing science. In summary, these steps are: 1. Literature review and identification of the research question(s); 2. Locating the field(s) online; 3. Ethical considerations; 4. Data gathering; 5. Data analysis and interpretation; and 6. Abstractions and trustworthiness. LiLEDDA is a research tool for gathering data from online forums. We would like to further elaborate on the use of LiLEDDA as we find the development of such a tool to be a step in nursing science in the context of the expansion in Internet use in society. One limitation of LiLEDDA is that it was created to study privileged populations who have access to the internet and internet forums and therefore have the possibility to express and debate issues online. A wide range of the human population consists of marginalized populations, including those without electricity, homeless people, analphabetics, and people living in countries governed by dictators, those who are imprisoned and those who not speak the language of forum. Although internet usage is increasing exponentially, Internet World Stats show that only 13 % of the population in Africa has internet access, although this rate has grown by almost 3000% between 2000-2011.[40]

Within nursing science, there has been a long tradition of promoting face-to-face interviews as a way to gather qualitative data, which, to our understanding, has its roots in the nursing discipline, and derives from the concept of presence as central and interconnected with inter subjective connections, engagement, and interaction.[74] We agree that traditional research approaches and designs for interacting with informants are important for the science and contribute to in-depth knowledge. However, we also argue that it is to develop more up-to-date research methods and study designs applicable to nursing science that reflect contemporary online socializing. Presence is no longer existent in face to face interactions only. As Chen and Yen[75] elaborate, online presence exists through interactivity on the Internet. Further, Rau, Gao and Ding[76] hold that both verbal and affective intimacy exists online in social networks and is correlated with the frequency of postings. With this paper, we want to highlight that there are reasons to review established concepts as interactivity in nursing research and the inter-subjectivity of the researcher and the “informants”.

People, with their specific needs, problems and desires, sometimes become interesting for scientific studies conducted by nurses, psychologists, occupational therapists and so on. Especially when a physician has given them a diagnostic number, or when they are in some way given the epithet ‘patients’ (sometimes consumers). Whatever they are labelled, these people hold specialized knowledge about their own feelings, thoughts and values in life. Many individuals have problems and needs that surpass those of the average citizen. Ironically, as the occidental society, from some perspectives, becomes more and more individualized and liberated[77], deviant behavior still seems to be stigmatized and regarded as taboo; for example as in the case of psychiatric illness[78],sexual deviations[79], living with HIV[80], poverty[81], and obesity[82]. Regardless what kind of stigmatized groups of people or subcultures one considers, some of these will automatically be more interesting as research participants than others because of personal, political or economic interests. Nevertheless, traditional research approaches are also limited in studying these non-normative and non-mainstream life-worlds and their cultures. From a nursing science epistemological orientation toward humanity issues, health, environmental living, problems and nursing needs, as well as human suffering, it is not always possible to gather data by using traditional study designs. Our article suggests that this method of gathering data in the Internet-age is inevitable when studying specific cultures that would be very time consuming and hard to access using traditional approaches and study designs. As Murray and Sixsmith[83] report, online communications yield more honest responses, particularly from those participants who are asked to provide personal and sensitive information. Because the web is important for interacting and sharing in people's lives around the globe, taking a step forward from ethnonursing research (i.e., 11) to nethnonursing research gives vital trajectories for science based knowledge in the fields of nursing science for the future. Therefore, our final and summary stance is that the online netnographic forum-based method, LiLEDDA, is strongly advisable for use in nursing science.

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Abstract
In Sweden as well as in many other countries, nursing and caring science exist in a health care context that is characterised by increasing reliance on the economics of diagnoses and measureable symptoms. This presents a challenge for caring science to defend person - and lifeworld-centred care. Nursing as a caring science must make clear its position in modern health care. The objective of this paper is to show how health oriented nursing, grounded in caring science, advocates expanded nursing care. The paper revisits the relationship between nursing and caring science, specifically the insights from new caring science research that emphasises carers' capacity for expanded awareness. In addition, the ever-present question of evidence is addressed.

Key words caring science, clinical sensitivity- theoretical reflection, expanded awareness, expanding caring, evidence, nursing

Expanded Awareness as a Way to Meet the Challenges in Care that is Economically Driven and Focused on Illness – A Nordic Perspective

ALBERTINE RANHEIM & KARIN DAHLBERG

Introduction

Caring is the primary focus of nursing. From a Nordic perspective, we believe that highlighting nurses' expanded awareness contributes to health and well-being by providing contemporary health care with a focus that includes both economics, and processes of health and illness.[1]

Nursing and caring are difficult concepts to define and distinguish, and globally the significance of both is unclear (2). In Swedish Universities alone there exist five different definitions of the nursing and caring discipline[3] and in international theory, the parameters of caring and nursing are even more unclear than in Nordic countries.[4]

However, lately North European researchers have revisited the idea that caring science tradition emanates from explicit, distinguishable values derived from existential knowledge and understanding.[1,5,6] These scholars conclude that the aim of caring is to support and strengthen the individual patient's health processes, and it is the aim of caring science to create the knowledge that renders such care possible. With this definition of caring, Dahlberg and Segesten[6] go further, describing caring that supports and strengthens health, including the experience of well-being, which is defined as the ability to carry through one's large and small life projects. Understood this way, health means life-power, life-lust and life-courage. In this context, health is also related to meaning and coherence, and there is a balance between the vulnerability and freedom of existence.[7] Further, health means having a capacity for movement and activity as well as stillness, peace and life rhythm.[5,6]

Nursing that is grounded in caring science is faced with several challenges. One is that health care in general and medicine in particular is focused on illness. The economically driven ideals of today demand diagnoses and measurable symptoms. Nurses who practise caring science often find it hard to convince professional colleagues, e.g. physicians, that caring science supports patients' well-being and enhances health autonomy, and the value of this. It can be a challenge for those outside caring science to accept abstract concepts such as life-power let alone see it in movement, stillness and life-rhythm.

Economically driven care also means that professionals are required to provide care that is measureable and reliable. In this context, health care in general, and not least nursing, is focused on doing more than being. As Pearcey[8] comments, in the current health care atmosphere, caring is those things you are not supposed to do. Granted, it is possible to provide nursing care without caring, but then the extent to which nursing engenders positive change for health is curtailed.

For nursing, caring means embracing the particular basic value that comprises the core question of caring: how can nursing care support and strengthen the patient's health processes? From a caring science perspective, nurses are more relationally-focused than task-oriented. It is in the relationship between nurses and patients that health, well-being and competence thrive.

Method

This excursus is based on previously published research.[1] The aim of the original project was to reveal the meaning of caring to nurses working in municipal elderly care. Using reflective lifeworld research[9,10], we returned to the empirical findings of the project, which were further interpreted using a Nordic philosophy and research in caring science and nursing published by Dahlberg and Segesten[6], Galvin and colleagues[11], Finlay[12], and Finlay and Gough[13]. We also drew on Gadamer's[14] view of health.

Nurses' expanded awareness

Encountering patients in ways that give room for existence, the experience of health and well -being, and that helps them to go on with their life projects demand an expanded awareness[15] from nurses. Expanded awareness means the cultivation and widening of one's experiential horizons. With acuity of the senses, self-awareness and self-confidence, nurses may more readily recognize patients' unspoken needs and encounter deeper, existential concerns.

With expanded awareness, the world becomes enlivened and immediate. When patients open up their lifeworlds, nurses can respond with open wondering, lingering and dwelling, all the while aware of "not knowing." Nurses are health and caring experts, but do not necessarily know how patients experience health phenomena. Nurses who believe they already "know" run the risk of having their preconceptions confirmed as the opportunities for patients to divulge something previously unknown is lost. When this happens, a patient has nothing to say to the nurse.

Open wondering includes the sense-aesthetics of human life, which Martinsen[16] emphasizes. In hectic, everyday caring work, nurses are situated in movements of rapid reflection where the expeditious intellect dominates the senses. As Martinsen says, these caring encounters are "pregnant with impressions of meaning".[17 p135] She claims that sense impressions have a two-fold function: the impressions touch us sensually and lead us to work on being open to what the impression wants to reveal to us.

The above-mentioned research[1] was further interpreted using a meta-synthesis of caring science research that focused on the general phenomenon of health and caring, including philosophical analysis.[6] We argue that in order to meet patients' lifeworlds, nurses need to open up their senses, feelings and sensitivity. Expanded awareness is essential in caring encounters where a nurse can reach a patient's lifeworld. In such encounters there is a "wakefulness and being-in-the-world as authentic presence".[18, p74] According to Gadamer, there is a self-evident immediacy to this kind of presence. He refers to Aristotle's concept of "entelechia" which reveals the meaning of such caring presence: "a kind of presence in which our authentic existence, so to speak, realizes its telos, its perfect form /…/ the full completion and realization of a living meaning".[18 p74] Expanded awareness increases a nurse's ability to see the other person and her/his lifeworld.

Expanded awareness and the sense-aesthetic attention that Martinsen and Gadamer talk about open up one's capacity for the existential that can be cultivated, developed, or, conversely, closed down. Such openness carries an inherent risk of leaving nurses feeling vulnerable and less inclined to remain open. If not trained for reflection, openness withers. In the economically driven and illness focused health care system of today, the sense-aesthetic dimension of caring runs the risk of vanishing. Consequently, the question of strengthening and supporting the sense-aesthetic meaning of caring is urgent.

The development of experiential horizons

Developing one's experiential horizons means letting go of the emphasis on doing, and giving room for an open encounter between lifeworlds. Open wondering, dwelling and lingering are about the art of "bridling" which is a term developed for human science research epistemology and methodology.[10] Bridling means abstaining from immediate intellectualizing in order to let something appear, to let impressions stay for a while, to just sense without conceptualizing and reframing with theories. Bridling requires concentrated effort and demands cultivation of open awareness, self-awareness and reflexivity.[19] The challenge is to endure the frustration produced by endeavouring "to not understand" and "to not make definite what is indefinite".[10, p121]

Nurses are given multiple opportunities to expand awareness in encounters and practical tasks during everyday care. Feeding, bathing, helping to dress a patient, teaching situations, giving an injection or other treatments are all examples of everyday situations where nurses can practice and strengthen expanded awareness. In particular, caring encounters that emphasize the intersubjective aspect of caring, e.g. caring dialogues and caring touch, offer opportunities to cultivate one's capacity for presence, attentiveness and expanded awareness. In a clinical context it is, at least partly, an act of will and intention to be open to sensory impressions.

However, for professionals to remain in a state of "not immediately knowing" is a challenge since it means adventuring into the unknown. It is so much easier to remain in one's usual mode of unchallenged expert. Todres (20) has described "home and adventure" as an eternal movement of the human mind. The challenge, he argues, is to make friend with the unknown and bring the adventure home. Understood this way, the movement between home and adventure is an excursion out into the unknown and return back home to that which is known. It is thus an intertwining of what is known and unknown.[18] The crucial moment in this movement is not, in fact, the adventure or the excursion into the unknown, but the return. Gadamer makes explicit the engraftment of the unknown and the art of making the unknown known - and to put it in play. After the task of educating one's senses and developing an expanded awareness, there is the issue of transforming the experience into language and communicating it in nursing.

One cannot demand from a person who does not read Swedish to understand a text written in Swedish and grasp the intentions of that text. Likewise, one cannot demand from carers, if they are educated in the restricted perspective of medicine, to recognize patients' lifeworlds, their suffering and existential demands.[6] The education of one's senses and feelings, and the development of an expanded awareness, are the tasks of all health care practitioners, but they must be given opportunities to learn and they must themselves be open to such learning opportunities.

It takes time but does not need time

What Ranheim (1) describes is an approach to nursing that can nourish all caring activities. To adopt and develop a stance of expanded awareness requires time. But the approach to patients needs no extra time. The understanding of care that is explicated here is the foundation of every nursing act.

Thinking is quick. In our contemporary culture, one's intellectual mind is highly stimulated and challenged. Intellectual knowledge is the most cultivated knowledge and the intellectual mind is in demand - for good and for bad. The relatively slower knowledge of one's senses and feelings is dismissed or left unacknowledged.[21,22] Without doubt, professional and scientifically based nursing and caring need cultivated, intellectual minds, but such caring also needs the nurturing of all the senses and of "entelechia".

However, we want to avoid a dualistic conflict that separates intellectual minds from the sense-aesthetical dimensions. Instead, we want to see these human capacities intertwined by cultivating the expression and expansion of intellect and thinking blended with pre-cognitive, sensual impressions. Such understanding characterizes the reflective practice that is developed from a phenomenological perspective.[7,12,13,19,20] We also argue that the caring intellect is nurtured by the sense-aesthetical dimensions. Nurses with such an expanded awareness are more likely to draw correct conclusions about the nature of the care needed for patients.

The question of evidence

The economically driven care of today is closely related to the demands for evidence-based care. Only what can be measured is valued. Let us therefore take a quick look at the world of caring and make explicit that the demand for evidence cannot be reduced to a question of statistics.

Research on caring phenomena offers insights into context-specific inter-relational processes between caring professionals and their patients. Both parties have their own as well as shared lifeworlds, and on both sides there are questions of life meanings, intentions, dreams and goals.

Their common ground is support and strengthening of the patient's health processes. For the professional side of the caring relationship there are further aspects, such as personal and professional maturity and ethical beliefs. It is, as Galvin and Todres put it, a complex view of knowledge that is "relevant to nursing because immersion in practice demands a way to overcome the 'deep inseparability' of truth, ethics and action in the complex and marginal situations that nurses have to manage".[11, p523] None of these aspects of care can be fully measured.

Further, it is indeed unscientific to force caring phenomena, epistemologically understood as unmeasurable, into matrices that reduce them to measurable entities, sometimes past recognition.[9] Mathematics is a wonderful gift to science and should be used whenever the numbers match the phenomenon properly. When the focus of research is on the world of experience, words are better than numbers. By looking for both explicit and implicit meanings in descriptions of caring phenomena, we can come closer to the truth of caring.[10,23]

Quantification does not fit the phenomenon of expanded awareness, which demands insights into the lifeworld. From our empirical experience and a phenomenological perspective, we argue that mediating caring through expanded awareness should become second nature in nurses' work. Nurses form a caring science agency by mediating caring actions and intentions. The mediation of care and the affects of a caring science agency must essentially be evaluated by patients. From our research[1,6], we have enough evidence to confidently say that patients benefit from nurses' expanded awareness that opens their minds for the individual patient's lifeworld.

Scientific research, no matter the approach or method, must be interpreted and transformed in order to establish validity and evidence. All research results have an original context from which the results are extrapolated to other situations and give rise to new questions. For example, statistical research, always group-based, is interpreted in relation to individual lifeworlds in order for the knowledge to be properly transformed and practised. The meaning of research results for patients depends on how practitioners understand and use such knowledge.

Conclusions

In Sweden as well as in many other countries, nursing and caring science exist in a health care context dominated by the economics of curing through diagnoses and measureable symptoms. There is a belief today that by integrating general quality insurance programs based on statistics and protocols, the quality of caring will increase and healthcare will be more economically sound. We believe that the opposite is more likely: by implementing standardized programs, individual discernment gets lost, along with the possibilities for developing an expanded caring awareness. As a result, the cultivation of clinical sensitivity and the humanity of caring are greatly diminished.

We have evidence of the value of an expanded awareness in our common research.[6,15] We encourage nurses to include more of caring science in their horizons of knowledge in order to be more health oriented and thereby improve their caring and nursing ability. To achieve an expanded awareness, professionals not only need critical reflection but also sensitive reflection; and most of all, they need the strength to maintain openness long enough for new insights to grow about patients' lifeworlds and health processes. Professionals are experts, but must also be expert enough to be receptive to their patients' own expertise in their lifeworld. In such a way, nursing can be the power that supports patients' health processes and by including caring science, nursing can make clear its position in modern health care.

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3

Résumé
Cet article propose une conception systémique de la pratique infirmière afin de l'appréhender dans sa complexité et poursuivre son élaboration théorique. Une recension systématique et une analyse des conceptions de la pratique de théoriciennes infirmières fut entreprise à partir du cadre théorique de Jean-Louis Le Moigne. Une modélisation de la pratique infirmière comportant huit thèmes est proposée. On y identifie les composantes structurelles, fonctionnelles, téléologiques et spatio-temporelles de la pratique. Ce modèle balise des dimensions à partir desquelles poursuivre l'élaboration de théories sur la pratique infirmière, tout en créant une ouverture sur des questions émergentes. En particulier, la réflexivité de la pratique constitue une piste à partir de laquelle élaborer davantage le concept central d'environnement dans nos théories en sciences infirmières. Pour ce faire, nous sommes d'avis qu'il importe d'élargir le répertoire des théories sociales auxquelles référer pour conceptualiser plus finement la pratique infirmière et son agir complexe.

Mots clés complexité, modélisation systémique, pratique infirmière, systèmes complexes, théorie en sciences infirmières

Modélisation de la pratique infirmière comme système complexe : une analyse des conceptions de théoriciennes en sciences infirmières

LAURALIE RICHARD, SYLVIE GENDRON & CHANTAL CARA

Introduction

Que nous intervenions dans les domaines de la clinique, de la recherche, de la formation ou de la gestion, il nous arrive, comme infirmières, d'être confondues par l'infinie variété des interdépendances et des dynamiques qui transforment les expériences et les phénomènes qui nous préoccupent. Le monde dans lequel nous vivons est complexe et la pratique infirmière n'y échappe pas.

Les procédures et dispositifs de soins sont en changement constant[1], vue la transformation des savoirs dans le champ des sciences biomédicales. Les situations et expériences de soin, de même que la quantité d'informations que gèrent les infirmières au quotidien, se diversifient et se multiplient.[2] Ceci exige de mobiliser et de mettre à jour une vaste gamme de connaissances et de compétences spécialisées.[3] De plus, les infirmières interviennent auprès d'individus et de familles vivant des problématiques de santé multiples et sont les témoins privilégiées de trajectoires de vie marquées par des inégalités sociales de santé et l'exclusion.[4,5] Par ailleurs, l'organisation des services dans laquelle agissent les infirmières comporte davantage de processus de collaboration[6-8], ce qui peut les amener à redéfinir leur rôle au-delà de ses frontières disciplinaires et à élargir le spectre des réseaux dans lesquels elles participent.[9-11] Dès lors se confrontent les exigences organisationnelles d'acteurs d'horizons variés. Dans ce contexte, il n'est donc pas surprenant que de plus en plus d'auteures en sciences infirmières s'entendent à l'effet que la pratique infirmière se déroule dans un monde complexe.[12-17]

La complexité n'est donc pas étrangère à la pensée infirmière.

Pour aborder cette complexité, des théoriciennes en sciences infirmières ont eu recours à une approche systémique[12,14] ou à des théories des systèmes pour le développement de la théorie infirmière.[17-19] À cet égard, un nombre important de théoriciennes se sont particulièrement inspirées de la Théorie du système général[20] pour développer leurs conceptions de la pratique et pour élaborer les concepts centraux de la discipline. Cette tradition systémique en sciences infirmières se reflète principalement dans les travaux de Neuman (*Neuman's Systems Theory*[21]), de Rogers (*Rogers's Theory of Unitary Human Being*[22-25]), de Roy (*Roy's Adaptation Model*[26-30]), de King (*Imogene King's Theory of Goal Attainment*[31,32]), d'Orem (*Orem's Self-Care Deficit Theory*[33-35]) et de Johnson (*Johnson's Behaviour Systems Model*[36]).[14,15,17] Dans l'ensemble, les travaux de ces théoriciennes contribuent à une conception renouvelée du monde dans lequel l'infirmière intervient. Toutefois, la théorie des systèmes a connu plusieurs développements et diverses formes de pensée systémique se sont succédées au courant du siècle dernier, certaines avec des orientations fort différentes.[37,38] En particulier, les approches systémiques cybernétiques desquelles se sont généralement inspirées les théoriciennes reposent sur une conception relativement *fermée* des systèmes.[15] Dans un autre ordre d'idées, l'approche systémique de la complexité propose de concevoir les systèmes comme étant résolument ouverts[37], donc imprévisibles et changeants. Vu de la sorte, ce ne serait donc pas que le monde complexe de la pratique qui est à considérer, mais la complexité de la pratique, en soi, comme système résolument ouvert. L'approche systémique de la complexité pose alors la question centrale de *l'agir complexe*.

Partant de ces constats, l'objectif de cet article est de proposer une modélisation systémique de la pratique infirmière à partir d'une analyse des conceptions de théoriciennes en sciences infirmières et d'un cadre théorique qui permet de réfléchir l'agir complexe. Il s'agit de s'appuyer sur les écrits de théoriciennes infirmières pour contribuer au développement de la théorie de la pratique en sciences infirmières.

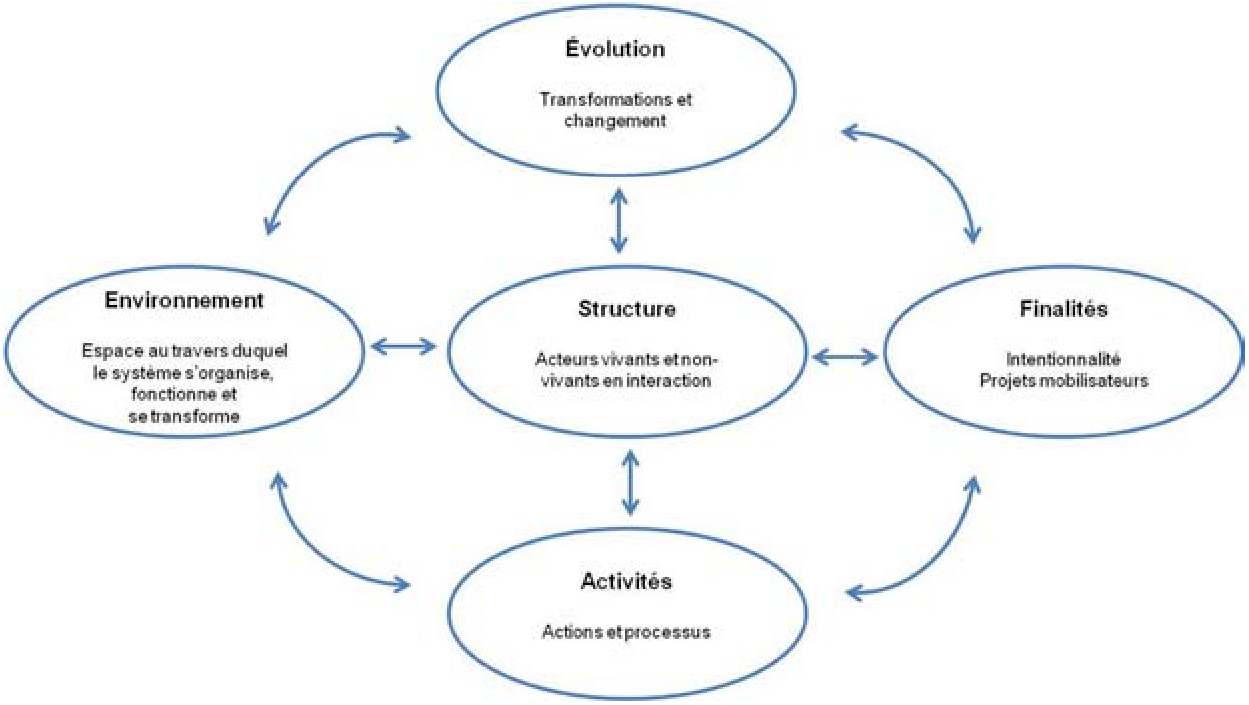
Appréhender la complexité de la pratique infirmière

Un intérêt croissant pour la complexité marque le 20ème siècle. On s'intéresse aux mécanismes qui créent et qui entretiennent la complexité, de même qu'aux méthodes permettant de la décrire, de l'analyser et de la comprendre.[39] C'est ainsi que, suivant la trace de quelques grands pionniers et penseurs de la science des systèmes comme Giambattista Vico, Léonard de Vinci, Paul Valéry, Gaston Bachelard, Ludwig Von Bertalanffy et Edgar Morin, Jean-Louis Le Moigne s'attarde depuis une quarantaine d'années à développer des réflexions et à forger des concepts nous aidant à former nos intelligences de la complexité des systèmes.[40] Ce dernier est un auteur clef de la pensée systémique complexe fondée sur la notion de systèmes ouverts. De plus, il propose la méthode de la modélisation des systèmes complexes[41-43] pour réfléchir et concevoir l'agir complexe. Cette méthode constitue notre point d'ancrage théorique pour définir et concevoir la pratique infirmière.

Pour Le Moigne[41-43], la complexité se caractérise comme suit. Il s'agit d'un ensemble d'éléments et d'événements qui sont en relation à travers des actions, qui sont organisés en fonction de finalités et qui se transforment dans l'espace et à travers le temps. Ce faisant, la complexité comporte, à la fois, des processus émergents, indéterminés et irréductibles, qui donnent lieu à des changements.[38,39,43,44] Toujours selon Le Moigne, la complexité n'est pas une caractéristique ou une propriété du réel. Il s'agit plutôt d'une propriété qui est attribuée par des acteurs à propos de phénomènes qu'ils se représentent comme étant complexes.[43] Il s'agit donc, en quelque sorte, d'une lentille pour appréhender les phénomènes et notre monde vécu. C'est dans cette optique que Le Moigne propose un modèle à base de cinq composantes pour appréhender la complexité. L'alliance de ces cinq composantes représente un système qui est suffisamment formalisé pour être communicable et intelligible.[43] Les cinq composantes du modèle sont la structure, les activités, les finalités, l'environnement et l'évolution. Voici une brève description de chacune d'elles.

La première composante du modèle proposé par Le Moigne est la *structure*. Elle réfère aux éléments en interaction qui constituent le système et qui contribuent à son organisation. Plus particulièrement, il s'agit des acteurs vivants et non-vivants, tels les intervenants d'une équipe ou, encore, des propriétés inhérentes aux acteurs comme leurs savoirs, leurs valeurs, leurs outils de travail ou de communication. Les *activités* représentent l'aspect fonctionnel du système, lequel constitue le champ des actions et des processus. Les *finalités* renvoient aux intentionnalités du système et de ses acteurs. Elles correspondent, par exemple, aux projets qui mobilisent les acteurs, qui à leur tour, se transforment et contribuent à l'organisation du système. Ce faisant, le fonctionnement du système et son organisation sont intimement liés aux finalités poursuivies. Un système complexe étant ouvert, il importe également de réfléchir ses interactions avec son *environnement*, qui correspond à l'espace au travers duquel le système s'organise, fonctionne et se transforme. L'*évolution*, la dernière composante du modèle de Le Moigne, nous invite à considérer la trajectoire développementale des phénomènes complexes et la dimension temporelle des transformations émergeantes et organisatrices du système. L'environnement et l'évolution constituent la dimension spatio-temporelle dans laquelle le système change et produit du changement.

Figure 1: La pratique infirmière comme système complexe, selon les composantes du modèle de Le Moigne



Inspiré du modèle de Le Moigne[43]

La figure 1 présente ces cinq repères que nous retenons pour appréhender la pratique infirmière, comme système complexe. La pratique est donc ici définie comme un système qui comporte des acteurs vivants et non-vivants en interaction, qui poursuit des actions et processus selon des finalités, et qui s'organise, évolue et se transforme à travers un environnement. Dans ce qui suit, nous présentons la méthode que nous avons employée pour produire une modélisation systémique permettant de réfléchir l'agir complexe de la pratique infirmière.

Méthode

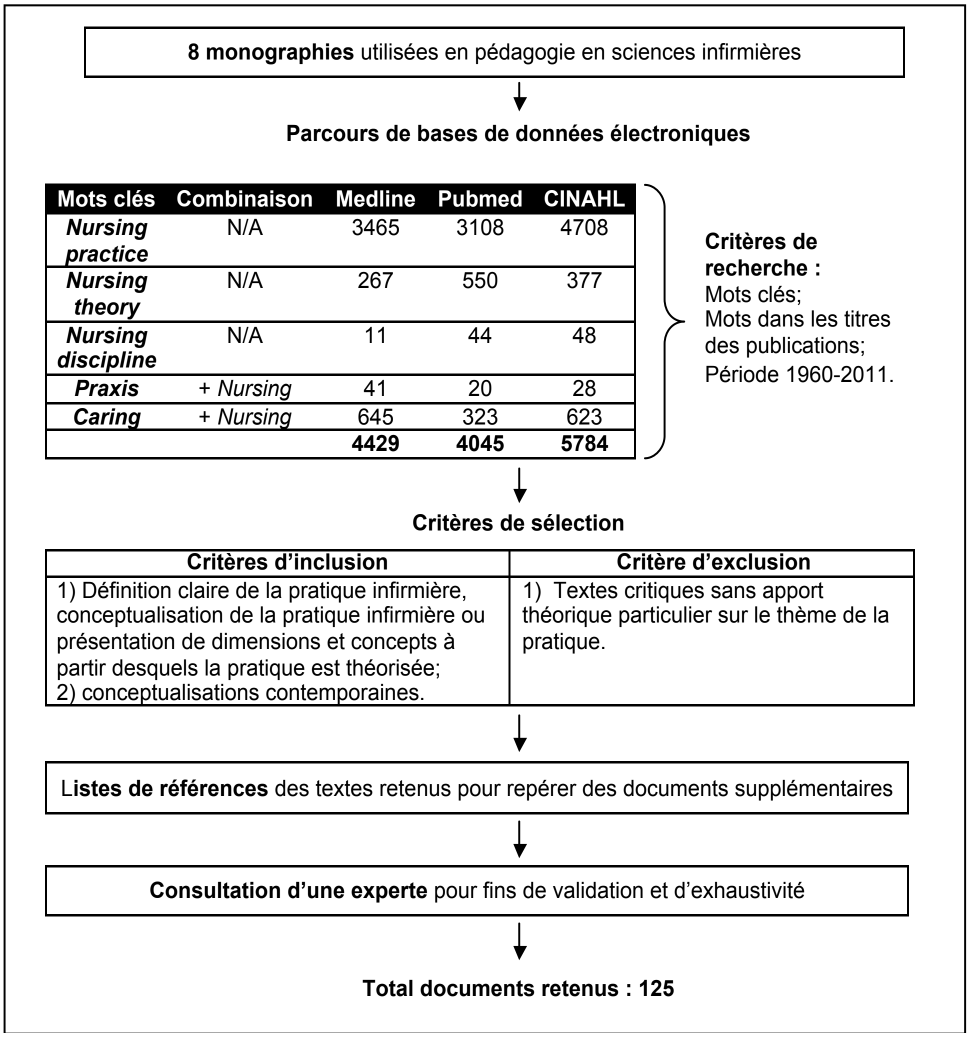
Ayant situé notre horizon théorique, nous avons procédé à une synthèse systématique des écrits portant sur les conceptions de théoriciennes infirmières au regard de la notion de *pratique infirmière*. Précisons ici que l'appellation « théoriciennes infirmières » correspond à la fois aux auteures qui ont contribué à l'élaboration du métaparadigme infirmier (les méta-théoriciennes), de même qu'à celles dont les travaux ont porté sur les concepts centraux de la discipline. Il s'agit donc de prendre appui sur ces écrits afin de contribuer au dialogue contemporain portant sur la théorie de la pratique infirmière.

Nous avons retenu une approche de synthèse des écrits qui privilégie le recours à un cadre théorique ou un modèle désigné à priori. Cette approche permet d'aiguiser la capacité interprétative en cours d'analyse.[45,46] Un cadre présélectionné sert ainsi de repère pour mettre en

Tableau 1: Formulation de questions à partir des composantes du modèle de Le Moigne

Composantes du modèle	Questions systémiques
Structure	Quels sont les éléments constitutifs de la pratique infirmière, en tant que système? Quels sont les acteurs vivants et non-vivants, quels sont leurs attributs?
Activités	Quelles sont les activités qui précisent le fonctionnement de la pratique infirmière?
Finalités	Quelles sont les projets et intentions poursuivis par les acteurs ou le système?
Environnement	Comment qualifier le contexte dans lequel se déroule la pratique infirmière?
Évolution	Quels éléments nous renseignent sur la capacité évolutive et transformationnelle de la pratique infirmière dans le temps?

Figure 2: Titre : Recension des écrits : Méthode



8 monographies utilisées en pédagogie en sciences infirmières

Parcours de bases de données électroniques

Mots clés	Combinaison	Medline	Pubmed	CINAHL
Nursing practice	N/A	3465	3108	4708
Nursing theory	N/A	267	550	377
Nursing discipline	N/A	11	44	48
Praxis	+ *Nursing*	41	20	28
Caring	+ *Nursing*	645	323	623
		4429	**4045**	**5784**

Critères de recherche :
Mots clés;
Mots dans les titres des publications;
Période 1960-2011.

Critères de sélection

Critères d'inclusion	Critère d'exclusion
1) Définition claire de la pratique infirmière, conceptualisation de la pratique infirmière ou présentation de dimensions et concepts à partir desquels la pratique est théorisée; 2) conceptualisations contemporaines.	1) Textes critiques sans apport théorique particulier sur le thème de la pratique.

Listes de références des textes retenus pour repérer des documents supplémentaires

Consultation d'une experte pour fins de validation et d'exhaustivité

Total documents retenus : 125

relation des éléments des écrits répertoriés et pour identifier des hypothèses de même que des pistes de réflexion et de développement théorique à poursuivre concernant le sujet à l'étude.[47] Dans cet article, le modèle présenté à la figure 1 constitue le point de repère permettant d'organiser la recension et l'analyse des écrits portant sur les conceptions de la pratique en sciences infirmières.

En particulier, des questions ont été formulées à partir des composantes du modèle de Le Moigne[43] afin de guider notre démarche. Tel que l'indique le tableau 1, une question a été formulée pour chaque composante du modèle et chaque écrit retenu pour cette recension a été examiné à la lumière de ces questions. En ce qui a trait à la *dimension structurelle* du système, il s'agissait d'identifier les acteurs vivants et non-vivants constitutifs de la pratique infirmière, selon leurs attributs. La dimension fonctionnelle, soit les *activités*, a permis de cerner les actions et processus de la pratique infirmière. Toujours selon les propos des théoriciennes en sciences infirmières, les *finalités* ont été examinées en termes d'intentions et de projets poursuivis à travers la pratique infirmière. L'*environnement* renvoie généralement aux contextes particuliers dans lesquels la pratique se déroule. Enfin, les éléments nous renseignant sur la capacité évolutive et transformationnelle de la pratique infirmière dans le temps ont été répertoriés sous la rubrique intitulée *évolution*. Ces questions ont permis l'organisation du contenu en vue de produire une modélisation systémique de la pratique infirmière comme agir complexe.

La figure 2 retrace le processus d'identification de documents ayant servi à cette recension. Premièrement, de récentes monographies utilisées en pédagogie en sciences infirmières et décrivant les travaux les plus marquants de théoriciennes de la discipline ont été consultées; par exemple: 17-19, 48, 49-52. Deuxièmement, les bases de données Medline, PubMed et CINAHL ont été explorées. La combinaison des mots clés suivants, apparaissant dans les titres des articles publiés au cours des cinquante dernières années (1960-2011), s'est avérée la plus productive: *nursing practice, nursing theory, nursing discipline, praxis+nursing, caring+nursing*. Ce parcours des bases de données a permis de recenser près de 6000 articles. Des critères de sélection ont ensuite été utilisés afin de cibler les documents à retenir : (A) les textes sélectionnés devaient offrir une définition claire de la pratique infirmière, proposer une conceptualisation de la pratique infirmière ou identifier des dimensions ainsi que des concepts à partir desquels elle est théorisée; et (B) lorsqu'un concept ou une idée avait changé à travers le temps, nous retenions que les propos les plus contemporains. Un critère d'exclusion a également été appliqué: les textes faisant principalement état d'une critique à l'égard de la contribution d'une théoricienne infirmière ou d'une conception de la pratique, plutôt qu'une proposition, ont été exclus. Troisièmement, les listes de références des textes retenus furent examinées pour y repérer des documents supplémentaires correspondant aux critères de sélection. Enfin, une experte détenant une connaissance approfondie des théories en sciences infirmières a complété et validé la liste de références, ce qui a contribué à assurer l'exhaustivité des ouvrages portant sur la théorie de la pratique infirmière.

Ainsi, seuls des textes de nature théorique ont été retenus. À cet égard, il importe de préciser que nous avons pris appui sur la définition de Watson quant au concept de théorie : « une théorie est un regroupement imaginatif de savoirs, d'idées et d'expériences qui sont représentés symboliquement et qui visent à élucider un phénomène donné» [traduction libre].[53, p1] Sachant que plusieurs théoriciennes en sciences infirmières n'ont pas nécessairement utilisé une démarche scientifique pour développer leur théorie[54], nos critères de sélection ont permis de composer avec des textes comportant une pluralité des modes de développement de savoirs en sciences infirmières.

Au total, 125 textes furent retenus, résumés, puis classés à l'aide d'une base de données bibliographiques *Endnote*. Chaque texte a fait l'objet d'une analyse thématique, laquelle constitue la technique la plus courante pour extraire le sens d'un ensemble de contenu narratif.[45] Les questions formulées à partir du modèle de Le Moigne[43] (voir tableau 1), ont permis d'organiser le matériel en huit thèmes qui distinguent les principales dimensions à partir desquelles les théoriciennes infirmières élaborent leur conception de la pratique.

Résultats

Le concept de pratique en sciences infirmières

Le tableau 2 présente les huit thèmes issus de la recension systématique des écrits, où chacun correspond à une composante du modèle de Le Moigne. À terme, nous avons jugé pertinent de retenir les quatre concepts centraux du métaparadigme infirmier, puisqu'ils précisent les caractéristiques de la discipline[55,56], orientent nos activités de développement de savoirs et guident la pratique[17,57-59]. Ces thèmes renvoient plus particulièrement au soin, à la personne, à l'environnement et à la santé. À ceux-ci s'ajoutent les thèmes de l'identité, des savoirs, de l'idéal moral humaniste de la pratique infirmière et de la réflexivité.

Dans ce qui suit, chaque thème est élaboré en relation avec une composante du modèle de Le Moigne.[43] Bien qu'un thème puisse alimenter la réflexion à propos de plus d'une composante, l'agencement proposé procède des réponses formulées aux questions systémiques présentées précédemment. Ce faisant, puisque les thèmes sont intimement liés les uns aux autres, leur mise en relation comporte un potentiel d'élargissement de notre réflexion à l'égard des conceptions de la pratique en sciences infirmières.

Tableau 2: Agencement des thèmes aux composantes du modèle de Le Moigne

Composantes du modèle	Thèmes issus de l'analyse thématique	Éléments de définition pour chaque composante du modèle
Structure	Personne Savoirs Identité	Éléments en interaction qui constituent le système et qui contribuent à son organisation. Acteurs vivants et non-vivants.
Activités	Soin	Aspect fonctionnel du système. Actions et processus.
Finalités	Santé Idéal moral humaniste	Intentionnalité du système et de ses acteurs. Projets qui mobilisent les acteurs, qui à leur tour, se transforment et contribuent à l'organisation du système.
Environnement	Environnement*	Espace au travers duquel le système fonctionne et se transforme.
Évolution	Réflexivité	Dimension temporelle du système. Trajectoire des transformations émergeantes et organisatrices du système.

* Le terme prend ici une signification différente de ce qui est généralement entendu par les théoriciennes infirmières.

La structure du système

La composante de la structure inclut trois thèmes, soit la personne, l'identité infirmière et les savoirs. Le premier thème renvoie aux acteurs vivants avec lesquels l'infirmière est en interaction dans sa pratique; tandis que les deux autres thèmes réfèrent à des éléments non-vivants qui composent la structure d'un système.

Dans la littérature recensée, le premier thème, celui de la *personne*, représente autant l'individu et la famille que le groupe et la communauté.[59-61] Ces derniers, toutefois, figurent comme des cibles plus marginales des interventions infirmières.[62] Par ailleurs, selon les conceptions de la pratique de théoriciennes, la personne possède des attributs différents. Des théoriciennes vont la décrire comme un être pan-dimensionnel unique, en croissance continue.[63,64] D'autres la présenteront comme un être détenant un pouvoir d'agir et un potentiel illimité de s'adapter aux expériences de santé et de maladie, d'interagir et de se transformer en relation avec son environnement; par exemple: 25,35,65,68.

En tant qu'élément non-vivant, mais distinctif de la structure de la pratique, le thème de *l'identité infirmière* est traité, soit directement ou indirectement, lorsque les théoriciennes conceptualisent le soin. Cette identité, en tant que soignante et accompagnante[69-71], non seulement façonne l'infirmière comme personne, mais introduit des frontières qui structurent la pratique. Bien que cette propriété identitaire ne soit pas exclusive aux infirmières, qui partagent l'univers des soins avec d'autres professionnels, elle incorpore un ensemble de valeurs, de normes professionnelles et légales, et de standards éthiques qui leur permettent de se distinguer au plan professionnel[72] et de contribuer à leur mandat social[73]. En somme, l'identité infirmière, principalement décrite à travers un ensemble de dimensions personnelles, interpersonnelles et sociohistoriques[69], est le fruit d'un ensemble de dispositifs et de conventions qui structurent la pratique et qui servent de repères aux infirmières pour concevoir leur champ d'action et de compétences.

Outre ces dispositifs liés à l'identité infirmière, les théoriciennes rendent également compte d'une diversité de modes de développement et d'application des *savoirs* pour guider la pratique.[17] À l'instar des propos des théoriciens de la sociologie de la traduction[74-77], les savoirs, en tant qu'objets techniques non-vivants, constituent un ensemble de théories et de représentations qui conjuguent des entités, qui mobilisent des échanges entres des acteurs et qui donnent une cohérence à l'action.[78] Les savoirs, sous leurs diverses formes, constituent ainsi des dimensions essentielles structurant la pratique infirmière comme système complexe. Les savoirs personnels, esthétiques, éthiques et empiriques[79] figurent parmi les plus discutés dans la littérature infirmière. Des auteures reconnaissent aussi la contribution des savoirs socioculturels, politiques et émancipatoires.[49,68,80] Les travaux de Carper[79], de Benner[81,82] ainsi que de Chinn et Kramer[48,49,83] soulignent avec éloquence la diversité et les alliances de savoirs possibles pour soutenir l'avancement de la discipline infirmière. Les méthodes et les théories à partir desquelles élaborer les connaissances pour la pratique sont des sujets récurrents des écrits recensés.[49,84] Ces savoirs divers, interconnectés, permettent de structurer notre pratique.

Les activités

La composante des activités réfère à l'aspect fonctionnel d'un système, aux modalités d'action, donc aux interventions ainsi qu'aux processus. En sciences infirmières, cela se traduit essentiellement par le thème du *soin*, qu'il soit abordé à travers les domaines de l'intervention clinique, de la formation, de la gestion ou de la recherche.[17] Il s'agit du sujet le plus discuté dans les écrits recensés. Le soin est présenté comme l'action fondamentale des infirmières dans les conceptions de la pratique de nombreuses théoriciennes (par exemple: 19,33,48,53,61,85-90), mais aussi comme une tradition essentielle de la discipline[71,89]. Sa généalogie, qui prend forme à travers les écoles de pensée infirmière, comporte une diversité de définitions. Peu importe le prisme à travers lequel il est étudié, le soin se positionne comme la raison d'être de la pratique infirmière[19], son activité première[85]. Des auteures conçoivent le soin comme une action humaine et relationnelle, à travers laquelle se transforment l'infirmière et le patient.[67,91-93] Que les théoriciennes infirmières conçoivent l'activité de soin comme étant centrée sur l'assistance à l'autre ou en tant que fonction d'accompagnement, que celle-ci mette plus ou moins d'emphase sur le développement de l'autonomie de la personne, l'accomplissement de ses besoins fondamentaux ou encore le renforcement de ses capacités d'adaptation (par exemple: 29,30,34,65,66,86,94), elle a généralement pour principales cibles l'individu et la famille[95]. Le soin, tout comme l'aspect fonctionnel du système complexe, n'est pas que technique. Sous cet angle, la pratique infirmière ne se résume pas qu'à un ensemble d'activités, mais recèle toutes les dimensions que représente le système de Le Moigne.

Les finalités

La composante des finalités de la pratique comme système complexe comporte ici deux thèmes, soit la santé et l'idéal moral humaniste.

La *santé* est résolument abordée de manière multidimensionnelle par les théoriciennes en sciences infirmières[96], à travers son caractère biophysique, comportemental, psychologique, social, culturel, spirituel ou environnemental; par exemple: 35,63,64,66,67,94,97,98.

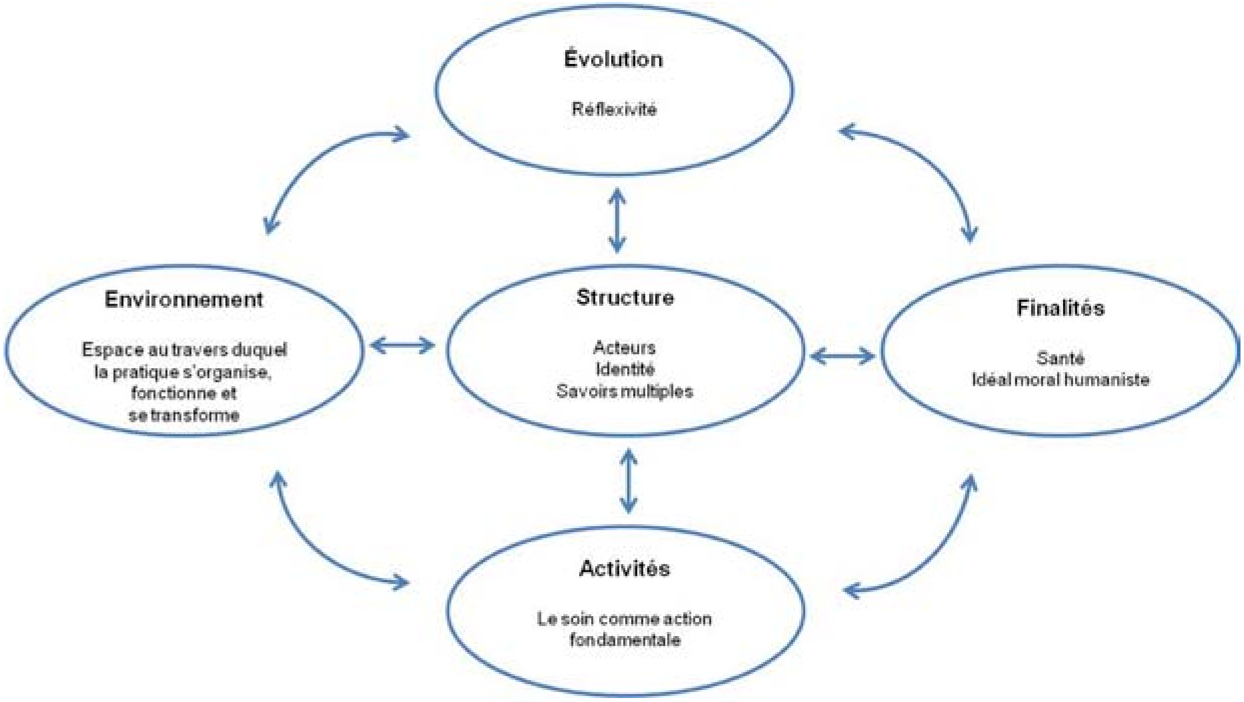
Elle constitue depuis déjà plus d'un siècle l'une des finalités de la pratique infirmière.[99,100] La santé est fréquemment conçue à partir d'une lentille médicale et comportementale, mais des auteures en sciences infirmières utilisent aussi une approche socio-environnementale et politique, qui tient compte de la relation de la santé aux environnements dans lesquels vivent et évoluent les acteurs.[101] La santé, souvent élaborée au travers du concept de soin par les théoriciennes infirmières, réfère aussi à une composante centrale de certaines conceptions de la pratique;[102] un projet autour duquel les infirmières se mobilisent.

Un *idéal moral humaniste* est également mis en évidence comme finalité de la pratique infirmière. Cette finalité de la pratique est aussi fréquemment élaborée en relation avec le thème du soin, soit l'activité à travers laquelle les infirmières contribuent à faire le bien dans la société; par exemple: 48,53,81,86,89,91,103-107. Pour certaines auteures[86,108,109], le champ de la moralité est inhérent à la pratique infirmière, puisque celle-ci implique l'obligation morale des infirmières de répondre aux besoins et de favoriser le bien-être de la personne. Les travaux de Benner[81] élaborent autour de cette prémisse et insistent sur le caractère indissociable de la moralité à la compétence infirmière, qui modèle et structure la capacité d'agir et d'être en relation des acteurs dans la pratique. L'idéal moral dont il est question s'inspire d'un ensemble de principes d'action et de valeurs humanistes[63,67,68,97], telles que la reconnaissance du potentiel de la personne et le respect de la dignité humaine[110-112], qui sont, pour certaines auteures[111,113), le reflet d'une pratique empreinte d'amour et de bonté. Le développement d'une éthique du caring[108,109], à laquelle réfèrent de plus en plus d'auteures en sciences infirmières, est un exemple de la manière dont cet idéal moral humaniste guide les infirmières dans leur pratique.

L'environnement

L'*environnement*, composante essentielle d'un système, est un thème central à plusieurs conceptions de la pratique infirmière.[19] À ce jour, il est principalement décrit comme un ensemble de facteurs qui influencent la personne, comme le contexte de soins, ou encore comme l'environnement immédiat du patient; par exemple: 35,60,64,66,68. Des propositions plus dynamiques sont aussi élaborées par certaines théoriciennes, qui utilisent les concepts abstraits de champ d'énergie[25,98] et de *patterns* co-constitutifs[63,97] pour le concevoir. Plusieurs théoriciennes reconnaissent que la personne est en interaction continuelle avec son environnement, particulièrement celles dont les travaux ont été influencés par la théorie des systèmes de Bertalanffy[20]; par exemple: 21,22-26,31-33,35,36,66,114. Ce qui caractérise les propos des théoriciennes infirmières, c'est principalement que l'environnement «entoure» la personne. Toutefois, la pratique infirmière conçue à partir

Figure 3: Modélisation de la pratique infirmière comme système complexe



Inspiré du modèle de Le Moigne[43]

d'une approche systémique situe l'agir dans/avec un environnement ouvert. L'environnement est ainsi considéré en tant qu'élément constitutif de la pratique infirmière. De cette manière, l'environnement comme concept central rend une signification différente.

L'évolution

L'évolution du système, sa transformation qui prend forme dans l'interaction dynamique entre ses différentes composantes, renvoie ici à la *réflexivité*. Cette composante est abordée par un nombre important de théoriciennes, notamment au travers de la dimension relationnelle de la pratique infirmière et de la notion de praxis.

La dimension relationnelle de la pratique, soit la relation infirmière-personne, est certainement au cœur des préoccupations de théoriciennes en sciences infirmières depuis plusieurs décennies.[18] Les travaux de Peplau[115] ou encore ceux d'Orlando[116] en sont des exemples éloquents. Dans le sillage de ces pionnières, la pratique est présentée comme une rencontre interpersonnelle entre l'infirmière et le patient; par exemple: 67,69,91. L'engagement de l'infirmière auprès de la personne soignée, que ce soit au plan moral, spirituel ou social, ainsi que la relation thérapeutique d'aide, sont ainsi abondamment abordés. Par ailleurs, il est désormais généralement admis que cette relation infirmière-patient comporte un potentiel émancipatoire de transformation mutuelle des acteurs; par exemple: 53,67,81,97,107,111. Ce processus, en soit, exige pour les infirmières de développer leur capacité réflexive, soit une conscience de soi et de l'autre[67,97,117], pour entrer en relation et cultiver cet espace relationnel. Dans un autre ordre d'idées, selon diverses auteures en sciences infirmières (par exemple: 6,7,118,119), la dimension relationnelle de la pratique prend forme dans la collaboration qu'il importe de créer, maintenir et renforcer entre les acteurs des différentes professions évoluant autour des personnes, familles ou communautés. De tels liens supposent des actions orientées vers un but commun et sont généralement conçus comme des avenues privilégiées pour assurer la qualité, la continuité et l'efficience des pratiques dans le système de santé actuel.[6] À travers ces liens entre les acteurs, c'est toutefois l'ensemble du système qui s'inscrit dans un processus réflexif de transformation. En particulier, l'espace de collaboration introduit des savoirs de divers acteurs, lesquels savoirs se transforment et transforment les pratiques.[120,121]

En ce qui a trait à la notion de praxis, un nombre grandissant de théoriciennes infirmières invoquent ce concept pour réfléchir la conjugaison, l'intégration et la co-construction de savoirs théoriques, du savoir faire et du savoir-être au cœur de la pratique infirmière.[92,122,123] L'alliance entre la théorie, la pratique et l'art du soin (par exemple: 84,101,123-129) interpelle ainsi des processus réflexifs qui permettent le partage, le développement de nouveaux savoirs et la transformation de la pratique infirmière[129]. Retenons ici que la praxis met de l'avant une épistémologie qui reconnaît la valeur des différentes formes de savoirs pour orienter la pratique infirmière.[128,130] Elle permet de dépasser une conception dualiste de la pratique infirmière en tant qu'art ou science[86] afin de réfléchir, plutôt, à l'interface et aux relations entre la théorie et la pratique. La réflexivité, thème fédérateur de la composante de l'évolution, revêt un potentiel particulier pour aborder la transformation de la pratique infirmière comme système complexe et pour appréhender le changement.

La figure 3 illustre l'agencement des huit thèmes aux composantes du modèle de Le Moigne.[43] Il est à noter que le modèle produit ne constitue pas, en soit, une représentation fixe ou finie.[42] Il s'agit plutôt d'un outil pour organiser nos connaissances et réfléchir à la question de l'agir complexe de la pratique infirmière. La pratique infirmière est représentée par l'ensemble des composantes en interaction. Les dimensions de la pratique étant inter-reliées, le fonctionnement de la pratique et ses acteurs, les environnements actifs dans lesquels elle s'exerce et les projets par rapport auxquels elle est identifiable sont tenus pour inséparables au système. Cela met en exergue l'aspect constitutif des composantes de la pratique infirmière conçue comme système complexe.

Discussion

L'analyse thématique des écrits, réalisée à l'aide du modèle de Le Moigne[43], a permis de proposer un cadre systémique pour réfléchir l'agir complexe de la pratique infirmière. Dans ce qui suit, nous présentons cinq contributions qui méritent d'être soulignées.

Premièrement, comme bon nombre de théoriciennes infirmières, ce cadre systémique situe le soin en tant qu'activité fondamentale de la pratique infirmière. Il n'en demeure pas moins qu'il ne s'agit pas de l'unique dimension de la pratique infirmière. Ce n'est que l'une de cinq dimensions à partir desquelles réfléchir et composer avec la complexité. La pratique ne se limite donc pas à sa dimension fonctionnelle, bien que celle-ci en soit une composante essentielle.

Deuxièmement, le modèle systémique nous invite à reconnaître la diversité d'acteurs et de savoirs qui structurent la pratique infirmière, ce qui n'est pas sans conséquences sur la poursuite du développement de théories sur notre pratique. Les acteurs incluent tant les bénéficiaires de soins et leur famille que les infirmières et les autres personnes ou collectifs avec lesquels elles collaborent. Ceci dit, la mise en évidence de l'élargissement du réseau d'acteurs au cœur de la pratique infirmière permet d'entrevoir l'élargissement du réseau de savoirs qui structurent la pratique, par le biais de la contribution des divers acteurs en présence. L'approche systémique nous invite ainsi à concevoir les acteurs, tant les infirmières que les personnes avec lesquelles elles interagissent, non seulement comme des sujets agissants, mais aussi comme des sujets pensants et connaissants[41], lesquels constituent, en retour, une ressource inestimable pour réfléchir à la pratique. Il s'agit de sources de savoirs complémentaires aux savoirs développés par les chercheures et théoriciennes infirmières. Vue de la sorte, le modèle systémique proposé ici soutient une plus grande implication d'une diversité d'acteurs dans les processus de développement de savoirs. Des approches de recherche qualitatives, narratives et participatives[131,132], faisant davantage de place aux différents points de vue dans les processus de développement des savoirs, s'avèrent donc des avenues plus que légitimes et prometteuses pour contribuer au développement de théories de la pratique infirmière; par exemple: 84,85,119,123,126. En somme, une modélisation systémique de la pratique infirmière, comme repère au développement de savoirs, comporte le potentiel de faire émerger la richesse de la diversité des perspectives et des points de vue des acteurs afin d'enrichir notre compréhension de l'agir dans la complexité.[132]

Troisièmement, la composante des finalités nous invite à reconnaître l'intentionnalité de la pratique conçue comme système, qui selon Morin[38], ne peut être complètement prévisible ou contrôlable. Elle nous convie, en particulier, à considérer l'intentionnalité des acteurs, soit les projets qu'ils poursuivent et qui façonnent leur pratique[38,41-43], de telle sorte que celle-ci n'est ni neutre, ni dénuée de sens[38]. À partir d'une telle conception, on peut soutenir, par exemple, que la pratique est portée par des acteurs stratégiques dotés d'intentions, d'intérêts et de projets, qui, de surcroît, peuvent être divergents.[133] Une telle perspective peut alors servir de fondement à une vision plus politique de la pratique infirmière.[134]

Quatrièmement, ce cadre systémique pour réfléchir l'agir complexe nous invite à reconnaître l'environnement comme un élément *constitutif* de la pratique infirmière.[42] Il s'agit de concevoir l'environnement comme dimension qui informe, transforme et est transformé par la pratique, plutôt que de le situer comme un déterminant exogène de la pratique.[135] Plusieurs théoriciennes en sciences infirmières abordent le concept central d'environnement et certaines (par exemple: 25,63,97,98) proposent même de le concevoir de manière dynamique. Toutefois, tel que précisé plus tôt, les concepts à partir desquels elles élaborent cette dimension de l'environnement demeurent plus ou moins élaborés.[18,50] Par ailleurs, la lentille systémique permet de dépasser les propos de théoriciennes infirmières qui soulignent l'interrelation continue, mutuelle et simultanée de la personne à son environnement[136], en rappelant que l'environnement n'est pas qu'en interaction dynamique avec des acteurs, mais est également en interrelation avec les acteurs non-vivants, les activités et les finalités de la pratique. À ce stade de notre analyse, nous sommes d'avis que le concept d'environnement en sciences infirmières est un aspect qui mérite véritablement une élaboration théorique plus poussée. À ce propos, il pourrait être pertinent de référer aux théoriciens en sciences de l'environnement, en design ou en architecture par exemple, pour concevoir l'action et l'agir dans un espace ouvert et ainsi élaborer davantage l'idée que la pratique infirmière est *modulée* par et *module* l'environnement.

Cinquièmement, la lentille systémique développe notre sensibilité à l'égard de l'aspect réflexif de la pratique infirmière. Toutefois, cette réflexivité ne se résume pas qu'à la réflexion dans l'action[137] et à la praxis, telle que souvent abordée par les théoriciennes infirmières; par exemple: 84,101,124-129,138. Nous l'avons abordé plus tôt, la modélisation proposée nous invite, en quelque sorte, à réfléchir la pratique comme un espace social et politique d'interactions, lesquels comportent un potentiel de transformation. À cet égard, des théoriciens du social (par exemple: 74,78), ayant développé leur pensée sur ces processus transformateurs, devraient être davantage considérés dans l'élaboration de la théorie de la pratique infirmière. De manière plus spécifique, la réflexivité renvoie à la nature changeante du monde dans lequel la pratique se déroule, de même qu'aux processus à partir desquels elle se transforme en transformant le monde. Les travaux de Giddens et de Beck[139,140] sur la modernité réflexive ainsi que ceux d'Edgar Morin sur la causalité récursive[38] constituent des contributions significatives pour réfléchir la réflexivité inhérente de la pratique infirmière, c'est-à-dire, les processus à partir desquels les pratiques changent et produisent du changement.

Un dernier commentaire s'impose afin de mettre en perspective ces composantes et contributions potentielles de notre modélisation de l'agir complexe de la pratique infirmière. Nous l'avons vu, une lentille systémique comporte un tissu d'interactions entre les éléments constitutifs d'un système.[38,42-44] Ceci nous permet de relier plutôt que de disjoindre chacun de ces éléments, et voire même, à travers leurs interactions, de faire émerger des qualités nouvelles du système. L'émergence est une propriété systémique qui semble offrir un riche potentiel pour la poursuite du développement de nos théories de la pratique infirmière. L'approche systémique adoptée ici n'est donc pas un outil d'analyse[44] qui propose une série d'étapes particulières à suivre ou qui vise à expliquer un phénomène par l'étude de ses parties ou en prédire les conséquences.[38,42,44]

Ainsi, le modèle de Le Moigne et notre modélisation qui en résulte ne nous permettent pas de prétendre à une théorie «achevée» de la pratique infirmière. Les cinq composantes et contributions potentielles de notre modélisation pour appréhender l'agir complexe de la pratique infirmière ou son élaboration théorique ne doivent être considérées ni prescriptives, ni dogmatiques.[141] Il s'agit de repères qui soulèvent des questions et qui peuvent créer une ouverture sur l'émergence. À notre avis, les questions relatives à l'organisation, au fonctionnement ou à l'évolution de systèmes complexes, pour tenter de rendre plus intelligible et communicable sa complexité, développent notre sensibilité, voire notre acuité, pour la poursuite de l'élaboration théorique de la pratique infirmière.

Conclusion

Cet article propose une conception systémique de la pratique infirmière qui permet de l'appréhender dans sa complexité, tout particulièrement comme un agir complexe. Il s'agit d'une proposition qui situe la complexité non seulement au niveau du monde dans lequel pratique l'infirmière, mais au cœur même de sa pratique. Par ailleurs, l'analyse thématique des écrits de théoriciennes infirmières s'est avérée un point de départ intéressant à partir duquel réinterpréter, à la lumière du modèle systémique de Le Moigne, les thèmes autour desquels elles élaborent leurs conceptions de la pratique. De surcroit, cela a permis d'apporter un nouvel éclairage à la complexité de la pratique infirmière, particulièrement à travers les liens qu'on peut établir entre les différentes composantes qui lui sont constitutives.

Partant de la modélisation proposée, il importe toutefois de poursuivre notre réflexion. En particulier, tout comme certaines auteures en sciences infirmières[142-146], nous sommes d'avis qu'il importe d'élargir le répertoire des théories sociales auxquelles référer pour conceptualiser plus finement la pratique infirmière, comme son agir complexe. Par exemple, la modélisation systémique proposée suggère que le soin, bien qu'une dimension essentielle de la pratique infirmière, gagnerait à être théorisé selon des dimensions structurelles, téléologiques et spatio-temporelles. Ceci permettrait de poursuivre l'élaboration, à la fois, de ses dimensions relationnelles, stratégiques, politiques et dynamiques. Enfin, la réflexivité de la pratique infirmière que souligne notre modélisation semble constituer une piste à partir de laquelle élaborer le sens du concept fondamental de l'environnement dans nos modèles, théories ou philosophies en sciences infirmières. L'environnement, abordé comme une composante constitutive de la pratique infirmière, trouve une résonnance certaine avec des théories sociales qui élaborent la modernité réflexive[139,140] ou, encore, la causalité récursive des processus humains[38]. Concevoir la pratique infirmière comme étant réflexive suggère à la fois qu'elle change et génère du changement. Cela crée inévitablement de la complexité, qui quoiqu'imprévisible, demeure intelligible grâce à la modélisation.

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4

Résumé
Certains nouveaux anticancéreux sont extrêmement onéreux et apportent peu de bénéfices par rapport à leur coût. La question d'inscrire ou non ces médicaments sur la liste des produits assurés a récemment donné lieu à des débats houleux. L'opinion publique sur les enjeux sociaux se construit en grande partie à partir de ce qui se dit dans les médias. Notre objectif est d'identifier et d'analyser les principaux thèmes et de voir dans quelle mesure cette couverture est équilibrée. Nous avons procédé à une analyse thématique des articles de journaux qui soulevaient la question de l'accès aux anticancéreux. Nous avons aussi codé les articles en fonction de leurs sources. Les contenus analysés sont largement en faveur d'une plus grande couverture publique. Les sources les plus proéminentes sont celles qui sont le plus enclines à défendre un plus grand accès. De plus, les histoires de patients mourant se voyant refuser l'accès à des médicaments ont une valeur médiatique considérable.

Mots clés accès, anticancéreux, évaluation des médicaments, médias, journaux

La question du remboursement des anticancéreux onéreux telle que présentée dans les journaux Canadiens

DAVID HUGHES & JOHANNE COLLIN

Introduction

Les nouveaux médicaments onéreux représentent un défi considérable pour les décideurs. Ces derniers ont le mandat d'assurer, dans des délais raisonnables, l'accès par les patients à des médicaments sécuritaires et efficaces. Ils ont aussi le mandat d'utiliser l'argent des contribuables de manière responsable et efficiente tout en allouant les ressources équitablement entre les groupes de patients atteints de différentes conditions cliniques. Enfin, ils doivent contrôler l'augmentation des dépenses en médicaments de manière à préserver la pérennité de l'offre et à s'assurer que les générations futures aient aussi un accès équitable aux médicaments. L'*efficience*, l'*équité* et la *pérennité* peuvent entrer en conflit avec l'*accessibilité*. Il s'agit alors de trouver un équilibre entre ces différents objectifs.

Certains nouveaux anticancéreux sont extrêmement chers et apportent peu de bénéfices par rapport à leur coût. La question d'inscrire ou non ces médicaments sur la liste des assurances publiques provinciales a récemment donné lieu à des débats houleux. Les journaux ont rapporté ces débats ou en ont été le théâtre. Les médias ont le pouvoir d'influencer l'agenda politique. Entre autres, cette influence s'exerce sur l'établissement des priorités en matière de soins de santé, notamment sur les décisions de rembourser les anticancéreux.[1-3]

Parce qu'elle peut entrainer une limitation de l'accès aux médicaments, la mise en place d'une politique efficiente et équitable d'assurance médicament requiert l'adhésion du public. L'opinion publique sur les enjeux sociaux se construit en grande partie à partir de ce qui se dit dans les médias. Mais les citoyens sont-ils exposés à une couverture complète et équilibrée de la problématique des anticancéreux onéreux? Ont-ils tous les éléments leur permettant de se faire une opinion informée? Dans cette étude, nous avons entrepris d'analyser le contenu des journaux canadiens sur la question de l'accès aux anticancéreux.

Cadre théorique

La production des contenus médiatiques

Les contenus médiatiques sont façonnés par un ensemble de facteurs. Les sources sur lesquelles s'appuient les médias ont un impact important sur les contenus. Pour la couverture médiatique de la santé et de la maladie, les sources privilégiées sont les professionnels de la santé, les revues scientifiques ainsi que les communiqués de presse.[4-6] De plus, l'industrie pharmaceutique s'impose comme une source incontournable. Lors du lancement d'un nouveau médicament, certains fabricants organisent des conférences de presse et distribuent des trousses comprenant un assemblage d'informations sur le médicament, de communiqués de presse et de citations d'articles scientifiques et d'experts.[7] Certains observateurs accusent l'industrie d'utiliser les médias afin de discréditer le travail des agences d'évaluation lorsque leurs décisions ne sont pas favorables à leurs produits.[8,9] Sur certains enjeux, d'autres acteurs comme les groupes de défense des patients passent aussi par les médias pour faire valoir leurs intérêts.[2]

Les sources ont un rôle fondamental dans la formation des contenus. Cependant, il faut aussi que les contenus soient d'un certain intérêt pour les médias eux-mêmes, qu'ils aient une certaine valeur médiatique (*news value, news worthiness*). De nombreuses études se sont employées à dégager les caractéristiques que doivent posséder les contenus médiatiques.[10-13] Un des principaux indicateurs de valeur médiatique est le « *human interest* », c'est-à-dire la charge émotive de l'événement, son caractère spectaculaire ou dramatique.

Dans son étude de la couverture médiatique de la santé et de la maladie, Seale[14] s'inspire d'un courant en études des médias qui applique aux contenus médiatiques une méthode d'analyse des récits. Ces dernières ont révélé l'existence de structures narratives fondamentales constituées d'oppositions telles que le bien et le mal, le bon et le méchant, l'ordre et le désordre, le danger et la sécurité, etc. qui se succèdent pour générer une tension dramatique et des émotions chez le récepteur. Dans sa forme la plus simple, le récit commence par un ordre initial, puis un élément « malfaisant/maléfique » vient perturber l'équilibre, faisant des victimes au passage, souvent bonnes et innocentes, l'ordre est par la suite rétablit par l'intervention d'un élément bénéfique, souvent magique ou héroïque. Chaque article ou reportage particulier ne contient pas toujours tous les éléments narratifs fondamentaux. Cependant, le paysage médiatique pris comme un tout réunit l'ensemble des oppositions présentes dans un récit. En présence d'un de ces fragments, le récepteur peut remplir les trous, reconstruire la trame complète à partir du stock de connaissance qui lui vient de la culture médiatique.

Appliqués aux contenus médiatiques sur la santé, ces idées apportent un éclairage intéressant. Les éléments compris dans un fait de santé remplissent chacun une fonction narrative, deviennent le terme d'une opposition dans le paysage médiatique consacré à la santé : A- le malade joue le rôle de la victime ou du héro luttant pour sa vie; B- les professionnels de la santé et les chercheurs sont aussi des héros; C- les médicaments et biotechnologies font office de baguettes ou de potions magiques; D- le danger ou le vilain sont incarnés par les agents pathogènes de toutes sortes, la maladie, la nourriture contaminée, un personnage malveillant, etc.

Les histoires de cas sont souvent employées dans les médias car elles permettent au lecteur de mieux s'identifier à la « victime » et de susciter un sentiment d'empathie. Plus la victime est vulnérable, plus son sort est tragique, plus la tension dramatique est grande.[14] L'idéal type est ainsi l'enfant malade, comme en témoigne la couverture exceptionnellement importante qu'a reçue le cas de Jaymee Bowen, cette enfant atteinte de leucémie à qui les autorités avaient refusé un traitement expérimental onéreux.[15]

La nature des contenus médiatiques

De nombreuses études ont fait l'analyse des contenus médiatiques sur le cancer. Ces analyses ont révélé que les médias se focalisent sur le caractère « effrayant » de cette maladie, empruntent principalement la perspective biomédicale et négligent les facteurs sociaux et environnementaux.[16-26] Par ailleurs, des analyses des contenus médiatiques sur les médicaments ont révélé une accentuation des bénéfices et/ou un manque important d'information sur les risques et effets indésirables.[7,27,28] Les études des contenus sur les médicaments contre le cancer vont dans le même sens[3,23,29-32]. De plus, la couverture se concentre davantage sur les visées thérapeutiques et ignorent les usages palliatifs, donnant ainsi une image démesurément positive des anticancéreux.[33]

À notre connaissance, seulement trois (3) articles analysent les contenus médiatiques sur l'accès aux anticancéreux.[3,29,34] Une seule de ces études porte sur les journaux canadiens mais elle se focalise sur un seul médicament, Herceptin, et emploie une méthode quantitative.

Dans le cadre de l'étude actuelle, nous procédons à l'analyse qualitative du contenu des journaux canadiens sur l'accès aux anticancéreux. Notre objectif principal est d'identifier et d'analyser les principaux thèmes puis de voir dans quelle mesure cette couverture est complète et balancée. Un deuxième objectif est de voir dans quelle mesure la nature ces contenus s'expliquent par les sources choisies et par la notion de « valeur médiatique ». Pour ce faire, notre étude combine une approche « politique », fondée sur l'influence des sources et leurs intérêts d'une part, et une approche fondée sur la valeur médiatique et inspirée des travaux de Clive Seale d'autre part.

Méthode

Nous avons sélectionné 16 quotidiens en fonction de l'importance du tirage et la représentativité régionale (tableau 1). Les articles ont été identifiés et collectés à partir de la base de données *Eureka* (pour les journaux francophones) et *ProQuest-Canadian Newsstand* (pour les journaux anglophones). Les journaux de Terre-Neuve (*The Telegram* et *The Western Star*) et du Yukon (*The Whitehorse Star*) n'ont pas été inclus parce qu'ils ne sont pas accessibles via Canadian Newsstand. Les Territoires du Nord-Ouest ne publient pas de quotidien.

La période couverte s'étend du 1 janvier 2010 au 31 juillet 2011. Nous avons effectué une recherche à partir des termes « cancer ET médicaments », « cancer AND drugs ». Nous avons retenu les articles qui soulevaient la question de l'accès aux anticancéreux. Nous avons aussi essayé d'autres mots clés tels que « leucémie / *leukemia* », « hodgkin » et « chimiothérapie / *chemotherapy* » sans obtenir de nouveaux articles traitant de la question du remboursement.

Nous avons intégré tous les articles retenus (n=80) dans le logiciel *NVivo* et avons procédé à une analyse thématique des articles. Les textes ont été codés de manière à faire

Tableau 1: Échantillon

Province	Articles / province	Journal	Propriétaire	Tirage / semaine*	Articles / journal
Nouvelle-Écosse	0	The Daily News	Transcontinental Inc.	33 562	0
Île-du Prince-Édouard	0	The Guardian	Transcontinental Inc.	110 453	0
Nouveau-Brunswick	9	Telegraph Journal	Brunswick News Inc.	197 667	9
Québec	24	La Presse	Power Corp. of Canada	1 505 992	11
		Le Devoir	Indépendant	178 363	6
		The Gazette	Canwest Mediaworks Publications	1 144 504	7
Ontario	29	The Globe and Mail (national)	CTV Globemedia Inc.	1 891 629	19
		Toronto Star	Torstar	2 199 214	3
		Natinoal Post (national)	Canwest Mediaworks Publications	939 874	7
Manitoba	0	Winnipeg Free Press	F.P. Canadian Newspapers Ltd.	895 323	0
Saskatchewan	5	The Star Phoenix	Canwest Mediaworks Publications	324 840	2
		The Leader Post	Canwest Mediaworks Publications	291 665	3
Alberta	7	Edmonton Journal	Canwest Mediaworks Publications	830 343	7
		Calgary Herald	Canwest Mediaworks Publications	872 247	0
Colombie-Britannique	6	The Vancouver Sun	Canwest Mediaworks Publications	1 053 434	4
		The Province	Canwest Mediaworks Publications	976 588	1
		The Times Colonist	Canwest Mediaworks Publications	454 408	1
Total	80				80

* Penney S. The Circulation Data Report 2009. Toronto: Canadian Newspaper Association, 2010.

Tableau 2: Sources

Sources	**Nombre d'articles (%)**
Groupe de défense des patients	38 (48)
Oncologue et/ou chercheur biomédical	32 (40)
Patient individuel et proches	28 (35)
Représentant du gouvernement	24 (30)
Expert/chercheur non-biomédical	10 (13)
Agence d'évaluation	8 (10)
Industrie pharmaceutique	1 (1)

émerger, sans grille préalable, les thèmes en lien avec l'accès aux anticancéreux. Nous avons aussi codé les articles en fonction de leurs sources.

Résultats

1. Les sources

Les sources qui ont le plus souvent la parole dans les journaux canadiens sur les questions d'accès sont les groupes de défense des patients, les oncologues et chercheurs biomédicaux, ainsi que les patients individuels et leurs proches. Viennent ensuite les représentants gouvernementaux, les experts et chercheurs des domaines non biomédicaux, les agences d'évaluation et l'industrie pharmaceutique (tableau 2).

2. Les thèmes

La variation interprovinciale

La variation de l'offre de médicaments entre les provinces est le thème le plus récurrent. Il est employé comme argument en faveur d'une plus grande couverture publique des anticancéreux. Il apparait dans 51 articles (tableau 3). Ce thème renvoie à ce qu'on appelle parfois « la loterie du code postal » (*postcode lottery*) selon laquelle l'offre de services varie en fonction de la location géographique. Il s'agit de souligner qu'un médicament n'est pas offert dans une province alors qu'il l'est dans une autre :

> Bill Niblock has the same cancer as hundreds of others in Canada, but he can't obtain identical treatment. Because he lives in Ontario, he will receive a lesser

Tableau 3: Principaux thèmes

Thèmes	**Nombre d'articles (%)**
Variation interprovinciale	51 (64)
Coûts pour les patients	50 (63)
Efficacité des médicaments	37 (46)
Coûts pour les assureurs	34 (43)
Lenteur du processus d'évaluation	20 (25)
Efficience / coût-bénéfice	14 (18)
Refus = condamnation à mort	11 (14)
Données épidémiologiques	8 (10)
Dépenses générales en médicaments	5 (6)
Allocation entre groupes de patients	5 (6)
Prix de la vie	5 (6)
Investissements locaux des pharmas	3 (4)
Fixation des prix par les fabricants	1 (1)

> therapy, making him the victim of what experts label a geographic lottery. (...) If he lived out west, he would be prescribed rituximab in British Columbia, Manitoba and Saskatchewan. (GM : 2010.01.05)

> Both are Andrew Goodridge et Shirley Elford are victims of the Canadian healthcare system. The quality of care cancer patients receive may vary according to the province they live in. (TS : 2011.05.31)

> Quant aux six médicaments rejetés par le Conseil du médicament, en Ontario ou en Colombie-Britannique, ils sont soit en cours d'étude soit déjà sur les listes des médicaments acceptés. (Pr : 2010.11.24)

> It's not fair (…) that some provinces fund some therapies while other provinces do not. (Gz : 2011.05).

L'argument est surtout employé en Ontario et au Québec. Cependant, même en Colombie-Britannique où l'offre d'anticancéreux est la plus généreuse, on le rencontre à l'occasion :

> The drug is not funded in British-Columbia. (…) Tykerb is funded in other provinces. Why can someone living in Nova Scotia who has metastatic breast cancer get coverage for this drug but I can't? (GM : 2011.05.20)

En Ontario, les médias ont beaucoup parlé d'un cas sensiblement différent de « *postcode lottery* ». La variation interprovinciale en question ne porte pas sur la disponibilité du médicament mais sur les critères d'éligibilités à ce médicament. En effet, contrairement à plusieurs autres provinces, l'Ontario ne couvrait Herceptin que pour les personnes atteintes du cancer du sein présentant une tumeur de plus de 1 cm. Comme dans les cas de remboursement, la comparaison avec les autres provinces est un moyen de souligner le caractère inéquitable de la situation :

> That Ontario medical guideline is in contrast to British Columbia, Alberta and Saskatchewan, all of which cover the drug for smaller tumours. (GM : 2011.03.09)

Le débat ontarien entourant Herceptin pour les petites tumeurs a été personnifié par Jill Anzarut, une mère de 35 ans. Le cas apparait dans 9 articles ontariens de mars à mai 2011 :

> … Ms. Anzarut, mother to Benjamin, 4 and Laila, 2, begins her first day of chemotherapy, still uncertain whether the Herceptin she needs to start in May will be publicly funded. (GM: 2011.03.09)

> Jill Anzarut, 35, made a last-ditch attempt to obtain the drug Herceptin through Ontario's exceptional access program. She found out from her oncologist on Thursday that her request was turned down. "I feel defeated. I don't know what I expected to happen, (...) I feel like I am fighting a constant uphill battle". (Gz: 2011.03.11)

Lorsque le gouvernement accepte finalement de payer Herceptin, Jill Anzarut est présentée comme une championne de la cause :

> Jill Anzarut, a thorn to government, a champion to breast-cancer activists. (GM : 2011.05.13)

Au Nouveau-Brunswick, l'argument de l'iniquité interprovinciale ne porte pas tant sur la disponibilité des anticancéreux que sur leur financement. Dans les articles, on rappelle souvent que la province est une des deux seules à ne pas offrir d'assurance publique pour les médicaments onéreux :

> New Brunswick and Prince Edward Island are the only two provinces in Canada without catastrophic drug plans. (TJ : 2010.06.16)

Les coûts financiers pour les patients

Les coûts pour les patients est un autre argument fréquemment utilisé en faveur d'une plus grande couverture publique. Il apparait dans 50 articles (tableau 3). Ces coûts sont très souvent chiffrés. Les chiffres avancés vont de 20000$ à 75000$ par année, 65000$ par année étant le montant le plus souvent évoqué. Certains articles rappellent aussi les conséquences catastrophiques de ces coûts sur les finances personnelles des patients :

> Certaines personnes âgées doivent retirer leur REER [régime enregistré d'épargne-retraite] pour éponger leurs dettes médicales. (Dv : 2010.08.06)

> Many patients end up selling their homes or going bankrupt to pay for new therapies not yet approved by Quebec. (Gz : 2011.05.20)

Le cas de Kelly Mah, qui a été repris dans 3 autres articles, présente une histoire dramatique à laquelle le lecteur peut s'identifier :

> Subsequent to the chemotherapy, I was advised that I would be taking a new drug called Lapatinib (also known as Tykerb) and would take it for the rest of my life if it was successful in managing my cancer. What I learned was that Lapatinib is not covered under Alberta Health Care, nor is it covered under Blue Cross and as such, will cost me $3,500-$4,000 per month. Both my husband and I have good jobs, but a cost of $3,500-$4,000 a month for the rest of my hopefully long life would be financially crippling. I became so stressed and depressed that I even contemplated forgoing the drug and letting nature take its course. I mean how could I feel good about financially ruining my family? I didn't want to leave my family struggling for money just to keep me alive. (EJ : 2010.11.12)

Le cas Andrew Goodridge illustre le même dilemme tragique:

> When Andrew Goodridge, a Fredericton property manager, was diagnosed with colorectal cancer in

> March 2009, he faced a Solomon-like decision: financial ruin or the funeral home. (GM : 2010.09.30)

L'efficacité des anticancéreux

Trente-sept (37) articles contiennent des énoncés qui portent sur l'efficacité des anticancéreux. Selon la très grande majorité de ces énoncés, les médicaments sont efficaces. Cependant, la plupart des articles contiennent très peu de détail sur la nature et l'ampleur de cette efficacité :

> … life-prolonging biologics such as bevacizumab (Avastin)… (GM: 2010.01.29)
>
> … medical evidence showing patients live longer when on it … (GM: 2010.05.13)
>
> ... potentially life-saving cancer drugs... (NP: 2011.03.22)
>
> ... targeted therapies with drugs are crucial to prolonging the lives of patients. (Gz: 2010.07.17)
>
> … certainement plus efficaces en termes de prolongement et de qualité de vie. (Dv: 2010.08.06)
>
> … they [patients] respond for years to a pill that causes a little bit of diarrhea… (Gz : 2010.12.03)
>
> …un médicament très efficace lorsqu'un cancer du sein fait des métastases. (Pr: 2010.12.09)
>
> …had been shown to significantly extend the lives of people suffering from acute myeloid leukemia... (Gz: 2010.12.18)

D'autres énoncés, tout aussi vague sur l'efficacité, sont cependant plus enthousiastes :

> The drug has turned one of the most aggressive forms of the disease into the most treatable. (GM: 2011.05.13)
>
> Les plus récents médicaments contre le cancer, qui font déjà des miracles dans d'autres provinces… (Dv: 2010.12.09)

Dans 6 articles, l'efficacité est principalement anecdotique et fondée sur des histoires de cas :

> I am the living proof that Tykerb works and is worth fighting for. (EJ: 2010.12.05)
>
> I'm living testimony that on the right treatment you can stay stable, and you can stay well. (LP: 2010.07.17)

Onze (11) articles quantifient d'une manière ou d'une autre l'efficacité des médicaments. Quatre (4) de ces articles expriment cette efficacité en termes relatifs qui ont peu de signification pour le lecteur :

> Herceptin, when used with chemotherapy, has been found to half the rates of recurrences within four years of diagnosis. (GM : 211.03.09; 2011.03.18; 2011.03.21)
>
> Torisel significantly increased survival from diagnosis to death by 49 per cent. (LP: 2010.03.24).

Seulement 7 articles expriment l'efficacité de manière plus comprehensible et accessible :

> … the initial study of Tykerb in recurrent HER2-positive breast cancer provided an improvement in overall survival of about 10 weeks for the group who received chemotherapy and Tykerb compared with the group who received only single-agent chemotherapy. (GM: 2011.05.20)
>
> Avastin was found to increase the survival time by 4.7 month for patient with colorectal cancer, and by two month for patients with lung cancer. (SP: 2010.12.30)

Enfin, 12 articles mentionnent des cas où les anticancéreux sont inefficaces et/ou signalent des effets secondaires. Cependant, dans 7 de ces articles, lorsqu'on évoque l'inefficacité de certains médicaments c'est pour souligner la nécessité d'avoir recours à un autre médicament efficace dans ce cas :

> For some, Tykerb is the last line of defense after the cancer drug Herceptin is no longer effective. (TS : 2010.05.13)
>
> Because radiation and chemotherapy are ineffective in treating kidney cancer when it has spread to other parts of the body, what are known as targeted therapies with drugs are crucial to prolonging the lives of patients. (Gz: 2010.07.17)

La lenteur du processus d'évaluation

Vingt (20) articles soulèvent la question du temps que prend le processus d'évaluation des nouveaux médicaments. Dans la très grande majorité des articles, on déplore le fait que le processus soit trop lent :

> … the public policy think-tank, the Fraser Institute, reported that the slow drug approval process and delays by provincial drug plans in approving the medicines for reimbursement keeps some Canadians from getting the best care. (VS: 2010.03.25)
>
> The biggest problem arises with newer drugs (...), often funding comes years after approval by health Canada. (GM: 2010.03.25)
>
> The drug Torisel was approved by Health Canada in 2007, but provinces have been slow to agree to add it to their drug plans. (Gz: 2010.07.17)

Seule la Colombie-Britannique est présentée positivement sur ce plan:

> "We have access to a large number of drugs and we have access to them early," says Charles Blanke, the B.C. Cancer Agency's vice-president of systemic therapy. (TS: 2011.05.31)

La condamnation à mort et le prix de la vie

Onze (11) articles contiennent des énoncés selon lesquels la décision d'inscrire ou non un médicament est une décision entre la vie et la mort :

> How dare Zwozdesky have the authority to decide who lives or die? (EJ: 2010.12.09b)
>
> ... il faut le dire franchement, il y a des gens qui meurent à la suite de ce refus. (Dv : 2010.11.27)
>
> Des Québécois meurent inutilement du cancer chaque année parce que le gouvernement leur refuse l'accès à des médicaments de pointe… (Pr : 2010.12.09)

Ce thème est lié à celui de l'efficacité puisqu'il implique indirectement que les médicaments sauvent la vie.

Encore une fois, les histoires de cas sont employées pour incarner ce point. M. Niblock, un ontarien de 68 ans atteint de leucémie lymphoïde chronique, n'a pas accès à rituximab:

> Without the drug, I will fatigue away and it will overcome my system it will kill me. (GM: 2010.01.05)

Une autre patiente, Deborah Warkus,

> spent the last moments of her life fighting the Ontario health ministry to gain access to a $4,000-a-month drug to treat her invasive breast cancer. By the time the province agreed, it was too late and the 50-year-old Brampton mother died. (TS: 2010.11.20)

Benoit Bisson, un père de famille atteint du cancer du rein :

> Maintenant que l'Afinitor n'arrive plus à contenir la progression de mon cancer du rein, je dois passer à un autre médicament. Mon uro-oncologue m'a prescrit du Sutent. Il veut aussi me prescrire du Zometa. Pour les mois qui viennent, je suis à la merci de la décision d'un Conseil auquel je ne comprends rien, comme un jury qui a sur moi un droit de vie ou de mort. (Pr : 2010.11.27)

Dans le même registre, 5 articles soulèvent la question du prix de la vie :

> Is the government playing god? (…) They've put a price on human life. (TS : 2010. 11.20)
>
> Si la vie a un prix au Québec, qu'on le dise ouvertement et publiquement. (Pr : 2010.10.22; Pr : 2010.11.24; Dv : 2010.11.27)
>
> J'aimerais bien que la personne qui envoie ces lettre de refus me rencontre, moi, ma blonde, mes enfants. J'aimerais qu'elle me regarde dans les yeux et me dise pourquoi ça coûte trop cher de me laisser vivre. (Pr : 2010.11.27)

Les coûts pour les assureurs publics et privés

Trente quatre (34) articles soulèvent la question des coûts des anticancéreux du point de vue des assureurs. Certains énoncés sont plutôt neutres, se contentant de rappeler qu'ils sont chers pour les assureurs :

> As new innovative oncology drugs are discovered to benefit patients, the cost becomes significantly more expensive. (NP : 2010.02.03c)

D'autres sont plus clairement des arguments employés – le plus souvent par des décideurs – pour défendre une limitation de la couverture :

> Health minister Don McMorris said at the time that the government couldn't fund every new drug, indicating the reality of having to make hard choices. (VS: 2010.08.07)
>
> Ms Matthews said the province does not have the financial resources to pay for every drug doctors recommend. (GM: 2011.03.11)
>
> Having processes, rules, policies and cost controls is too often portrayed as bureaucratic, penny-pinching and inhumane. But it is a necessity (...). (GM: 2011.03.17)
>
> 'I believe it's going to move the employer drug plan into an era of unaffordability and unsustainability' said David West of Mercer Human Resources Consulting. (NP: 2011.04.14)

Pour d'autres, le plus souvent des médecins, le recours à l'impact budgétaire afin de justifier une limitation de la couverture est inadmissible :

> What is worse, say Gerald Batist of the Jewish General Hospital and Normand Blais of Notre Dame Hospital, is that the Conseil du Médicament appears to be more concerned about keeping costs down than saving or extending the lives of cancer patients. (Gz: 2010.12.03)
>
> ... le Dr Audet-Lapointe (...) accuse Québec de faire des économies sur le dos des patients. (Dv: 2010.12.09)
>
> ... lors des refus, les arguments financiers prennent trop de place. (Pr : 2010.12.09)
>
> Il faut faire fi, dans un premier temps de l'objectif de contrôler le budget qu'on leur consacre. (Pr : 2010.12.14a)

Seulement 16 articles quantifient ces coûts pour les assureurs. Pour donner une idée de l'impact budgétaire que peuvent avoir les anticancéreux, il est plus utile pour le lecteur d'avoir des coûts agrégés. Or, 5 articles fournissent de telles données :

> … the drug had been approved at $750 000 per year, which the province expects will cover the cost of the drug for 48 women. (EJ: 2011.03.02)
>
> Under the new program, the bill for an estimated 120 additional Ontario cancer patients would come to about $4-8 million annually. (GM: 2011.05.13).

Deux (2) articles nous laissent faire le calcul :

> ... a full course of treatment ranges from $14,400 to $24,000 per patient (...). An estimated 200 to 300

> patients a year are expected to use the drug. (GM: 2010.05.13)

Les 9 autres articles, bien qu'ils se placent du côté de l'assureur, ne donnent que les coûts par patient.

L'efficience

Quatorze (14) articles soulèvent la question de l'efficience, c'est-à-dire du rapport entre le coût et les bénéfices des médicaments. Aucun article ne quantifie clairement l'efficience (ex. coût/QALY, etc.) et le concept est rarement expliqué. On se contente de présenter l'efficience comme un critère d'évaluation en employant des expressions plus ou moins éclairantes telles que :

> …it's high cost dosn't match its effectiveness… (Prov: 2010.03.05)
>
> Mr. Morrisson said the drug is cost-effective. (GM: 2010.05.13)
>
> ... value-for-money issues... (TS: 2010.11.20);
>
> ...economic and pharmaco-economic criteria. (Gz: 2010.12.18)

Quelques-uns des articles sont un peu plus explicite :

> Or, plusieurs nouveaux anticancéreux coûtent extrêmement chers et apportent très peu de bénéfices, soit à peine quelques mois de survie. (Pr : 2010.12.14b)
>
> Tout comme le Québec, l'Ontario choisit de rembourser des nouveaux médicaments lorsque leur prix est compensé et justifié par le bénéfice que ces nouveaux médicaments procurent aux consommateurs, par rapport aux médicaments déjà commercialisés et remboursés. (Pr : 2010.12.17)

Enfin, seulement 4 articles problématisent la notion d'efficience et/ou en soulignent la légitimité :

> We have a publicly funded health system. We owe it to ourselves to spend our health dollars as prudently and efficiently as possible. (...) Are the angry, unabashed supporters of Ms. Anzarut seriously suggesting that an insurance program – be it public or private- has to pay for every single drug and every single treatment no matter how marginal the benefit, how high the cost and how grave the risk? (GM : 2011.03.17)
>
> [Il faut] déterminer combien il est raisonnable de payer pour chaque année de vie ajustée par la qualité de vie (QALY) apportée par un médicament. (Dv : 2010.04.30)
>
> Même si le traitement coûte environ 20 000$ par années, les bénéfices sont évidents. La question ne se pose pas. Mais ce n'est pas toujours aussi clair… (Pr : 2010.05.22)
>
> Une évaluation de qualité doit être capable de faire des recommandations impopulaires comme lorsqu'une technologie apporte peu de bénéfices par rapport aux coûts. (Pr : 2010.12.14b)

Les dépenses générales en médicaments

Cinq (5) articles replacent leur contenu dans le contexte des dépenses générales en médicaments. Ils rappellent que ces dépenses augmentent à un taux de plus de 10% annuellement. Un seul article chiffre ces dépenses :

> In 2005, $20.6 billion was spent on outpatient prescription drugs (…). (TJ : 2010.09.08)

L'allocation des ressources entre groupes de patients

5 articles soulèvent des questions d'équité et d'allocation des ressources entre les personnes atteintes de cancer et les autres groupes de patients. Deux (2) articles contiennent des énoncés selon lesquels on devrait prioriser davantage le cancer en allouant plus de ressources à cette maladie :

> Re-balancing the cost distribution within the drug portfolio may allow spending for priority treatment options such as those for cancer and other serious illnesses. (NP : 2010.02.03c)

Les 3 autres soulèvent la question sans clairement prendre position.

Investissements de l'industrie dans les économies locales

Trois (3) articles soulignent le lien entre le remboursement public des médicaments et le développement économique local. En effet, la décision des gouvernements de rembourser des médicaments peut avoir un impact sur la décision des manufacturiers d'investir en recherche et développement dans ces juridictions, et vice versa.

La fixation des prix par les fabricants

Étonnamment, un seul article soulève la question de la fixation des prix des médicaments onéreux par les fabricants:

> La question du prix des médicaments pourrait même être réglée à la source, croit Jack Shapiro : "Les fabricants fixent leurs prix en toute liberté, avec très peu de transparence. Nous ne savons pas jusqu'à quel point ils sont peut-être exagérés". (Dv : 2010.08.06)

Discussion

Une couverture déséquilibrée

Notre analyse révèle que les contenus vont essentiellement dans le sens d'un plus grand accès aux anticancéreux et que la couverture manque sérieusement d'équilibre. Les médicaments sont présentés comme sauvant/prolongeant des vies et le refus de les rembourser est une condamnation à mort. Cependant, cette efficacité est rarement quantifiée ou quantifiée en termes relatifs. Or, l'expression des bénéfices en termes relatifs a peu de signification pour les lecteurs. Par exemple, si une condition médicale se détériore chez 2 personnes touchées sur 100, et qu'un médicament réduit ce taux à 1 sur 100, on dira en termes absolus que le médicament réduit les risques de détérioration de 1%. Cependant, en terme relatifs, cette réduction de 2 à 1 sur 100 équivaut à 50%. Sans informations sur les quantités absolues, dire qu'un médicament réduit les risques de 50% frappe l'imaginaire mais a peu de signification.[35]

La variation entre les différentes provinces quant à l'accès à ces médicaments est abondamment soulignée. Les coûts des médicaments pour les patients sont très souvent chiffrés et les conséquences du manque d'accès sur les finances et la vie des patients sont souvent décrites de manière dramatique.

La question de la pérennité de l'assurance médicament est peu discutée. Les coûts pour les assureurs du remboursement des anticancéreux n'est pratiquement pas quantifié et sont souvent présentés comme un argument non valable. L'efficience n'est pas quantifiée et est peu présente dans le corpus compte tenu de son importance centrale dans l'évaluation des médicaments. Enfin, une plus grande présence de thèmes comme « les dépenses générales en médicaments », « l'allocation des ressources entre les différents groupes de patients », et « la fixation des prix par les fabricants » contribuerait aussi à offrir une couverture plus complète et équilibrée.

À cet égard, le code de l'Association of Health Care Journalists (AHCL) [36] contient des principes pertinents qu'il convient de rappeler :

> Recognize that most stories involve a degree of nuance and complexity that no single source could not provide. Journalists have a responsibility to present diverse viewpoints in context.
>
> Distinguish between advocacy and reporting. There are many sides in a health care story. It is not the job of the journalist to take sides, but to present an accurate, balanced and complete report.

Le lien entre les sources et les contenus

Les sources qui ont le plus souvent la parole sur les questions d'accès sont aussi celles qui sont le plus enclines à défendre un plus grand accès. Les groupes de défense des patients sont les sources les plus souvent citées dans notre corpus. Un de leurs rôles est de tenter d'influencer les décideurs sur les questions qui concernent les patients qu'ils représentent et les médias sont un des canaux qu'ils empruntent. Cependant, comme ces groupes reçoivent le plus souvent du financement de l'industrie pharmaceutique, de nombreux observateurs questionnent leur indépendance. Ils attirent la sympathie du public et peuvent servir de cheval de Troie pour une industrie qui inspire moins confiance. Ces groupes sont ainsi pour le moins en conflits d'intérêt apparent lorsqu'ils militent pour le remboursement des médicaments de leurs partenaires financiers.[37,38]

Les médecins et les chercheurs dans les domaines biomédicaux sont eux aussi très souvent cités. Ils se prononcent sur l'efficacité des médicaments mais aussi sur des questions –dont celle de l'accès- qui dépassent largement leur expertise première. Ils se prononcent à partir de leur perspective de soignant et en fonction de leurs intérêts et de ceux de leurs patients. Des études ont démontré que les oncologues ont un seuil de tolérance excessivement élevé en ce qui concerne le rapport coût-bénéfice des anticancéreux. Ce seuil serait en moyenne de plus de 245 000(US)$ par QALY[39,40], ce qui est extrêmement élevé. Les expertises en éthique, en allocation des ressources, en économie / politiques / administration de la santé sont plus pertinentes mais beaucoup moins sollicitées.

Les journalistes doivent être prudents dans leurs rapports avec les sources. Le code de l'Association of Health Care Journalists (AHCL)[36] prescrit de toujours varier les sources, de prendre en considération leurs intérêts personnels ou professionnels et de divulguer et les conflits d'intérêts potentiels :

> Be vigilant in selecting sources, asking about, weighing and disclosing relevant financial, advocacy, personal or other interests of those we interview as a routine part of story research and interviews.
>
> Investigate and report the possible links between sources of information (studies or experts) and those (such as the manufacturers) who promote a new idea or therapy. Investigate and report the possible links between researchers and private companies, researchers and public institutions, patient advocacy groups and their sponsors, celebrity spokespersons and their sponsors, non-profit health and professional organizations and their sponsors.

Considérant les sources proéminentes dans notre corpus, il n'est pas étonnant que les contenus soient largement en faveur d'une plus grande couverture publique. Mais les sources choisies ne sont probablement pas la seule raison pour laquelle les contenus prennent cette forme. Afin d'être retenus et publiés, les contenus doivent aussi posséder une certaine valeur médiatique.

La structure narrative générale de « l'histoire » médiatique de l'accès aux anticancéreux

En appliquant la grille d'analyse de Seale (*danger; vilains;*

victims; heroes), on peut révéler la structure narrative générale de l'histoire médiatique de l'accès aux anticancéreux :

> Le cancer menace la vie de victimes innocentes. Il y a des médicaments qui sauvent/prolongent la vie mais le gouvernement ne veut pas payer. Les patients meurent ou bien paient eux-mêmes pour les traitements et se ruinent. Des patients et des médecins se battent contre le gouvernement pour avoir accès aux médicaments.

Comme le rappellent Ferner et al., les histoires de patients mourant se voyant injustement refuser l'accès à des médicaments « miracles » ont une valeur médiatique assurée.[8] Elles mettent en tension la vie et la mort, l'espoir et le désespoir, la rédemption et la condamnation, l'équité et la discrimination.

Les patients sont doublement « *victimes* », du cancer et du gouvernement. En lui-même le cancer a une aura de catastrophe, il possède les caractéristiques idéales pour représenter la source du « *danger* » dans une histoire médiatique et susciter la peur chez le lecteur.[16] Le gouvernement, en ne payant pas pour les nouveaux anticancéreux, fait des économies sur le dos des patients et les condamne une deuxième fois. Il met un prix sur la vie humaine. Le sentiment d'injustice est accentué par le fait que ces médicaments sont offerts dans d'autres provinces. En ce sens, le gouvernement est le « *vilain* » par excellence. On prend bien soins de ne pas quantifier l'efficience et l'impact budgétaire de ces médicaments, ce qui pourrait aider à comprendre la décision des autorités. Par contre, les coûts des médicaments pour les patients, eux, sont très souvent quantifiés et les conséquences sur leurs conditions matérielles sont soulignées de manière dramatique : « *Many patients end up selling their homes or going bankrupt to pay for new therapies* », laissant les patients face à un dilemme tragique : « *I didn't want to leave my family struggling for money just to keep me alive* »; « *financial ruin or the funeral home* ». On quantifie peu et mal efficacité des médicaments (qui souvent se limite à prolonger la vie de quelques mois) donnant ainsi l'impression que l'enjeu est entre la vie et la mort.

Enfin, la lutte pour l'accès est souvent présentée comme un combat : « *"I feel like I am fighting a constant uphill battle"* » et ceux qui s'y consacre comme des héros : « *Jill Anzarut, a thorn to government, a champion to breast-cancer activists* », ce que Seale appelle les héros profanes (lay heroes).[41] Ce caractère héroïque des personnes atteintes de cancer a été observé dans les représentations des journaux britanniques[42] et les magazines féminins australiens[43].

Les histoires de cas sont souvent employées dans les médias car elles permettent au lecteur de mieux s'identifier à la «victime» et suscitent chez lui un sentiment d'empathie. Plus on donne d'informations sur la victime, plus l'histoire la rend familière, plus la réaction émotive est grande. Ce phénomène psychologique est connu sous le nom de « *identifiable victim effect* ».[44,45]

Conclusion

Les agences d'évaluations et les décideurs ont la responsabilité de trouver un équilibre entre différents objectifs des régimes d'assurance médicament : l'accessibilité, l'efficience, l'équité et la pérennité. En ce qu'elle peut entrainer une limitation de l'accès aux médicaments, la mise en place d'une politique efficiente et équitable d'assurance médicament requiert l'adhésion du public. L'opinion publique sur les enjeux sociaux se construit en grande partie à partir de ce qui se dit dans les médias. Mais les citoyens sont-ils exposés à une couverture complète et balancée de la problématique des anticancéreux onéreux?

Notre analyse révèle que les contenus vont essentiellement dans le sens d'un plus grand accès aux anticancéreux et que la couverture manque sérieusement d'équilibre. Les sources les plus souvent citées sur les questions d'accès sont aussi ceux qui sont le plus enclins à défendre un plus grand accès : les groupes de défense des patients, les oncologues et chercheurs biomédicaux, ainsi que les patients individuels et leurs proches. De plus, les histoires de patients mourant se voyant «injustement» refuser l'accès à des médicaments ont une valeur dramatique considérable et constituent ainsi du bon matériel médiatique.

Des contenus favorables au remboursement des anticancéreux présentés dans des histoires vécues auxquelles le lecteur peut s'identifier ont le pouvoir d'imposer le point de vue des patients individuels au détriment du collectif. Un plus grand accès aux anticancéreux devient l'enjeu principal au détriment des questions d'efficience, d'équité et de pérennité.

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Method or Madness?: The Dominance of the Systematic Review in Nursing Scholarship

ANNEMARIE JUTEL

In 1972, Irving Zola published his seminal piece, "Medicine as an institution of social control," in the journal *Sociological Review*. This eloquently written article defines medicalisation and develops an explanatory theory for medicine's expanding jurisdiction and social authority in contemporary society. This piece stood in contrast to his earlier empirical social science research, interviewing attendees at the Ear Nose and Throat clinic about their presenting complaints.[1] He could not have known at the time, any more than could have his publishers, the impact that his reflections on medicalisation would have on the field. Presented differently, reflecting different methodological perspectives, both publications nonetheless contributed to furthering of the sociology of health and illness.

As the example of Zola underlines, there are many ways to advance knowledge, and scholarship takes many forms. A discipline which is generous in determining what it values as scholarship and how it can be presented is poised to embrace the novel, the exceptional and the transformative. Who would have thought, for example, that comedy might contribute to academic discussions of medicine? The benefit of hindsight shows us the importance of Leonard Stein's 1968 "Doctor-Nurse Game".[2] This text was included in a tome entitled "classic texts in health care"[3], and is cited prolifically in nursing, medical and interdisciplinary journals which explore inter-professional relationships in health. Remarkably however, this article was presented as humour, complete with cartoon caricatures of swan-necked, white-capped sisters, and eyebrow-raised, stethoscoped medical specialists throwing darts at a professional wheel of fortune. It is not alone in its genre. Richard Smith's[4] light-hearted "In search of non-disease" made important points about the social framing of disease which have been well-exploited by numerous academic writers since its rather recent publication.

Like humour, simple stories also deliver important truths. Arthur Frank's *At the Will of the Body*, an account of his personal experience of serious illness is a poignant example of scholarship through narrative. His stories and others like it now buttress a wide range of disciplinary discussions in nursing, social science and medicine. I take particular inspiration in my own work from Suzanne Fleischmann[5] and Mildred Blaxter's[6] respective (and poignant) accounts of the diagnostic trajectory in illnesses which were ultimately to prove fatal to both. They "speak" eloquently to me as nurse, as I identify with the authors' suffering, but they also highlight important critical principles like the transformative nature of the diagnostic label, and the silencing impact of diagnostic technology.

Medical journals acknowledge the importance of such stories in health care practice: *Annals of Internal Medicine* includes a regular doctor-as-patient stories, just as the *British Medical Journal* invites authors to submit stories about memorable patients, mistakes, and anything else that conveys "instruction, pathos, or humour."

Despite the example set by medicine and sociology, nursing is restricting, rather than expanding, what it allows authors to present. This is a situation which requires rapid redress. In the paragraphs to come, I will describe how the journals which stand for the mouthpiece of nursing have become overly concerned with presenting its scholarship and talking about its discipline in a standardised and exclusionary manner. This reflects a positivistic, audit-oriented belief in knowledge generation that is stymieing our profession and its scholars. This approach emerges from a devotion to evidence-based practice, and persists to the detriment of the field. An over-reliance on systematic review trivialises nursing's intellectual autonomy, instead, instilling method and design into a hierarchically unjustified supreme position.

The idea of combining the results of more than one study of a similar phenomenon in order to increase their impact is at the heart of the systematic review. Early attempts at this approach were undertaken by Karl Pearson[7,8] and Ernest Jones, whose work was only "discovered" in 2003[9] by an Anglocentric field, ignorant of Jones' publication (written in French) which reviewed material published predominantly in French and German. Ronald Fisher presented statistical techniques for using the results of independent studies to predict probabilities in 1932.[10]

But the practice did not become prevalent until the second half of the 20th century. In the late 1970s, a number of summarizing research papers were published, including Hall's[11] "Gender Effects in Decoding Nonverbal Cues," Smith and Glass'[12] "Meta-analysis of Psychotherapy Outcome Studies," and Rosenthal and Rubin's[13] summary of 345 experiments studying the tendency of researchers to obtain results they expect because of their influence in shaping responses. This study did not attempt to assess the quality of the individual experiments, rather to encompass the results of all existing studies. Their paper, they suggested, could serve as a methodological template for summarizing other entire areas of research.

Evidence based practice enhanced the prominence of this method, as both rely upon the same premises. Archie Cochrane's 1972 diatribe on Effectiveness and Efficiency is at the base of the contemporary evidence based practice movement. There, he lamented the absence of measurement of effectiveness of medical interventions and described the randomised controlled trial as a tool for "open[ing] up the new world of evaluation and control" and perhaps saving the national health service.[14]

The systematic review is "the application of scientific strategies that limit bias to the systematic assembly, critical appraisal, and synthesis of all relevant studies on a specific topic".[15, p167] This definition emerged from the Potsdam Consultation: a consortium organised to assess and address the production of high quality meta-analysis and review of randomised controlled trials. The Potsdam Consultation developed a list of guiding principles and a methodological overview covering protocol development, search strategy, study selection, quality assessment, analysis, evaluation of heterogeneity, subgroup analyses, sensitivity analyses, presentation, interpretation, and dissemination.[15]

The over-arching theme in definitions of the systematic review is the notion that the review is a form of research itself. Webb and Roe refer to the systematic review as "Pieces of research, which aim to identify, appraise and summarise studies of relevance to a particular topic".[16] Straus and colleagues describe it as "A summary of the medical literature that uses explicit methods to systematically, search, critically appraise, and synthesize the world literature on a specific issue".[17]

In any case, the prominence of the systematic review is buttressed by the similar prominence of evidence-based practice in clinical practice and decision-making. Yet, Goodman[7] has pointed out that there is an important tension between between efforts to make medicine more scientific and remain true to "clinical judgement," a tension which is present in nursing discussions of EBP. Many have railed against the prominence that the tenets of evidence-based practice have assumed in nursing. Gary Rolfe, for one, has maintained that EBP is open to many of the criticisms that it directs at other forms of knowledge generation. It lacks the "hard" evidence to support claims of its validity that it requires of other forms of practice. Evidence based practice fails to meet its own standards, "it is no more based on evidence than the forms of practice it seeks to replace" he writes .[18 p85]

Others have pointed out that evidence-based practice is the fascist imposition of a empirical project–a dominant ideology excluding alternative forms of knowledge.[19] The dominant hierarchy privileges certain kinds of research, and particular positions. Morse[20] positions EBP as a politics of ignorance—myopic and exclusionary—which uses Cochrane standards for evaluating funding for all forms of research. It is a fine sieve which ends up funding drug trials by the powerful, and relegating qualitative researchers unable to access funds, credibility, and importantly, power.

Many authors, including myself, have argued that EBP is a significant means for advancing nursing knowledge, but not one which should be used to the exclusion of all others. I have used the example of 'overweight' as a heuristic for understanding the limitation of EBP. Whilst EBP may be useful for describing epidemiological trends in BMI, the effectiveness of interventions for reducing weight, or the correlation between overweight and other pathologies, its preferred forms of evidence can neither capture nor explain the depth and breadth of the weight loss question. It fails to demonstrate the use of weight as an unreliable proxy measure for lifestyle practices; the ethnic insensitivity of BMI and its contribution to the marginalisation of underprivileged populations; the range of commercial interests are served by the promotion of overweight-as-disease; the role of aesthetics in clinical assessment; the cultural and historical frames in which the discourse of weight is a reflection of inner character, and so forth.[21]

Despite the fact that there isn't full agreement about the place that evidence based practice should hold in nursing, it has an iron grip. And, we're not working hard enough to loosen it. This is a shame; rather than increasing nursing knowledge, EBP is replacing it, substituting its episteme for ours.

I'll return to the review article, which is EBP par excellence, and what's more, is a perfect heuristic for recognising how we've sold out. Reviews have a constitutive role for a field. They juxtapose, explain and analyse an assembly of related concepts which both author and publisher believe worthy of dissimilation to the discipline. They are used as research resources, teaching tools, and in the digital age, means by which journals and authors achieve notoriety. Because of their function as broad-brush summary of a topic, and subsequent utility as pedagogical aid, they result in high citation counts, which in turn result in high bibliometric ranking: a measure of status in contemporary academe. Unabashedly, most nursing journals recruit the review, knowing full-well its ability to influence the field, and reap benefits for the journal.

The review article is a criterion by which nursing defines itself and its priorities: those subjects worthy of review. In a Bourdieuan framework, the review is part of the cultural field or the "series of institutions, rules, rituals, conventions, categories, designations, appointments and titles which constitute an objective hierarchy, and which produce and authorise certain discourses and activities".[22, p21]

When one looks at the discursive construction of the review article, in any of a number of contemporary nursing journals, one is confronted by the dominant and unwavering presence of evidence based practice. Instructions to authors include the mandatory use of sub-titles such as "design," "methods," "quality appraisal," "data abstraction," "synthesis" and "results." Links to useful resources point authors exclusively to QUORUM statements, Cochrane Collaborations, EPPI, NICE and other EBP-based assessment tools. There is a salient absence of references to the academic traditions of reading and writing, promoting the systematic review as the standard to which nursing authors should aspire.

The language used these journals is the kind that MacLure[23] describes as a mix of scientific positivism and audit culture rhetoric, reifying the way in which texts must be approached. As MacLure so aptly represents, what is left unspoken in the discursive representation of the systematic review are the important themes of analysis and interpretation. The lexicon privileges audit over textuality, reproducibility over illumination. She describes the,

> ...fantasy of a text-free knowledge economy, where nuggets of evidence can be extracted from the rhetorical contaminations of persuasion, argument, justification, context and partiality that are inherent in all texts ... an ancient and persistent delusion.[23 p399]

Journal content in our discipline reflects either the supreme position of the systematic review within the profession, or more likely, the impact that journal policies have in shaping that which the profession judges worthy of publication. Journals have significant power to mould what they contain, even more so now in the day of manuscript management software which includes required form fields that an author cannot skip: an abstract must be structured, a method identified, an article category designated. But beyond the mechanics of manuscript control, the more powerful the journal, the more powerful its ability to influence the presentation and even the epistemologies of nursing knowledge. And, the power of the journal is also based in the review article.

With research evaluation exercises, and performance-based research funding, the impact factor of a journal (already a positivistic/problematic bibliometric category) constitutes its cultural capital. The more the journal's content is cited, the higher its impact factor.[a] The higher its impact factor, the more submissions it is likely to receive, and the higher the quality of the resultant publication.

Nursing researchers become compliant docile subjects as they conform to journal standards which "other" traditional ways of treating the synthesis of research material. Reporting methodology--including tables to organise "evidence," and presenting a range of justifications of trustworthiness, from methodological algorithms to quality assessment tables, and detailed search criteria--confirms inflexible bonds within which nursing is compelling its academics to reflect.

One could argue that there's room for a traditional review within these discursive constraints. A savvy author could arrange a benign expression that would fit into the various sub-sections of the methodology and quality analysis description. This is a "narrative" review; quality appraisal can consist of "evaluating whether the material presented a cogent, supported argument for the themes it presents;" the discursive post-methods discussion can tolerate the header "results."

However, there are two reasons to reject this conformity. Firstly, there isn't room, amongst these headings, to express the things that matter. I present as an example, a review I have written for a prominent journal of sociology a few years ago.[25] I drew together therein many threads from a range of theoretical and historical perspectives to describe a nascent sub-discipline of medical sociology. I presented both a history and a platform: including classical texts, and mad ones. Mad they might have been, but the latter garnered significant popular interest, and despite (or perhaps because of) their heretics, played an important role in shaping discussions, as other scholars scuttled to respond, and set the story right. These little bits of sociological lunacy wouldn't pass quality analysis, yet explain the direction the discussion has ended up taking. It's simultaneously the heterogeneity and the similarities of the articles I bring together that create the base for my argument. When dialectic is the method, a "summary table" will capture neither content nor direction.

Secondly, conforming to the structured abstract kowtows to an unjustified technology of control. As Avis wrote "New academic identities are being created in which values such as academic independence, intellectual curiosity and expert judgement are being replaced by industriousness, rule-following, compliance and self-imposed endorsement of 'the hegemonic position of managers'".[23, p297]

That reviews are systematic is perhaps but one symptom in a more generalised attempt of the nursing journal to be submissive itself to what it sees as the scientific, or more precisely, the professional imperative. It is by producing and using research, wrote Fawcett, that "nursing will be able to declare its independence".[26 p39][b]

But there's also that dogged need in the nurses' search for professionalization for them to withdraw from the Doctor Nurse game, that game where "nurse is to be bold, have initiative, and be responsible for making significant recommendations, while at the same time ... appear[ing] passive ... so as to make her recommendations appear to be initiated by the physician".[2] The professionalization of nursing has compelled nursing to consider how professional knowledge is constructed, and in the profession from whose grip they wish to escape, this is via EBP. Bonnell[27] has argued that nursing will be marginalized if it rejects the empirical, quantitative research, regardless of the legitimacy of their counter-argument.

For nursing to establish itself as a credible field it must have the means and techniques to imagine itself into existence, and then to represent, manifest and valorise itself in a consistent manner to its own members and to other fields. If EBP is our only tool, we have at stake here the survival of the field. We are at a place where we establish the credibility of our thoughts on the basis of our method, rather than of our arguments.

We would do well to seek inspiration from the publications of our medical counterparts. The Lancet devotes a sub-section to "Articles that advance or illuminate," encouraging debate and opinion via such fora as Viewpoint, Essay, Reportage, and the Departments of Medical History, Ethics, Medicine and Art, and Literature and Medicine.

As Goodman's has written: "…weighty burdens are borne by leaders and soldiers of the evidence-based movement, who , at great scientific and moral peril, might presume closure in complex domains, terminating debate and chilling research in cases where more debate and research are precisely what is wanted".[7, p49]

Notes

a. Impact factor is calculated as the number of citations in the current year to items published in the previous two years for a give journal, divided by the number of substantive articles and reviews published in the same two years in that journal.

b. It must be said that Fawcett also argued in this article for, in addition to research compliance, for "NOT [caps mine] relying on others for the knowledge which shapes our practice" : a position which should be seen to support other ways of knowing, of researching…and of undertaking reviews!

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