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Commentaire/Commentary

Pourquoi davantage de médecins ne résoudra pas les problèmes du système de santé

R. WARREN BELL

En Colombie-Britannique, au Canada, près d'un million de patients n'ont pas d'accès établi aux soins primaires. Ma profession, les médecins de famille, proclame haut et fort que ceci est dû à un manque de médecins, ou encore au fait que nous ne sommes pas suffisamment payés. Le vrai problème n'est pas là selon moi et selon la plupart des observateurs qui ne sont pas médecins ou qui ont une compréhension globale de la situation. J'écris donc le présent commentaire avec un mélange d'étonnement et de tristesse, dans l'espoir d'un avenir meilleur dans cette région du monde.

Le 10 mai 2022, le ministre de la santé de la Colombie-Britannique, Adrian Dix, a prononcé un discours à l'Assemblée législative au sujet de la restructuration du système de santé

provincial afin d'aborder le problème du manque de praticiens de première ligne pour près d'un million de personnes.^[1] Il a « osé » dire que parfois (pas toujours, mais parfois) les infirmières praticiennes performent mieux que les médecins, en grande partie dû au fait qu'elles passent plus de temps avec leurs patients.

Ce commentaire (un parmi bien d'autres dans son discours) a provoqué un tollé immédiat — et embarrassant. Doctors of BC (l'association médicale de même qu'une organisation de lobbying pour les médecins de la province) ainsi que de nombreux médecins de famille et certains politiciens ont fortement dénoncé les propos du ministre Dix; les médecins ont par ailleurs promis des revendications « plus stridentes » pour accroître le nombre de médecins de famille, identifiés par plusieurs comme la seule solution valable au problème des patients « orphelins » (c'est-à-dire sans médecin attitré).

Je qualifie cette réaction d'embarrassante parce qu'elle s'appuie sur une interprétation tellement étroite d'un problème complexe et qu'elle est évidemment intéressée.

Voici pourquoi

Tout d'abord, le nombre de médecins de famille diplômés d'universités au Canada est en croissance depuis plusieurs décennies. À l'Université de la Colombie-Britannique seulement, les finissants s'élèvent maintenant au nombre de 288 étudiants; lorsque j'y étais dans les années 1970, nous étions 60. Il s'agit d'une augmentation de 480%. Pendant la même période, la population de la Colombie-Britannique a presque doublé. Il y a donc plus de médecins — mais malgré cela le nombre de personnes sans médecin de famille, lui, a augmenté de façon notable.

Par ailleurs, et plus important encore, le nombre de médecins par 1000 habitants n'est pas directement lié aux résultats de santé d'une population. Au Canada et ailleurs dans le monde, une bonne ou une mauvaise santé est bien plus influencée par un revenu minimum, l'état de la chaîne alimentaire, les opportunités d'emploi, les tendances climatiques (un problème grandissant), l'existence ou l'absence de violence et de conflit et le niveau général d'équité. Des indicateurs d'équité incluent notamment l'existence d'un système de soins de santé financé par les fonds publics et accessible à tous, l'absence de disparités salariales extrêmes, l'accès généralisé à des logements abordables et l'existence d'un filet de protection sociale disponible pour tous. De tels éléments influencent davantage les résultats de santé d'une population que le nombre de médecins.

Des données probantes robustes indiquent qu'une pénurie de médecins de famille n'est pas la véritable raison pour laquelle il y a tant de patients orphelins. Le problème est d'ordre structurel, résidant dans la manière dont le système de soins primaires fonctionne.

Les soins primaires désignent les soins prodigués en première instance à une personne pour un problème de santé qui n'a pas encore été qualifié. Ce sont des soins de niveau général plutôt que spécialisé, pour toute personne sollicitant un médecin, une infirmière ou un autre fournisseur de santé.

Soins « de base » ne veut pas dire soins « simples ». De fait, il peut être bien plus compliqué d'aborder un problème à partir de rien plutôt qu'un problème déjà caractérisé. Travailler en soins primaires est très exigeant — de bien des façons, bien plus exigeant que les soins spécialisés, où les interventions sont souvent prévisibles et routinières.

La manière dont les médecins pratiquent en Colombie-Britannique, toutefois, a fortement changé depuis les 30-40 années. Les médecins de famille sont bien moins accessibles pour leurs patients. En-dehors des heures régulières de bureau,

les seules options pour la plupart des gens sont les cliniques sans rendez-vous (communément appelée la « McMédecine ») ou les départements d'urgence. Il est intéressant de constater que les Canadiens recourent aux départements d'urgence à une fréquence largement supérieure à la moyenne des pays développés. En Colombie-Britannique, bon nombre de médecins de famille limitent leurs rendez-vous à 10 minutes, exigeant que les patients ne présentent qu'un seul problème par visite. Plusieurs postent d'ailleurs des affiches à cet effet. De plus, les heures pendant lesquelles les médecins voient des patients sont généralement beaucoup plus courtes maintenant — typiquement de 10h à 16h.

Plusieurs médecins ne prennent pas d'appels. Je ne fais pas référence ici aux consultations téléphoniques implantées dans le cadre de la COVID-19, mais des appels de patients s'informant de résultats de tests, désirant poser une question ou nécessitant un renouvellement de prescription. Au lieu de cela, les patients doivent prendre des rendez-vous formels pour de tels motifs, surchargeant par le coup même les horaires des médecins avec des visites mineures qui seront facturées au système de santé.

Plusieurs raisons sous-tendent ces problèmes structurels

Historiquement, les écoles de médecine étaient financées à même les fonds publics, de telle sorte que les étudiants payaient peu de frais pour leurs cours. L'on présumait que leur rôle en société était assez important que le financement de leurs études était un bien public. De nos jours, les universités reçoivent moins de fonds publics et opèrent donc davantage comme des entreprises, notamment par le biais de systèmes de recouvrement de coûts — un terme poli désignant le fait de refiler aux étudiants la presque totalité des frais de leur scolarité.

Et les études médicales coûtent cher. Lorsque j'ai obtenu mon diplôme dans les années 70, j'avais une dette étudiante de 1 500\$, contractée avant mon entrée à l'école de médecine. Je n'étais pas plus endetté à la fin de mes études et ce, incluant ma résidence en médecine familiale. Mon épouse travaillait à temps partiel, et moi aussi lorsque c'était possible, et nous vivions de façon modeste. Mais les études médicales étaient peu coûteuses : aujourd'hui, les étudiants paient pour la presque totalité de leur scolarité et il n'est pas rare qu'ils aient contracté des dettes allant jusqu'à 300 000\$. D'ailleurs, les banques leur prêtent de telles sommes avec enthousiasme, sachant que le système de paiement des médecins ne fera jamais défaut et qu'ils recouvreront l'entièreté des sommes prêtées.

Cet état de fait nuit au système de santé de plusieurs façons

Premièrement, cela amène les médecins à se concentrer principalement sur le remboursement de leurs dettes d'études pendant leurs premières années de pratique — ce qui les attire souvent vers la « McMédecine » (sans rendez-vous) ou d'autres moyens d'augmenter rapidement leurs revenus afin de rétablir leurs finances.

Deuxièmement, cela veut dire que, à moins d'avoir des parents fortunés ou une autre source de revenus, un.e étudiant.e avec une aptitude pour la médecine pourrait décider de se consacrer à autre chose, faute de pouvoir payer les frais de scolarité requis.

Troisièmement, et particulièrement dommageable, les étudiants en médecine n'ont pas un sentiment net que la société veut d'eux. Au début de leurs études, on leur dit qu'ils sont uniques, spéciaux et importants, mais par la suite ils se heurtent à des coûts significatifs qu'ils doivent assumer seuls. Ils développent le sentiment qu'ils doivent se débrouiller seuls et que l'école de médecine est un fardeau financier personnel — un sentiment contraire au signal que la société valorise leurs services (même si c'est le cas).

Pour les étudiants en médecine, toute disposition altruiste qui pourrait les avoir inspirés à choisir cette profession peut se voir écraser par une lourde dette et remplacer par un sentiment plus pragmatique les amenant à se préoccuper d'eux-mêmes et à rechercher des compensations maximales pour leurs activités professionnelles. Il est surprenant qu'un nombre non-négligeable d'étudiants reçoivent leur diplôme tout en conservant un certain idéalisme et un désir de servir.

Lorsque les étudiants terminent leurs études, ils entrent dans le système standard de paiement des médecins, c'est-à-dire le paiement à l'acte : chaque fois qu'un médecin voit un patient, il ou elle reçoit une rémunération fixe peu importe les interventions réalisées. Un frais de visite ordinaire est d'environ 40\$.

Les consultations téléphoniques, implantées pendant la pandémie à la COVID-19, rapportent le même montant. Auparavant, il n'y avait pas de frais associés aux appels; par conséquent, les médecins appelaient rarement leurs patients. Maintenant, cette activité peut être facturée, faisant que ces appels sont devenus communs. Dans certains cas, ils sont devenus trop routiniers, parfois remplaçant complètement des consultations en personne. Les rendez-vous téléphoniques favorisent les consultations brèves et très ciblées, car il est plus facile pour le médecin de contrôler le déroulement de la

discussion et d'y mettre fin lorsqu'il ou elle le désire. Ces visites rapportent autant que des échanges plus longs et détaillés. Ceci tend à décourager l'attention portée au contenu des rencontres et à encourager la brièveté de celles-ci.

Pourtant, de nombreux médecins n'apprécient pas le modèle de paiement à l'acte et préféreraient être à salaire (ou quelque chose de semblable) afin de pouvoir passer plus de temps avec leurs patients et se concentrer sur la qualité plutôt que sur la quantité des visites.[2] Cependant, de nombreux médecins plus établis sont résistants à un tel changement, tout comme ils résistent à donner leur contrôle de leur pratique à quelqu'un d'autre.

Il y a encore un autre élément digne de mention. Lorsque les étudiants en médecine débutent leur formation, ils se font encore dire qu'ils sont no1 (c'était déjà le cas dans les années 70, à mon plus grand agacement!). On leur dit encore qu'en tant que médecins, ils sont foncièrement spéciaux et d'une importance critique. Dans un monde où l'on a de la difficulté à accepter la valeur, le rôle et la situation sociale de chaque personne et où reconnaître la « diversité » fait partie de nos meilleures aspirations collectives, se faire endoctriner avec la notion que l'on fait partie d'une stratosphère rarissime de supériorité est décidément obsolète et déconnecté. Cela crée des attentes inutiles auxquelles il est impossible de répondre dans le vrai monde — notamment en ce qui concerne les coûts d'éducation assumés par les étudiants.

À Cuba, en revanche, l'éducation est financée par les fonds publics jusqu'au niveau postdoctoral. Il n'est pas surprenant que les médecins cubains soient reconnus pour leur altruisme remarquable, à Cuba même et ailleurs dans le monde. L'on crée quelque chose de puissant lorsque la communauté valorise un travail suffisamment pour qu'elle en assume les coûts de formation.

Des expériences réalisées avec un revenu minimum garanti, d'ailleurs, ont démontré la même chose

La recherche montre que, dans presque tous les pays, un système de santé en vertu duquel les soins sont prodiguer dans des équipes coordonnées et au sein duquel les activités de prévention s'articulent avec les soins directs donne de meilleurs résultats de santé qu'un système fragmenté en « silos ». Le Costa Rica, par exemple, s'est doté d'un système en ce sens, et les statistiques de santé de ce pays sont excellentes, bien que son PNB par personne équivaille à 25% de celui du Canada.[3]

En Colombie-Britannique, plusieurs aspects du système de santé peuvent être modifiés afin d'améliorer son fonctionnement.

Les infirmières praticiennes notamment — l'élément de controverse avec lequel j'ai débuté ce commentaire — font partie du système de santé canadien depuis plus de 100 ans, pratiquant principalement dans des régions éloignées où les médecins ne voulaient pas travailler. Elles sont maintenant plus répandues et plus visibles, avec des programmes de formation sophistiqués et organisés. Et elles travaillent enfin en centres urbains où les médecins pratiquent aussi. Ma profession, en Colombie-Britannique en particulier, s'est montrée à la fois orgueilleuse et excessivement sensible, pour les raisons susmentionnées, à l'égard de toute suggestion qu'elle ne soit pas l'élément le plus important de l'équipe de soins.

En tant que médecins, nous devons être plus nuancés et ouverts aux solutions permettant de remédier aux enjeux des soins de santé. Nous devons reconnaître que le fait de travailler en équipes multidisciplinaires, de connaître nos patients de façon plus intime et approfondie et d'accepter la valeur des autres professionnels de la santé facilitera grandement l'identification de solutions et l'amélioration des résultats de santé.

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Commentaire/Commentary

Why more doctors won't solve the health care system's problems

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The Canadian province of British Columbia (BC) has nearly one million citizens who do not have established access to primary care. My profession, Family physicians, loudly declaims that it is because there are not enough doctors, or because we are not paid enough. I do not think that is the real problem, and neither do most observers of the health care scene who are not physicians, or who have a broad view of the current situation. So I write this commentary with a mixture of wonder and sadness, and hope for a better future for health care in this part of the world.

On May 10, 2022, BC's Minister of Health, Adrian Dix, spoke in the Legislature about restructuring the health care system to address the nearly 1 million persons who have no primary care practitioner.^[1] He "dared" to say, at one point, that sometimes

(not all the time, but sometimes) Nurse Practitioners did a better job than doctors, in large part because they spent more time with their patients.

The immediate uproar over this remark (just one of many he made in his speech) has been intense — embarrassingly so. The Doctors of BC, the lobby group/union for doctors in the province, as well as a whole bevy of family physicians and some politicians, have loudly denounced this remark; physicians have promised to be "more strident" in their demands for ramping up the supply of family physicians, identified by many as the singular and only valid response to the presence of "unattached" people (those without an identified family doctor of their own).

The reason I called the uproar "embarrassing" is because it is based on such a limited interpretation of a complicated problem, as well as being rather obviously self-serving.

Here's why I think this way

First, the number of family doctors graduating from

universities in Canada has been increasing for decades. At the University of British Columbia alone, the graduating class now numbers 288 students; when I was in attendance in the 1970s, it was 60. That is a 480% increase. During the same time, BC's population has roughly doubled. So there are more doctors available — but the number of people without a family doctor has still increased significantly.

Furthermore, and more importantly, the number of doctors per 1000 population is not directly related to health outcomes. In Canada and around the world, good or poor health is far more directly connected to basic income, to the state of a country's food supply, to opportunities for employment, to overall climate patterns (an increasing concern), to the presence or absence of violence and conflict, and to the general level of equity. Examples of equity include: having a health care system that supplies publicly funded health services to all citizens; living in a country where differences in income are not extreme; having widespread access to affordable housing; or having a social safety net available to everyone. These and other similar factors all increase health outcomes more than the number of available doctors.

Strong evidence suggests that a shortage of family doctors is not the real reason there are so many "unattached" persons. The problem is a structural one: how the primary care system works.

Primary care means care given to someone who seeks care right away for a problem that has not yet been characterized. It is healthcare at a generic rather than specialized level, and for people who initially approach a physician, nurse or other care provider for treatment.

"Basic" does not mean "simple". It is actually more complicated to figure out a problem from scratch than one that has already been defined and categorized. Working in primary care is a very demanding occupation — in many respects, far more demanding than specialty care, where much of what is done is routine and predictable.

The way doctors practice in BC, however, has changed radically over the last 30-40 years. Family doctors have become less and less accessible to their patients. Outside regular office hours, the only options for most people in BC are either a walk-in clinic (colloquially called "McMedicine") or an Emergency Room (ER). Interestingly, Canadians use ERs well above the average for developed countries. In BC, a fair number of family doctors limit almost all appointments to 10 minutes, often insisting on addressing only one health problem per visit; some have even posted signs saying this is how their practice is structured. In addition, office hours during which doctors see patients are

now generally much shorter — typically 10:00 am till 4:00 pm.

Many doctors do not take phone calls. I am not referring to phone visits implemented during the response to COVID-19; I am talking about calls by patients asking for test results, posing a quick question, or seeking to re-order medication. Instead, patients are expected to make a formal appointment to come to the office for such reasons, thus filling up (and burdening) the doctor's schedule with minor visits for which Medicare is charged.

There are some important underlying reasons for these day-to-day structural problems

Medical school used to be subsidized by public funds, so that students paid very little, if anything at all, for their courses. It was assumed that their role in society was important enough that paying for them to study and train was a public good. Now universities get less public money, and so function more like businesses; they engage in what is called "cost recovery", which is a polite term for billing students for almost the full cost of their training.

And medical school is expensive. When I graduated in the 1970's, I had a student debt of about \$1500 — acquired before I went into medical school. I had no further debt when I completed my training, including my residency in family medicine. My wife worked part-time, and so did I when I was able, and we lived modestly. But costs of training were low. Today students pay for most of their schooling; it is not uncommon for medical students to leave their training program with \$300,000 owed to the bank. Unsurprisingly, banks loan money to doctors with unabashed enthusiasm. They do so because they know that the payment system for doctors is so incredibly secure that it is almost guaranteed that they will be fully paid back.

This situation does several harmful things to health care

First, it means doctors are focussed intensely on repaying their debts for the first few years of practice — often being drawn to "McMedicine" (walk-ins) or other fast money situations in order to get their finances in order.

Second, it means that unless he or she has wealthy parents or an independent source of income, a student who has an aptitude for medicine will nevertheless steer clear of it because he or she cannot afford it.

But third, and most unhelpful, medical students are not given a clear sense that society wants them. At the beginning of the training program, they are told they are special and unique and important. But then they are confronted with a mounting barrage of significant costs, for which they are personally

responsible. They acquire a feeling that they are on their own and getting through medical school is a personal financial ordeal – the antithesis of a signal that society as a whole values their services (even if it does).

For medical students, any altruistic feelings that might have initially inspired them to go into medicine can be severely challenged by a crushing burden of debt, and replaced by a more pragmatic sense that one might as well look after oneself, and seek maximum recompense for every professional act. It is actually remarkable that a fair number of medical students still graduate with some sense of idealism and a desire to be helpful.

When students finish their training, they are then brought face-to-face with the standard system for paying doctors for their work. This system is called “fee-for-service”: every time a doctor sees a patient he or she receives a flat fee for whatever is done. An ordinary visit fee is about \$40.

A telephone call “visit”, since the COVID-19 pandemic began, pays the same. For many years before that, there was no fee for any telephone call with a patient; consequently most doctors rarely called their patients. Now that there is a fee for doing so, telephone visits have become routine. In fact, they have sometimes become too routine, replacing in-person visits to a great extent or even completely. Phone appointments facilitate short, narrowly focussed visits, because it’s easier for a physician to control the flow of the visit and terminate it when it suits him or her. Yet short visits pay the same as longer, more detailed exchanges. This has resulted in a downward pressure on content, and an upward pressure on brevity.

Interestingly, a lot of new doctors are not happy with the fee-for-service system and would prefer to be paid a salary (or something similar), so that they can take more time with a given patient and concentrate on quality rather than quantity of visits.[2] But more established doctors are resistant to this change, just as they are resistant to handing over control of their practice venue to anyone else.

There is one other element in this picture that deserves mention. When students enter medical school, they are still told that they are #1 (this was already the case in the 1970s, much to my personal annoyance!). They are still told that, as doctors, they are utterly special and critically important. In a world where we are all struggling towards accepting the value of every person and their role and station in life, where acknowledging “diversity” is what characterizes our best collective aspirations, being indoctrinated with the notion that one is part of a rarefied stratosphere of superiority is decidedly old-fashioned and out of touch. It creates unnecessary expectations that are

not met in real life – and especially so when it comes to the student-borne cost of training.

In Cuba, by contrast, all education is publicly financed up to the post-doctoral level. Not surprisingly, Cuban doctors have become famous for their astonishing altruism, both in Cuba and around the world. There is something powerful that arises from the notion that your community values what you do enough that it will cover the cost of your entire training experience.

Experiments with a “universal living wage”, by the way, have shown the same thing

Research has also shown that in almost all countries, a health care system where care is delivered in coordinated teams, in which preventive activities are coordinated with direct clinical care, produces better outcomes than one that is fragmented into separate “silos”. Costa Rica, for example, has a system that works like this, and that country’s health statistics are very good, despite having a national GDP per person that is 1/4 that of Canada.[3]

In BC, there are many elements of the health care system that can be changed to make it work better. Nurse practitioners in particular — the place of controversy where I started this commentary — have been part of the Canadian health care scene for over a hundred years, primarily working in remote settings where doctors were not always willing to practice. Now they are becoming more mainstream, and more visible, with organized and sophisticated training programs. And for the first time, they are practicing in urban centres where doctors also provide care. My profession, especially in BC, has been both prideful and also overly sensitive, for reasons noted above, to any suggestion that they are not the single most important and valuable part of the health care team.

We doctors have to be more balanced and open to solutions to resolving the problems that beset health care in this part of the world. I think we must recognize that working in multi-disciplinary groups, establishing more detailed and intimate understanding of our patients, and accepting the value of other kinds of practitioners will help make finding solutions — and improving health outcomes — that much easier.

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Abstract

There has been growing interest about procedural justice in mental health tribunals. A process considered procedurally just increases adherence to treatment, increases compliance with judicial decisions and allows efficient community reintegration. Yet, little is known about how procedural justice is carried out and the role of professionals in its implementation. Stemming from the results of a critical ethnography of the Ontario Review Board, in this article we examine how procedural justice materializes during Review Board hearings and the role of nurses in this materialization. We do so by leveraging Goffman's work on total institutions and institutional ceremonies. Our findings suggest that nurses participate in activities that provide a perception of procedural justice, rather than serve their patients' right to true procedural justice. We conclude by recommending that nurses engage in reflections about the distal effects of their clinical practice to broaden the possibilities for resistance within the forensic psychiatric system.

Key Words critical ethnography, forensic psychiatry, mental health tribunals, procedural justice, review board hearings

Nurses and the Discursive Construction of Procedural Justice in Review Board Hearings

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Introduction

In recent years, increased attention has been paid to the notion of procedural justice in mental health tribunals [1-8] and in mental health nursing.[9] Broadly defined, procedural justice is the way in which individuals evaluate "the fairness of the processes by which legal authorities make decisions and treat members of the public [including themselves]."[10 p284] In mental health tribunals, a process considered procedurally just has been found to increase adherence to treatment,[1] reduce psychiatric symptoms,[4] reduce future involvement in the criminal justice system,[6] increase compliance with

judicial decisions and allow for a more efficient reintegration of offenders in the community.[1,2,6,8] Yet, little is known about the way procedural justice is carried out before, during and after hearings held by mental health tribunals and para-judiciary tribunals, and the role of different professionals in its implementation, including that of nurses.

Supported by the results of a critical ethnography conducted in Ontario, Canada, the aim of this article is to examine how procedural justice materializes during Review Board (RB) hearings, a para-judicial mental health tribunal, and the role of nurses in this materialization. The article is divided in five sections. First, an overview of RBs and their hearings is presented followed by a brief description of procedural justice. Second, the methodological and theoretical considerations of the study are detailed. We then present our results and discussion. We illustrate that procedural justice in the context of RB hearings is illusory; its operationalization places patients in staged social situations where their voices can be heard, but is rarely considered. Finally, we provide a reflection on the implications of such findings for nursing practice.

Review Boards and their Hearings

In Canada, RBs determine the modalities of detention and the supervision conditions that must be imposed on persons found unfit to stand trial (UST) or not criminally responsible on account of mental disorder (NCR) to maintain public safety.[11] During regularly scheduled hearings, evidence is presented by the person UST/NCR's attending psychiatrist to the RB; a panel composed mainly of legal and medical experts. This evidence is produced based on the observations and assessments made by nurses and other health care professionals which are documented and compiled in the medical file.[12] At the end of each hearing, the RB must determine, based on the evidence presented to them, whether the person UST/NCR poses a significant threat to the safety of the public.[11,13,14] If so, it formalizes conditions ranging from in-hospital detention to community-based supervision, in a document entitled a disposition.[11] Another document, the reasons for disposition, provides the RB's justification for the disposition. Considering the significant impact RB decisions can have on the lives of persons UST/NCR, there is a growing interest related to the notion of procedural justice within RB processes.

Procedural Justice

According to Tyler [10], two elements define whether decisions rendered by authorities, such as judges, police, or administrators, are procedurally just. First, decisions need to be perceived as having been rendered with objectivity and without prejudice; authorities must take an unbiased approach and provide opportunity for the subjugated party to present their version of events.[10] Second, and somewhat complementarily, during the process by which the decision is taken, the subjugated party must be treated with dignity and respect, and their situations/concerns must be taken into consideration.[10] In recent research, mental health tribunals were generally found to be procedurally just by various groups of stakeholders to the extent that courts engage accused individuals in conversations with legal and medical professionals with whom they have a high differential of power.[15-18]

To this date, we only identified one Canadian study [18] that has specifically explored stakeholders' perceptions of procedural justice during RB hearings. Stakeholders in this study include persons UST/NCR, family members, mental health professionals and legal professionals. Although the authors of this qualitative study find that RB hearings are generally perceived as procedurally just, they identify certain factors which can impede such a perception, namely the adversarial tone of the hearing, inaccuracies in the evidence presented to the RB, and the punitive sentiment associated

with dispositions rendered. Livingston et al. [18] provide recommendations for changes to RB hearings processes to increase the perception of procedural justice, including the use of strength-based risk assessment tools and the suggestion that mental health professionals should "meet with people found NCR prior to each RB hearing to discuss what should be expected in relation to the procedures as well as the evidence and recommendations that will be offered by the team". [18 p181] They explain this last intervention might help the person NCR build and maintain a therapeutic alliance with mental health care professionals. Other Canadian studies of stakeholder perception of procedural justice in other parajudicial mental health tribunals, such as Consent and Capacity Boards,[3,5] have provided similar findings/conclusions.

While Livingston et al. [18] elicited stakeholder accounts through interviews to assess the perception of procedural justice in RB hearings, we believe including observations as sources of data to understand how procedural justice materializes in RB hearings is essential. Aside from a similar study conducted during the same timeframe in another jurisdiction,[19] our study is the only one to use observations to study the operationalization of procedural justice during RB hearings and the role of nurses in its realization.

Methodological Considerations

Results presented in this article stem from a critical ethnography of the Ontario RB, the purpose of which was to explore how the forensic psychiatric system produces specific identities for persons UST/NCR, and the role of nurses in this identity construction process. This study constituted the first author's PhD project. Critical ethnography was used as a methodology as it allowed for various practices and rituals inherent to the forensic psychiatric system, such as those that contribute to perceptions of procedural justice during RB hearings, to be investigated and problematized.[20-22] Data was collected from interviews with forensic psychiatric nurses (n=6), from observations of RB hearings (n=27 hearings, 41 hours), and from reasons for disposition (n=18). Fairclough's [23] three-step critical discourse analysis framework was used to analyse the data. This framework allowed for a problematization of the ways in which contemporary structures, such as RB hearings, and public safety discourses enabled the production of specific identities for persons UST/NCR. The first step aimed to understand why, how and by whom the data was produced, and why, how and by whom it was used. The purpose of the second step was to look at the language used in the data and to critically examine the words mobilized, the grammatical choices made and the overall thematic and discursive content of the data. The findings were subsequently interpreted

using theories that consider concepts of privilege and power relations to understand how the data collected sustain the structures in which they materialize;[21] these include the theories of Foucault, Goffman and Garfinkel. For this article, we leaned primarily on Goffman's [24] work regarding institutional ceremonies to achieve this interpretative task. We decided to combine a critical ethnography methodology with a data analysis method rooted in critical discourse analysis because it allowed us, as clinicians in the field of mental health, to maintain a critical stance throughout the research process. Such an approach prevented us from feeling constrained and compelled to produce results consistent with disciplinary expectations in the field of nursing, while permitting us to reflect on the way nursing care both supports and perpetuates certain discourses.

Research Ethics Board approval for this project was obtained from the forensic psychiatric hospital where nurses were recruited (#2019014) and from the first author's institution (# H-07-19-4797). Ethics approval was not required for observations of RB hearings, nor was it required for accessing the reasons for disposition of persons UST/NCR as both were publicly accessible. Nevertheless, prior to accessing RB hearings, we communicated with the hearings administrator of the Ontario RB to inform them of our presence and to request the hearing schedules. Further, at the beginning of each hearing observed, the first author presented himself as a PhD candidate in nursing if given the opportunity by the chair of the hearings. Reasons for disposition were publicly available through the Lexis Advance® Quicklaw® database. Nurse participants were recruited by e-mail and by face-to-face contact at unit meetings. Informed consent was obtained before proceeding with the interviews. Given the small number of participants required for the project and its sensitive nature, anonymity and confidentiality were central considerations. Anonymity was achieved by giving participants the power to decide where interviews would take place (i.e., local coffee shop, library, office), by anonymizing the content of their interview during the transcription, by not collecting or reporting demographic information and by giving every participant an alphanumerical code (i.e., N01, N02..., N06). Confidentiality was achieved through secure storage of raw data, deletion of interview recordings once transcription was completed, and by limiting access to raw data to the first three authors.

Theoretical Considerations

Goffman [24] identified that the social condition of psychiatric patients was not different from the social condition of inmates detained in other institutions with similar characteristics, such as prisons, monasteries, and army barracks, which he named

"total institutions". Goffman [24] explained that total institutions create a separation between the inside world of the institution and the outside world, thus allowing for the development of intra-institutional societies that recreate a reality similar to the outside world (e.g., work, leisure and eating schedules). Within such institutions, all facets of inmates' lives, including sleep, play, and work, are conducted in proximity to other inmates. [24] These activities are carefully planned to meet the goals of the institution, which include reform, societal protection, penance, and community reintegration, and their execution is closely monitored and documented by the staff.[24-27]

The inside/outside separation is also replicated within total institutions insofar as a marked separation exists between inmates and staff.[24,26,28] Indeed, Goffman [24] explains that the points of juncture between the inside and outside worlds represent a risk to the sustainability of the total institution. These may include when visitors enter the institution and when inmates are authorized to leave the institution. On one hand, such interactions between both worlds may expose the total institutions' stark living conditions to the outside world. On the other, they may allow for inmates to catch a glimpse of the outside world, thereby disturbing the inner functioning and purpose of the institution. To limit and control the interactions between both worlds, total institutions heavily regulate and sanitize the information entering and exiting its confines.[24]

The RB hearings are events during which the inside world of the forensic psychiatric hospital has the potential to be exposed to the outside world via RB members who act as formal visitors to the institution. Goffman [24] explains that in preparation for such visits and during these visits, institutions strongly control which information they will share. For example, staff members carefully plan which areas of the institution are visited, what information about inmates is shared and which therapeutic activities are highlighted to visitors. In his book, Goffman dedicated a whole section to these visits, which he named "institutional ceremonies".[24 p93] In interpreting Goffman's writings for this study, the concept of "institutional ceremonies" refers directly to RB hearings or what Goffman might also conceive as a form of "theatre" where social interactions can be compared to a play, where people (patients, families, caregivers, judges, etc.) are actors on the stage of life.[29]

Indeed, institutional ceremonies are theatrical performances, serving as opportunities to display total institutions in their best light.[24] In anticipation of institutional ceremonies, various activities are conducted to decide which truths about the inside world of the institution are to be shared with visitors. These activities may include vigorous cleaning efforts, enhancement of food offerings, and glamorous portrayals

of modern treatment modalities.[24] With this framework in mind, we continue with the results of the study.

Results

Our results illustrate nurses' involvement in intricate processes that allow for RB hearings to be considered procedurally just. Through this illustration, we challenge the purported humanistic intent of procedural justice and suggest that, through staged "institutional" ceremonies, persons UST/NCR are given the illusion that their voices are heard during RB hearings. The results are presented in two sections. In the first, we highlight the minutia with which health care teams composed of nurses and other professionals prepare for RB hearings. In the second, we demonstrate the structured way in which RB hearings unfold and the limited opportunities for the voices of persons UST/NCR to be heard within this structure.

The Staging of Procedurally Just RB Hearings

Nurses mentioned participating in clinical activities directed towards ensuring RB processes appear to be as procedurally just as possible to persons UST/NCR. Some of these activities were geared towards ensuring the voices of persons UST/NCR were heard during the RB hearing, while others were directed at supporting them on the day of their hearing.

In the weeks preceding the RB hearings, nurses disclosed that the clinical care team met formally with the person UST/NCR during "pre-RB conferences" to make a team decision regarding the significance of the person's threat to the safety of the public. Health care teams did so by considering various factors, sometimes presented in a risk assessment format:

[Reports] included information about the mental status of the patient throughout the year, including the presence of any suicidal or homicidal ideations, the presence of any 'symptoms,' how the patient engages with their activities of daily living, the interactions they have with their peers, the presence of any family contact, any medical issues that may have come up during the year, the medications they are taking, the 'PRN usage' [as needed medications]. Nurses [also] list and describe any incidents that have occurred over the past year and indicate whether they are verbal or physical. Beyond any aggressive incidents, they would also indicate if there were any other significant incidents such as an elopement. (Nurse 2)

Nurses explained this team discussion served to provide psychiatrists with the necessary information to justify the hospital's opinion regarding a person UST/NCR's threat to the safety of the public and to prepare them to be "cross-examined" during RB hearings:

All the disciplines, including nursing, will typically give

a one-year summary report to the psychiatrist that really help them build a good compilation of data so the psychiatrist can show up prepared to be cross-examined and have a good understanding [of the person's clinical status] (Nurse 5).

Pre-RB conferences were thus described as a venue for "team[s] to come to a conclusion about doing what is best for the patient" (Nurse 2) and as an opportunity for a "snapshot of the [person UST/NCR]'s whole year" (Nurse 1) to be shared with the team and the psychiatrist in preparation for an RB hearing.

Some nurses explained that during pre-RB conferences key conversations often took place without the involvement of persons UST/NCR. On that topic, participant 2 specified that the involvement of persons UST/NCR was typically limited to them "checking-in" at the end of the meeting: "the meeting begins without the patient. Every person gives input and discusses what the patient wants out of the hearing. Then the patient would check in". Indeed, it appears persons UST/NCR were only permitted to "speak for themselves" after the multidisciplinary health care team had already discussed their case and their treatment plan:

The team meets, the doctor and the team that's involved with that patient. And the nurse will go too and then the team leader will read off the conference notes and we all share, we'll go around the table and give our opinion or our thoughts on how they [persons UST/NCR] have progressed, or the opposite, and then after everybody has their say and we discuss what might change or might not change. Then, we bring the patient in and they get to speak for themselves, and sometimes it seems rushed, I'm just being honest here, you know these people, they waited six weeks for this, or they have waited a whole year, and I think they should have their say, you know, whether it takes half an hour or ten minutes. This is about them, . . . so they have to be able to say how they feel, and how they feel they're progressing, they should be able to have their time (Nurse 6).

Only involving persons UST/NCR at the end of case conferences is a covert form of exclusion. It gives the appearance of including them in a team-based discussion about their future and induces a feeling of agency in RB hearing processes—a core principle of procedural justice [10]—all the while excluding them from crucial conversations. In such circumstances, health care teams appear to uphold the perception of procedural justice only, rather than serve the interest of persons UST/NCR and their right to true procedural justice.

Another clinical activity in which nurses were involved to ensure RB processes appeared to be procedurally just was to provide persons UST/NCR with various forms of support.

One nurse explained this support took the form of general reassurance on the day of a person UST/NCR's RB hearing:

First thing would be to check in with that patient, make sure they're feeling, or they seem stable and that they're able to be in a room with a number of people who might be saying potentially hard things to hear, that tends to be my focus is, this person going to be going through some challenges maybe today and, how do they, how do they, how do they look like; I'll deal with that (Nurse 3).

By providing support to their patients on the day of RB hearings, nurses attempted to preserve the dignity of persons UST/NCR while they were exposed to harsh and sometimes inaccurate information in a public venue.[18] One nurse believed that this type of supportive intervention served to align the expectations of persons UST/NCR with what the hospital believed to be the likely outcome of the RB hearing:

I like to verify their expectation of the hearing is pretty clear...Patients don't always have a clear understanding of what they can get out of a review board hearing, sometimes, they want something that's already on their disposition. Or they think there's going to be maybe big changes coming up, but really the hospital is the one that hasn't moved them forward in terms of full utilization of their disposition, so the review board isn't necessarily going to make big changes because the disposition is already quite generous. . . I usually don't just do this the morning of though, I'll usually [start] weeks before, I just try to . . . gently point toward what the reality of it is (Nurse 5).

Aligning the expectations of persons UST/NCR with the "reality" of the RB amounts to preparing persons UST/NCR to agree with the recommendations put forward by the forensic psychiatric hospital. Although being presented as a gentle way to reduce potential surprises out of respect and dignity for persons UST/NCR, this nursing intervention helped prevent behavioural challenges by preparing patients to be exposed to negative information being said about them and by preparing them to accept the outcome of the RB hearing. Strikingly absent from nurses' descriptions of their role was providing general information to persons UST/NCR about RB hearing procedures, coping mechanisms that could be used during the hearing and all possible outcomes of the hearing.

Later in the interview, the same nurse went on to mention that "most of the time" their impression was that RB hearings were mere formalities meant to inscribe the hospital's recommendations in a disposition:

Sometimes, there are those interesting moments where [persons UST/NCR] are going to request a conditional or absolute discharge [disposition], right, and we [the hospital] are not too sure. The psychiatrist has said he probably won't support it, but they might have a chance, they have a good lawyer, so those are obviously more interesting. But most of the time, it's not really how it works. [RB hearings] are formalities almost, we go through it, and hope that, they have this sense of importance (Nurse 5).

The ways in which nurses speak about the process suggest that they see themselves as extensions of the forensic psychiatric hospital; their practice is aimed at bringing persons UST/NCR to accept and internalize recommendations/decisions made by the hospital. The "sense of importance" infused by forensic psychiatric nurses in persons UST/NCR about "what they can get out of RB hearings" provides a smokescreen for procedural justice. Despite being presented as a venue that theoretically gives persons UST/NCR an opportunity to refute the claims of forensic psychiatric hospitals, most of the time RB hearings are ritualistic, wherein recommendations made by forensic psychiatric hospitals are formalized in a disposition. In effect, Crocker, Charette, et al. [30] highlighted that, in Ontario, 92 percent of the recommendations put forth by forensic psychiatric hospitals were upheld during RB hearings.

Although the outcomes of RB hearings seem to favor forensic psychiatric hospitals, as highlighted above, these hearings can nevertheless represent an institutional threat for the hospitals to the extent that they represent instances where the inside world of forensic psychiatric hospitals is exposed to the outside world.[24] During RB hearings, members of the RB are given the opportunity to identify and evaluate institutional incoherencies and dysfunctionalities related to the treatment/management of persons UST/NCR. Thus, when psychiatrists are not well prepared for RB hearings or when their requests lack rigorous clinical and procedural justification, members of the RB may put in question the psychiatrists' expertise at treating/managing persons UST/NCR. The following excerpt illustrates the case of a psychiatrist being scolded by an RB member for requesting that a person NCR be absolutely discharged from the RB instead of being gradually reintegrated in the community:

The RB member asked when the patient became "suitable" for community placement. The psychiatrist answered that given the patient's numerous medical problems, the team didn't get to try community placements given that long-term care is what was needed. The RB member mentioned that the patient's

previous community placement was in a long-term care facility and that it didn't work out and, as a result, the patient was readmitted. The RB member pointed out that the patient didn't need an absolute discharge to try long-term care placement. The psychiatrist explained the hospital didn't move forward given medical concerns. The RB member pointed out that "adjustment to community facility" hasn't been tested. The RB member to the psychiatrist said "With the current detention order, you could have tried, but you didn't." (Observation 22)

While overt questioning of psychiatrists' expertise at treating/managing persons UST/NCR occurred rarely, they nevertheless illustrate that RB hearings represent threats for forensic psychiatric institutions. Therefore, the information shared to RB members must be carefully selected to preserve the institution's legitimacy at treating persons UST/NCR and at protecting the public.

The Structure of RB Hearings

The inquisitive nature of RB hearings [11] and the structured way in which they unfold provides a sense of objectivity and fairness to the process. By allowing both the psychiatrist and the person UST/NCR to share their own evidence, RB hearings appear procedurally just to the extent that they symbolically place, for a short period of time, persons UST/NCR on an equal footing with psychiatrists.

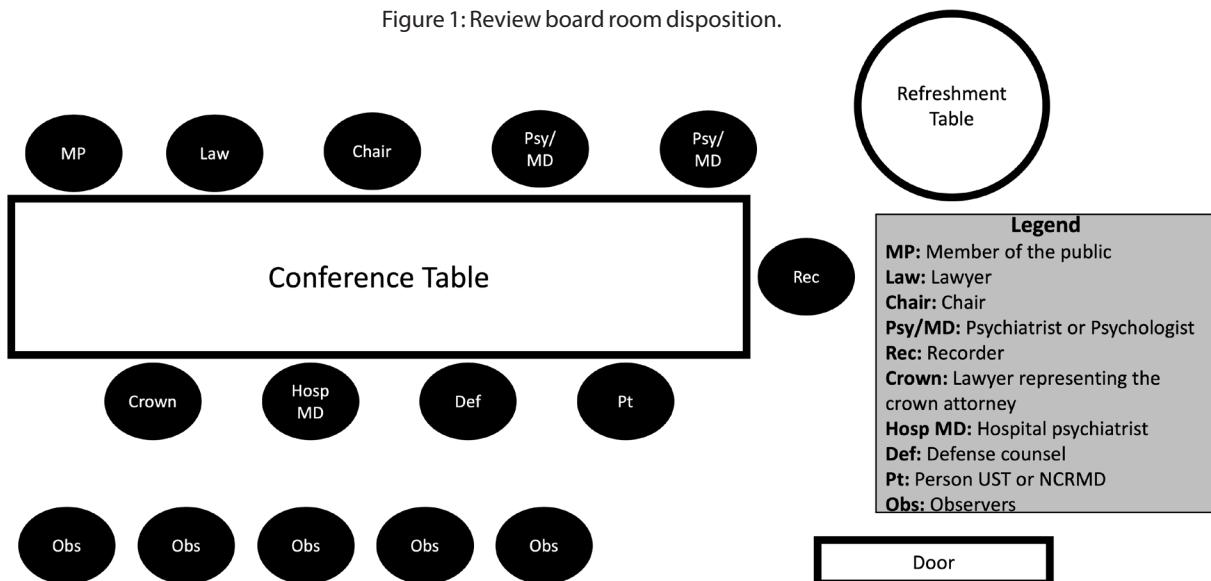
Procedural thoroughness, another core tenant of procedural justice [10], was achieved by the methodical way in which RB hearings took place: the spatial disposition of stakeholders during RB hearings rarely changed, as did the speaking order of all parties. The RBs typically comprised five members, namely one

member of the public, two legal members, one of whom served as the chair of the hearing, and two health care professionals, one of whom was a psychiatrist. These RB members always sat in the same order on one side of the conference table: member of the public, legal member, chair, psychiatrist/psychologist, and psychiatrist/psychologist (see Figure 1). The other parties at the hearing were seated on the other side of the table in the following order: the Crown attorney, the hospital psychiatrist, the defence counsel, and the person UST/NCR. Anybody observing the RB hearing was required to sit along the wall behind the person UST/NCR. When individuals deviated from this specific order, RB hearing attendees were reminded of the rules and instructed accordingly: "Once we all sat in the room, one of the community workers sat at the table between the psychiatrist and the defence lawyer. The psychiatrist told her to sit back with the observers" (Observation 2).

Similarly, the speaking order of parties at RB hearings rarely changed. The following discernable pattern, reminiscent of criminal tribunals, became evident through our analysis of RB hearing observations:

1. Introductions—during this period the chair spoke directly to the person UST/NCR.
2. Chair confirms the list of exhibits—these always included the most recent reasons and disposition, and a report submitted by the hospital.
3. Initial positions of the parties (Crown, hospital & defence).
4. Highlights the psychiatrist wants to make about his report and the progress of the person UST/NCR.

Figure 1: Review board room disposition.



5. Questions from Crown and defence counsel [to psychiatrist].
6. Questions from the board members [to psychiatrist].
7. Questions arising from the board members' questions [to psychiatrist].
8. Any new evidence from parties—Crown and defence counsel.
9. Final positions.
10. The chair adjourns the meeting, thanks the person UST/NCR and informs them that a decision would be rendered within one week and that the reasons would follow. (Observation 16)

Individuals engaged in dialogue with others only when it was their turn to speak and in accordance with the above-mentioned sequence. During one RB hearing, the chair inadvertently violated this order by asking the hospital psychiatrist if he had additional evidence to present (Step 8) before asking other RB members if they had questions for him (Step 7). The chair was reminded by the hospital psychiatrist that he had missed a step: "The chair then asked if the psychiatrist had any more evidence to submit. The psychiatrist then said, 'maybe you want to ask your colleagues if they have questions first'" (Observation 14). The psychiatrist's intervention demonstrated the internalization of the RB's order of speaking, which ensured that the correct order was maintained and that procedural rigor was preserved.

Similarly, when persons UST/NCR deviated from this speaking order, by reacting to the things being said about them, for instance, they were either ignored or reminded to remain silent until they were given the right to speak. We documented in our fieldwork journal numerous occasions, like this one, where a person UST/NCR was ignored by the RB:

Crown then asked if the patient was currently limited to directly supervised privileges. Psychiatrist confirmed and said that the patient only entered the community accompanied by staff on two occasions at which he accessed local shops. Crown then said: "So on the five occasions he tested positive [for drug use], he was on the grounds?" The patient said, "It was only once." The board ignored the patient and the Chair asked the defence if he had any questions for the psychiatrist (Observation 10).

On other occasions, the defence counsel of persons UST/NCR actively asked them to remain quiet:

Psychiatrist then mentioned that overall, in the past 18 months, he did see some progress in that the patient was no longer smoking in the washroom and that he is cooperative, although there remains some issues relating to substance use. Patient said: "I only tested positive once." Defence said to the patient "shhhh." Psychiatrist then added: "and impulse control" (Observation 10).

Defence counsels most likely silenced their clients because they feared such interjections might substantiate claims suggesting lack of self-control, negatively affecting the outcome of the hearing. In the above excerpt, for example, the hospital psychiatrist took the unauthorized verbal interjection of the person NCR as proof of their impulsivity. Despite the underlying reason for the person's interjection—to clarify the veracity of the information being shared about them—precedence was given to respecting the order of speaking during the RB hearing.

On the rare occasions where persons UST/NCR spoke for themselves and provided evidence during RB hearings, RB chairs ensured they spoke in very constrained ways. For instance, RB chairs would ask the person NCR to modify the way they presented information if it was felt they were "leading the delivery of evidence" as opposed to answering questions specifically formulated by their defence counsel:

The defence counsel asked the patient if he would continue treatment should a conditional discharge be ordered. The patient said yes. He continued saying he sees the benefits. He said he wants to go to independent housing; not supervised. That is why he wants a conditional discharge. The patient said "I've got a lot of protective factors" and then started listing them. He said that he participates in 20 hours or more a week of vocational jobs, [...] attends numerous alcoholic anonymous meetings, has a sponsor, sees the psychologist, volunteers at Alcoholics Anonymous, goes to the YMCA, has job prospects. [...] The chair interrupted telling the patient to "let the counsel lead, she will ask you questions (Observation 4).

On other occasions, persons NCR were simply ignored by RB members or even mocked by other individuals in the conference room while they provided evidence:

The defence then mentioned that the patient would

like to speak. The patient said that he was first brought into hospital in [year] and that he has been in detention for 15 years without reason. Fifteen years of medication. He said: "I've never been sick in my life. The doctor is telling lies, he is punishing. No nurse is qualified here." The defence asked the patient if he would like to return to his apartment. The patient said "Yes, anytime. I've had a perfect condition for 15 years. I want to live in my own apartment." The defence asked the patient how he felt about his treatment team. The patient says that they come to him with threats and accusations. **Nurse and other unspecified hospital staff laughing while patient spoke** (Observation 26).

In our ethnographic field notes, we also noted: "when the patient gave his testimony, all the parties at the board, except the defence [counsel], were writing and not paying attention to the patient speaking . . . in striking contrast to when any other of the parties speak, such as the psychiatrist" (Observation 26). Although the language of the person NCR's testimony did not contain the typical words contained within expert testimonies, the truths it conveyed, namely that they felt the psychiatrist was punishing them and that staff members were threatening them, were relevant. However, the lack of seriousness associated with the testimony subjugated these truths. It is worth noting that the laughter of hospital employees was tolerated by the RB chair despite the otherwise stringent rules.

In all our observations, persons UST/NCR were the only actors to have been ignored or requested to wait their turn to speak. When other RB actors asked questions or sought clarifications, albeit infrequently, they were not reminded of the speaking order or required to conform to a particular way of speaking. Furthermore, persons UST/NCR were expected to be docile and remain quiet when hospital psychiatrists presented evidence about them—even if this evidence was identified in the literature as being difficult to hear and strewn with inaccuracies.[18] This was particularly apparent during one defence counsel's intervention at the end of an RB hearing: "The defence said the [person NCR] did not want to 'rock the boat' [during the RB hearing] so he asked [the defence] not to introduce a contrary position [to the one presented by the hospital]. He did not want to upset things" (Observation 18). By adhering to the hospital's interpretation of their character, the person UST/NCR refrained from "rock[ing] the boat" out of fear that the RB would be more stringent in their issuance of a disposition order should they contradict the hospital's recommendation.

Discussion

The results of our study complement those of Livingston et al. [18] in that they illustrate how procedural justice materializes during RB hearings, how it is staged in processes at their periphery, and how it can be leveraged to ensure procedural efficiency. By seeming procedurally just, RB hearings may entice persons UST/NCR to comply with their disposition orders and obediently engage in various activities and treatments to reduce the perceived threat they pose to the public.[1,2,6,8] Thus, procedural justice is not necessarily the end goal; it is a means to an end. The mere illusion of procedural justice is sufficient to achieve docility, compliance, and efficiency. Considering the significant effects of RB hearing outcomes on the lives of persons UST/NCR,[12,18,30] serious ethical questions arise regarding the clinical practice of nurses who participate in the staging of procedurally just RB hearings.

Notwithstanding the humanistic intent of nurses who work in forensic psychiatry, our findings demonstrate that their practices give persons UST/NCR the impression that they are on a level playing field with psychiatrists during RB hearings. In effect, our results suggest that nurses conduct essential work to prepare forensic psychiatrists and, by extension, the forensic psychiatric hospital for RB hearings. They participate in a series of orchestrated clinical activities to determine what information about the person UST/NCR is to be presented to the RB, and how it is to be presented. This work conducted prior to RB hearings allows for truths about persons UST/NCR and about the forensic psychiatric hospital to be regimented and presented to RB members in calculated ways. Seen through Goffman's [24] lens on total institutions, these preparatory activities serve to project a doctored image of the forensic psychiatric hospital, of its processes and of persons UST/NCR to visitors entering hospital; in this case, the visitors being RB members. Preparatory activities provide a safeguard against potential inaccuracies in the testimonies of psychiatrists, against scrutinizing questions of RB members and against "cross-examinations" from persons UST/NCR, or their defence counsels.

Indeed, RB hearings constitute opportunities for psychiatrists to re-establish psychiatry as the medical discipline with the required expertise to define who constitutes a threat to the safety of the public and how this threat should be managed. [31] If psychiatrists were to err when providing their testimony, or if their professional opinions were to be scrutinized by RB members (as illustrated in the first section of the results), their expertise could be put into question as could the forensic psychiatric hospital's legitimacy for treating threatening individuals, thus jeopardizing the sustainability of the total institution [24]. On this subject, Foucault [32] described a

procedure at psychiatric hospitals for presenting mentally ill patients—complete with their life histories and clinical progression—in front of an audience comprising the patient, students, and other clinicians. In such procedures, he wrote, “doctors constitute themselves as masters of the truth”.[32 p185 free.trans] Because of this mastery of truth, psychiatrists can “exercise within the asylum an absolute super-power and associate themselves with the body of the asylum, thereby constituting the asylum as a medical body that cures through the eyes, ears, words, and actions of psychiatrists”.[32 p185 free.trans] By providing testimonies about the lives and clinical progress of persons UST/NCR during RB hearings, forensic psychiatrists establish themselves as experts and masters in the identification and reform of threatening individuals, and likewise establish forensic psychiatric hospitals as institutions responsible for their treatment.

Nursing activities that are aimed at achieving “procedural justice”, such as “gently pointing [the person NCR] towards the reality [of the RB]” or including persons UST/NCR in meetings after decisions have been made, are therefore essential as they serve to prevent errors or inaccuracies during the delivery of evidence, to limit the presentation of opinions contrary to that of the hospital, to reduce potential challenges by persons UST/NCR and to protect forensic psychiatry against threats to its discursive hegemony. Thus, behind the illusion of respect, dignity, equity, and procedural justice, we purport, like Pariseau-Legault et al.,[19] that the decorum maintained in RB hearings highlights and perpetuates the power imbalance that exists between the person UST/NCR and the forensic psychiatric apparatus.

By participating in the preparation and staging of RB hearings, nurses protect forensic psychiatric hospitals, forensic psychiatrists and, ‘psych’ disciplines more broadly, against threats to their discursive hegemony, sometimes at the expense of the social wellbeing of their patients.[31,32] Framed in this manner, forensic psychiatric nursing is reduced to serving as an extension of forensic psychiatry; that is, nurses are less concerned with advocating for the patient’s best interest and are more concerned with protecting the institution of forensic psychiatry and its role in the so-called protection of society. In these circumstances, the specific contribution of mental health nurses to the care of persons UST/NCR, such as the utilization of strength-based approaches, the accompaniment and preparation for RB hearings, and the upholding of equity and human rights,[33,34] seems to get lost insofar as their practice objectifies patients as problems needing to be fixed.

Strength and Limitation

The strength of this project resides in its methodology and methods. This study is only one of two studies, the other being that of Pariseau-Legault et al.,[19] to use observations as a source of data to examine the notion of procedural justice in the context of RB hearings. The study conducted by Livingston et al. [18] relied exclusively on experiential accounts of individuals who had participated in RB hearings, including health and legal professionals, persons NCR and their family members. By using observations, rather than assessing the perception of procedural justice, we were able to see how it materialized, or not, during RB hearings. Interviews with nurses allowed us to take our analysis one step further and to understand the clinical activities and processes that take place within the forensic psychiatric hospital to ensure persons UST/NCR perceive RB hearings as procedurally just. Conversely, we consider the fact that persons UST/NCR were not interviewed as part of this study to be a limitation. Their perspectives could have further contextualized our observations and analysis.

Implications for Nursing Practice

In a context where psychiatric hospital staff “pointedly establish themselves as specialists in the knowledge of human nature, who diagnose [and] prescribe on the basis of this intelligence”[24 p89] the results of this study bring us to reflect on the ethical complexities of providing nursing care in forensic psychiatry. Nurses participate in various coercive processes at the junction of law and psychiatry [35-38] and they have been recognized, in this study, as indispensable actors for the staging of procedurally just and efficient RB hearings. Whether or not, and to what extent, nurses appreciate that the support they provide to persons UST/NCR before, during and after RB hearings may serve additional purposes external to the domain of care, is unknown. Nevertheless, as health care providers with ethical responsibilities, nurses must be able to engage in critical reflections about the effects of nursing care beyond the proximal relationship they develop with patients, such as the effects of aligning the expectations of persons UST/NCR with the “reality of RB”. Such a reflection could bring forensic psychiatric nurses to critically examine how they contribute to maintaining a system that discounts patients’ voices through a veneer of procedural justice. Like that of others (see, for example, Morse;[39] Pariseau-Legault et al.;[19] Paradis-Gagné et al.[38]), our results identify a need to raise nurses’ awareness related to the political and ethical ramifications of their taken-for-granted clinical practices, particularly in the domain of psychiatry and forensic psychiatry.

With such an awareness, much like Cloyes [33] suggests, we see nurses as having a central role in fostering an environment and establishing processes where persons UST/NCR can exert their own agency. In areas where nurses have direct procedural influence, they could advocate for structural changes permitting persons UST/NCR to increase the frequency or intensity with which their voice can be heard, by having them participate during the entirety of their pre-RB hearing conference, for example. In areas where they cannot influence the processes, instead of attempting to silence the voice of persons UST/NCR, like it appeared to be the case in our results, nurses could educate their patients about the different avenues where they could, albeit with many constraints, make their opinions heard.

In this vein, a neutral third party that has no direct relationship with the forensic psychiatric system could provide education to nurses working in forensic psychiatry about the RB hearing procedure and opportunities for persons UST/NCR to make their voices heard. While acknowledging that our results paint a picture of the forensic psychiatric system as a structure that silences certain truths emanating from marginal(ized) discourses while perpetuating other dominant discourses (i.e., those related to psychiatry and public safety), we believe such education could entice nurses to act in a way which could alter the narrative produced about persons UST/NCR during RB hearings. Coupled with opportunities for ethical and critical reflections about their practice, our hope is that nurses who receive such education could advocate for the already limited procedural rights of patients, thereby preventing situations where persons UST/NCR decide not to present positions contrary to those of the hospital, out of fear that they would “rock the boat” and “upset things.” In effect, conceptualizing the role of nurses in forensic psychiatry as one that upholds the human rights of persons UST/NCR is closely aligned with Timmons’ findings who purported that two core functions of forensic psychiatric nurses was to practice with humanity, and promote equality, diversity, and human rights.[34]

While our recommendations would not inherently change the role of nurses within the forensic psychiatric system, they might destabilize its functioning by providing space for reflection and critique and by broadening the possibilities for resistance. Although focused on forensic psychiatric nurses, these implications are transferable to many other domains of health sciences, including public health, general psychiatry, geriatric nursing, and palliative nursing.

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Abstract

Whistleblowing about critical issues by care staff is an essential component of any well-functioning health care system. During a pandemic, rapid communication of critical information is essential to identify and solve problems. In times of crisis, however, this kind of communication is difficult. In the province of Quebec, Canada, testimonies from nurses, licensed practical nurses (LPNs), and other health professionals during the COVID-19 pandemic indicate that the province's health care settings have met whistleblowers' concerns with insufficient corrective measures and, in some cases, retaliation against whistleblowers themselves. This crisis led a union to create an online platform to collect testimonials from the public and quickly make them available to the public and the media. By presenting a content analysis of testimonials submitted by nurses and LPNs, this article aims, on one hand, to identify the issues raised and, on the other, to examine the role and usefulness of this kind of platform for nurses who engage in acts of whistleblowing.

Key Words content analysis, whistleblowing, pandemic, nurses, retaliation

Nurses whistleblowing during the COVID-19 pandemic: Content analysis of the "Je dénonce" platform

AMÉLIE PERRON, CAROLINE DUFOUR, EMILY MARCOGLIESE & MARILOU GAGNON

Introduction

Whistleblowing about critical issues by nursing staff (understood to include registered nurses and licensed practical nurses [LPNs]) is an essential component of any well-functioning health care system. It is particularly useful to highlight practices that threaten the safety and wellbeing of patients and workers. During a pandemic like that caused by the novel COVID-19 coronavirus, rapid communication of critical information is essential to identify and solve problems while the health system attempts to slow the pathogen's spread and limit its harmful, often lethal, effects on the population. In

times of crisis, however, this kind of communication is difficult. It is also assumed that organizations under pressure are actually willing to receive this critical information. In Quebec, testimonies from nurses, LPNs, and other health professionals during the COVID-19 pandemic indicate that health care settings have met whistleblowers' concerns with insufficient corrective measures [see examples 1-3] and, in some cases, retaliation against whistleblowers themselves, despite the merits of their actions [see examples 4, 5].

In Quebec, the crisis prompted the province's largest nursing union, the Fédération interprofessionnelle de la santé du Québec (FIQ), to create an online platform. The Je dénonce ("I denounce") platform collects testimonials from the general population and professionals in caring and non-caring roles (across all occupations) and quickly makes them available to the public and the media in order to expose challenges in how the health care sector is managing the pandemic. Such a platform is unprecedented in health care. It therefore provides an opportunity to deepen our understanding about whistleblowing by nursing professionals who raise the alarm

about concerning, dangerous, or illicit situations in their practice settings. Through a content analysis of testimonials submitted to Je dénonce by nurses and LPNs, this article aims, on one hand, to identify the issues raised and, on the other, to examine the role and usefulness of this kind of platform for nurses who engage in acts of whistleblowing after witnessing unsafe or objectionable practices.

Background

In health care, people who blow the whistle do so after having witnessed professional/clinical practices (by health professionals) or administrative practices (by managers or decision-makers) that disregard applicable rules, norms, or laws. Here, "whistleblowing" is used as defined by Near and Miceli: "The disclosure by organisation members (former or current) of illegal, immoral or illegitimate practices under the control of their employers, to persons or organisations that may be able to effect action" [6 p4]. Current research shows that most people who reach outside an organization to raise their concerns first attempted to do so through internal channels. [7,8] The act of whistleblowing is usually perceived as an affront to organizational expectations of employee conformity and loyalty. [9,10] It is therefore generally assumed that external whistleblowing is only acceptable when all other (particularly internal) means of reporting have been exhausted. [see for example 11]

Nurses may have access to a variety of reporting options, including informing their superiors, filling out incident reports, or using anonymous internal reporting systems. [12] However, in many cases, these reports fail to produce concrete results and many whistleblowers note that issues persist. Numerous studies show that nurses have little confidence in organizational procedures for dealing with their complaints, [13,14] which may lead them to turn to external channels. Several authors believe that external whistleblowing is a clear indication of organizational failure that could be resolved if organizations strengthened their internal reporting mechanisms, efficiently managed the problems reported, and promoted a culture of integrity, transparency, and improvement. [8, 15, 16]

Whistleblowing has serious consequences for everyone involved. For whistleblowers, internal reporting can lead to increased surveillance of their work by their superiors, arbitrary performance evaluations, and peer isolation. [17, 18] In cases of escalating reporting strategies, whistleblowers' judgment and competence may be discredited and their performance increasingly monitored; they may also experience ostracism, harassment, threats, and retaliation up to and including

loss of employment. Every study consulted reports serious emotional consequences: isolation; loss of self-confidence; disengagement with patients; desire to leave the profession; anxiety, depression; and, in more extreme cases, suicide. [17,18] For organizations, whistleblowing is generally negatively perceived, even when the issues in question have been recognized. (19) Although it is possible to implement constructive responses that do not affect the whistleblower, they are astonishingly rare. [9, 19] In most cases, constraints are rapidly put into place to control both the public impact of the whistleblower's actions (minimizing the situation, evoking an isolated incident, discrediting the whistleblower, etc.) and the whistleblower's ability to speak or act, often to an extreme extent. [7,9]

During the COVID-19 pandemic, whistleblowers came forward around the world and reports indicate that the aggressive responses they experienced during this crisis are no different from those in pre-pandemic times [for an overview of notable cases, see 20]. This is no less true in Canada, and particularly in Quebec, where nurses and nursing organizations (primarily unions) have spoken up in exceptional numbers. [21] In light of issues arising from the continued pandemic and its increasingly incoherent management, at the end of March the FIQ launched a platform called "Je dénonce" ("I denounce") to collect testimonials about unsafe and objectionable practices within the health care system.

Je dénonce is available to anyone who wishes to publicly denounce situations or practices that could or do place patients and health care workers (in care, non-care, management, and other roles) at risk. More specifically, the union seeks to position these testimonials in contrast to information about the crisis provided by government authorities. On the platform's website, the FIQ states that

This website was created to bring together all the testimonials about health professionals' on the ground experiences during the current public health crisis. We seek to highlight the gap between what the government says and the reality faced every day by health care professionals in the system. [22] (original translation)

In addition to this short description of the platform's objectives, one of the page's menu tabs presents potential users with considerations in both French and English. It specifically provides reminders about freedom of expression and its limits, while also offering guidance for how to safely sound the alarm, given the public nature of whistleblowing.

The whistleblowing tools itself presents users with a simple form to collect their name, job title, and workplace.

Whistleblowers can decide whether to make their identity public or not; most submissions consulted for this analysis indicate that whistleblowers prefer to remain anonymous. A description of the reported issue can be entered in a free text field, and users have the option to include photos or videos to support their testimonial. Each person's consent is confirmed before they can submit their testimonial to the platform. Testimonials are verified before being posted online (Fédération interprofessionnelle de la santé du Québec, personal communication, June 28, 2020). The first testimonials were submitted on March 29, 2020. The vast majority of whistleblowers are nurses and LPNs, but other types of workers (e.g. patient attendants, social workers, respiratory therapists, physicians, maintenance staff) and members of the public have also submitted testimonials.

The purpose of this study was to analyze the reports made public through the Je dénonce platform and to determine its degree of usefulness in addressing critical pandemic-related concerns. This article presents the results of a content analysis of nurses' and LPNs' testimonials submitted via Je dénonce over a two-month period; in doing so, it seeks to first identify the types of issues raised and second to examine the role and value of this kind of tool for nurses who engage in acts of whistleblowing after witnessing unsafe or objectionable practices.

Methods

In keeping with our goal to study nurse whistleblowing experiences, we analyzed testimonials submitted specifically by nurses and LPNs between March 29th and May 31st, 2020. This period was chosen to capture reports covering the platform's launch, the peak of the crisis, and the following weeks, while also obtaining a robust dataset. A total of 611 testimonials were initially collected for this time span, fourteen of which were discarded because they were provided by members of the public or were off-topic. Our sample consisted of 597 testimonials by nurses and LPNs.

Content analysis was performed on our dataset. This approach allowed us to identify and describe themes emerging from nurses' testimonials. Our analysis was conducted according to conventional principles for this approach. [23,24] We followed an inductive method and allowed categories to emerge from the analysis. To begin, 50 testimonials were randomly chosen to identify general themes. Next, 20 additional testimonials were added to test and refine our analytical strategy. This process

produced twelve categories. We tested these categories with ten additional randomly chosen testimonials and, finally, with the entire sample. No ethics approval was required to conduct this analysis, as testimonials are freely available to the public.

Results

Through our analysis we identified 12 categories (Figure 1) and determined the frequency of each within our sample (Figure 2). The categories are: 1. Hierarchy; 2. Invalidation; 3. Instrumentalization; 4. Control measures; 5. Overwork; 6. Insufficient resources; 7. Multiple inconsistencies; 8. Violation of infection prevention and control standards; 9. Fear; 10. Suffering; 11. Resistance; 12. Resignation. Descriptions of each category are presented below.

Hierarchy

The notion of hierarchy is brought up in 48 testimonials (8%). Hierarchy is intrinsic to Quebec's health care system and determines its care management model. It also dictates the position of certain groups and specialties within that system. The pandemic appears to exacerbate inequalities between certain professionals; those of higher status benefit from better protection from the virus and different information about it, as illustrated in the following excerpt.

I'm a nurse, they ask me to limit the use of medical equipment because of the PPE [personal protective equipment] shortage. But, for medical specialists (gynecologist), the recommendation is to wear a mask and glasses and/or shield at all times given the risk of community spread. (Testimonial 370).

Health care settings are also hierarchized. Consequently, disparities in equipment and budget allocations are reported across departments and specialties.

At the long-term care centre, management wanted us to take every resident's temperature QD, but we don't have a portable thermometer, we asked for a thermometer on the COVID-19 budget. The answer was "Long-term care centres are last on the list to use the COVID-19 budget". (Testimonial 625)

Figure 1: Number of testimonials for each category

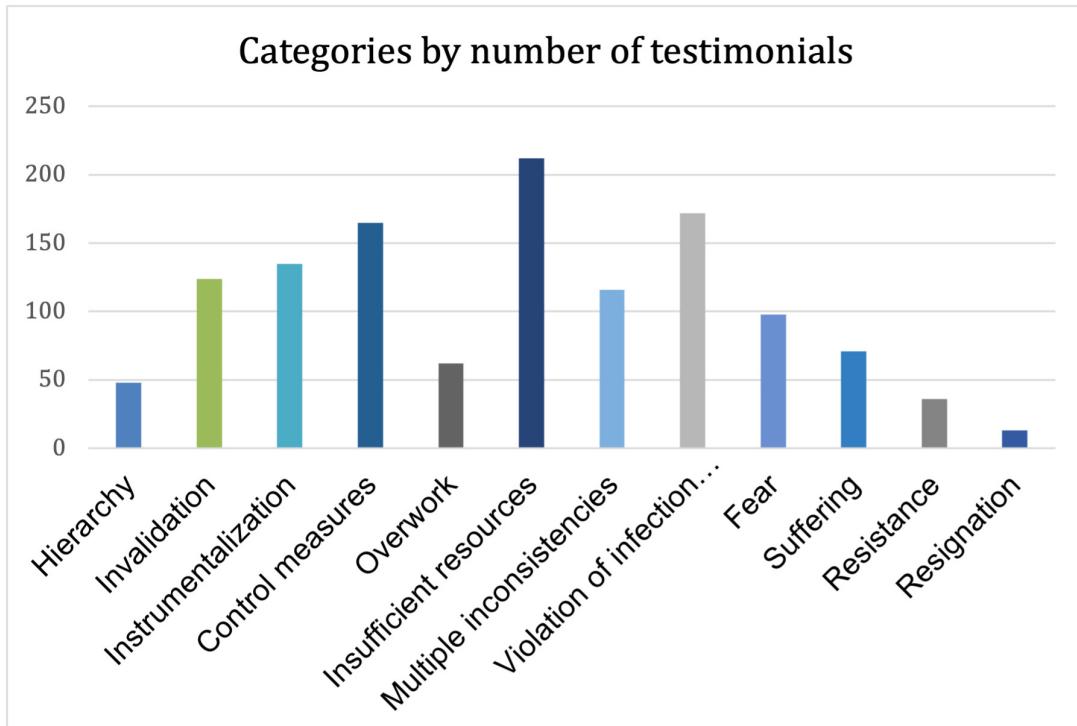
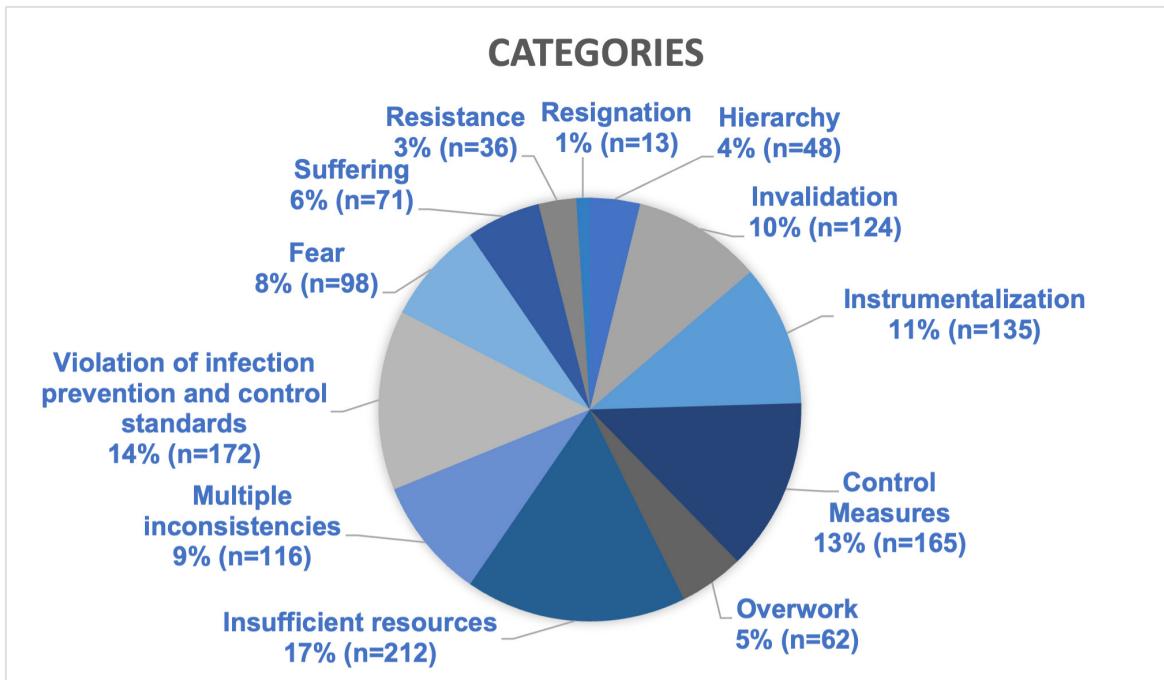


Figure 2: Distribution of percentages for each category (one testimonial can appear in more than one category)



Nurses and LPNs also report that immediate supervisors (department heads) have limited decision-making power and that problematic decisions are made by higher authorities.

I'm not blaming management, because they're working the best they can, but really the problem is higher up.
(Testimonial 831)

Invalidation

Being invalidated is reported in 21% of nurse and LPN testimonials (n=124). Invalidation is understood as having one's observations, concerns, and suggestions ignored. Many whistleblowers describe having their clinical expertise, experience, and judgment devalued in this way.

One morning an infection prevention specialist came to talk to us... She gave us instructions that went against everything we had been taught and recommended to date... No gloves, we just have to wash our hands. No waterproof gown covering the entire body, the short yellow fluid-resistant gown is enough. (...) It didn't matter that we explained that once we're on the unit we have to intervene with patients who are decompensating. We're not just passing through here. We're at the bedside. We act, we are professionals who perform invasive acts. (Testimonial 706)

Many testimonials also recount difficulty getting answers to questions or even communicating problematic situations to a manager. The following excerpt describes such an instance.

I knocked on every door, I wrote a 16-page testimonial to ask for help from several people... I sent emails, I used Messenger, I called... But no one came, no one helped us. (Testimonial 840)

Other testimonials denounce the fact that supervisors do not seem to consider nurses and LPNs as valid sources of information regarding issues such as changes on their unit for example.

... last Friday it was decided that a wing on my floor would be dedicated to COVID-19 and they decided to start on a Saturday, when I got to work nothing was ready, no one knew about it, no one on the floor had had a fit test in case a patient decompensated or presented severe respiratory symptoms. (...) Plus, there were no managers on site despite this unusual situation. I'm discouraged. (Testimonial 615)

A significant proportion of excerpts that mention the invalidation process also reflect nurses' and LPNs' feelings of discouragement and powerlessness – a point we will return to later.

Instrumentalization

Being instrumentalized was reported by 135 nurses and LPNs (23%). Instrumentalizing a person means treating them as an object rather than a human being. Submitted testimonials indicate that nurses seem to be perceived as interchangeable pawns that can be transferred across units and departments based on administrative needs, without regard for their skills or experience.

We get the impression that HR management is taking advantage of the situation to increase workforce mobility, to put all the nurses on float teams, a

management technique that will persist after the pandemic. They show that, for them, a nurse is the same as any other and the expertise gained in a specialized field means nothing, each nurse is easily replaced by another after perfunctory training. Thank you for showing your nurses just how easily replaceable they are, even when patients suffer from the loss of expertise in your facilities. (Testimonial 775)

In the same vein, testimonials point to a lack of concern for nurses' wellbeing and trivialization of working conditions in ways that compromise their physical and mental health.

Since COVID-19 I have anxiety because I have to be on the front line (with patients) even though I have a chronic illness, uncontrolled asthma from birth. My employer does nothing and refuses to transfer me into a safe job for my condition (office work). He leaves me at home without pay, despite my desire to go work, he refuses! Despite a medical certificate. This is not how you take care of your staff or act like a human being. It's not normal, when I have a friend who works at Tim Hortons and is also asthmatic under control, and her boss understood, he is more humane than mine and sent her home and she's paid... IT DOESN'T MAKE SENSE, THIS IS HOW THEY TREAT US? (Testimonial 402)

Similarly, many testimonials indicate that pregnant and immunosuppressed nurses and LPNs are forced to work without being removed from risky environments.

Even knowing my health status (immunosuppressed), they refused to take my specialist's medical certificate into consideration. I was told that I would be assigned to the hot unit this Sunday (very contagious zone), whose current COVID-19 status I know. (Testimonial 824)

This analysis highlights irritants in certain care centres regarding nurse compensation. For example, some testimonials describe how bureaucratic decisions allow some hospitals to evade payment of premiums meant to compensate nurses working in units impacted by the pandemic.

We're a unit with several specialties, including pneumology. We won't get the 8% bonus promised by the government because the unit has two corridors and the other corridor is a cold zone, so we're penalized. (Testimonial 698)

In my hospital, to avoid having to give the bonus to too many people, they changed the definitions of hot and warm zones. One of the floors has a section for

suspected or positive covid-19 cases, but the people who work there won't get the bonus because now it's considered a "warm" zone. (Testimonial 873)

The instrumentalization expressed in these testimonials is striking, given the numerous statements by elected officials, health centre administrators and members of the public praising nurses' dedication and heroism. As such, the trivialized instrumentalization of nurses during the pandemic is at odds with how one might expect so-called "guardian angels" to be treated. Many nurses and LPNs denounce this situation and the perversity underlying the name "guardian angel".

Angels? No. We're slaves to our system, at our own risk, at the risk of our children. Why do we have to be on the front lines, without protection, unpaid if symptomatic and with so little recognition. (Testimonial 287)

We're like cannon fodder. Slaves to the CISSS [Integrated health and social services centre]. Treated like numbers. (Testimonial 102)

Control measures

Analysis indicates that 28% of testimonials (n=165) concern control measures imposed on nurses and LPNs. These measures, which narrowly restrict nurses' work to doing what is strictly expected of them, operate on different levels. For example, many testimonials describe how protective equipment is often controlled by being locked away so staff must obtain special permission to gain access.

I'm in a nursing clinic in a local community service centre, since the beginning of the pandemic, we have only had access to surgical masks for the last few days, we have two boxes available in the clinic, the others are hidden and locked away. We're only allowed to use the masks for PICC line care and are monitored by the [assistant nurse clinician to the immediate supervisor] when we use them. (Testimonial 578)

Masks locked away by our manager, hand sanitizer removed from our offices and home care supplies. Disinfectant wipes unavailable or in limited quantities to disinfect our home care equipment. We're regularly told that supplies are not available for disinfection. We feel like we're being watched every time we use supplies. In home care it is critical to disinfect our equipment between each client!!! (Testimonial 548)

Nurses and LPNs also report managers using threats to control the sharing of information.

Every day our superiors send emails warning us not to denounce the lack of supplies and staff management. (Testimonial 508)

Many nurses and LPNs also report being bullied and suffering retaliation for questioning directives. Refusing to follow orders, even those contrary to public health directives, leads to sanctions. The example below was provided by an LPN working in a long-term care facility with no COVID-19 cases who refused to go work in another facility known to have around one hundred positive cases, for fear of triggering an outbreak in her original place of work.

They tell me that I have the least seniority, so I'm the one who has to go and there could be sanctions if I REFUSE to go!! I ask what sort of sanctions? Because I don't want a note on my file! He (assistant head nurse) answers with uncertainty that he's heard of fines up to \$4000 or that after 3 refusals they would take away all my seniority that I WORKED FOR AND DESERVE!! I think about it (...) I decide and say NO! After I refuse, my assistant contacts the coordinator who tells him to send me home!!! (Testimonial 856)

Many testimonials report tight controls imposed on workers according to ministerial orders. They describe administrators' abusive application of this exceptional measure to fill staff shortages that predated the pandemic, even in the absence of COVID-19 cases. These abuses translate into imposed full-time work over multiple shifts; the obligation to be mobile and transfer to other departments or even institutions; and the cancellation of vacation time.

I find it strange that my institution is applying the ministerial order. They've already started to cancel vacations, stat holidays, and impose full-time hours even though there's absolutely no need... I work in intensive care where there have been no COVID cases because we transfer them automatically. We can't get the 8% bonus for this very reason! Why apply the decree since we aren't getting the bonus under the pretext that we are not in a COVID crisis!!! There are several staff surpluses every day but they're going to impose full-time hours? My institution uses the tools the government gives it even if it doesn't need them, just because they have the right! I'm discouraged. (Testimonial 797)

Such practices worry many whistleblowers, who fear these abusive management practices will become routine after the pandemic.

Overwork

Sixty-two nurses and LPNs (10%) report being overworked. This category reflects an imbalance between workload and the time and resources available to ensure quality care and patient safety. Nurses and LPNs attribute overwork primarily to increased complexity of care and lack of human resources across health professions (pre-existing staff shortages, absences due to COVID-19, etc.). This lack of resources creates unsafe nurse/LPN-to-patient ratios.

It's not safe to work, no safety for patients, no confidence in the staff. I talked to a colleague yesterday, he feels the same way I do. This morning I heard that last night another colleague was... my god. He was all alone with a new nurse too and 1 casual care attendant. He said he didn't get a break, 1 fall and 2 deaths. A coordinator who only spoke to him on the phone told him to leave the bodies for the morning shift, inhumane. No physician to certify the deaths. (Testimonial 765)

As a result, care is not provided and patients suffer.

A patient left in her room, poop on the floor, feverish. At 2pm lunch tray on the table untouched, breakfast tray in the garbage... Dehydrated++ No staff on the floor! It smelled like death in her room!!!! I screened her but I think that as I write these words, she must be dead from dehydration and not from COVID! CRIMINAL negligence!!! (Testimonial 925)

Insufficient resources

This theme emerges in 36% of testimonials (n=212) and focuses specifically on a lack of basic material resources to provide care, highlighting time lost and increased burden of care.

There's a supply shortage. Yesterday to start an IV, I had to check stocks in 4 different departments (red, or yellow). This morning so I could continue the IV, for a resident who was transferred, I had to get special permission from the on-site department head to get the supplies I had set aside for her on a so-called red unit. An hour of time lost for two litres of solution, 1 vial of rocephin and some 100 ml NS pouches. (Testimonial 876)

Furthermore, physical environments are often inadequate. For example, in some places, workspaces do not allow physical distancing or they lack change rooms to change clothes before and after a shift.

Most [patients] cough a lot and my workspace is less than 4 metres from patients. The morgue that comes to collect the bodies is better equipped than us (95, visor and full suit). (Testimonial 748)

Lack of protective equipment (medical/surgical masks, N95 masks, uniforms, gowns, gloves, etc.) is a problem for a large proportion of nurses and LPNs (178 testimonials, 84%). In the most extreme cases, they have to share protective equipment, reuse it, or even craft their own.

Masks locked away by our manager, hand sanitizer removed from our offices and home care supplies. Disinfectant wipes unavailable or in limited quantities to disinfect our home care equipment. We're regularly told that supplies are not available for disinfection. We feel like we're being watched every time we take supplies. In home care it is critical to disinfect our equipment between each client!!! (Testimonial 548)

I work on the floor where we now screen for COVID-19. (...) The day they wanted to admit these persons [COVID-positive patients], we had no masks, no visors, no gowns. One morning we were asked to watch a video to see how we're supposed to get dressed and undressed. The same morning they had us practice and at the end of the day they asked us to admit our first patients without protective equipment. Our administrative agency placed a rush order. We get glasses when we were only trained on visors. We have 10 disposable gowns for 16 hrs of work. And not enough N95 masks for everyone, there weren't enough of some sizes. So they ask us to wear expired masks. A binder was placed at the nursing station to find information, the binder is not kept up to date. The information is outdated. They ask us not to use all the recommended equipment for fear we'll run out. We have to direct our superiors to INSPQ [Quebec Public Health Institute] guidelines to get permission to use the equipment and we have to refuse to enter a room to get results. (Testimonial 39)

We had to make our own "visors" out of acetate sheets that we shared and washed. It doesn't make sense and it's not at all professional. (Testimonial 166)

Multiple inconsistencies

One hundred and sixteen testimonials (19%) report multiple inconsistencies, that is, disconnection between information provided by health care administrators on one side and,

on the other, information required to perform one's work provided by public health authorities or obtained through professional training. Analysis of these testimonials reveals lack of communication, training, and consistency in the information provided. Nurses and LPNs also experience considerable stress due to inconsistent instructions and the speed at which information changes.

... this week, they showed us how to remove N95 masks with elastics very carefully by the elastics to avoid splashing and throw them out immediately during airborne isolation for an aerosol procedure with a COVID patient, they asked us to put the mask in a brown paper bag (supposedly so the mask can breathe...) and reuse the mask 5 times. To reduce contamination. It's an intubated person... At the same time they're trying to convince us, they post their own procedures in the rooms, step-by-step instructions for dressing and undressing for airborne isolation approved by the institution and the CIUSSS [Integrated University Health and Social Services Centre]. On this lovely sheet the procedure tells us to throw the mask in the garbage. (Testimonial 450)

Department heads give us very little information and often contradict themselves. We ask them questions and they're often unable to answer. Not very reassuring, to say the least. The anxiety is palpable on the unit, the girls [nurses] are scared and many are saying they're going to quit if it starts to pose a risk for us and our families. We don't feel protected. (Testimonial 39)

Violation of infection prevention and control standards

Another high frequency category, violation of infection prevention and control standards, is described in 172 testimonials (29%). This theme reflects non-compliance with established standards to prevent the spread of COVID-19. Nurses and LPNs provide examples of inappropriate patient and personnel transfers between hot zones (units with patients confirmed positive for COVID-19), warm zones (units with patients suspected of COVID-19), and cold zones (units with no COVID-19 cases), as well as institutional non-compliance with directives from the Quebec Public Health Institute.

At the long-term care centre where I work, there are no positive cases for now. But all weekend we had employees going from one centre to another including some who have worked in a centre with about ten cases. Managers are not respecting ministerial directives. (Testimonial 694)

Nurses and LPNs recognize that these situations are problematic, but indicate that they are not being listened to and lack the decision-making power to rectify the situation.

Fear

Ninety-eight testimonials (16%) reflect fear in nurses and LPNs who believe they put their safety and professional license at risk every day. They're also concerned with their health and that of their families, colleagues, and patients. Many also say they fear retaliation if, for example, they express their opinion or refuse a directive they consider unsafe.

My biggest fear is the possibility of contaminating one of my vulnerable patients and them dying on my conscience. I would blame myself for the rest of my life... Nurses and other home care professionals all share the same fear. (Testimonial 430)

Suffering

Seventy-one testimonials (12%) describe intense physical and/or moral suffering. This suffering stems from nurses' and LPNs' difficult work conditions during the pandemic and it entails real consequences.

In my case before the crisis I couldn't function anymore, I couldn't get to the end of the week, my morale is gone, I'm beat, tired, I won't last much longer. Every morning I wonder if I'll make it to work, every night I wonder how I made it through the day, there's no point living and working in these conditions. I'm sinking fast right now, I've become a shadow of myself. (Testimonial 788)

In these testimonials, lack of protection, not being heard, instrumentalization, and control measures are most frequently identified as sources of distress.

Resistance

Thirty-six testimonials (6%) report acts of resistance. Some nurses and LPNs indicate refusing to submit to pressures and threats and resisting their superiors. Several whistleblowers communicated with the media, others wrote letters and emails, while others still questioned procedures or outright refused to obey orders they deemed abusive or unsafe.

I had been in contact with a patient suspected of having COVID whose result came back + yesterday during the day. I work nights, yesterday the department head wanted to move a nurse from this floor to care for patients in SSU [short-stay unit], us three nurses had to

band together to refuse because we believed the risk of contaminating another department was too high. During this argument the IPC (infection prevention and control) specialist was present and didn't see a problem with transfers between floors with staff from the COVID floor. According to him, in principle there should be no risk of contaminating others if we follow hygiene measures... (that change by the minute). I told him that in principle the Concord Bridge overpass in Laval shouldn't have collapsed either!!!!!! (Testimonial 522)

We can also consider using the Je dénonce platform as an additional act of resistance.

Resignation

Sixteen nurses and LPNs (2%) expressed a desire to resign or had already tendered their resignation.

24 years of service and the first time I'm seriously thinking about quitting! It's completely unbearable! (Testimonial 134)

Unfortunately, I had to stop volunteering, because my physical and mental health can no longer be ensured by the long-term care centre or the CISSS [Integrated health and social services centre]. (Testimonial 840)

Collectively, we're at the point of wanting to quit and recently our employer met with us to bully us. One nurse received a disciplinary notice yesterday, she quit on the spot which means the day shift has to do mandatory overtime. (Testimonial 571)

Resigning from one's position constitutes a significant act. These testimonials show that resignation, as a last resort, is used to protect nurses' and LPNs' physical and mental health from workplaces they deem intolerable.

Discussion

The 12 categories identified in the analysis of Je dénonce testimonials cover a broad range of intimately connected concerns, highlighting practices that harm patients' and nurses' wellbeing, safety, and rights. Although some of these issues are clearly linked to the pandemic (eg. availability of personal protective equipment, following public health directives), it should be noted that many of these concerns had already been the subject of analysis and criticism for several years, both in Quebec and elsewhere. Examples of these include organizational procedures that reify and invalidate care

and those who provide it, abusive management practices, worsening conditions for care work, and muzzling of nursing staff [see 25-30 for instance]. In light of our analysis, it appears that the pandemic not only perpetuated, but also amplified these issues. In particular, the March 21, 2020 decree by the Ministry of Health and Social Services [31] allowing the suspension of many care workers' rights gave health care administrators unprecedented power to dispose of them as they wished within an absolute hierarchy, rather than through consultation, respect for professional expertise, and collaboration.

When contrasted with discourses dominating the public space since March 2020, which portray the work of health care professionals as nothing less than "heroic", testimonials collected through the Je dénonce platform reveal a completely different reality for nurses and LPNs. For example, the extent to which nurses' observations and opinions were ignored, and in many cases stifled, is difficult to explain given that managers and elected officials should be capitalizing on all available information to make consistent decisions to protect the (physical and emotional) health and safety of patients and care staff. Similarly, while managers lament the shortage of care workers to deal with the crisis, the number of nurses and LPNs who were suspended for refusing to obey orders that contradicted public health directives suggests that maintaining authority nonetheless remains the priority in many health care settings. This analysis demonstrates the extent to which the pandemic has created a fertile ground for mounting tensions among different understandings of issues (e.g. organization of care; administration of protective equipment; personnel management, including staff transfers) that can be difficult to reconcile when the health care system is already dealing with chronic management problems (especially of human resources), tense work environments, and diminished confidence between employers and employees. Each of these points clearly emerges from the corpus of testimonials. As noted by Simard et al.,

when employees feel that the relational climate is positive and based on confidence and mutual respect, they identify more strongly with the [organization] and tend not to dramatize the risks in their work, while, conversely, if they feel that the relational climate is negative and based on domination and exploitation, they tend to perceive issues of health and safety as a symbol of their employer's lack of consideration for them. [32 p4] (authors' translation)

Research invariably shows that employees who lack confidence in their employer are more likely to turn to external

whistleblowing channels to expose recurring problems in their organization (7), an observation that is equally true for nurses. [33]

As the pandemic persists, the Je dénonce platform makes it possible to follow the emergence and evolution of critical issues in Quebec's health care system in near-real time. The fact that it represents the only tool of its kind available to health care workers and the public in Canada makes it an interesting object of study to better understand both nurse whistleblowing as a phenomenon and the forms it can take during a crisis. Significant use of the platform since launch shows that nurses and LPNs are ready to incorporate such a tool into their whistleblowing practices. It is also reasonable to conclude that they consider it a useful strategy to rectify problematic health care practices.

Potential advantages of the platform

We have compared the features of the Je dénonce platform to criteria set forth by whistleblowing researchers. Lee and Fargher have outlined the characteristics of different whistleblowing systems to determine which are most beneficial. [34] Although focused on the private sector, their analysis describes several elements applicable to public institutions. Specifically, they identify the opportunity for anonymous, confidential reporting as a vital component of effective whistleblowing tools. Moreover, maintaining whistleblowers' anonymity ensures protection against retaliation – a reality faced by a significant number of whistleblowers. [33,35] Whistleblowing tools should also be accessible, available, and easy to use. They should also give whistleblowers control over their information. Researchers and experts agree that whistleblowing tools must meet these criteria to encourage their use by whistleblowers.

Je dénonce meets all of these criteria by concealing informant identities, protecting them from retaliation, and giving them control over the information they wish to share. It is also easy to use (no training required), accessible (web platform), and available (online 24/7). It should be noted that it is also accessible to journalists and members of the public, who can consult testimonials whenever they wish. Regarding information control, the platform allows whistleblowers to decide on the amount of detail they want to share. They can formulate submissions in their own words and include supporting documents (photos, videos) if they choose. The platform also confirms the person's consent before registering their testimonial.

In terms of clinical and organizational practices, this kind of

tool provides rapid access to critical information so essential during a pandemic (eg. to eliminate practices that facilitate pathogenic spread). It also facilitates detection of problematic patterns in specific settings or impacting certain professions. In addition, it allows a broader view of the issues and a means to identify potential systemic elements. A systemic perspective may also increase the likelihood of these issues being addressed; conversely, the perception that these problems are isolated cases or merely subjective interpretations reduces the probability of rigorous follow-up. [7,19] By consulting testimonials, journalists were able to paint a more complete picture of the evolution and effects of the pandemic throughout the health care system, the loss of control over outbreaks in some institutions, and the risks to which certain groups of workers were disproportionately exposed (eg. patient attendants, LPNs, nurses).

From a political point of view, we consider the Je dénonce platform an additional strategy available to nurses and other workers. It facilitates the transmission of critical information and therefore contributes to preserving the public interest. Furthermore, in cases where internal reporting procedures do not resolve the issue (a point often raised in testimonials), using external reporting channels like Je dénonce can help put pressure on organizations that ignore or respond ineffectively to concerns raised by their nurses, thereby changing the power dynamics between workers and employers.

Ultimately, we believe that Je dénonce is useful to researchers because it creates a dataset capable of revealing issues that may otherwise be difficult to access. It also creates opportunities to perform frequency, narrative, and simple or comparative analyses. Disseminating such analyses in public and academic forums can also help raise awareness and mobilize different groups to address the challenges faced by nurses during the pandemic. It amplifies the visibility of these issues and allows for deeper discussions about effective solutions.

Potential limitations of the platform

Various web-based tools have existed for many years to help whistleblowers share information safely. Generally speaking, reports submitted through these tools are received by designated agents (ombudsperson, compliance officer, etc.) whose responsibility it is to follow up. According to Lee and Fargher, follow-up is one of the criteria of a good whistleblowing tool [34]. In the case of Je dénonce, however, reports are not intended for someone with a specific mandate, but for anyone in the general population who might be interested in accessing the disclosed information. In other

words, the platform is not linked to a formal reporting process that follows a specific procedure intended to lead to remediation. Consequently, government representatives and leaders of institutions where these issues occur are free to ignore the reports published on the platform. The Je dénonce tool also lacks an integrated mechanism to ensure that those responsible for the sound governance of health care settings are held to account. Although this is not an objective of the platform, which is designed to enable the flow of information, the absence of a follow-up mechanism may discourage some whistleblowers from using it. [34]

Because the platform is accessible to all, it could be used inappropriately, for instance to make unfounded accusations or to burden the platform with provocative posts (trolling). That being said, a review of submissions before publication helps confirms their validity or delete corrupt ones, which addresses this issue. In the case of Je dénonce, our analysis reveals that nurses and LPNs submitted targeted, factual descriptions of serious problems. Furthermore, issues raised were abundantly documented elsewhere and recognized, indicating that nurses's and LPNs' reports were founded, unexaggerated, and submitted in good faith.

Given the often-critical nature of accounts submitted to Je dénonce, it is possible that some testimonials could be considered defamatory and subject to legal action in order to find their authors, shut the platform down, or act against the organization responsible for its operation (in this case, the FIQ union). Although this risk is theoretically possible, it is unlikely, given Quebec's current sociopolitical context. First, public opinion leaned heavily in favour of nurses following a number of reports exposing poor working conditions (eg. mandatory overtime, professional burnout, etc.); second, heavy media coverage allowed the public to see the gross mismanagement of the pandemic (and the resulting loss of life) and, therefore, whistleblowers' essential role in public life. Consequently, we believe there would be little interest and high political risk for governments and health administrators to undertake expensive legal proceedings, paid through public funds, to identify anonymous informants and act against them.

What does the future hold for whistleblowing platforms like Je dénonce?

Normalizing whistleblowing across all sectors is an essential step toward sound social and public governance. Creating effective whistleblowing systems and tools has in fact been identified as a necessity we can no longer afford to ignore. [7, 36]

We argue that tools like Je dénonce are socioeconomically and politically useful to counterbalance discourses and practices that go against the public interest. We believe they also facilitate the democratization of information because they are available to anyone wishing to expose issues within health care systems. Specifically, they increase the visibility of challenges faced by often-underrepresented workers (including non-care personnel) while also allowing health service users and the broader public to submit their own experiences and concerns. This platform sets itself apart by including people often excluded from conventional forms of consultation and by expanding debates that are traditionally dominated by health administrators and members of the medical profession. This redistributes both the power to speak and the information required to promote and protect the public interest.

In health care settings, the availability and transmission of information alone are insufficient to modify or eliminate practices that negatively affect the health of patients, care personnel, and health care settings themselves. Mechanisms are required to force such information in decision-making processes and ensure accountability, so that health care institutions can fully fulfil their mandate relating to quality and safety. These mechanisms are subject to various clinical, organizational, economic, ideological, and other considerations and can be disrupted during crises – precisely when they need to be most effective. Absent or ineffective mechanisms can create serious, lasting consequences. This also increases people's willingness to turn to whistleblowing to communicate their concerns to the public at large.

To this day, whistleblowing is rarely discussed in public spaces in Quebec and Canada. One could assume that current federal and provincial laws protect whistleblowers and make such debates unnecessary. However, according to many experts, existing legal frameworks are inadequate because the protection they provide is much too narrow and limited to be at all useful; their performance record is nothing short of dismal. [37-39] St-Martin suggests that effective whistleblowing tools could help remedy current legal shortcomings. [39] He argues that given the failure of current legislation to promote transparency and integrity in socioeconomic sectors (including health care), investigative journalism has positioned itself as one of the only entities in Canada capable of holding offending organizations to account. From this perspective, without effective mechanisms and reliable laws, facilitating the flow of information between whistleblowers and journalists, as does the Je dénonce platform, is a significant asset.

Conclusion

The impacts of the COVID-19 pandemic are rapidly evolving; decision-makers at every level (e.g. leaders in government, health care institutions, and care units) require the most up-to-date information possible. It is essential that information come from multiple sources to avoid blind spots that can hinder understandings about critical issues. [35] Whistleblowing platforms through which various actors can report reprehensible situations meet this need. But in times of crisis, a whistleblowing platform cannot effect change on its own. In the case of Je dénonce, whistleblowers seek changes that depend on other agents such as journalists and members of the public to hold decision-makers accountable for their management decisions during the crisis.

The Je dénonce platform was created when a need was identified to disseminate essential information on the evolution of the COVID-19 pandemic in health care settings. The platform's concrete impact is difficult, if not impossible, to qualify or quantify. The platform succeeded in capturing the attention of journalists writing about the effects of the crisis and the health care system's failures to manage it. It is more difficult to determine the extent to which it contributed to correcting objectionable organizational practices or policies. However, given the volume of testimonials submitted to the platform, there is no doubt that nurses and LPNs consider it a useful resource to raise their voices about dangerous, unethical, or unlawful situations.

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Résumé

Même si l'on reconnaît généralement que le personnel infirmier et les enjeux liés aux soins infirmiers sont sous-représentés dans les médias, l'inverse est également vrai pendant des crises sanitaires d'envergure comme l'Ebola et le SRAS (syndrome respiratoire aigu sévère). Nous constatons la manifestation de ce même phénomène pendant la pandémie de COVID-19, car le personnel infirmier et les enjeux liés aux soins infirmiers sont le sujet d'une forte couverture médiatique au Canada et à l'international. Pour mieux comprendre cette couverture médiatique, nous avons analysé le contenu d'articles de presse canadiens publiés en anglais et en français au cours des cinq premiers mois de la pandémie de COVID-19. Le présent article présente les résultats de notre analyse et identifie les grandes leçons tirées de celle-ci. Ces résultats représentent selon nous un important point de départ pour mieux comprendre l'agentivité du personnel infirmier et le savoir-faire démontré par ce dernier pendant les premiers mois de la pandémie.

Mots clés Canada, analyse de contenu, COVID-19, médias, personnel infirmier, soins infirmiers

Voix infirmières pendant la COVID-19 : Une analyse de la couverture médiatique au Canada

MARILOU GAGNON ET AMÉLIE PERRON

Introduction

Depuis déjà plusieurs décennies, la représentation médiatique du personnel infirmier et des enjeux liés aux soins infirmiers constitue un sujet d'intérêt. En 1997, le Woodhull Study on Nursing in the Media a trouvé que le personnel infirmier était fortement sous-représenté dans l'actualité sur la santé, représentant seulement 4 % des sources citées dans les articles. [1] En reproduisant l'étude de Woodhull vingt ans plus tard, Mason et ses collègues ont conclu que cette représentation avait effectivement diminué avec le temps, passant de 4 % à 2 %. [2] Lors d'entrevues auprès de journalistes pour cerner ce phénomène, plusieurs facteurs ont été identifiés, notamment

le fait que le personnel infirmier et la profession infirmière en général ne sont stratégiques ni dans leur utilisation des médias ni dans leur engagement auprès de ceux-ci. [3] L'étude de Mason et collègues note aussi que les employeurs sont connus pour empêcher le personnel infirmier de parler aux médias en incluant dans leurs contrats d'emploi des clauses de non-dénigrement ou portant explicitement sur les médias; en imposant du haut de la hiérarchie organisationnelle des politiques exigeant l'approbation de la haute direction selon un processus lent à multiples étapes; et en punissant le personnel infirmier qui parle aux médias, créant ainsi une culture de peur et de silence. [3]

Même s'il est généralement admis que le personnel infirmier et les enjeux liés aux soins infirmiers sont sous-représentés dans les médias, l'inverse est également vrai pendant des crises sanitaires d'envergure comme l'Ebola et le SRAS (syndrome respiratoire aigu sévère). [4-5] Nous constatons actuellement ce même phénomène pendant la pandémie de COVID-19, car le personnel infirmier et les enjeux liés aux soins infirmiers font l'objet d'une forte couverture médiatique

au Canada et sur le plan international. Pour mieux comprendre cette couverture médiatique, nous avons analysé le contenu d'articles de presse canadiens publiés en anglais et en français au cours des cinq premiers mois de la pandémie de COVID-19. À la différence des analyses médiatiques précédentes, qui ont tendance à se pencher sur les représentations médiatiques du personnel infirmier et des enjeux liés aux soins infirmiers (par ex. la violence au travail, les salaires, les pénuries), [4-8] nous cherchons spécifiquement à analyser les voix du personnel infirmier, tant collectives qu'individuelles. Pour ce faire, notre objectif était d'examiner l'utilisation des médias par le personnel infirmier canadien pour partager ses expériences, faire part de ses préoccupations, prendre la parole, sonner l'alarme et défendre ses propres intérêts et ceux des patients pendant la COVID-19. Ces résultats représentent selon nous un important point de départ pour mieux comprendre l'agentivité du personnel infirmier et le savoir-faire démontré par ce dernier pendant les premiers mois de la pandémie.

Méthodologie

Afin de mener rapidement une analyse rigoureuse de la couverture médiatique, nous avons choisi de réaliser une analyse qualitative de contenu (AQC). L'AQC est née de l'analyse quantitative de contenu, une méthode élaborée

dans la première partie du vingtième siècle afin d'analyser de grandes quantités de données textuelles (provenant principalement des médias) pour déterminer la fréquence d'idées et de concepts. [9,10] L'objectif de l'AQC est différent, car elle cherche à décrire le véritable contenu des données et offre de nouvelles perspectives au sujet de l'unité d'analyse. [9,10] Nous avons effectué notre recherche à l'aide de la fonction de recherche avancée de Google, qui offre la possibilité d'utiliser et de combiner des mots-clés et de limiter la recherche à un pays particulier pendant une période donnée. Nous avons utilisé cinq combinaisons de mots-clés pour effectuer la recherche dans la couverture médiatique de langue anglaise et huit combinaisons de mots-clés pour effectuer la recherche dans la couverture médiatique de langue française. Nous avons également limité la recherche aux articles de presse publiés au Canada entre le 1er janvier et le 21 mai 2020. Après l'examen de notre échantillon initial de 119 articles de presse et l'élimination de doublons, non liés à la COVID-19 ou qui n'incorporaient aucune voix infirmière collective ou individuelle, notre échantillon final comptait 83 articles de presse (Voir Tableau 1).

L'analyse de chaque article a été réalisée à l'aide d'une série de questions : Qui parle? Cette personne parle-t-elle au nom d'une collectivité infirmière (par ex. syndicat, association professionnelle, organisme de réglementation) ou comme

Tableau 1 : Échantillon

Pays	Canada	
Dates	1 ^{er} janvier au 21 mai 2020	
Anglais	Whistleblowing (or Whistleblower) AND nurses AND COVID	3
Anglais	Speaking out AND nurses AND COVID	19
Anglais	Reporting AND nurses AND COVID	3
Anglais	Denounce AND nurses AND COVID	4
Anglais	Nurses AND COVID	9
		38 (total)
Français	Dénonce ET infirmières ET COVID	13
Français	Dénonciation ET infirmières ET COVID	2
Français	Sonne l'alarme ET infirmières ET COVID	2
Français	Signale ET infirmières ET COVID	8
Français	Lanceur d'alerte ET infirmières ET COVID	1
Français	Omerta ET infirmières ET COVID	4
Français	Cri du cœur ET infirmières ET COVID	2
Français	Infirmières ET COVID	13
		45 (total)
TOTAL		83

individu œuvrant dans le domaine? Ces individus sont-ils anonymisés ou identifiés (par ex. nom complet avec ou sans photo)? Qu'est-ce qui est dit dans les articles? Quelle est l'essence du message? En quoi le message change-t-il au fil du temps? Le contenu obtenu de cette première analyse de haut niveau a ensuite fait l'objet d'une deuxième analyse inductive plus approfondie afin d'identifier les thèmes communs.

Résultats

Vue d'ensemble de la couverture médiatique

Des 83 articles de presse recueillis, 38 (46 %) étaient publiés en anglais et 45 (54 %) en français. La totalité des articles publiés en français provenait de la province de Québec. Des articles publiés en anglais, 4 avaient une portée nationale, 15 provenaient de l'Ontario, 10 du Québec, 5 de la Colombie-Britannique, 1 de Terre-Neuve, 1 de la Saskatchewan, 1 de l'Alberta et 1 de la Nouvelle-Écosse.

Dans l'échantillon complet, 66 % de la couverture médiatique mettait en vedette des voix infirmières collectives ou individuelles du Québec. Plusieurs facteurs pourraient avoir contribué à cette importante couverture médiatique, notamment :

- Le Québec était au centre de la pandémie de COVID-19 au Canada; en date du 27 juin 2020, la province comptait un total de 55 079 cas et 5 448 décès.
- Comme les autres provinces, le Québec a déclaré l'état d'urgence en mars mais, à la différence d'autres provinces, il a émis un arrêté ministériel (2020-007) modifiant les conventions collectives et imposant des changements aux horaires, congés et vacances, à la mobilité du personnel, etc.
- Le 30 mars 2020, la Fédération interprofessionnelle de la santé du Québec (FIQ) a lancé la plate-forme en ligne « Je dénonce » afin d'encourager le personnel infirmier et d'autres fournisseurs de soins, ainsi que le public, à signaler toute situation dangereuse ou répréhensible pendant la pandémie de COVID-19.
- Le 16 mai 2020, le gouvernement du Québec a lancé une nouvelle boîte courriel, « On vous écoute », pour encourager les fournisseurs de soins à signaler les problèmes et les pratiques problématiques dans leurs milieux pendant la pandémie de COVID-19.
- Depuis septembre 2017, la province a vécu une vague inédite de dénonciations publiques par le personnel infirmier (par ex. sit-ins, interventions médias, médias

sociaux, forums publics, manifestations), un phénomène actuellement à l'étude.

Afin de répondre à la question « Qui parle? », nous avons déterminé si les membres du personnel infirmier figurant dans les articles de presse parlaient au nom d'une collectivité (par ex. syndicat, association professionnelle, organisme réglementaire), comme individus ou les deux. Des voix collectives et individuelles figuraient souvent dans un même article. Afin de simplifier la présentation des résultats, nous avons donc choisi de compter le nombre de cas où apparaissait une voix collective et avons répété le processus pour les voix individuelles. Les voix collectives, majoritairement par l'entremise de syndicats, figurent 52 fois dans notre échantillon. Les voix syndicales les plus souvent présentées dans les articles médiatiques étaient celles de la Fédération interprofessionnelle de la santé du Québec (FIQ) ($n=26$ ou 57 %), la Fédération canadienne des syndicats d'infirmières et d'infirmiers (FCSII) ($n=5$ ou 11 %), la Ontario Nurses Association (ONA) ($n=3$ ou 7 %) et la British Columbia Nurses' Union (BCNU) ($n=3$ ou 7 %).

Les voix individuelles de professionnels infirmiers figurent 44 fois dans les articles de presse. Nous avons trouvé un nombre équivalent d'articles qui dans lesquels ces infirmier.e.s sont identifié.e.s ($n=20$) et dans lesquels ils/elles demeurent anonymes ($n=20$), ainsi que 4 articles où certain.e.s sont identifié.e.s et d'autres non. La principale raison fournie pour la protection de leur identité était le risque de représailles et de sanctions (dont la perte d'emploi) pour avoir parlé aux médias.

Les données de plus près

Pendant la deuxième ronde d'analyse, nous avons identifié un fil conducteur selon lequel la pandémie de COVID-19 est évoquée à l'aide de métaphores de guerre. Ceci est soutenu par quatre thèmes communs (voir Figure 1).

Le premier thème, « Répondre à l'appel », capte les premiers jours de la pandémie alors que les articles se concentraient principalement sur le personnel infirmier appelé à se présenter comme bénévole, à sortir de la retraite, à terminer ses études de manière prématurée, à assumer de nouveaux postes, à se redéployer dans de nouveaux milieux de soins, et ainsi de suite. L'accent était mis sur les caractéristiques des « bonnes infirmières » qui, comme des soldats, étaient décrites comme toujours prêtes et disposées à répondre à l'appel du devoir face à l'inconnu. Pourtant, alors que la COVID-19 commençait à se propager, il est devenu évident que le personnel infirmier avait été envoyé à la guerre sans les équipements appropriés (ou sans aucun équipement), sans assez d'informations, sans

Figure 1: Thèmes



les ressources humaines ou physiques nécessaires et sans assez de soutien ou de rémunération (par ex. allocations pour la nourriture ou la garde d'enfants, primes de risque, congés de maladie payés). C'est ici qu'émerge notre deuxième thème : « Les infirmières comme soldats de première ligne ». La majorité des articles de presse publiés entre la fin mars et le milieu du mois de mai 2020 présentent des rapports détaillés de la dure réalité vécue en première ligne (décrise comme « zone de guerre » par plusieurs), que nous résumons à l'aide de cinq sous-thèmes :

1. Manque d'accès aux équipements de protection individuelle adéquats en raison de pénuries, de rationnement sévère ou de recyclage d'équipements, dont les uniformes, les masques, les visières, les blouses, etc.;
2. Obligation de travailler malgré des risques pour la santé (par ex. grossesse, immunosuppression, maladie respiratoire chronique), des symptômes de COVID 19 ou des conditions de travail non sécuritaires (dont des ratios infirmières-patients non sécuritaires);
3. Être témoins d'événements intolérables, notamment les personnes clientes tombant malade et mourant, souvent dans des conditions déplorables, et des collègues « tombant comme des mouches » en raison de négligence systémique;
4. Être aux prises avec l'impact physique de la COVID-19 et l'impact psychologique de travailler au sein d'un système brisé et mal préparé (par ex. stress, anxiété, épuisement, SSPT); et

5. Incapacité de se conformer aux meilleures pratiques pour prévenir la propagation de la COVID-19, pour fournir des soins sécuritaires de qualité et pour se protéger et protéger les autres.

Le troisième thème, « Exposition des échecs et des abus du système », émerge d'articles médiatiques portant sur les témoignages individuels troublants de membres du personnel infirmier. Au Québec tout particulièrement, ceux-ci incluent les deux témoignages hautement médiatisés des infirmières Nadia Lambert et Kristy-Lyn Kemp, ainsi qu'un grand nombre de témoignages disponibles au public sur « Je dénonce », une plate-forme mise en ligne de la FIQ. Grâce à ces témoignages, le public apprenait que la COVID-19 exacerbait des problèmes existant dans le système de soins de santé depuis déjà longtemps (par ex. pénuries, ratios infirmières-patients non sécuritaires, mobilité du personnel, mauvaise communication, etc.) et qu'elle intensifiait des pratiques dangereuses comme les heures supplémentaires obligatoires. [11] Les témoignages publiés sur « Je dénonce » révélaient aussi un éventail de violences, allant de l'enfermement au travail par des gestionnaires au musèlement et aux menaces par les employeurs. Le quatrième thème inspiré d'un article d'opinion intitulé « We are not essential. We are sacrificial. » (« Nous ne sommes pas essentiels. Nous sommes sacrificiels. » (traduction libre), publié dans le New York Times le 5 mai 2020. Cet article, rédigé par Sujatha Gidla, conductrice chez la Metropolitan Transportation Authority, résume parfaitement les perspectives exprimées par les membres du personnel infirmier canadien au sujet de leur position comme travailleurs

jetables dans le système de santé; de leur traitement comme soldats de première ligne par les gouvernements et les milieux de soins de santé; et de la perception de leur santé et de leur vie comme dommages collatéraux dans la « guerre » contre la COVID-19. Par conséquent, plusieurs ont été cités dans les médias, affirmant « Je ne suis pas ici pour mourir au travail » (traduction libre).

Discussion

Nos résultats concordent avec les analyses médiatiques précédemment menées par l'universitaire canadienne McGillis Hall et ses collègues après les épidémies d'Ebola et de SRAS (4-5). Leurs recherches ont aussi montré que les médias mobilisaient souvent la métaphore de la guerre et celle du personnel infirmier comme « héros de la guerre » lors d'importantes crises sanitaires (4-5). Dans notre échantillon, nous avons constaté que le personnel infirmier faisait lui aussi appel à cette image pour décrire ses expériences, ses sentiments, les défis rencontrés, le traitement vécu, les répercussions de celui-ci et l'impact physique et émotionnel de ces expériences stressantes. Bien que plusieurs infirmier.e.s aient adopté l'identité de héros dans les premières semaines de la pandémie, une identité continuellement renforcée partout au pays par les médias, les organisations professionnelles infirmières, les gouvernements, les leaders en santé et le public, au bout du compte, une écrasante majorité a fini par la rejeter. Les infirmières « ne se sentaient pas comme des héros » (traduction libre), comme l'indiquaient plusieurs d'entre elles dans les articles de presse. Dans un article d'opinion publié dans *Le Devoir* le 24 avril 2020, Martin et ses collègues soutenaient d'ailleurs que le personnel infirmier doit être très critique d'une reconnaissance qui ne sert que les intérêts de l'état, non pas ceux des travailleurs eux-mêmes. Plusieurs infirmières qui se sont opposées aux discours de héros ont adopté cette perspective critique.

Notre analyse médiatique s'est différenciée de celles menées précédemment en se focalisant explicitement sur les voix du personnel infirmier qui fournit des soins directs aux patients. Autrement dit, elle se penche sur leurs paroles, non pas sur ce qu'en disent les médias. Il s'agit d'une différence importante. La couverture médiatique des premiers mois de la pandémie de COVID-19 était inhabituelle, car elle présentait des articles de presse décrivant l'utilisation par le personnel infirmier de son agentivité, de son pouvoir et de son savoir-faire pour communiquer ce qui selon lui était important, manquant, nécessaire, etc. Ces récits découlaient aussi de l'utilisation habile des médias sociaux (Facebook en particulier) et de plates-formes en ligne, dont « Je dénonce ». Par exemple,

le témoignage hautement médiatisé de l'infirmière Nadia Lambert a d'abord été publié sur Facebook et partagé 20 000 fois en 24 heures, ce qui a incité les médias à relater son histoire. Dans le même ordre d'idées, le lancement de la plate-forme en ligne « Je dénonce » a donné aux médias un accès aisément à plusieurs centaines de témoignages, augmentant du coup la couverture médiatique axée sur les voix du personnel infirmier et amplifiant la voix collective de la FIQ.

La FIQ constitue une voix collective importante dans notre échantillon, représentant 57 % des voix syndicales présentes dans la couverture médiatique canadienne. Dans le cadre de notre travail sur la dénonciation infirmière, nous avons déjà abordé l'importance d'explorer le rôle des syndicats infirmiers dans la facilitation de la divulgation de situations répréhensibles. [12] Il en va de même pour le rôle des syndicats dans la facilitation de signalements anonymes à grande échelle de situations dangereuses ou condamnables pendant des crises sanitaires, ainsi que dans l'amplification de la voix de leurs membres. Les recherches actuelles n'abordent pas ce rôle, malgré le besoin de trouver le moyen d'augmenter la représentation du personnel infirmier dans les médias. Trop souvent, l'objectif des chercheurs et des organisations infirmières consiste à positionner le personnel infirmier comme expert de la santé aux yeux des médias, alors qu'une attention similaire, voire plus grande, devrait être accordée à la normalisation et à l'augmentation de l'utilisation des médias par le personnel infirmier comme outil de revendication et d'action politique. Ceci pourrait en être concrétisé en fournissant au personnel infirmier des formations médias tout en sensibilisant les journalistes aux bienfaits d'inclure ce groupe comme source d'information clé pour leurs reportages. Ceci encouragerait le personnel infirmier à utiliser les médias pour se prononcer et revendiquer, comme outil de changement et comme stratégie pour protéger l'intérêt public.

Conclusion

Notre analyse offre des perspectives supplémentaires permettant de mieux comprendre l'agentivité du personnel infirmier et de son savoir-faire médiatique pendant les premiers mois de la pandémie de COVID-19. Elle nous amène à conclure que, bien que la reconnaissance dans les médias du personnel infirmier comme expert en santé soit bénéfique, ce dont les infirmières ont urgentement besoin est une plus grande liberté d'expression, la capacité d'amplification d'une voix collective forte et du pouvoir d'utiliser les médias et les technologies de communication, dont les médias sociaux, pour influer sur les débats publics et sur les politiques sanitaires. La COVID-19

nous a montré que quand le personnel infirmier parle, les médias écoutent.

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Abstract

Using a review of literature consisting of peer-reviewed articles and grey literature, this paper presents a narrative and graphic representation of the key concepts underpinning the benefits nurses perceived deriving from caring for patients during the HIV/AIDS pandemic. Our review indicates that benefits were seldom the focus of the literature and were mostly integrated within documents pertaining to the negative aspects of caring for these patients. In such a context, this research identified self-enhancement benefits in three domains (work benefits, work attributes, and work ethos), and self-actualization benefits in three domains (relationships, transformation, and humanity). During the COVID-19 pandemic, researchers are once again enticed to write scientific literature about the impact of caring in a “war zone”. Using the underpinning concepts identified through the benefit-finding research in the context of the HIV/AIDS pandemic, researchers could identify the many perceived benefits nurses derive from caring for infected patients during this pandemic.

Keywords Benefit finding, benefit of caring, rewards, positive aspects, and silver lining, HIV/AIDS and COVID-19 pandemics, nurses and caregivers, self-enhancement, self-actualization, and stress-related growth

The Elusive Silver Lining: Caring for Patients in the HIV/AIDS “War Zone”. How Did Nurses Sustain It? Benefit-Finding Analysis

CARL GA JACOB, DANIEL LAGACÉ-ROY & PATRICIA LUSSIER-DUYNSTEE

Introduction

Many researchers investigated and developed theoretical frameworks around the benefits, rewards, positive aspects, and silver lining of individuals in various situations. Their research centered on individuals who were afflicted by serious diseases, such as cancer, multiple sclerosis, rheumatoid arthritis, and myocardial infarction, or important harm, such as spinal cord injuries.[1-2] Only a few studies were conducted among individuals who were grieving a separation, or a loss, such as a partner, were living with children with severe health

issues, served in war, were HIV/AIDS patients, or are living through the COVID-19 pandemic.[1-4] Even fewer benefit-finding investigations focused on individuals who cared for, or continue to care for the above-mentioned individuals, many of whom were or are nurses.[5] It has been shown that the benefits of caring help individuals (e.g., nurses) deal effectively with illness and adversity, and improve their emotional well-being.[6-7] Furthermore, it helps individuals, such as nurses, better understand the meaning of life and work during a crisis.[8] In the context of the HIV/AIDS pandemic, existing literature investigates mainly the negative impacts of caring for HIV-infected patients, as well as suffering and dying AIDS-patients, at the height of the HIV/AIDS pandemic (the early 1980s to the late 1990s). These negative impacts were physical and psychological in nature, uncovering the downside of such work, its challenges, as well as the negative attitudes, beliefs, emotions, and feelings many of the nurses harboured towards their patients.[4, 9-21]

For example, some nurses expressed anger, rejection, and non-acceptance of patients who were deemed difficult,

manipulative, mean, non-compliant, and uncooperative.[22-23] Moreover, the fact that they often exhibited a distinct lifestyle, i.e., being gay, bisexual, transgender, intravenous drug users, prostitutes, or came from religious, cultural, and ethnic backgrounds different from theirs, also played a role in the inappropriate way they treated patients.[20, 22-24] This behaviour was expressed using blame, contempt, displeasure, hostility, indignation, intolerance, judgment, or refusal to care, as if the patients were "lepers".[10, 20, 23-32] Some nurses displayed signs of burnout, the effects of being overtaxed, and the long-term effects of stress, due to prolonged exposure to the excessive physical and mental demands placed on them, as they cared not only for their patients, but also for their patients' immediate and extended families.[18, 33] These stress symptoms were often exhibited by a loss of concentration, chronic fatigue, neglect of self and others, irritability, difficulty sleeping, nightmares, and feelings of anxiety, known as compassion fatigue.[10, 22, 31, 34-35] Some nurses showed fear and panic because of their repeated exposure to the infection, the unknown susceptibility of infection (contagion), and the possibility of bringing the infection home to family members.[10, 20, 24, 28, 31, 36-37] Some displayed signs of helplessness, loss of control, or overwhelmingness with the situation because the information circulating about the infection, and how to treat it, was constantly changing, and the patients for whom they were caring were young, terminally ill, and frequently dying.[37] Some nurses exhibited prolonged feelings of loss, grief, and vulnerability because of their over-identification with their patients,[22, 38] in addition to the constant presence of death. Such feelings were expressed through anxiety, apprehension, concern, and fright. [10, 21, 30]

Researchers also mentioned that nurses were constantly in toxic environments, either at work, or at home, as some health care providers, family members, friends, and significant others reacted negatively to their professional choices by showing disgust, distaste, discrimination, ostracization, stigmatization, judgment, prejudice, and shame.[9, 24, 39] To avoid such reprobation, and public moralization, the nurses' HIV/AIDS work was often performed in secrecy.[35] HIV/AIDS effectively became the illness that no one liked to name and went to great lengths to avoid discussing it openly.[10, 16, 20, 35] Finally, researchers emphasized that while their patients might die, the nurses who cared for, or about them, remained behind.[40] Those "left behind" were knowledgeable and capable nurses who experienced the cumulative impact of loss, known as the multiple loss syndrome.[41] In looking back at the challenging facets of HIV/AIDS work, researchers have overlooked the many benefits, rewards, positive impacts, or even silver lining, which may be derived from such work, that may help nurses

compensate the negative impacts they experienced.[4]

A scan of such research, using a review of literature methodology, revealed that nurses experienced key benefits while caring for HIV-infected and AIDS-patients, and their immediate and extended families, throughout that pandemic. [42] Therefore, the objective of this research is two-fold. It intends to present a narrative and graphic representation of the key concepts underpinning the positive impacts that nurses perceived deriving from caring and providing support for and comfort to HIV-infected and AIDS-patients, as well as their immediate and extended families. This research also suggests that positive impacts, as opposed to only negative ones, can be uncovered when examining the context of nurses caring and providing support for and comfort to COVID-19 patients throughout the present pandemic.[43]

For this paper, HIV-infected patients are individuals who are infected with the human immunodeficiency virus while AIDS-patients are HIV-infected individuals who have fewer than 200 CD4+ T cells, and have been diagnosed with one or more life-threatening opportunistic infection, such as pneumonia (pneumocystis pneumonia (PCP), and skin cancer (Kaposi's sarcoma [KS])).[44] A pandemic is an epidemic that spreads to multiple continents or across international borders.[45-46]

Benefit finding is often associated with two terms, post-traumatic growth (PTG) and stress-related growth.[3, 47-49] This research paper's focus is not on nurses' post-traumatic growth (PTG), because it does not address benefits once the HIV/AIDS pandemic is over and HIV has become a chronic disease. Instead, it focuses on the benefits that nurses perceived deriving from caring in adverse conditions while being in the pandemic "war zone", stress-related growth, making it a meaningful construct in theories addressing the issue of coping with adversity.[31, 50-51] Akintola defines it as, "the positive subjective feelings, or objective changes, both internal and external, in the volunteer caregivers' [nurses'] lives resulting from their caregiving situation".[52, p. 2-3] However, stress-related growth is not always a given for those under extreme stress. It also raises the question of why they wanted to enter and/or remain in the field of caring for HIV-infected and AIDS-patients.[53-55] Nurses who continue to work in a stressful, highly charged, and challenging role, use a form of cognitive adaptation or coping strategy to find benefits.[55] Benefit finding may involve interpersonal dimension modifications, such as developing new relationships and changing one's self-perceptions and philosophy of life.[22, 56-58] It may also involve intrinsic rewards, such as personal development on the job, and extrinsic rewards, appreciation and recognition of one's work, for example.[52, 59-60] Benefit finding requires that

nurses reassess their concept of caring in a positive manner during a pandemic.[22] It may involve looking for possible gains, which may improve creative thinking, facilitate problem solving, and diminish negative emotions, such as anxiety and depression, thereby minimizing or mitigating the negative impacts of the pandemic and safeguarding their self-worth. [48-49, 54, 61] Finally, benefit finding during a pandemic does not require the individual to have prior experience of such an event.[62]

We believe that the choice and exchange theory, which has not yet been applied to research pertaining to the rewards nurses perceived receiving while caring for HIV/AIDS patients, will help shed light on this topic. This theory assumes that "rewards are things wanted and costs are things one would prefer to avoid".[63, p480] It is supported by nine propositions, namely: "1. Human beings seek rewards and avoid costs to maximize their Goodness of Outcomes (profits). 2. Costs being equal, individuals will choose the alternative which supplies or is expected to supply the most rewards. 3. Rewards being equal, individuals will choose the alternative which exacts the fewest costs. 4. Immediate outcomes being equal, individuals will choose those alternatives which promise better long-term outcomes. 5. Long-term outcomes being perceived as equal; individuals will choose alternatives providing better immediate outcomes. [...] 6. Costs and other rewards being equal, individuals will choose the alternative which supplies or can be expected to supply the most social approval. [...] 7. Costs and other rewards being equal, individuals will choose statuses which provide the most autonomy. [...] 8. Costs and other rewards remaining equal, individuals will choose activities and positions which provide the greatest financial remuneration and/or the smallest financial expenditures. [...] 9. Costs and other rewards being equal, individuals choose associates and friends with opinions and values which agree with their own and try to avoid those who consistently disagree with them". [62, p. 221-222] From these propositions, several preliminary themes emerged which we used in our research, such as social approval, autonomy, similarity of values and beliefs, conformity to norms, ambiguity, equality, and money.[62]

In this research paper, stress-related growth is defined as the result of self-enhancement and self-actualization benefits. Therefore, stress-related growth evidence may be an increase in self-awareness and coping skills and may instigate an increase in self-esteem and perceived self-efficacy. Self-enhancement is defined as the importance that a person places on social power, dominance, wealth, authority, influence, and success [64]. In contrast, self-actualization is defined as "the desire to become more and more what one is, to become everything

that one is capable of becoming" [65, p382] or "the desire for one to see oneself in his fullest potential".[66, p35]

Methodology

A literature review was performed using a content analysis methodology to gather and review (critique and summarize) the body of literature pertinent to the present research topic [67]. Content analysis is often used to "analyze the important, and sensitive phenomena of nursing";[68, p400] in the context of "exploratory work in an area where not much is known".[68, p400]

This methodology involved identifying search words associated with benefit finding. At first, the non-comprehensive list contained only two words, benefits, and rewards. The list expanded as the literature pertaining to the research topic increased in number, depth, and scope. Therefore, the comprehensive list included such words as, benefits, rewards, positive impacts, and any potential silver lining related to caregivers, nurses, HIV, and AIDS, to help locate relevant literature from the early 1980s to present.

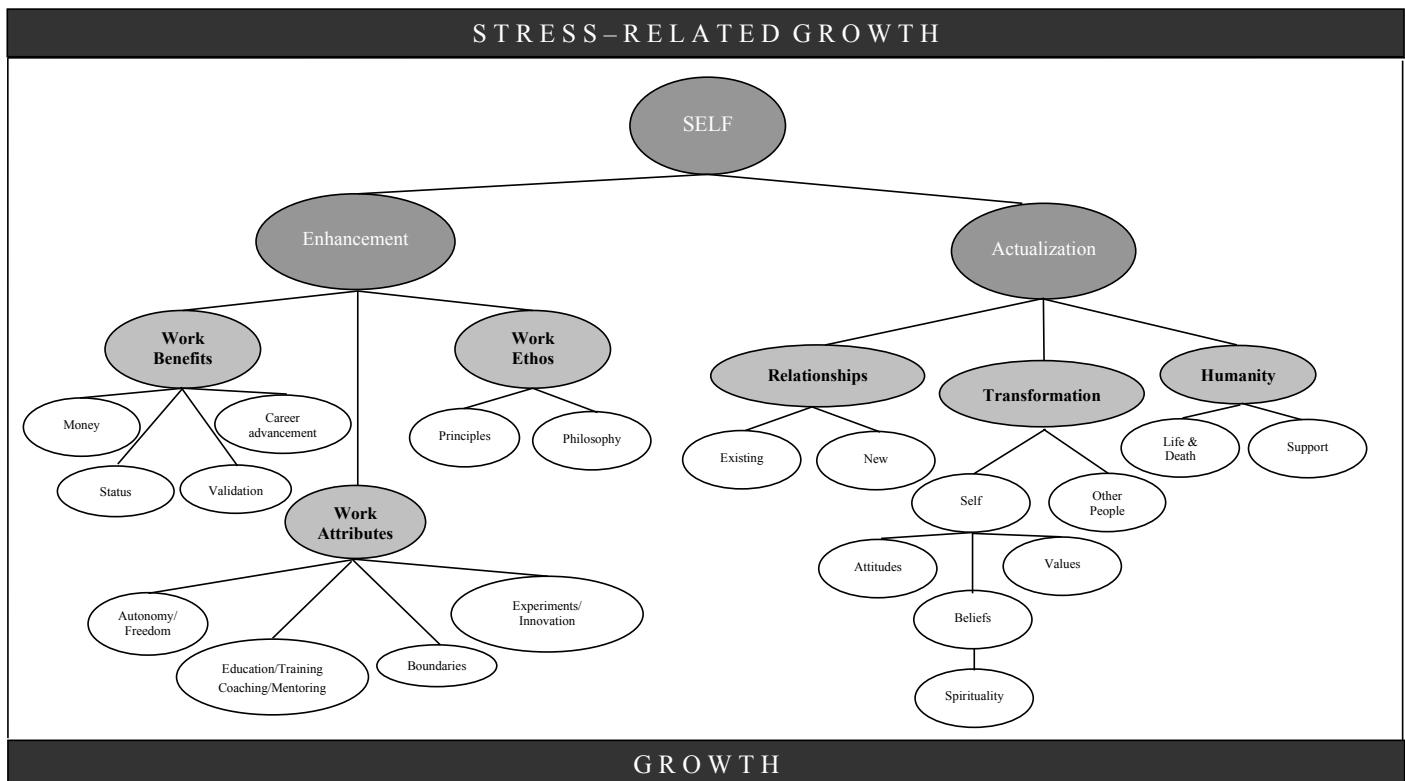
It is with the use of electronic databases, including, but not limited to, Research Gate, Google Scholar, the Virtual University of Ottawa Library, and the Internet, that scientific peer-reviewed articles, books, and grey literature, such as reports, and Web pages, were identified. The electronic search gathered 83 documents: 33 general benefit-finding, 50 HIV/AIDS specific documents, of which 35 documents are HIV/AIDS and topic related (see Table 1: Main HIV/AIDS Topic-Related Documents). The documents that related specifically to HIV/AIDS benefit-finding content, as well as statements related to perceived benefits, rewards, positive impacts, or any potential silver lining nurses perceived deriving from caring for HIV-infected and AIDS-patients, and their immediate and extended families, were retained.

Using a content analysis methodology, data were identified within the retained documents.[68] Thereafter, researchers immersed themselves into the data to try to make sense of it all, and to organize it in a meaningful manner. They chose the components to be analyzed using a 'paper and scissor' technique, while detecting patterns. A reflexive approach was used to collate statements using an iterative process. Multiple categories, themes and sub-themes emerged. Finally, the information was presented in narrative, graphic, and table formats (see Table 1: Main HIV/AIDS Topic-Related Documents, Graph 1: Benefit Finding for Nurses Caring for Patients during the HIV/AIDS Pandemic: A Conceptual Framework, and Table 2: Quotes from the Research Paper). The research also presents the contribution of the research to the benefit-finding domain.

Table 1: Main HIV/AIDS Topic-Related Documents

Date	Author	Metho.	Type	Examples
1988	Ross, M.W., & Seeger, V.	Quanti.	Rewards	Intellectual stimulation.
1992	Bennett, L.	Quali.	Rewards	Male nurses not having to conceal their homosexuality
1992	Breault, A.J., & Polifroni, E.C.	Quali.	Rewards	Making a patient comfortable, seeing a patient able to go home, helping patients die with dignity, caring for individuals who needed it.
1994	Barbour, R.S.	Lit. Rev.	Rewards	Admiration for patient courage, being able to help, intellectual stimulation, interactions with patients, male nurses not having to conceal their homosexuality.
1994	Giami, Al.	Quali.	Benefits (French)	A privileged nurse-patient relationship, working in a unit like non others.
1994	McGarrahan, P.	Quali./Book	Rewards	Enlarge nurses' understanding of human problems, opportunity to be the kind of nurses they always wanted to be, a chance to organize care on nursing principles, skills attitudes & performance validated & approved, gratitude from patients, learning on the job, to be able to put their ideals in practice & develop a holistic practice, more autonomy & independence on the job, able to experiment & innovate, able to be themselves at work, can grow professionally.
1996	Bennett, L.; Ross, M.W., et al.	Quanti.	Rewards	Personal effectiveness, emotional & social supports, empathy, self-knowing.
1997	McCann, T.V.	Mix	Rewards	Opportunity to learn new & challenging information, being able to have continuity of care & treatment & long-term professional relationships with patients.
1999	Hayter, M.	Mix	Rewards	Social recognition, closeness of the nurse-patient relationship, autonomy in one's practice.
1999	Manus, J.-M.	Other	Benefits (French)	Creation of privilege ties, 'bonds'.
1999	Sherman, D.W., & Ouellette, S.C.	Lit. Rev.	Benefits/Rewards	Personal & professional.
2000a	Sherman, D.W.	Quali.	N/A	Chemistry or connection with patients, helping patients live fully until death, appreciation of the human spirit, making patients comfortable, providing emotional & spiritual support, opportunity for emotional & spiritual growth.
2000b	Sherman, D.W.	Quali.	N/A	Growth as a person, finding new faith, discovering what was important in life.
2003	Mccausland, J., & Pakinham, K.I.	Quanti.	Benefit Finding	Personal growth, increase of understanding of others, positive personality change, increase in knowledge, start or strengthening of relationships, sense of satisfaction & achievement, gained perspective.
2005	Ferri,	Kindle Book	N/A	Professional development, learn about treatments, infections & body reactions, & educating medical staff,
2006	Fournier, A.M.	Book	Rewards	Reward from taking care of those no one else wants to care for.
2007	Dageid, W.; Sedumedi, S.D.; et al.	Quali.	Benefit Finding	Personal growth, positive changes in personality, better understanding of HIV positive people, development of new relationships, perceived achievements & satisfaction with oneself, altered priorities & goals in life.
2007	Nolan, S.	Book	Rewards	Exciting times to be a promising young scientist might have been unemployed without AIDS, opens one's eyes to new things, opportunity to deal with social issues.
2008	Davhana-Maselesele, M., & Igumbor, J.O.	Quanti.	Rewards	Highly regarded by friends due to work in HIVAIDS domain, valuable contribution to society, gratitude from patients, status & recognition for involvement in HIV/AIDS domain, positively influence on others' life, positive peer relationships.
2008	Munro,	Quali./Book	Positive aspects	Close relationship with clients, personal growth, mutual growth (nurses and clients benefit from the care relationship, gay nurses openly about their sexuality and free from workplace prejudice & stigma, & humour
2009	Mullins, I.L.	Quali.	Rewards	Support from co-workers, social rewards, relationships with patients.
2010	Akintola, O.	Quali.	Rewards	Extrinsic: constructive feedback, development on the job, made patients happy, new skills & competencies, participation in decision making, recognition. Intrinsic: gratification, personal, emotional & psychological development self, satisfaction, transformation of attitudes & perceptions.
2010	Malatji, T.	Quali.	Rewards	Recognition, receiving positive feedback, providing support & comfort, counseling patients & families, developing meaningful relationships with patients & families.
2010	Vervoort, S.C.J.M.; Dijkstra, B.M., et al.	Quali.	N/A	Job satisfaction.
2011	Bellingham, C.	Other	Benefits	Benefits outweigh the negative.
2014	Saag, M.	Book	Positive impacts	Breaking down the doctor-patient borders, validation.
2014	Valjee, L., & van Dyk, A.C.	Quali.	Positive aspects	Sense of personal accomplishment, helping others, making a difference to the lives of patients, seeing a smile on patients' faces, job satisfaction.
2015	Ball, S.C.	Book	Positive aspects	Sense of community: taking in patients & families (immediate & extended).
2016	Qiao, Z.; Chen, L. et al.	Quanti.	N/A	Intrinsic & extrinsic job satisfaction.
2016	Varsalone, D.P. & Deering, S..	Book	N/A	Learning something new, teach what you learn to people around the world, make a difference.
2018	Baxter, D.	Book	N/A	Training staff, teaching students, mentoring & being included in conversations.
2019	Matzer, E., & Hugues, V.	Book	N/A	Develop new relationships, get to know & nurture patients & families, live life-changing experiences, meet new challenges, make a difference in someone's life, to shape life & practice in a way nothing else would ever do.
2020	Journo, E.	Other	N/A	Praise, gratitude.
2021	Smith, N.	Other	N/A	Make one's life count.
2021	Yeates, C.	Other	N/A	Developing new relationships, accepting environment for male nurses, good memories.

Figure 1: Benefit Finding for Nurses Caring for Patients during the HIV/AIDS Pandemic: A Conceptual Framework



Literature review

Data gathered from 35 HIV/AIDS, and topic-related documents were divided into two main categories: (1) self-enhancement benefits; and (2) self-actualization benefits. For each category, this paper presents multiple themes and sub-themes which help develop a graphic representation of the concepts underpinning the benefit-finding domain for nurses caring for patients during the HIV/AIDS pandemic (see Graph 1: Benefit finding for nurses caring for patients during the HIV/AIDS pandemic: A Conceptual Framework).

Category 1 Self-enhancement benefits

Many nurses cited that they experienced self-enhancement benefits from caring for and providing support and comfort to HIV-infected or AIDS-patients, as well as their immediate and extended families. Such benefits, reported in the literature, were grouped under the following three themes: (1) work benefits; (2) work attributes; and (3) work ethos.

1. Work benefits

The work benefits' sub-themes were identified as money, status, career advancement, and validation. If nurses were receiving a salary while working in the HIV/AIDS domain, they reported

that being able to make "a steady living", [69, p29] because of a better pay (in countries [e.g., South Africa, and United States] where pay for work was an issue), benefited them.[52, 69] They reported that they gained a certain level of "status [...] due to my [their] involvement in the area of AIDS", [13, p69] which included finally becoming "somebody", [69, p29] and receiving "social recognition".[70, p989] For some nurses working in a domain unlike any other, because of its highly technical and emotional demands,[71] benefits accrued from knowing that their work was "becoming almost fashionable", [69, p180] and that it had "an impact greater than in other specialties".[72, p109] Nurses also stated that they benefited from "opportunities to grow professionally", [72, p168] with "opportunities otherwise not often available in nursing, [...] the kind of job they have been searching for".[72, p46] These jobs gave them "opportunities for capacity and career development", [52, p3] with potential to achieve higher positions with more responsibility.[69] Finally, one nurse mentioned that it gave her something to "latch onto and work for and work towards". [22, p128]

In terms of being validated by the work they were performing, nurses spoke of how rewarding and satisfying it was to work in an environment that was formally and informally recognized, appreciated, and supported by patients, their immediate

Table 2: Quotes from Research Paper

1. Self-Enhancement – 1.1 Work Benefits
- make “a steady living”
- gained “status [...] due to my [their] involvement in the area of AIDS”
- “finally becoming someone”; receiving “social recognition”; “becoming almost fashionable”; and [making] “an impact greater than in other specialties”
- “opportunities to grow professionally”; “opportunities for capacity and career development”; and “opportunities otherwise not often available in nursing, [...] the kind of job they have been searching for”
- gave [nurse] something to “latch onto and work for and work towards”
- being “included in the [doctors’] conversations”
- “It makes me know that the work I’ve been doing is worth it”; and “I can see the difference I am making”
- “that they are doing something important for another person”
- “Oh my God, you’re an absolute hero for working in that environment”
- “I wanted to take this opportunity to make my life count”; and “It was the best way to make a difference, to care for someone, to be needed”
1. Self-Enhancement – 1.2 Work Attributes
- “closeness and isolated client [therapeutic] relationship”; and “have a real impact on patients’ lives”
- “I have accomplished many worthwhile journeys in the job”
- “the chance to be themselves”; being free from “prejudice and secrecy”; “not having to conceal their sexuality”; and “could work in an environment that would accept me [him] for being gay”
- could “develop on the job”; and experience “intellectual stimulation from AIDS-related work”
- “a source of personal [emotional and psychological] satisfaction”
- “continue to learn what they do well”; [learn] “new skills and new competences”; and “new and challenging information from biomedical and psychosocial perspectives”, for example: [increase] “knowledge and understanding of medicine-related issues, such as: HIV/AIDS, AIDS-related health professionals, [opportunistic] illness [es]”
- “patients become teachers and nurses learn from patients”
- [create] “several specific training”; and “conduct several lectures”
- “The things Valery learned; they would shape her life and practice in a way nothing else would ever do”
- “The life of every nurse is like a roller-coaster ride, one day your patient dies, or you get that sinking feeling when a friend calls to say they have just been diagnosed [with HIV]. The next day your hard work takes you to a place where you can learn something new and teach what you learned to people all over the world and try to make a difference”
- “Working in the hospice was very formative [...], learning about yourself and about compassion and death and dying, and understanding that death is part of life [...]”
- “doing things we [they] never imagined”, for example: [developing] “their own practice”; “counseling patients and their families”; “doing research”; opportunities “to experiment and innovate”; “put their ideas into practice”; and use the “creative process”
- “something new and challenging, something that demands concentration and attention”; “ingenuity, inventiveness, and imagination”
- “take care of HIV-infected patients
1. Self-Enhancement – 1.3 Work Ethos
- “a chance to organize care on nursing principles”, for example: “assisting their patients to live as fully as possible until death”
- “part of the appeal of caring for HIV-infected patients can be the pleasure of working with dynamic and caring colleagues”; and “working with like-minded staff, [...] [and] colleagues whose values and practice match their own”, “a particular philosophy of care”
- “be the kind of nurse they always wanted to be”; “do the job right”; “make a difference”; “help, in however limited capacity”; “meaning in care giving”; and “develop a holistic practice”
- “the unity of what Western culture has separated for analytic purposes into separate categories: the sensory, rational, and emotional realms”
- “come face-to-face with existential mysteries of human life”
- “live fully and live out some of the major social issues of our time”
- using “their skills and talent to the fullest” “for people who don’t expect it”
- “their philosophy of care is founded on a moral stance according to which every human being is worthy, and thus worthy of care”

Table 2: Quotes from Research Paper (continued)

2. Self-Actualization – 2.1 Relationships
<ul style="list-style-type: none"> - "to connect with other human beings"; [opportunity to strengthen] "an existing relationship [...]: closeness, bonding, commitment, [and] communication" - "a new relationship with care recipients" and "with the patients' family" - "She felt privileged being with her patients as they took their last breath", "I felt very lucky to have been a part of it" - "a connection was established when patients sought information about them as a person, by asking them about their family lives, their hobbies, or shared interests" - "nurses share in their patients' courage and fortitude" - "<u>I always needed to be with the patients</u>"
2. Self-Actualization – 2.2 Transformation
<ul style="list-style-type: none"> - [transformed their] "attitudes and perceptions" - [attitudes] "to a patient population [gay, prostitute, and drug-injection communities] that has suffered the effects of being lonely and stigmatized" - [increased] "understanding of self, such as an appreciation for one's health and well-being, and others, such as people in general, [...], and medical professionals" - "seeing families and other personnel develop similar attitudes" - "took comfort in the fact that they made a difference in the lives of their patients" - "I feel I am positively influencing other people's lives through my work" - "One of the most important things I've learned on my journey is simple: To a Nurse, it should never matter why or how someone becomes sick. Everyone deserves to be treated with dignity so that when their time comes, they can leave this good earth feeling love, compassion, and the loving touch of someone holding their hand" - [Nurses perceived] "that human transformation is possible"; and they "believed in helping other people" - [Nurses were] "spiritually guided into nursing", an "opportunity for spiritual growth" - [Nurses] "develop ways of confronting and transcending it" [HIV/AIDS]
2. Self-Actualization – 2.3 Humanity
<ul style="list-style-type: none"> - "get close to some of [...] the best human beings are capable of"; "patients' courage" - being in "touch with much that is admirable in peoples' lives" - "their understanding of human problems" [empathy]. - "respond to the central challenge of human life, the inevitability of death" - "being fully and humanly involved in their work" - "If you don't let yourself feel this, you're missing out on what really matters. You want to be a healer? This is the cost. This is the essence of what we do" - [Nurses] "achieve a better understanding of how to make the most of life, and in the transformations that they witness[ed] and support[ed]" - [Nurses] "benefited for noticing "the support patients were getting from their significant others" - [Nurses] "benefited from noticing the support patients were giving "one another"
3. Stress-Related Growth
<ul style="list-style-type: none"> - [When] "the personal, professional, and political are in harmony" - [Results in] "improve self-esteem"; and "inner strength and confidence" - [When] "effectively coping with stressful situations"; and "feeling exhilarated after working closely with" [patients] - [Resulting in a] "sense of personal accomplishment" - [When] "making a patient comfortable" - "experiences led to the discovery and development of 'the self'" - "when horrific events occur, good people do good things simply for goodness' sake"

colleagues, and other health care providers.[13, 21-22, 73-75] Validation was also received from family members, friends, community members, and stakeholders.[15, 75-76] Formal words of appreciation and gratitude, constructive feedback, improvements in the condition, or quality of life of a patient, and participation in decision making were various ways of validating a nurse's work,[15, 52, 69] as well as being "included in the [doctor's] conversation" [32, p226] about their patients with other doctors, specialists, interns, and residents.

It is through their work that nurses experienced loving and caring for patients who needed them. [43] Informally, it is through their patients' happiness, smiles, and the knowledge that they played a pivotal role in helping a patient die with dignity, that nurses recognized that they improved their patients' quality of life. [10, 13, 15, 18, 21, 27, 52, 59, 74, 77-78] To that extent, validation helped them see purpose and meaning in their work.[31, 43] One nurse noted: "It makes me know that the work I've been doing is worth it",[69, p166] while another mentioned: "I can see the difference I am making". [52, p10] As such, these nurses perceived "that they are [were] doing something important for another person".[72, p109] As one nurse noted being told, "Oh my God, you're an absolute hero for working in that environment".[77, p6] Another said, "I wanted to take this opportunity to make my life count";[78, p4] while a third one mentioned, "It was the best way to make a difference, to care for someone, to be needed".[49, p29]

2. Work attributes

There are attributes inherent to the work itself that brought benefits to nurses. They can be grouped under the following sub-themes: autonomy/freedom, education/training, coaching/mentoring, established boundaries, and experiments/innovation. Nurses alluded to the fact that the very nature of HIV/AIDS care increased intimacy, "closeness, and isolated client [therapeutic] relationships";[43, p353; 70, p990] created opportunities for freedom (to innovate in their work or to be completely involved in their work), autonomy, and independence which they perceived as a benefit.[69, 72] It gave nurses the opportunity to have "a real impact on patients' lives".[72, p108] As stated by one nurse, "I have accomplished many worthwhile journeys in the job".[13, p71] For gay male nurses, the nature of the work greatly benefited them as it gave them "the chance to be themselves"[72, p165] in their professional career for the first time, to be free from "prejudice and secrecy";[39, p229] "not having to conceal their sexuality".[35, p125] One male nurse said he "could work in an environment that would accept me [him] for being gay".[77, p6]

Nurses spoke about the benefits they experienced while working in an environment where they could "develop on the

job";[52, p1] experience "intellectual stimulation from AIDS-related work";[79, p396] and satisfy their curiosity and interests in identifying and responding to patients' needs.[70] Such work was "a source of personal [emotional and psychological] satisfaction";[10, p26] because it enabled them to "continue to learn what they do well";[72, p115], and to learn "new skills and new competences";[52, p1] to help patients [69]. New skills may include communication skills, while new competences may be about how to deal with life experiences, and the reciprocal love between nurses and patients [52, 80]. It also provided them with an opportunity to acquire knowledge and understanding of "new and challenging information from biomedical and psychosocial perspectives";[81, p1035] As examples, they increased their "knowledge and understanding of medicine-related issues, such as: HIV/AIDS, AIDS-related health professionals, [opportunistic] illness [es]";[58, p862] HIV wasting, and treatments, as well as nursing-related issues, such as improving quality of care and self-care.[80] They realized that they greatly benefited from a context where there was a reciprocal exchange between patients and nurses, for example when "patients become [became] teachers and nurses learn [learned] from patients";[72, p107] Nurses were also able to develop "several specific training";[69, p111] "conduct several lectures";[69, p112] (e.g., for fire departments), as well as train staff, teach students, and mentor other nurses [32, 69, 80]. The following quote summarizes the learning gained by nurses. "The things Valery learned (e.g., "the horrors and cruelties of the world");[69, p52] they would shape her life and practice in a way nothing else would ever do".[69, p60] Another nurse stated, "The life of every nurse is like a roller-coaster ride, one day your patient dies, or you get that sinking feeling when a friend calls to say they have just been diagnosed with HIV. The next day your hard work takes you to a place where you can learn something new and teach what you learned to people all over the world and try to make a difference".[66, p195] Finally, nurses mentioned that "Working in the hospice was very formative [...], learning about yourself and about compassion and death and dying, and understanding that death is part of life [...]"[22, p128]

Nurses reported that they had the opportunity to push boundaries within their scope of work. They found themselves "doing things we [they] never imagined";[27, p143] and working where boundaries could be stretched to incorporate duties not part of their normal, everyday, work description, such as developing "their own practice";[72, p159] "counseling patients and their families";[15, p21] and "doing research";[69, p173]

Nurses found that the appeal of HIV/AIDS patient care came from the opportunity it gave them "to experiment and innovate";[72, p160] and "put their ideas into practice".[72,

p159] In fact, the work environment became part of a “creative process”[72, p108] allowing them to set up “something new and challenging, something that demands concentration and attention”.[72, p44] Moreover, such a creative process called for “ingenuity, inventiveness, and imagination”.[72, p160] Therefore, from the start, they found themselves establishing approaches and/or programs to “take care of HIV-infected patients”.[72, p43] and/or initiating drug or treatment strategies, as examples.[69]

3. Work ethos

In this research paper, work ethos focuses on two sub-themes, namely: work principles and philosophy. Nurses mentioned that they perceived deriving benefits when getting “a chance to organize care on nursing principles”,[72, p109] which included “assisting their patients to live as fully as possible until death”. [18, p117] They also stated that “part of the appeal of caring for HIV-infected patients can be the pleasure of working with dynamic and caring colleagues, [...] working with like-minded staff, [...] [and] colleagues whose values and practice match their own”. [72, p45] Some would go as far as to say that they benefited from a work environment where they could share humor and fun.[43] Finally, some nurses knowingly broke “(government) rules (concerning non-citizens), [as they thought they were] answering to a higher authority”. [32, pxv]

Nurses alluded to the fact that they benefited from working in this domain because they could put into action “a particular philosophy of care”[72, p174] that they believed in. Such a philosophy provided them the opportunity to “be the kind of nurse they always wanted to be”,[72, p109] “do the job right”,[72, p43] “make a difference”,[72, p104] “help, in however limited capacity”,[79, p397] and find “meaning in care giving”. [12, p18] It also gave them the chance to “develop a holistic practice”,[72, p159] stated as “the unity of what Western culture has separated for analytic purposes into separate categories: the sensory realm, the rational, and the emotional”,[72, p124] “come face-to-face with existential mysteries of human life”,[72, p105] and “live fully and live out some of the major social issues of our time”[72, p172] while using “their skills and talent to the fullest”[72, p47] “for people who don’t expect it”. [72, p104] Finally, “their philosophy of care is founded on a moral stance according to which every human being is worthy, and thus worthy of care”. [72, p174]

Category 2 – Self-actualization benefits

Many nurses cited that caring for and providing support and comfort to HIV-infected or AIDS-patients, and their immediate and extended families, offered “a venue conducive to self-actualization”[72, p117] which included the following themes:

(1) relationships; (2) transformation; and (3) humanity.

1. Relationships

In this research paper, the theme relationships is divided into two sub-themes: existing and new relationships. Nurses reported that they perceived deriving benefits from being able “to connect with other human beings”,[72, p125] and having the opportunity to strengthen “an existing relationship [...]: closeness [...], bonding [...], commitment [...], and communication”. [58, p863] They also perceived benefits from being able to develop “a new relationship with care recipients”,[58, p862] by interacting with them in an honest way, on a short- or long-term basis, so that they could get to know, nurture and love them, as well as having the opportunity to interact “with the patients’ family”,[10, p26] immediate or extended, as the case may be.[15, 18, 19, 69, 72, 77, 79] One nurse mentioned that “She felt privileged being with her patients as they took their last breath”[77, p11] while another one stated, “I felt very lucky to have been a part of it”[77, p11] (a patient’s struggles until death). Ultimately, they felt that “a connection was established when patients sought information about them as a person, by asking them about their family lives, their hobbies, or shared interests”. [18, p119] As such, “nurses share in their patients’ courage and fortitude”. [72, p109]

Therefore, the privileged nurse-patient relationship went well beyond medical and biological monitoring and verification, as well as administration of treatments.[82] As mentioned by a nurse, “I always needed to be with the patients”. [69, p232] Moreso, nurses literally crossed the professional nurse-patient boundary by “hold [ing] a patient’s “hands”,[69, p96] get [ting] attached to her [their patients]”,[69, p129] and let [ting] patients stay with us [them]”. [69, p136] They even went further by taking “turns getting to his [their patients’ apartment [s]]”,[69, p147] “laid [lying] in bed with him [them at the patients’ residences]”, as well as going to dinner at patients’ residences, being present at patients’ death beds at home, and attending wakes for their patients.[69] Nurses often got attached to their patients.[69]

2. Transformation

The transformation theme focuses on two sub-themes, namely: self and others. Nurses said they benefited from the work in this domain because it helped them modify their values, beliefs, and attitudes toward life, such as a new appreciation of things and the modification of their priorities.[58] They transformed their “attitudes and perceptions”[52, p7] in order to embrace those of acceptance (non-judgmental), compassion, openness, respectfulness, selflessness, tolerance, and understanding “to a patient population [gay, bisexual transgender, prostitute, and drug-injection communities] that has suffered the effects

of being lonely and stigmatized”[10, p26] They also increased their “understanding of self, such as an appreciation for one’s health and well-being, and others, such as people in general, [...], and medical professionals”[58, p862] in particular while “seeing families and other personnel develop similar attitudes”[72, p108] and perceptions.[43] Relationships with HIV-infected and AIDS-patients benefited nurses as it enabled them to leave their professional role behind and adopt a new one that was positioned in the affect domain.[22, 71] Finally, nurses “took comfort in the fact that they made a difference in the lives of their patients”.[21, p7] One nurse mentioned, “I feel I am positively influencing other people’s lives through my work”[13, p71] Another nurse stated, “One of the most important things I’ve learned on my journey is simple: To a nurse, it should never matter why or how someone becomes sick. Everyone deserves to be treated with dignity so that when their time comes, they can leave this good earth feeling love, compassion, and the loving touch of someone holding their hand”[66, p239] Some nurses said that they benefited when patients and families showed them “that human transformation is possible”[72, p106] families accepting their child’s lifestyle, for example. Finally, caring for HIV-infected and AIDS-patients was sustained when patients were “taking [en] into” the care community which often consisted of doctors, nurses, social workers, chaplains, and psychiatrists.[83]

As well, nurses, who “believed in helping other people”[21, p7] alluded to the fact that some were “spiritually guided into nursing”[66, p85] Moreover, working in such a domain presented an “opportunity for spiritual growth”[18, p123] and “to develop ways of confronting and transcending it [HIV/AIDS]”[22, p141]

3. Humanity

In this research paper, the humanity theme is divided into two sub-themes, namely: life and death, and support. Nurses shared that they perceived deriving great benefits from being able to “get close to some of [...] the best human beings are capable of”[72, p105] i.e., the “patients’ courage”[79, p397] They alluded benefiting from being in “touch with much that is admirable in peoples’ lives”[72, p105] enlarging “their understanding of human problems”[72, p107] (empathy); and being able to “respond to the central challenge of human life, the inevitability of death”[72, p137] Finally, nurses perceived deriving great benefits from “being fully and humanly involved in their work”[72, p162] As mentioned by a caregiver, “If you don’t let yourself feel this, you’re missing out on what really matters. You want to be a healer? This is the cost. This is the essence of what we do”[31, p80]

As well, nurses said that they benefited from helping patients “achieve a better understanding of how to make the most of life, and in the transformations that they witness[ed] and support[ed]”[72, p109] They benefited from noticing “the support patients were getting from their significant others”[80, p397] and were giving “one another”[72, p107]

Self-Related Growth (professional, personal/self)

Nurses experienced some form of self-related growth from caring for and providing support and comfort to HIV infected and AIDS-patients, and their immediate and extended families, during that HIV/AIDS pandemic. Such growth was achieved because of the self-enhancement and/or the self-actualization benefits they perceived receiving. They mentioned that working in the HIV/AIDS domain accrued the greatest stress-related growth when “the personal, professional, and political are in harmony”[72, p169] They also benefited when they were able to “improve self-esteem”[52, p3] through acquired “inner strength and confidence”[52, p7] thus “effectively coping with stressful situations”[21, p1] such as the death of a patient, “feeling exhilarated after working closely with”[13, p71] their patients, and having a “sense of personal accomplishment”[21, p7] by “making a patient comfortable”[10, p26] Nurses reported that they experienced the most personal growth/change in the “character” realm by understanding one’s emotions, personal strength, patience, self-awareness, self-acceptance, compassion, and courage.[22, 58] Ultimately, their “experiences led to the discovery and development of ‘the self’”[52, p7] Finally, one must remember that “when horrific events occur, good people do good things simply for goodness’ sake”[31, p66]

Summary of Results

This literature review suggests that nurses perceived deriving benefits (rewards, positive impacts, or a proverbial silver lining) from caring for their HIV-infected and AIDS-patients, and their immediate and extended families, during the HIV/AIDS pandemic, between the early 1980s and the late 1990s, in three distinct categories: self-enhancement, self-actualization and stress-related growth.

The benefits in the self-enhancement category revealed that there are specific areas, i.e., status, career development, and validation, where nurses felt their work was recognized by doctors, peers, patients, and families, to name a few. The work-benefits area are related to receiving a “proper” salary for the work performed. The importance of receiving a salary means that there is a tangible incentive attached to their work, with greater possibility for career advancement. While salary was a contributing factor in discerning benefits, the work

environment greatly influenced how nurses perceived those benefits. In fact, if the work environment allowed them to enjoy a certain amount of autonomy or freedom, nurses felt encouraged to develop professionally through education and training, and to coach, and/or mentor staff. This autonomy or freedom gave them permission to push professional boundaries to perform other duties, such as research; as well as experiment and innovate new treatment protocols. Benefits were also perceived when the work that they were performing was congruent with their personal work ethos, or when the work principles and philosophy were aligned with theirs.

The benefits gained in the self-actualization category included the possibility of developing new relationships, mostly with patients, and their immediate and extended families, or strengthening existing ones, predominantly with peers. Other benefits helped them modify their own values, beliefs, and attitudes toward life and others: namely their patients. In fact, some nurses were able to experience the raw humanity of human beings, mostly their courage in the presence of death. Such a situation offered an opportunity for spiritual growth. Benefits in terms of being supported for their work were perceived when it was expressed by different stakeholders, other healthcare providers, patients, and their immediate and extended families.

Finally, because of the accumulated self-enhancement and self-actualization benefits nurses perceived deriving from caring for HIV-infected and AIDS-patients, and their immediate and extended families, during that pandemic, they mentioned that they experienced stress-related growth, either at the personal level, and/or professional level.

This research identified, collated, and summarized research previously published in the benefit-finding domain related to nurses caring for and providing support and comfort to HIV-infected and AIDS-patients, and their immediate and extended families, during the HIV/AIDS pandemic, from the early 1980s to present (see Table 1: Main HIV/AIDS Topic-Related Documents). It also created a graphic representation of the key concepts underpinning this domain of research (see Graph 1: Benefit finding for Nurses Caring for Patients during the HIV/AIDS Pandemic: A Conceptual Framework). Finally, it put into a table format all quotes extracted from the body of the text, one after another, to give the reader a final opportunity to revisit the results under a different lens (see Table 2: Quotes from Research Paper).

Contribution and Value to the Benefit Finding Domain

This research paper is interested in a domain not often visited

by researchers studying nurses caring for and providing support and comfort to HIV/AIDS patients. Their studies have mostly focused on the burden of care, burnout, as an example. Therefore, this research paper contributes to the benefit finding domain and the choice and exchange theory in several aspects. First, through a review of literature methodology, it confirms the use of the choice and exchange theory in this research paper and expands its use to the benefits of caring domain. To do so, it offers a narrative and graphic representation of the categories, themes, and sub-themes representing the many benefits of caring as perceived by nurses derived from caring for and providing support and comfort to HIV-infected and AIDS-patients, and their immediate and extended families, during the HIV/AIDS pandemic. Second, it organizes the categories, themes and sub-themes in a conceptual framework (graphic representation) under two major categories, namely the self-actualization and self-enhancement benefits categories. Third, for the nursing profession, this research paper extends the understanding that out of negative, difficult circumstances, a positive gain can, and oftentimes is, realized, stress-related growth. Through difficulty comes enlightenment in the form of self-concept, self-efficacy, and professional satisfaction. Fourth, the results from this research paper expand the self-enhancement benefit-finding knowledge and confirm the self-actualization benefit-finding knowledge when applied to this context, by explicitly naming themes and sub-themes under each category, as well as providing numerous examples to substantiate the findings. For example, under the work benefits theme, the money, status, validation, and career advancement sub-themes are presented. Fifth, this research provides researchers with both a narrative and graphic framework to examine the perceived benefits nurses derive from caring for and providing support and comfort to COVID-infected patients, while standing in, i.e., as proxy, for the patients' immediate and extended families, at the height of the COVID-19 pandemic. Finally, this research provides the basic information needed to perform a systematic literature review, where other databases, such as CINAHL and MEDLINE/PUBMED could be used to further advance the benefit of caring for HIV/AIDS patients conceptual framework presented in this research paper.

Conclusion

Using a literature review methodology, the objective of this research paper was two-fold. First, it aimed to present both a narrative and a graphic representation of the key concepts underpinning the benefit of caring, within the benefit-finding domain, in the context of nurses caring for HIV-infected and AIDS-patients, and their immediate and extended families, during the HIV/AIDS pandemic, from the early 1980s to the late

1990s. To achieve this, benefits, rewards, positive impacts, and any potential silver lining for nurses who cared for HIV/AIDS patients, and their families/loved ones, were extracted from peer-reviewed articles, books, and grey literature. The literature search indicated that data on benefits were seldom the focus of the literature, and mostly integrated within documents pertaining to the negative aspects of caring for these patients in a "war zone," where nurses and other caregivers were "in a sniper battle against a huge and powerful enemy, dodging through the bushes, not sure where you are, wanting to believe that help is coming but not knowing when it will get here, or how effective it will be if it ever does", [80, p140] while trying to do "something brave and important". [80, p251] Benefits to nurses were noted as coincidental, rather than a primary outcome of caring.

This research expands the understanding of self-enhancement benefits and confirms the self-actualization benefits for nurses caring for and providing support and comfort to HIV/AIDS patients, and their family/loved ones. It adds to the benefit-finding knowledge by offering a graphic representation of the categories, themes and sub-themes forming the concepts underpinning the benefits-finding domain in the context of nurses caring for patients during the HIV/AIDS pandemic.

In the context of the COVID-19 pandemic, nurses are once again called upon to care for and provide support and comfort to COVID-19 patients, whose immediate and extended families are in absentia, while working in an environment comparable to the one that prevailed during the HIV/AIDS pandemic, where there was a high number of infected-individuals who were hospitalized, needed intensive care, and were suffering and dying, and where information about the infection was constantly changing. Therefore, researchers are once again enticed to write scientific literature about the negative impact of caring in a "war zone," where patients are at war against a virus and opportunistic infections, such as the downside and the intractable challenges of such work, as well as how nurses are physically and psychologically impacted by the COVID-19 health crisis. [5] Despite the negative impacts on them, many nurses are still drawn to and continue to care for COVID-19 infected-patients. Using the concepts identified through the benefit-finding research in the context of the HIV/AIDS pandemic, researchers can identify the many perceived benefits nurses derived from caring for infected patients during the COVID-19 pandemic. It seems that such benefits may perhaps help nurses manage both the physical and mental stress of working through the pandemic, as well as improve their emotional well-being, and understand the meaning of life and work during a crisis. Therefore, the concepts identified

in this literature review may inform the understanding of and support for COVID-19 nurses. "While the picture seems bleak, [...] there is a silver lining in the midst of the crisis": [4, p5] Therefore, "interventions should be designed to encourage people to look for the silver lining in the midst of the crisis, to find small things for which they can be grateful": [4, p6-7] as "it's okay, even rewarding, to care for those that nobody else cares about": [24, p91].

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Résumé

La coercition reproductive fait référence aux comportements de contrôle et de force infligés afin d'orienter la trajectoire reproductive des femmes. Les conséquences sont multiples : grossesses inopportunnes, recours accentué aux contraceptifs d'urgence et avortements, dépression. Malgré ces effets importants, les femmes qui en sont victimes éprouvent souvent de la difficulté à reconnaître leur expérience comme telle, ce qui contribue à limiter leur recherche de soutien. Cette analyse qualitative réalisée auprès de 12 femmes et d'une personne non-binaire ayant vécu de la coercition reproductive présente comment la reconnaissance d'une telle expérience se déploie sur un continuum qui intègre à la fois des facteurs qui facilitent la reconnaissance et d'autres qui la fragilisent. Nos résultats suggèrent que le processus de reconnaissance est paradoxal, et revêt un caractère narratif, intersubjectif et social. Contrastant nos résultats avec la reconnaissance honnethienne, des pistes critiques sont formulées en ce qui concerne notamment le déficit de ressources herméneutiques.

Mots clés coercition reproductive, reconnaissance, recherche qualitative, violence entre partenaires intimes, violence sexuelle

La paradoxalement de la reconnaissance de l'expérience de coercition reproductive : une analyse qualitative

AUDREY BUJOLD & SYLVIE LÉVESQUE

Introduction

En juillet 2022, la Cour suprême du Canada a statué qu'une personne pourrait être reconnue coupable d'agression sexuelle si les paramètres de la relation sexuelle telle que consentie incluait le port du condom, mais que le partenaire a retiré celui-ci à l'insu ou sans le consentement de l'autre partenaire.^[1] Ce jugement évoque le caractère contemporain des enjeux relatifs aux violences sexuelles, à la violence entre partenaires intimes (VPI), et plus précisément à la coercition reproductive (CR). En effet, la CR s'inscrit à la fois sous le joug conceptuel des violences sexuelles et de la VPI, deux termes sociaux plutôt que juridiques pour exprimer les violences dont

les femmes sont très majoritairement victimes. D'une part, les violences sexuelles comprennent tous les comportements sexuels commis sans le consentement libre et éclairé de la personne victime.^[2] Les violences sexuelles comprennent ainsi le harcèlement sexuel et l'agression sexuelle, mais aussi la violence sexuelle dite « ordinaire », c'est-à-dire celle qui se vit au quotidien et qui peut comprendre des paroles ou des gestes à caractère sexuel non convoités.^[3] D'autre part, la VPI qui peut se vivre dans toutes les configurations relationnelles intimes (p. ex. mariage, union de fait, fréquentation) se manifeste sous multiples formes dont les violences sexuelles et physiques ou la maltraitance psychologique notamment.^[4]

Pour sa part, la CR est un nouveau concept ayant émergé au sein de la littérature scientifique en 2010 grâce aux écrits de Miller et al.^[4] qui ont problématisé le lien entre la VPI et les enjeux qui s'apparentent à l'autonomie reproductive des femmes. La CR tel qu'initialement élaborée par Miller^[4] décrit donc une série de comportements le plus souvent perpétrés par un partenaire intime qui limitent l'autonomie reproductive des femmes, y compris le sabotage de la contraception (p. ex.

retrait non consensuel du condom, percer les condoms), la coercition liée à la grossesse (p. ex. pressions pour forcer une grossesse) et le contrôle de l'issue d'une grossesse (p. ex. forcer ou empêcher l'accès à l'avortement, menacer de quitter la partenaire si elle poursuit la grossesse).[5] La CR comprend ainsi tous les comportements visant à contrôler intentionnellement les choix reproductifs d'une femme en matière de contraception et de grossesse, par le biais de comportements qui sont souvent décrits par les femmes elles-mêmes comme coercitifs et violents.[6] Publiée en 2021, une revue systématique des écrits à ce sujet ajoute que dans certains contextes, la CR peut être perpétrée par d'autres membres de la famille et de la belle-famille (p. ex. pression pour fonder une famille) ou par des professionnels de la santé (p. ex. refus systématique de procéder à une demande répétée de contraception irréversible telle la ligature des trompes, stérilisation forcée des femmes autochtones).[7]

Les facteurs de risque liés à la CR sont nombreux : avoir un jeune âge[8,9], appartenir à un groupe racisé ou ethnoculturel [4,9-12], s'identifier comme étant de la diversité sexuelle et pluralité des genres [13], avoir des partenaires sexuels nombreux[13], être sans emploi[14] ou étudiante[8] et être en situation de handicap.[14] La VPI est également un facteur de risque central à la CR.[9,10,15,16] Alexander et al.[10] soulignent que seulement 10% des femmes ayant participé à l'étude ont déclaré avoir subi uniquement de la CR alors que près de 4 femmes sur dix ont déclaré avoir subi à la fois de la CR et de la VPI. La CR génère également des effets importants sur la santé sexuelle, reproductive et mentale des femmes qui en font l'expérience. En effet, la CR est associée à de la violence verbale [11]; à des grossesses non désirées ou non planifiées[4,9,17]; à des infections transmises sexuellement et par le sang [15,17]; à une hausse de symptômes dépressifs ou post-traumatiques [10,16,18]; et à une probabilité accrue de polyvictimisation. [19] En résumé, la CR se situe donc à l'intersection de deux préoccupations de santé publique : la violence faite aux femmes ainsi que l'autonomie et la santé reproductive.

À l'instar d'autres formes de violence commises en contexte de relations intimes, la reconnaissance et la qualification de geste posés comme violent peuvent être ardues, voire absentes dans certains cas.[20-24] Qu'en est-il dans le cas de la CR ? Les femmes ayant vécu de la CR reconnaissent-elles facilement cette forme de violence ? Qu'est-ce qui facilite ou, au contraire, freine cette reconnaissance ?

La reconnaissance de la violence vécue

Certes, l'introduction depuis 2010 de ressources herméneutiques liées à la CR, c'est-à-dire des mots, des

concepts et des récits qui permettent d'exprimer cette réalité, a contribué à ce que les femmes qui ont vécu de telles expériences donnent un sens à celles-ci et par le fait même arrivent dans certains cas à reconnaître leur vécu comme tel. Cependant, comme c'est le cas pour la VPI, les femmes qui subissent la CR peuvent avoir du mal à reconnaître leur expérience comme telle malgré une quantité croissante de témoignages de CR et une visibilité sociale grandissante.[25,26] En effet, quelques études sur la VPI tendent à démontrer que la reconnaissance de ces gestes au sein de sa propre relation intime demeure difficile pour de nombreuses femmes.[25,26] Par exemple, ayant pour objectif de mieux comprendre le processus de reconnaissance des femmes victimes de VPI, Clements et al.[18] soulignent qu'environ 38 % de leur échantillon (n = 633) a été en mesure de rapporter des gestes de violence posés à leur endroit par un partenaire intime, mais seulement 8% de celles-ci ont reconnu ces gestes comme étant de la violence. Wilson et Miller [23] précisent pour leur part qu'environ 60 % des victimes d'agression sexuelle en contexte intime ou non (telle que définie par les lois étatsunies) ne reconnaissent pas leur expérience comme un acte criminel; la plupart d'entre elles la qualifiant plutôt de grave erreur de communication. Elles ont ainsi tendance à se responsabiliser à l'égard de l'agression, ce qui complexifie leur processus de reconnaissance. Différents arguments internalisés par les femmes semblent participer à ce narratif de leur culpabilité : ne pas avoir exprimé son non-consentement avec fermeté, avoir consommé de l'alcool ou des drogues au moment de l'agression ou avoir, par le passé, consenti à des activités sexuelles avec le partenaire.[27] Or, les femmes qui ne se reconnaissent pas comme victimes de ces actes présenteraient un risque élevé de revictimisation par rapport à celles qui amorcent un processus de reconnaissance. [22] En ce sens, les femmes qui rapportent un bagage expérientiel s'apparentant aux critères légaux d'agression sexuelle ou de VPI, mais qui ne reconnaissent pas en avoir été victimes, éprouvent davantage de détresse psychologique et une difficulté accrue dans leur recherche de soutien, en plus d'utiliser de manière plus fréquente des stratégies d'adaptation comme la consommation de substances.[18,28] L'unique étude recensée s'étant intéressée à la reconnaissance de la CR en contexte canadien confirme que celle-ci peut être difficile à reconnaître, notamment lorsque les femmes entretiennent un lien émotionnel avec l'agresseur ou lorsqu'elles vivent des manifestations de CR qui ne sont pas violentes physiquement. [21] Le fait de reconnaître la CR constitue souvent une première étape vers la recherche de soutien, qu'elle soit formelle ou informelle, et est associé à un meilleur état de santé et de bien-être.[29] En somme, force est de constater que nonobstant l'émergence au sein de la littérature scientifique

d'un vocabulaire décrivant précisément une violence qui limite l'autonomie reproductive des femmes, le concept de CR semble avoir de la difficulté à se construire une place socialement et culturellement reconnue dans la population canadienne.

Au Canada et ailleurs dans le monde, à notre connaissance, la reconnaissance liée à la CR, soit la capacité des femmes à reconnaître qu'elles ont vécu une telle expérience, est encore peu étudiée malgré la place prépondérante accordée aux enjeux liés à la violence faite aux femmes en recherche. À partir du récit de femmes l'ayant vécu, l'objectif de cet article sera donc de poursuivre le travail exploratoire de Lévesque et Rousseau [21] en tentant de mieux comprendre comment le processus de reconnaissance de la CR se déploie sur un continuum qui intègre à la fois des facteurs qui facilitent la reconnaissance et d'autres qui la fragilisent.

Méthodologie

Financée par le Conseil de recherches en sciences humaines (CRSH), cette publication s'inscrit au centre d'un vaste projet de recherche-action à méthodes mixtes visant l'avancement des connaissances et l'adaptation des pratiques liées à la CR. Plus précisément, cette étude présente une analyse qualitative du processus de reconnaissance de la CR à partir d'entretiens individuels semi-dirigés menés auprès de 12 femmes et d'une personne non-binaire ayant subi de la CR dans le cadre de relations intimes. Les participantes ont été recrutées par échantillonnage raisonné afin de sélectionner des femmes qui présentaient des profils sociodémographiques et expérientiels diversifiés. Les critères d'inclusion étaient les suivants : 1) être âgée de 18 ans et plus au moment de l'étude, 2) être en âge de procréer au moment où s'est produite la CR, 3) s'identifier comme femme ou comme personne trans ou non binaire ayant un utérus et 4) avoir vécu un ou plusieurs épisodes de CR.

Entre mai et décembre 2021, les femmes ont été recrutées au Québec et en Ontario avec l'aide des partenaires des milieux de pratique qui incluent des organismes communautaires et des cliniques de planification familiale. Des stratégies complémentaires ont été utilisées à l'aide des espaces socionumériques et des babillards. Afin de diversifier l'échantillon, deux affiches différentes d'appel à la participation ont été diffusées, l'une ciblant précisément les femmes immigrantes, réfugiées ou appartenant à différentes communautés culturelles et l'autre ciblant le groupe des femmes dans sa globalité. Dans les deux cas, les affiches comprenaient des exemples des trois principales formes de la CR (sabotage contraceptif, pression pour devenir enceinte et coercition pendant la grossesse). Cette étude a été approuvée par le Comité institutionnel d'éthique à la recherche avec des

êtres humains de l'UQAM (# du certificat: 2020-3064). Toutes les participantes ont signé un formulaire de consentement et leur confidentialité a été préservée dès le processus de transcription des bandes audio. Les données numériques ont également été protégées par mot de passe. Des brochures présentant des ressources d'aide différencier pour le Québec et l'Ontario ont aussi été fournies aux participantes. Ces brochures disponibles en français et en anglais offraient les coordonnées de multiples services dédiés notamment à la santé sexuelle et reproductive ainsi qu'à l'aide aux victimes de violence conjugale ou d'agression sexuelle.

Chaque participante a été conviée à un entretien individuel semi-dirigé d'une durée moyenne de 90 minutes. Ciblant le phénomène global de la CR, le guide d'entretien abordait les thèmes suivants : le contexte relationnel; les manifestations de CR et d'autres types de violence (le cas échéant); les répercussions associées à la CR sur l'autonomie reproductive et le bien-être; les enjeux, défis et résistances associés aux trajectoires de recherche d'aide et de recours aux services. En ce qui concerne particulièrement la reconnaissance de la CR, les questions ouvertes cherchaient à mettre en lumière les facteurs qui ont facilité et entravé la reconnaissance. Une compensation financière de 30 dollars a été remise aux participantes.

Analyse des données

Les entretiens ont été transcrits et codifiés en utilisant le logiciel NVivo 11 (QSR International Pty Ltd.). Ne s'appuyant sur aucun cadre théorique, la codification inductive a été priorisée afin de générer des codes et des catégories enracinés aux matériaux de la recherche.[30] Plus précisément, durant le premier cycle de codification des données, les transcriptions ont été scrutées par la première auteure de cet article et une auxiliaire de recherche de 3e cycle afin d'identifier tous les extraits narratifs pertinents à la compréhension de la reconnaissance de la CR et ont été assignés à des codes descriptifs.[30] Durant le second cycle de codification, l'équipe de chercheuses qui inclut les deux auteures de cet article ainsi que deux auxiliaires de recherche de 3e cycle s'est rencontrée afin de mobiliser un processus réflexif et critique à l'égard de la codification initiale. Cette réflexion a mené à un remaniement des codes eux-mêmes, et à l'inclusion de certains extraits narratifs permettant de contextualiser la reconnaissance de la CR. Finalement, durant le troisième cycle de codification menée par la première auteure et révisée par la co-auteure de cet article, les codes descriptifs ont été amalgamés inductivement en catégories qui situent le caractère narratif, intersubjectif et social de la reconnaissance. Ce cycle a aussi permis de faire émerger la paradoxalement du processus lui-même en mettant de l'avant les facteurs qui facilitent et qui fragilisent la reconnaissance de la

CR pour chacun de ces trois niveaux d'influence. Ensuite, deux matrices intégrant les trois niveaux d'influence ont été créées : l'une verticale permettant de décrire de manière cohérente et synthétique les récits individuels liés à la reconnaissance de la CR et l'autre, horizontale, permettant de relier les récits individuels entre eux afin d'offrir une vision globale des facteurs qui facilitent et qui fragilisent la reconnaissance au sein des trois niveaux d'influence.[30] Ces matrices ont permis de regrouper et d'interpréter les données en faisant des comparaisons, en dénotant des relations entre certains éléments et en mettant en évidence certains pans de vécus récurrents.[30] Négociées en réunion d'équipe et révisées pour obtenir un consensus le cas échéant, ces matrices ont aussi permis de différencier et de contraster les récits individuels des participantes; des tactiques tout aussi essentielles pour Miles et ses collaborateurs [30] dans le but de renforcer la validité et la rigueur de l'analyse.

Résultats

Les récits de treize personnes participantes âgées de 23 à 49 ans ont été intégrées à cette analyse. Le tableau 1 présente le profil des participantes qui inclut les données sociodémographiques collectées (âge, pays de naissance, statut migratoire au Canada s'il y a lieu, identité sexuelle et de genre, statut matrimonial, enfants à charge, situation d'emploi et situation financière, antécédents de VPI s'il y a lieu) ainsi que les expériences de CR rapportées (sabotage contraceptif, pression pour devenir enceinte et contrôle de l'issue d'une grossesse). En ajout à ce tableau, il importe de souligner qu'en lien avec les gestes de CR vécus, cinq participantes ont eu recours à la contraception d'urgence et cinq à l'avortement, dont quelques-unes à plus d'une reprise.

L'analyse des données permet de relever le processus paradoxal de la reconnaissance des expériences de CR. Dans le cadre de cette étude, la nature paradoxale de la reconnaissance ne vise pas à réconcilier des oppositions, à surmonter des dilemmes ou à exposer le quelconque caractère illogique ou contradictoire de ce processus. La paradoxalement sert plutôt à conceptualiser les rythmes vivants propres au processus de reconnaissance. Cette perspective conceptuelle qui s'arrime aux écrits de la théoricienne infirmière Rosemarie Rizzo Parse [31] suggère que c'est par le paradoxe qu'il est possible de découvrir la pleine complexité d'un phénomène et que par conséquent, le processus de reconnaissance ne peut être connu véritablement qu'à partir de la lentille paradoxale des facteurs qui facilitent et qui fragilisent la reconnaissance de la CR. La paradoxalement devient donc le concept matriciel de cette analyse, puisqu'il organise et relie l'ensemble de nos résultats.

Ci-bas, la figure 1 intègre les catégories centrales de notre analyse et illustre le fait même la paradoxalement de ce processus, traversé à la fois par des facteurs qui peuvent faciliter et

fragiliser la reconnaissance de la CR. D'une part, le dégradé de couleur des catégories centrales vise à mettre en lumière le processus interrelié et dynamique qui s'opère entre ces trois catégories; la narrativité précise les modes de représentation personnels du processus de reconnaissance, l'intersubjectivité étend ce processus vers l'apport des relations interpersonnelles et la socialisation incorpore une dimension plus sociale à la reconnaissance. D'autre part, la flèche horizontale permet de situer les catégories centrales de la reconnaissance sur un continuum, c'est-à-dire comme un phénomène progressif et dynamique dans le temps et l'espace. C'est précisément ce continuum qui met de l'avant la paradoxalement et les tensions qui s'inscrivent au sein du processus de reconnaissance de la CR. En effet, les récits des 13 participantes oscillent de manière vivante, dynamique et interreliée entre les facteurs qui facilitent leur reconnaissance et ceux qui la fragilisent.

1. Narrativité : rendre intelligible | avoir de la difficulté à rendre intelligible la CR

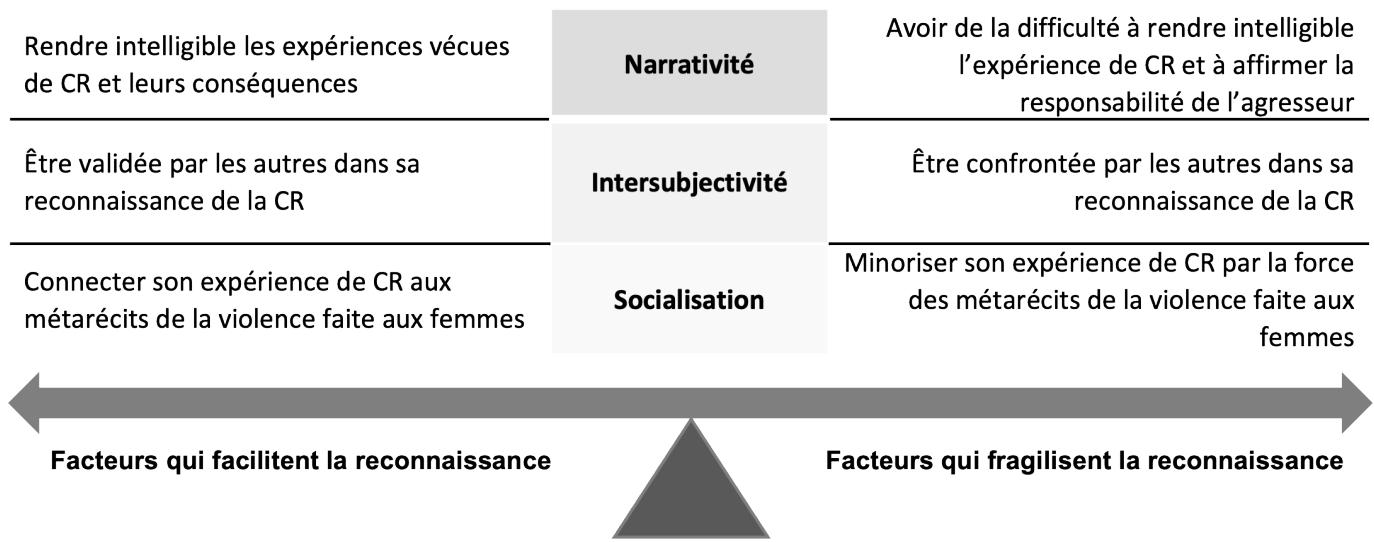
D'un côté, toutes les participantes expriment qu'elles sont capables de mettre des mots sur leurs expériences de CR, ce que nous considérons comme un facteur qui facilite la reconnaissance. D'abord, pour le sabotage contraceptif, les participantes ($n = 8$) nomment explicitement que l'expérience de CR s'articule principalement autour du retrait non consensuel du condom lors d'une relation sexuelle : « il y a une [relation sexuelle durant laquelle] mon partenaire a retiré le condom et continué la relation sexuelle à mon insu » (P6). Des participantes ($n = 6$) racontent aussi l'importance qu'elles accordent à la centralité de leur consentement à l'égard d'une relation sexuelle protégée avec un condom. Lorsque cette négociation contraceptive est bafouée, les participantes reconnaissent la CR comme une expérience à laquelle elles n'avaient pas consenti : « Je disais [à mes partenaires] que je ne voulais pas de... relations sans condom, mais qui sont rentrés quand même [sans condom dans mon vagin] » (P13). D'autres arrivent à rendre intelligible cette forme de sabotage contraceptif en reconnaissant les forts impacts émotifs et corporels associés à la CR ($n = 5$) : « C'est que je me sentais... quasiment violée de mon corps parce que je n'avais pas dit oui à ça » (P9). Les femmes ayant vécu de la CR avec un partenaire occasionnel ($n = 5$) avaient davantage de facilité à enclencher un processus de reconnaissance plus décisif et spontané, et à partager leurs préoccupations de CR à l'agresseur : « [Après la relation sexuelle où mon partenaire a retiré sans mon consentement le condom], je suis allée me doucher pis je lui ai dit : « Mais je pourrais avoir le sida! » (P2).

En ce qui concerne les pressions relatives à la grossesse, certaines participantes ($n = 3$) expriment aussi explicitement l'expérience de CR qui consiste à vivre de la pression pour la « la

Tableau 1: Profil des participant.es

Données sociodémographiques		Expériences rapportées de CR
P1	37 ans, née au Canada, cisgenre, hétérosexuelle, célibataire avec une ou des partenaires, 2 enfants, en emploi, estime ses revenus suffisants, antécédents de VPI	Sabotage contraceptif et contrôle de l'issue d'une grossesse
P2	36 ans, née en France (résidente permanente au Canada), cisgenre, hétérosexuelle, en relation avec un partenaire régulier, deux enfants, étudiante, estime ses revenus suffisants	Sabotage contraceptif
P3	40 ans, née au Canada, cisgenre, hétérosexuelle, célibataire avec un ou des partenaires, 2 enfants, prestataire de l'IVAC, estime ses revenus suffisants, antécédents de VPI	Sabotage contraceptif et contrôle de l'issue d'une grossesse
P4	29 ans, né.e au Canada (un parent né à l'extérieur), non-binaire et pansexuel.le, en relation avec un.e partenaire régulier.e, sans enfant, en emploi, estime ses revenus suffisants, antécédents de VPI	Sabotage contraceptif
P5	32 ans, née au Canada, cisgenre, hétérosexuelle, célibataire sans partenaire, un enfant, en emploi, estime ses revenus suffisants, antécédents de VPI	Sabotage contraceptif
P6	24 ans, née au Canada, cisgenre, bisexuelle, célibataire avec un ou des partenaires, sans enfant, étudiante, estime être en situation de pauvreté, antécédents de VPI	Sabotage contraceptif et contrôle de l'issue d'une grossesse
P7	36 ans, née au Canada, cisgenre, hétérosexuelle, en relation avec un partenaire régulier, sans enfant, étudiante, estime ses revenus insuffisants	Sabotage contraceptif, pression pour devenir enceinte et contrôle de l'issue d'une grossesse
P8	40 ans, née au Canada, cisgenre, hétérosexuelle, célibataire sans partenaire, 6 enfants, étudiante et rente d'invalidité, estime être en situation de pauvreté, antécédents de VPI	Sabotage contraceptif, pression pour devenir enceinte et contrôle de l'issue d'une grossesse
P9	22 ans, née au Canada, cisgenre, hétérosexuelle, célibataire avec un ou des partenaires réguliers, sans enfant, étudiante, se considère à l'aise financièrement	Sabotage contraceptif
P10	22 ans, née au Canada, cisgenre, hétérosexuelle, célibataire sans partenaire, sans enfant, étudiante, estime ses revenus suffisants, antécédents de VPI	Sabotage contraceptif
P11	31 ans, née au Canada, cisgenre, hétérosexuelle, en relation avec un partenaire régulier, un enfant, en emploi, se considère à l'aise financièrement, antécédents de VPI	Pression pour devenir enceinte et contrôle de l'issue d'une grossesse
P12	42 ans, née aux États-Unis (immigrante avec visa temporaire au Canada), racisée (noire) et autochtone, cisgenre, hétérosexuelle, en relation avec un partenaire régulier, sans enfant, travailleuse autonome, estime ses revenus insuffisants, antécédents de VPI	Pression pour devenir enceinte
P13	38 ans, née au Canada, cisgenre, bisexuelle et polyamoureuse, célibataire avec un.e ou des partenaires, sans enfant, en emploi, estime ses revenus insuffisants	Sabotage contraceptif et pression pour devenir enceinte

Figure 1: La paradoxalité du processus de la reconnaissance



devenir enceinte : « Lui, au début de la relation, il disait qu'il allait me convaincre d'avoir des enfants » (P13). D'autres reconnaissent les manifestations par lesquelles la CR se présentait : « Il calculait mes périodes d'ovulation et voulait me forcer à avoir des rapports sexuels quand il pensait que j'allais ovuler, et cela a duré cinq ans. » (P12). Finalement, cinq participantes expriment leur reconnaissance de la CR en mettant en exergue qu'elles ne disposent pas d'un contrôle sur leur corps durant la grossesse ou lors d'une relation sexuelle.

Sur le plan des facteurs qui fragilisent la reconnaissance, la majorité des participantes contrastent leur processus de reconnaissance par la difficulté à rendre intelligible l'expérience de CR et à affirmer la responsabilité de l'agresseur. D'abord, deux participantes ont de la difficulté à s'approprier le vocabulaire de la CR : est-ce qu'être une victime de CR dépend de l'intention de l'agresseur à commettre cette coercition ? La participante 6 exprime notamment cette difficulté à reconnaître son expérience comme de la CR, puisque l'objectif de son partenaire n'était pas qu'elle devienne enceinte, mais plutôt qu'il éprouve davantage de plaisir que lors d'une relation sexuelle protégée par un condom. En d'autres mots, les participantes expriment ainsi l'importance d'une perception claire d'intentions malveillantes du partenaire à leur égard pour pouvoir reconnaître leur expérience comme

de la CR. Sinon, elles hésitent à qualifier ces gestes comme de la CR. À cet égard, certaines participantes ont défendu les comportements de leur agresseur en remettant en question les intentions coercitives et violentes de ceux-ci. Par exemple, lors du retrait non consensuel du condom, cinq participantes ont reconnu cette expérience comme un acte inconscient et même folâtre de la part de leur partenaire. À cet effet, la participante 1 qualifie l'agression comme un acte « d'insouciance ». Parmi celles qui ont vécu de la pression pour devenir enceintes, deux participantes ont reconnu la CR comme une marque d'affection : « C'est sûr que c'était coercitif, mais je pense que... je ne sais pas comment dire ça. Au début, c'était assez innocent, c'était assez cute, tu sais » (P6).

Bien que toutes les participantes identifient l'expérience de CR, la moitié verbalise souvent se sentir responsable de la CR lorsque celle-ci s'est manifestée sans coercition physique. Par exemple, la participante 13, qui a vécu un retrait non-consensuel du condom, exprime que « c'est elle qui l'a laissé faire » alors que la participante 1, qui a vécu de la CR durant la grossesse, nomme qu'elle avait « juste à s'en aller avant de tomber enceinte ». D'autres participantes se sentent personnellement responsables de la CR en raison de certains comportements qui seraient favorables à cette forme de violence faite aux femmes, selon leurs dires. Plus précisément,

la « consommation d'alcool » (P6) ou un « rapport désorganisé par rapport à la sexualité » (P5) seraient des facteurs qui amènent les femmes ayant vécu de la CR à se responsabiliser.

Le temps que nécessite ce processus représente également un facteur qui peut fragiliser la reconnaissance des participantes. En effet, les femmes ayant vécu de la CR avec un partenaire ($n = 8$) pour lequel elles éprouvaient des sentiments amoureux avaient davantage tendance à décrire leur reconnaissance comme un processus nécessitant plus de temps et de conscientisation rétrospective.

Ça fait un an et quelques mois... je pense que je suis tout à fait capable d'en parler très bien. Mais, sur le moment... je pense que ça m'a pris un temps pour analyser la situation, pour comprendre ce qui s'était passé, pour me faire une tête. Pis [au moment où l'agression s'est produite], je n'aurais pas voulu en parler (P6).

Se situant parfois à l'intersection de plusieurs autres formes de VPI ($n = 5$), la répétition de la CR dans le temps semblait devenir un élément charnière à la reconnaissance de la CR. Par exemple, la participante 3 rapporte avoir pris conscience de la CR exercée par son partenaire amoureux seulement au moment où une situation similaire de coercition pour mettre fin à sa grossesse s'est reproduite.

En fait, c'est lorsque je suis tombée enceinte de ma fille que j'ai compris que j'avais eu une pression pis qu'il essaie de la répéter. [...] Avant, je n'avais pas pris conscience de ça pis c'est pendant j'étais enceinte de ma fille que je m'en suis aperçue (P3).

Dans cette logique, au-delà de la reconnaissance des manifestations de la CR, des femmes victimes de VPI avaient aussi besoin d'un temps variable selon les expériences contrastées ou similaires vécues pour reconnaître la gravité de ces violences. Les émotions initialement ressenties lors de l'expérience de CR se sont transformées en une reconnaissance plus importante de la gravité de l'expérience de CR subie au fil du temps. À cet effet, la participante 11 exprime qu'au départ, elle s'est sentie malaisée par le sabotage contraceptif exercé par son partenaire, mais à travers le temps, elle a reconnu qu'il y avait un problème « plus profond » que ce qu'elle avait identifié antérieurement. La participante 1 ajoute que la reconnaissance de ses expériences de CR (sabotage contraceptif et coercition durant une grossesse) s'est également précisée à travers le temps.

Finalement, comme le rapporte la participante 12 qui a vécu de la pression pour devenir enceinte, l'âge biologique ou la maturité développementale peut aussi contribuer à limiter la reconnaissance de leur expérience : « Je n'étais pas mature,

j'étais jeune. Je n'avais pas le vocabulaire pour exprimer ce que je ressentais ». Elle ajoute que la temporalité occupe une dimension centrale dans ce processus : « Au début, c'était juste la prise de conscience, devenir consciente de ce qui se passait réellement. Cela m'a pris des années pour être réellement consciente de ce dans quoi j'étais impliquée ». La majorité des participantes ont expliqué que la reconnaissance est un processus qui s'opère en étapes ainsi qu'à travers le temps et l'expérience. À cet égard, l'extrait narratif de la participante 13, qui a vécu de la CR avec des partenaires occasionnels, décrit l'importance de la temporalité pour faciliter le processus de reconnaissance : « Plus j'avancais avec l'âge et avec l'expérience, plus j'étais comme : Fuck off. Pas encore. ».

2. Intersubjectivité : être validée | être confrontée par les autres dans sa reconnaissance de la CR

La majorité des participantes rapporte avoir raconté leur expérience de CR à des personnes significatives dans le but de faire entendre leur récit. Ces dernières étaient aussi sollicitées pour valider la reconnaissance de la CR des femmes concernées. Ce partage relationnel était vécu comme un élément facilitant une reconnaissance de leur expérience singulière de CR : « Je pense que c'est plus ça. Plus une écoute. Une écoute active et... de m'aider à ne pas me voir comme responsable. Je pense que c'était ce qui a été le plus aidant dans le long terme » (P6). L'entourage exerçait donc une influence considérable sur le processus de non-responsabilisation de la victime à l'égard de son expérience de violence. Lorsque les proches reconnaissaient explicitement l'agresseur comme l'unique responsable de la CR, les participantes étaient en mesure de développer une reconnaissance intersubjective de leur vécu.

Moi, de mon côté, je me souviens d'en avoir parlé avec, avec une amie qui me disait : « Non, mais attend là. Tu sais qu'on est au Québec là, tu as quand même la possibilité de pas poursuivre ta grossesse si tu ne le veux pas » (P1).

À l'inverse, certaines participantes ($n = 6$) rapportent avoir été confrontées à l'égard de leur expérience de CR par des personnes significatives. La personne participante 4 exprime avoir été responsabilisé.e par des proches, rendant par le fait même sa reconnaissance de la CR moins compréhensible et justifiée : « le fait... que quand j'en parlais à des personnes, de pas me sentir validé.e faisait que je ne me sentais pas légitime ». D'autres ont partagé avoir été jugées par des proches en ce qui a trait à leurs expériences de CR : « Mais mon coloc, c'était dans son... attitude un peu. Tu sais, il m'a dit : « Ben voyons, pourquoi tu as accepté ça? ». [...] Je le sais que sans le vouloir, il m'a peut-être un petit peu accusée, mais il est comme ça » (P10). Quelques participantes soulignent pour leur part la banalisation de leur

expérience par des personnes significatives : « Ah tu sais, ce n'est pas si grave que ça » (P9) ou « Ah oui, c'est plate, mais... » (P9). Ces expériences intersubjectives ont mené certaines femmes ayant vécu de la CR à choisir avec attention les individus à qui elles allaient raconter leur récit. La participante 6, qui a vécu une expérience de retrait non consensuel du condom, a décidé de ne plus confier son expérience de sabotage contraceptif à des hommes, puisqu'ils auront tendance à « prendre le point de vue de l'autre [homme] ».

3. Socialisation : connecter | minoriser son expérience aux métarécits de la violence faite aux femmes

Plusieurs participantes ($n = 9$) se sont distanciées de leur vécu pour aborder celui des autres femmes victimes de violence, ou encore ont ouvert une réflexion plus large sur les représentations sociales liées à la CR. Pour trois des participantes, les réseaux sociaux ont permis de faire résonner leur expérience de CR avec le contexte socioculturel actuel favorable à la reconnaissance de la violence faite aux femmes. Comme le rapportent ces participantes, les « vagues de dénonciation » (P5) ou le mouvement « post-MeToo » (P2) encouragent un dialogue sociétal autour de la CR, mais aussi plus largement sur la violence faite aux femmes. La participante 2 exprime que la cristallisation de sa reconnaissance comme une victime de CR et de la gravité de cette expérience de retrait non consensuel du condom a été soutenue par des récits médiatisés autour de la CR. Elle fait notamment résonner son expérience avec celle de l'arrestation de Julian Assange, lui-même accusé de sabotage contraceptif et d'agression sexuelle. En effet, Assange a été accusé en 2010 d'avoir eu un rapport sexuel non protégé à l'insu de la plaignante, et ce malgré son souhait préalablement exprimé d'avoir une relation sexuelle protégée. La participante 1 verbalise pour sa part avoir reconnu son expérience de CR à travers les appels au recrutement du présent projet de recherche sur les réseaux sociaux, puisqu'il contribue à crédibiliser son expérience et à lui donner une voix. Finalement, près de la moitié des participantes ont aussi fait résonner leurs expériences de CR, quelle que soit leur forme, avec les théories ou mobilisations féministes. Pour certaines, ces réflexions s'insèrent dans un bagage intergénérationnel féministe alors que pour d'autres, il s'agit de la finalité d'une trajectoire universitaire qui offre une place centrale aux réflexions féministes. Par exemple, la participante 12, une femme noire et native américaine qui a vécu de la pression pour devenir enceinte décrit spécifiquement que son expérience s'insère à l'intersection de multiples oppressions :

J'ai commencé à être plus à l'écoute des problèmes des femmes, des problèmes des personnes racialisées,

parce que quand j'étais jeune, je pensais que si on travaillait dur, tout irait bien, que c'était aussi simple que ça. Mais à mesure que j'ai acquis de l'expérience dans la vie, j'ai appris que ce n'était pas si simple. Il y a beaucoup d'autres facteurs qui entrent en jeu. Et être une femme, être racialisé sont quelques-uns de ces facteurs. La situation socio-économique, vos croyances ou pratiques spirituelles, tout cela s'ajoute à l'image globale. Donc je dirais que finir mon éducation m'aide à mûrir, m'aide à changer mes opinions (P12).

Ce même contexte sociohistorique reconnu précédemment comme favorable à la reconnaissance peut aussi, pour maintes participantes ($n = 8$), contribuer à fragiliser la reconnaissance de leur expérience de CR comme une forme tangible et crédible de violence faite aux femmes. Ces participantes expriment une banalisation de leurs expériences de CR par la force des métarécits de la violence faite aux femmes, et en sont venues à hiérarchiser la gravité des violences faites aux femmes en situant la CR vécue comme une violence moins grave.

Ce n'était pas un gros viol sale. Tu sais, ce n'était pas comme une affaire full traumatisante. Comme quelqu'un qui me battait. C'était comme une light version. C'était quelqu'un avec qui j'avais envie d'avoir du sexe. Quelqu'un avec qui... j'avais des relations. Ce n'était pas quelqu'un que j'haïssais. C'était quelqu'un que je connaissais et que j'appréciais. Et ce n'était pas violent physiquement, genre agressif. C'est comme autre chose, mais ça reste que ... je suis restée avec un sentiment dégueulasse à l'intérieur très longtemps (P13).

La participante 2, qui a vécu un épisode de retrait non consensuel du condom, en vient aussi à minoriser son expérience en la comparant à une forme de CR qu'elle considère comme « plus grave » : « Mais ce n'est pas grand-chose par rapport à d'autres qui ont pu être obligées de... d'amener une grossesse à terme et tout. Mais, cela dit, ça fait aussi partie des petites agressions sexuelles dont les femmes sont victimes toute leur vie ». La personne participante 4 explique notamment le choix des mots qu'elle utilise pour décrire son expérience afin de tenir compte de cette hiérarchisation des violences faites aux femmes : « Avant, je disais : "Ah, j'ai vécu des violences, des abus." Je ne disais jamais : "J'ai vécu des viols." Parce que pour moi, ce n'était jamais assez grave, assez pire, assez comme dans les films. Tu sais, comme certaines personnes qui ont effectivement vécu des choses très horribles ».

Pour trois participantes, bien qu'elles reconnaissent avoir vécu de la CR, elles ne se reconnaissent pas pour autant

comme victime de violence. La hiérarchie de la violence faite aux femmes caractérise leur explication à l'égard du fait qu'elles ne s'approprient pas les référents socioculturels de la « victime » : « Mais c'est parce que j'ai entendu tellement d'histoires de victimes de violences que je trouve que ce que j'ai vécu n'est tellement rien vis-à-vis de ce que d'autres femmes ont pu traverser, tu vois. C'est comme si j'avais du mal à me dire que j'ai été victime, en fait » (P2). Finalement, le contexte sociohistorique actuel contribue aussi à relativiser la responsabilité du partenaire en associant le comportement de l'agresseur à un manque d'éducation sexuelle chez celui-ci (P6) ou encore à une non-responsabilisation sociétale des hommes envers la contraception (P4).

Discussion

Cet article avait pour objectif de mieux comprendre comment la reconnaissance de la CR se déploie sur un continuum où les facteurs qui facilitent et qui fragilisent la reconnaissance des femmes cohabitent. En résumé, nos résultats suggèrent que le processus de reconnaissance est de nature paradoxale, puisque les significations narratives, intersubjectives et sociales produites par les femmes dans un contexte de CR sont dynamiques, interrelées et vivantes. Sur le plan de la narrativité, nos résultats montrent que les femmes sont en mesure, à terme, de reconnaître les différentes formes de CR et ses manifestations, mais ont tendance à se sentir responsables de cette expérience ainsi qu'à attribuer elles-mêmes des intentions déculpabilisantes à leurs partenaires. Depuis les années 2000, nombreuses publications scientifiques ont partagé des résultats similaires en ce sens où les femmes ont de la difficulté à identifier et à étiqueter leur vécu de violence ou de CR comme tel en raison de cette perception selon laquelle l'intention de leur nuire doit être visible pour reconnaître le comportement coercitif, violent ou menaçant.[21,24,32] Or, en contexte de violence, la notion d'intention ne devrait pas être une caractéristique centrale à la conceptualisation de ces comportements, puisque les plus récentes définitions de la violence s'entendent pour inscrire le vécu et les conséquences réelles ou potentielles des personnes victimes au centre de cette conceptualisation.[33,34] À la différence des résultats de Littleton et al.[22] qui révélaient que les femmes ayant subi de la violence sexuelle avaient des soucis à rendre intelligible l'expérience vécue, nos participantes ont toutes été en mesure de décrire les manifestations de la CR qu'elles ont vécues. La temporalité de ce processus de reconnaissance est aussi un facteur important rapporté par les participantes. À l'instar d'autres études réalisées sur le sujet, nos résultats indiquent que la reconnaissance est façonnée temporellement par plusieurs éléments, dont la forme de CR vécue et le type

de relation unissant les partenaires notamment.[21,22] La reconnaissance nécessite donc du temps et une certaine maturité développementale afin de pouvoir identifier l'expérience vécue, sa sévérité et ses conséquences.[20,24,35]

Sur le plan de l'intersubjectivité, nos résultats ont mis de l'avant que le partage de leur expérience auprès de personnes significatives peut faciliter, mais aussi fragiliser la reconnaissance de la CR. À cet égard, pour certaines participantes, ce dévoilement a contribué à une banalisation de l'expérience vécue par leurs proches. Cette fragilisation se distingue des écrits qui portent sur la reconnaissance de la CR et des autres violences sexuelles.[21,22,24,36] En effet, les études antérieures ont révélé que le dévoilement de son expérience de violence sexuelle ou de CR était uniquement associé à une plus grande reconnaissance.[21,22,24,36] À notre connaissance, les risques liés à ce partage n'avaient donc pas été préalablement identifiés dans la littérature.

Sur le plan de la socialisation, nos résultats suggèrent que la reconnaissance peut être facilitée par la résonnance sociale et médiatique des récits de CR. Cependant, selon les participantes, cette collectivisation des expériences de violence participe souvent à une hiérarchisation des formes de violence faite aux femmes. Comme le rapportent de nombreuses chercheuses, puisque les expériences de CR s'arriment rarement aux scripts liés à l'agression sexuelle, les femmes ne reconnaissent pas leur vécu comme une violence : la valorisation de la violence physique par exemple pour quantifier la sévérité de l'événement coercitif est un des nombreux arguments internalisés par les participantes de cette étude pour banaliser leur expérience au regard de celle des autres.[37-39]

En ajout à ce survol des écrits scientifiques qui portent sur la reconnaissance de la CR et des violences sexuelles, nous proposons maintenant de porter une perspective critique sur nos résultats en nous appuyant sur la théorie de la reconnaissance d'Axel Honneth.[40] Pour ce philosophe, la reconnaissance se définit comme une réalisation de soi qui se construit à travers les rapports intersubjectifs de reconnaissance face à l'autre. La théorie de la reconnaissance honnéthienne différencie trois modes de reconnaissance effective : la reconnaissance affective, juridique et sociale. Selon Honneth[40], ces modes différenciés de reconnaissance impliquent aussi leur alter ego négatif qui se manifeste soit par le déni de reconnaissance, soit par la reconnaissance idéologique qui se cantonne uniquement aux enjeux symboliques de la reconnaissance. Dans les lignes qui suivent, nous décrirons donc chacun de ces modes et les appliquerons aux enjeux de la reconnaissance rapportés dans cet article.

En premier lieu, la reconnaissance affective fait référence aux relations intersubjectives et intimes qui contribuent à valider les besoins de l'individu, ou qui à l'inverse, lors d'un déni, peuvent entraîner des situations d'abus et de violence envers ce même individu. Nos résultats de recherche soulèvent l'importance de cette forme primaire de reconnaissance pour les femmes ayant vécu de la CR, et de son caractère essentiellement paradoxal. En effet, considérant qu'Axel Honneth nous encourage à penser en termes dialectiques, force est de constater que les récits des femmes témoignent de cette tension constante. D'un côté, sur le plan intersubjectif, certaines femmes sont en mesure de faire reconnaître leur expérience de CR dans leurs rapports interpersonnels avec l'autre alors qu'à l'inverse, plusieurs expriment plutôt le manque de légitimité et de compréhension de leurs proches envers leur vécu de CR. D'autres partagent même un déni de reconnaissance qui se traduit notamment par une remise en question de la gravité des conséquences subies en contexte de CR, et des motivations de l'agresseur.

En deuxième lieu, la reconnaissance juridique telle que conceptualisée par Honneth[40] traite principalement des enjeux de réciprocité entre les droits et les devoirs ainsi que des grands principes fondamentaux de la vie en société telle la dignité humaine. Quelques-unes de nos participantes ont explicitement souligné l'importance de la reconnaissance juridique dans la construction de leur identité, et dans la valorisation d'un respect de soi. A contrario, d'autres participantes ont plutôt décrit un déni de reconnaissance s'opérant par une dévalorisation de leur autonomie reproductive et une subordination de leur personne au bénéfice du partenaire lors des relations sexuelles.

En troisième et dernier lieu, la reconnaissance sociale se définit comme le contexte dans lequel s'inscrit la solidarité sociale qui permet aux femmes concernées de bonifier leur reconnaissance de la CR et de développer une estime de soi. L'autoréalisation sous-jacente à la reconnaissance sociale est un des éléments centraux de notre analyse du processus de reconnaissance des femmes ayant vécu de la CR. En effet, de multiples participantes ont rapporté l'importance de se connecter aux différents paliers socioculturels de la reconnaissance de la violence faite aux femmes notamment sur les réseaux socionumériques. De cette façon, les femmes arrivent à établir une mutualité dans les relations de reconnaissance qu'elles établissent avec les autres femmes victimes de violence. Le concept matriciel de « paradoxe » contraste par le fait même cette forme positive de reconnaissance : certaines participantes ont plutôt rapporté que les métarécris de la violence faite aux femmes ont contribué à une minorisation, une dévaluation de leur propre expérience de violence en contexte reproductif. Cette (non)reconnaissance

paradoxe expose que les rapports de reconnaissance sont ainsi mis sous tension par les structures sociales du présent, c'est-à-dire par les mécanismes de socialisation qui englobent ce processus.

En somme, ces constats soulèvent différents questionnements à la fois empiriques et philosophiques à l'égard du processus de reconnaissance de la CR : est-il possible que cette dynamique de la reconnaissance conceptualisée comme paradoxale se produise en raison d'un manque de ressources herméneutiques, ce qui limite la capacité des femmes victimes à comprendre elles-mêmes leur propre expérience de CR et à y donner un sens ?[41] Dans cette perspective, il y a lieu de questionner si la reconnaissance telle que décrite par les femmes s'imbrique davantage dans la reconnaissance dite idéologique de Honneth : est-ce que la reconnaissance de la CR par les femmes elles-mêmes facilite réellement la mise en place de conditions matérielles afin de les soutenir ou il s'agit plutôt d'une reconnaissance essentiellement symbolique? Associée à la reconnaissance honnethienne se trouve aussi la revendication. Or, c'est un aspect peu présent dans le propos des femmes rencontrées. Elles ne demandent pas justice ou réparation des torts causés, du moins pas dans ces termes. Est-ce que cette notion de revendication d'Honneth [40] pourrait être liée à la collectivisation des expériences ? Comme la CR est peu connue et demeure taboue parce que souvent située dans la sphère de l'intimité sexuelle, elle est probablement moins collectivisée que d'autres expériences. Dans cette logique, il sera donc assurément pertinent de poursuivre la construction d'un corpus de connaissances qui s'intéresse aux scripts de la reconnaissance, et par le fait de la revendication dans un contexte de CR.

Limites

Malgré l'importance de cette recherche novatrice visant à combler de nombreux « vides » de connaissances à l'égard de la CR, certaines limites inhérentes à cette étude doivent être mises en exergue. D'abord, l'un des critères d'inclusion de cette étude était d'avoir vécu de la CR. En ce sens, il est donc possible d'affirmer que toutes les participantes rencontrées avaient préalablement reconnu leur expérience de CR. Qu'en est-il pour les femmes qui en ont vécu, mais qui n'ont pas reconnu leur expérience comme telle ? Quels sont les enjeux liés à cette non-reconnaissance? Les prochaines études qui auraient pour objectif d'étudier la reconnaissance de la CR devraient aussi tenter de rencontrer des femmes à risque d'avoir vécu de la CR, mais qui ne reconnaissent pas encore avoir vécu de telles expériences. De surcroit, considérant que des recherches étatsuniennes démontrent que la CR touche de manière disproportionnée les femmes associées à la diversité

sexuelle et la pluralité des genres [13] ainsi que les femmes latinas, noires et autochtones [9,12], il serait décidément intéressant de cerner les particularités propres à leur processus de reconnaissance. Dans notre petit échantillon de 13 femmes, seulement une femme s'était désignée comme native américaine et trois femmes ont déclaré des identités liées à la diversité sexuelle et la pluralité des genres. Malheureusement, nous n'avons pas réussi à établir de constats spécifiques à leur réalité malgré le besoin criant dénoté dans les écrits recensés. Enfin, il serait nécessaire de poursuivre plus largement le travail exploratoire du phénomène global de la CR, notamment en tenant de mieux comprendre l'expérience et la reconnaissance des femmes qui ont vécu de la CR auprès de professionnel.les de la santé par exemple.[7]

Conclusion

En somme, se situant aux croisements des violences sexuelles et de la VPI, la CR qui inclut tous les comportements visant à réduire l'autonomie reproductive des femmes est un enjeu de santé publique significatif et concerne donc directement la pratique des professionnel.les de la santé. En ce sens, à la lumière de cette étude, il importe de promouvoir les pratiques de repérage en matière de CR, puisqu'elles sont essentielles au sein des services de santé sexuelle et reproductive. Ce repérage s'avère primordial même pour les usagères qui ne s'identifient actuellement pas comme vivant ou ayant vécu de la CR, car la reconnaissance de cette violence est souvent un processus dynamique et longitudinal qui exige un certain temps. Comme le montrent nos résultats, les conversations à ce sujet initiées par des personnes bienveillantes peuvent encourager les femmes à reconnaître leur expérience de CR et à comprendre comment cette violence contribue à restreindre leur autonomie reproductive ainsi qu'à affecter leur santé et leur bien-être. Les professionnel.les de la santé occupent également une position privilégiée pour déboulonner les mythes entourant l'agression sexuelle et promouvoir une reconnaissance sociale des violences qui sont banalisées, voire invisibilisées, par certains. À cet égard, une sensibilisation à large échelle sur cette forme de violence serait aussi importante, considérant la méconnaissance et les préjugés entretenus par les membres de l'entourage des victimes, de même que par les femmes victimes elles-mêmes.

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