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Éditorial/Editorial

L'association canadienne des infirmières et infirmiers en sidologie (CANAC/ACIIS) est un organisme national ayant pour mission de promouvoir le développement des soins infirmiers dans le domaine du VIH/sida. À cet égard elle a aussi comme mandat de prendre position face aux enjeux qui concernent la santé, les droits et la dignité des personnes vivant avec le VIH/sida. En mars dernier, plus de 170 délégués étaient présents à Montréal pour prendre part à la 19ème conférence annuelle de cette association qui visait à rassembler les professionnels de la santé, les intervenants communautaires ainsi que les chercheurs, autour du thème suivant : Prévention, dépistage, traitement du VIH : droits et inégalités. Cet évènement avait donc pour but de mobiliser ces divers acteurs et de les encourager à réfléchir collectivement à la question des droits et des inégalités en lien avec la prévention, le dépistage et le traitement du VIH. Par conséquent, il fallait appréhender cette question en considérant la prévention, le dépistage et le traitement du VIH comme des pistes d'action où de graves inégalités persistent – ces inégalités ont un impact significatif sur la santé des populations avec lesquelles les infirmières et les infirmiers travaillent sur une base quotidienne.

Tout au long de la conférence, la question des droits et des inégalités était au cœur des séances plénières et des exposés oraux alors que diverses problématiques au regard de la santé, des droits et de la dignité des personnes vivant avec le VIH/sida étaient exposées, puis débattues. Ces problématiques complexes s'articulaient suivant les axes suivants : criminalisation des personnes vivant avec le VIH/sida; survie des programmes de réduction des méfaits dans un contexte politique hostile; mise en place de politiques en matière de dépistage obligatoire et répercussions sur les nouveaux immigrants; parcours difficile, voire hasardeux, des demandeurs (séropositifs) d'asile au Canada; manques à gagner pour répondre aux besoins des populations dites « marginalisées » en ce qui a trait à la prévention, au dépistage et au traitement du VIH; vulnérabilité de certains groupes qui, années après années, sont affectés de façon disproportionnée par le VIH; impacts de la stigmatisation et de la discrimination sur le quotidien des personnes vivant avec le VIH/sida; défis auxquels doivent faire face les personnes vivant avec le VIH/sida dans certaines communautés (ex : communautés rurales, populations incarcérées).

Le thème de cette conférence faisait appel au mandat social de la profession infirmière et, plus particulièrement, au fait que les infirmières et les infirmiers doivent se tenir au courant des aspects relatifs aux principe de justice sociale touchant la santé et le bien-être des personnes et des populations. En tant que présidente de la conférence, je suis d'avis que le contenu de cette conférence mettait en lumière des enjeux spécifiques au domaine du VIH et s'attardait à des problématiques qui ne peuvent être ignorées dans le contexte actuel. Dans un effort collectif, il nous faut réfléchir et agir pour préserver et, dans bien des cas, instaurer un environnement où il est possible de prévenir, de dépister et de traiter dans le respect des droits tout en continuant d'exiger une plus grande équité au sein même des systèmes et des structures sociales. Qu'on se le tienne pour dit, cet effort collectif est non seulement une activité fondamentale mais une obligation professionnelle qui s'impose aux infirmières et aux infirmiers étant donné leur connaissance des enjeux actuels en matière de VIH/sida et leurs rapports avec des populations victimes de pratiques qui ne respectent pas les principes de justice sociale.

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Abstract
Legal obligations for reporting child abuse and neglect have positioned suspicion as a trigger for nursing responses. Suspicion dwells between emotion and thought, and is fraught with uncertainty. Given the importance of suspicion to initiating child protection, suspicion requires critical examination. Spinoza's ideas of the imagination, and his distinctive inclusion of emotions in understanding human knowledge, provide a framework to explore the human experience of suspicion. These theoretical dimensions of suspicion are illustrated using a recent newspaper article of a missing child in Sydney, Australia. This process reveals the ontological vulnerability of the human mind to construct knowledge that is heavily influenced by our emotionality, our close social connections and our social values. Attending to these vulnerabilities generates new possibilities for understanding and using human suspicions of child abuse and neglect more effectively and creatively in nursing practice.

Key Words child abuse and neglect, mandatory reporting, nursing practice, Spinoza, suspicion

Battling the Passions: The Birth of a Conceptual Understanding of Suspicion for Child Abuse and Neglect

ROCHELLE EINBODEN, TRUDY RUDGE & COLLEEN VARCOE

Introduction

> Suspicions amongst thoughts, are like bats amongst birds, they ever fly by twilight. …There is nothing makes a man suspect much, more than to know little; and therefore men should remedy suspicion, by procuring to know more, and not to keep their suspicions in smother. Francis Bacon[1 p158]

Suspicion is a common human experience, "a feeling or thought that something is possible, likely, or true."[2] Suspicion transverses the borderlands between emotions and rationality, and oscillates between knowledge and uncertainty. In his paper *Of Suspicion*, Francis Bacon[1] highlights the mysterious quality of suspicious thought, and suggests with dark overtures that it demands timely remedy.

As human agents, nurses experience suspicion within and outside of their practice. While relevant in many contexts, child abuse and neglect provides a particularly rich example to illustrate the complexity of suspicion and its implications. In several countries, legal obligations for reporting child abuse and neglect have set suspicion as a trigger for a cascade of responses to concerns about child safety. In this context, suspicion is usually constructed as simply present or absent, while health care providers struggle with a more illusive experience, and with the implications of reporting concerns to authorities.[3-5] Despite this, and the fact that an 'index of suspicion' seems integral to health care practice, there are surprisingly few theoretical discussions of suspicion in relation to child abuse.[4] In light of the role suspicion occupies in addressing the prevalence of a social problem as significant as child abuse and neglect, a conceptual understanding of the human experience of suspicion is warranted.[6]

In this paper, suspicion as it is discussed in key philosophical writings is introduced, and an analysis of the nature of suspicion is proposed by applying relevant theoretical dimensions of Spinoza's philosophy to how suspicion is represented within a recent column about a missing child. While Spinoza's perspectives remain on the margins of philosophical thought, a resurgence of contemporary support emphasises his ability to offer a departure from dominant ways of understanding the human condition and our social and political worlds.[7-10] Moving beyond familiar considerations of complex social issues, Spinoza "offers a refreshing perspective on traditional impasses concerning freedom and determinism, the mind and the body, and society and nature."[7 p593] Thus, Spinoza is useful for thinking through suspicion in the context of child abuse and neglect.

Spinoza's distinct conceptualisations of knowledge include human emotion and assert there are predictable flows or patterns to common emotive experiences.[11] He suggests while true ideas are not easily accessible to humans, wisps of truth can be revealed through reflection and reasoning on our nature and the patterns of our passions.[9,12] Of particular use for understanding suspicion are: Spinoza's epistemological concept of imagination (the most common type of knowledge that involves initial sense perception and interpretation); the three basic emotions (joy, pain, and desire); and the influences of these emotions on imagination. These ideas will be described and then illustrated using an analysis of a recent newspaper opinion column about a missing child.[13] An excerpt of this column will be presented initially, followed by philosophical ideas of suspicion, and finally, these ideas will be used as a framework for the analysis of how suspicion is presented in the opinion column. Through this discussion and analysis, suspicion will be pulled from an existence in the shadows towards a conceptual understanding, offering a new perspective on some of the challenges nurses face in relation to suspicion in the context of child abuse and neglect.

Suspicion illustrated: the case of missing Kiesha

Six-year old Kiesha Abrahams was reported missing from her home in suburb of Sydney, Australia, by her mother on August 1, 2010 at 10:00 am. The front door was ajar, with no evidence of forced entry. Kiesha was last seen when put to bed the night before at 9:30 pm. She had been absent from school and unseen by anyone outside her immediate family since the birth of her brother, three weeks earlier. Suspicions stormed though the imaginations of community; within days the family pleaded for the 'trial by media' to be called off and to be left alone. The following excerpt is from an opinion column in the Sydney Morning Herald written by Miranda Devine, on August 12, 2010:

> ***Kiesha's shrine reminds us why her name must be remembered***
>
> *…Outside a dismal, liver-coloured block of flats on busy Woodstock Avenue kind-hearted locals were gathering with their children, as they have done every day just after dusk, to light candles and lay toys at an impromptu shrine for missing six-year-old Kiesha Abrahams.*
>
> *In the 11 days since her reported disappearance, the shrine has spread the entire length of the fence outside the unit block where she spent her last mystery-shrouded days. By Monday there were more than 500 teddy bears, dinosaurs, dolls and assorted stuffed animals, a hundred candle holders, a set of rosary beads, a cross, and a dozen handwritten notes, many with cut-out newspaper photos of Kiesha with her now familiar clenched smile and brown ringlets.*
>
> *Such a heartfelt outpouring of concern is the other side of this forgotten area of Sydney, where social problems are epidemic and social services fail at every step. …They are the addresses most likely to crop up in news stories about damaged children.*
>
> *…Left to their own devices, the locals have forged a strong sense of community and purpose. Drawn to Woodstock Avenue by pictures of Kiesha in the media, they talk non-stop about a little girl they never knew as police work inside the first-floor unit, carrying carpet and doors out to forensic vans.*
>
> *…"It just amazes me how much people care," says Rhonda Hines, 47, a mother of six. "I'm so proud I live in Mount Druitt. People run it down but when something like this happens we all pull together."*
>
> *…"I feel so sad for the little child. It's not right," said Reno Scevola, 43, who has strong theories about what has happened to Kiesha, which are, of course, unprintable. Almost everyone has solved the case in their minds, and they discuss their theories endlessly, analysing the body language of Kiesha's mother, Kristi Abrahams, and stepfather, Robert Smith, on TV last week. Since telling police she woke up on August 1 to find Kiesha missing and fronting up to a media conference three days later in dark glasses and barely able to speak, she has scarcely been seen. The young mother and her family…have been staying in various motels. They returned briefly to pick up some clothes but missed a poignant ceremony in the park next door on Sunday, when about 200 people gathered to release balloons to guide Kiesha home.*
>
> *...At dusk whole families arrive. Cathy Stone, 38, brings a box of tea lights and kneels carefully to light them. "When you've got kids you just feel compelled to come here," says Stone… "Isn't it a wonderful thought that so many people care? There's not a person here that wouldn't have taken that little girl*

> *home and looked after her…It's nice to think you are lighting the candles to show her the way home, but I think she's probably not coming back."*
>
> *The public grief of the people who lived around Kiesha in her six short years may seem curious to outsiders, but it is this community concern that is the most important protection for children in dysfunctional environments. It is rooted in instinctive notions of right and wrong, which are often clearer to those at the bottom of the heap. They might have jumbled families of their own, but they know where the ice addicts live, and they know in which families children are safe and in which they aren't. When government bureaucracies and the rest of Sydney let them down, they have each other.[13]*

The case of Kiesha and this particular opinion column provide a useful contemporary context to consider suspicion. An analysis will follow the discussion of suspicion, and in particular, the application of Spinoza's ideas will illustrate how suspicion is fuelled by the materiality of imagination, emotion, and connections with the collective.

Philosophical foundations of suspicion

When Descartes cautioned that all is not as it seems, he influenced philosophy and scrutinised doubt with the development of the 'scientific method'.[14] Theologians demonstrate an interest in suspicion and in some instances, have positioned it in opposition to faith.[14,15] Ricoeur's essay, *Freud and Philosophy*, is an important work for suspicion conceptually, because it tracks its evolution in philosophical thought, develops ideas specific to the 'hermeneutics of suspicion' and identifies three masters of suspicion (Marx, Nietzsche and Freud). Ricoeur contrasts two interpretations of suspicion: a traditional one involving "recollecting meanings"[14 p32]; and a radical one, that aims at "reducing illusions and lies of consciousness".[14 p32] Highlighted between these two versions is a fundamental irreconcilability regarding the nature of truth.[16] Of particular interest to a contemporary conceptualisation of suspicion is the latter version, which is associated with the ideas of Marx, Nietzsche and Freud. Ricoeur draws theoretical connections between the three, identifying that they "seemingly dominate the school of suspicion…the intention that they had in common…[was] the decision to look upon the whole of consciousness primarily as "false" consciousness".[14 p32-3] Ricoeur asserts that this marks a threshold for a shift in philosophical thought and considers Nietzsche the most influential. According to Ricoeur,

> the whole of philosophy becomes interpretation. …It is no longer the Kantian question of how a subjective representation or idea can have objective validity; this question, central to a critical philosophy, gives way to a more radical one. …which is no longer either error in the epistemological sense or lying in the moral sense, but illusion. …[and] this use of interpretation as a tactic of suspicion and as a battle against masks; this use calls for a very specific philosophy which subordinates the entire problem of truth and error to the expression of the will to power.[14 p25-6]

Ricoeur weaves together these three 'masters', and hints at Spinoza's influence, but does not examine Spinoza's ideas closely. He does however, make reference to Spinoza shaking the foundations of interpretations of scripture with an alternative interpretation of nature, and suggests that the teachings of Spinoza's Ethics are relevant to understanding Freud's libido, Nietzsche's will to power, and Marx's imperialism of the dominant class. The assertion that Spinoza was Nietzsche's sole predecessor is shared by Deleuze and Nietzsche himself.[10,14] However, it is Spinoza's philosophy that provides the foundational ideas to conceptually understand the nature of suspicion within rationalist tradition, that is, it offers the ability to gain knowledge though the process of reasoning.

Spinoza and suspicion

Existing somewhere between emotion and thought, suspicion might be difficult to discuss within theories which explore rationality in opposition with, or as separate from, emotion. Rather than discounting emotions as irrational or in opposition to reason, Spinoza asserts that emotions may give rational insights into the human condition.[11,12] Suspicion can be illuminated within what Spinoza describes as the 'primary' way of knowing; imagination. According to Spinoza, there are three types of coexisting knowledge: imagination, rational thought, and intuition. Imagination is the most common human knowledge but also the most confused type and gives rise to 'inadequate' ideas or 'falsity'. This can be explained by Spinoza's ontological conceptualisations, specifically "the materiality of the imagination; its connections with collectives and hence with sociability; and its relations with emotion".[12 p12]

Spinoza asserts that all things are one substance, an indivisible entity, which he describes as 'Nature', or 'God'.[11] To Spinoza, Nature/God is essentially all that is; "there is, therefore, no substance other than God…this means that it is wrong to suppose, as theists do, that corporeal substance was created by a God who is fundamentally different from it".[17 p56] Instead of human bodies being distinct entities created by Nature/God, Spinoza demonstrates how we are singular finite expressions of Nature/God, or modes, of one infinite substance. Thus, singular human bodies are parts of the greater collective human body (just as they too are composed of parts). The essence of this one substance is its infinite attributes, expressed in an infinite number of finite thoughts, and an indefinite number of finite bodies; with human beings but one finite way Nature/God expresses itself in both thought and extension.[18] It follows that Nature/God has and is every thought and every body.[18]

The human mind is, for Spinoza, an idea of the body.[11] Therefore, by its very nature, it is inevitable that the human mind would narrowly focus only on the affections of its singular body.[12] This frame of reference for the human mind is significant in understanding imagination. Deleuze explores imagination by describing 'signs', or "the trace of one body upon another, the state of a body insofar as it suffers the action of another body".[9 p22] According to Deleuze (following Spinoza) signs are always effects, interpreted by states of the body in reacting to an engagement with surrounding bodies. A sign can have multiple meanings, and creates an affect that the body perceives (affection) as experiences of either physical strengthening or weakening.[9] The mind perceives affections as images of its affected body and the other bodies that affect it.[11,12] The imagination, with its confused images and signs, is influenced by the interpretations of the mind embedded in how its body is affected at a certain point in time. This influence is experienced by the body as either strengthening or weakening, and hence aligns positively or negatively to the affect (sign); pleasure as expressions of joy, pain as expressions of sadness. It is of key importance to recognise the symbolic nature of signs and images. They do not directly correspond to objects and they cannot be understood causally or concretely.[9] Instead, signs refer to other signs, and thus "have as their referent confused mixtures of bodies and obscure variations of power, following an order which is that of Chance or the fortuitous encounter between bodies".[9 p23-4] Following this, signs and knowledge of the imagination might be better understood optically,

> effects or signs are shadows that play on the surface of bodies…always on the border. …In Spinoza, everything is light, and the Dark is only a shadow, an effect of light, a limit of light on the bodies that reflect it (affection) or absorb it (affect). The variations of power …constitute degrees of chiaroscuro, the augmentation of power being a brightening, the diminution of power, a darkening.[9 p24]

These shadows are passively received imprints, and are how we are aware of our own body and other bodies, essentially, how we know we both exist, and exist as part of a greater collective, and of all infinite substance. Hence, we exist in a social state as embodied interaction between light and dark, power and powerlessness; our sociability embodied and experienced through the signs and images of imagination.

The imagination understands the world through shadows and gives rise to inadequate knowledge, or confused, false ideas.[11] Despite this, "Spinoza's version of imagination involves an equally strong emphasis on the reality of the mental. …The figments of the imagination are just as real – just as appropriate as objects of systematic investigation – as the modifications of matter".[12 p12] Thus despite their falsity, imagined ideas are experienced as no less real than true ideas. Thoughts that arise from being affected by the collective create "a multiplicity which both enriches the possibilities of human knowing and creates an unavoidable confusion at its very core".[12 p13]

If Spinoza's lens of imagination is applied to suspicion we have the opportunity to better understand it, and as suggested in the Ethics, continue toward truth. While confused, signs, as they occur in the context of knowledge in or through shadows and images, can lead us to rational knowledge (the second type of knowledge).[9] Spinoza explains,

> Real doubt is never produced in the mind by the thing doubted of. In other words, if there were only one idea in the mind, whether that idea were true or false, there would be no doubt or certainty present, only a certain sensation. For an idea is in itself nothing else than a certain sensation. But doubt will arise through another idea, not clear and distinct enough for us to be able to draw any certain conclusions with regard to the matter under consideration; that is, the idea which causes us to doubt is not clear and distinct. To take an example. Supposing that a man has never reflected, taught by experience or by any other means, that our senses sometimes deceive us, he will never doubt whether the sun be greater or less than it appears. Thus rustics are generally astonished when they hear that the sun is much larger than the earth. But from reflection on the deceitfulness of the senses doubt arises, and if, after doubting, we acquire a true knowledge of the senses, and how things at a distance are represented through their instrumentality, doubt is again removed.[19 p17-8]

Here, Spinoza addresses the sensation of doubt, describing how it arises with one idea in reference to another unclear idea. He demonstrates concerns with sense perceptions and how our senses deceive us by providing the analogy of the sun; for example, if we did not know the sun is bigger than the earth our senses would convince us otherwise, and that would be the only idea, nothing in question. However, if we learn that the sun is very far from earth and thus only appears smaller, we also correlate the idea of the sun with the ideas of limitations of our sense perception, and together doubt would disappear and we would actively reason truth about both the nature of the sun, and the nature of our senses. This process of reasoning (of which the human mind is capable) moves us into the second kind of knowledge described as common notions. Deleuze uses the analogy of light to explain the difference between our minds' rational abilities or the power of reason to bring about true ideas compared with the confused ideas of imagination,

> common notions are concepts of objects, and objects are causes. Light is no longer reflected or absorbed by bodies that produce shadows; it makes bodies transparent by revealing their intimate "structure" (fabrica). This second aspect of light, and the intellect is the true apprehension of the structures of the body, whereas the imagination merely grasped the shadow of one body upon another.[9 p24]

Emotions and the production of images

Spinoza describes three basic emotions desire, joy and pain, from which all other emotions are derived. For Spinoza, human vulnerability to doubt is rooted in challenges with sense perception and imagination, and in our materiality as part of a collective. As part of a collective body, we are deeply affected by emotions and affections of other human beings, however our knowledge of these affections is indistinct. Due to the singularity of our minds, we consciously experience affections from our social connections as confused with our own. Gatens and Lloyd explain:

> The body, of which the mind is an idea, is not insulated from the rest of nature; it is not a self-contained whole within the totality of the material world. In being aware of its body the mind is aware not just of one material thing but other bodies impinging on that body. …This experience of other bodies together with our own is the basis of imagination. But it is also the basis of Spinoza's account of the emotions or 'affects'. Where those bodies are like our own – human bodies which undergo similar modifications – this experience of other bodies can intensify our awareness of our own desires, joys and pains. Already, Spinoza's treatment of minds and bodies evokes a basic sociability which is inseparable from the understanding of human individuality.[12 p14]

Conceptualised as part of a collective, humans have common experience of 'passions' or emotions, but unique expressions of our singularity can be seen in the variations between conditions that trigger a response of joy or pain. These variations are related to the associations we develop within the context of our individual experience, not to unique affections; part of being human is to experience joy, pain and desire and these emotions have some predictable order.[12] The social aspects of existence influence humans in an embodied way, to which our minds are not immediately privy. However, at the same time we experience affects of the collective, which lead to more confusion. This creates 'order' of its own, allowing a rational investigation of the passions. Our unique experiences and expressions of emotions explain the fundamental difficulty with articulating common understandings of suspicion. Similarly shrouded by the collective, suspicion is influenced by affections of other bodies, which "intensify our awareness of our own desires, joys and pains".[12 p14] At the same time, like doubt, suspicion is evoked in relation to unclear ideas and affections, experienced and expressed by singular individuals uniquely. These unique experiences of common affections also illuminate our ongoing challenges to understand each other; as singular beings we learn that our emotional experiences differ from others in both range and intensity, even in seemingly similar situations.

All finite modes of substance seek to persevere in being, and move toward increasing power. Spinoza terms this tendency 'conatus'. The influence of passions confuses our ability to choose from the many of those ideas and bodies that actually increase our strength and power (experiences of joy or pleasure). Spinoza describes this, "if we imagine a thing which is accustomed to affect us with the emotion of pain to have something which is similar to another thing, which is accustomed to affect us with an equally great emotion of pleasure, we shall simultaneously love and hate the same thing".[11 p177] He explains how doubt is related to our connection with diverse bodies, and how the same object may elicit even contrary emotions in a singular body, identifying our lack of ability to sustain separation and the increase of ambivalence. Doubt weighs heavily, and in the context of time, fuels both hope and fear,

> hope is simply an inconstant pleasure which has arisen from the image of a thing that is future or past, about whose outcome we are in doubt. Fear, on the contrary, is an inconstant pain, which has also arisen from the image of a thing that is doubtful. If doubt is removed from these emotions, then hope becomes confidence and fear becomes despair: namely, pleasure or pain which has arisen from the image of a thing which we have feared or hoped.[11 p179]

Suspicion in synonymy with doubt works in a similar way, arising from unclear ideas, influencing joy, pain and desire, transforming them into variations of affection.

For Spinoza, desire is a passion which should be understood as productive instead of constructed in the context of lack.[10] Understanding desire as producing value and importance, rather than occurring in only the absence of an object is an important distinction, one which follows in the writings of

Nietzsche, Deleuze and Foucault.[10,20] In contrast, Freud and Lacan consider desire as lack, involving emotions such as envy.[10,21] Schrift discusses Nietzsche's position on the implications of desire in relation to knowledge, "One gets the sort of knowledge one "needs", and what one "needs" is conditioned by what one "wants", one's *interests*."[10 p178] There is "no object of desire without a desiring consciousness to constitute the object as *desirable*. But contrary to the view of desire-as-lack, the experience of desire is not derivative upon the object; rather, it precedes and "produces" the object desired".[10 p182] Instead of disinterested, dispassionate objectivity, Nietzsche follows Spinoza's assertions that objectivity and true knowledge arise from the ability to consider one's own interests, preferences and aversions while engaging openly with other perspectives, interpretations and affections.[10] This openness acknowledges one's own preferences as central to knowing, and self-awareness exposes and diminishes their illusive power, allowing for rational pursuit of true ideas. Thus, the effects of passions on the "logic of the imagination…yield systematic variations of intensity of attachment an aversion…fluctuations which are different from reason/logic…but have an order of their own which can be investigated".[12 p26] Spinoza's theory supports the possibility of revealing the structure of suspicion through a careful conceptual analysis, which attends to the symbolic nature of images or signs and the effects of passions within our social context.

Suspicion: conceptual beginnings

Remembering Francis Bacon's warning, "nothing makes a man suspect much, more than to know little",[1 p158] suspicion exists in the context of a privation of knowledge. Spinoza agrees: "Someone who has a true idea knows at the same time that he has a true idea, and cannot doubt about the truth of the matter".[11 p150] Like doubt, suspicion is a feeling or thought that arises in relation to another unclear idea or sensation in the body, and is correlated with a lack of knowledge. Spinoza confirms, "Falsity consists in the privation of knowledge in which inadequate, i.e. mutilated and confused, ideas involve".[11 p143] However, he postulates that it is not absolute lack of knowledge (ignorance of both mind and body); rather it is that the mind is deceived by shadows of the imagination. Spinoza exposes individual human autonomy to be a common deception of the human mind, existing only within imagination.

> Men are deceived in that they think themselves free, and opinion which consists simply in the fact that they are conscious of their actions and ignorant of the causes by which those actions are determined. This, therefore, is their idea of liberty: that they know no cause of their actions. For when they assert that human actions depend on the will, these are just words, of which they have no idea. They are all ignorant of what the will is and how it moves the body, and those who boast otherwise and invent dwelling-places and habitations for the soul tend to evoke laughter or disgust. So also, when we see the sun, we imagine it to be about two hundred feet distant from us; an error which consists, not in this imagination alone, but in the fact that whilst we imagine the sun in this way we are ignorant of its true distance *and of the cause of this imagination*. For even after we get to know that the sun is distant from us by over six hundred diameters of the earth we shall still imagine it to be close at hand. For we imagine the sun to be so close, not because we are ignorant of its true distance, but because of an affection of our body involves the essence of the sun in so far as the body is affected by the sun.[11 p144, italics added]

For humans to continue to battle the deceptions of our imagination is to tackle suspicion at its core. However, even true ideas cannot dispel the image from the mind; we will still for example, see the sun in the same way. This can be understood within our corporeal realities,

> This tenacity of the image in no way suggests a flaw in human nature; it is just the mind's confrontation with the body – the nature of the mind as idea of body. An image understood, nonetheless, has a different place in the life of the mind from that of an image whose causes are not understood. The mind which understands the causes of its awareness of action and appetite, is …a very different mind from one which has the awareness of action and appetite without that understanding. The lives of the wise are very different from the lives of the ignorant, although both are subject to the same necessities.[12 p37]

Of central importance is the understanding that suspicion flits amongst tenacious shadowy images and signs as an effect. Common understandings settle this. When we do not think about how our senses are routinely illusionary, imagination gets pushed to the back of our minds, but when disrupted, illusion erupts doubt and shadow everywhere. Suspicion cannot offer truth, only affected and confused ideas that persist despite awareness of these limitations.

Suspicion illustrated

The opinion column presented at the outset of this paper follows an eleven-day media saturation of Kiesha's disappearance. The columnist applauds the community's activities and inundates readers with both images garnered from aspects of Kiesha's case which are described in detail, as well as those which are conspicuously missing. Following Spinoza, each person reacts to information about a missing child uniquely depending on personal histories and experiences. However, there are common and patterned reactions as well. Common reactions are related to the necessity of each human mind to develop knowledge primarily through images and the mind's vulnerability to the influence of our emotions and those of others. Passions infiltrate our thinking and stir up confused images, which in turn are intensified by the multiplicity of expressions of the collective; in this case, passions are fuelled by practices of mass media. Ideas and images of a missing child rupture the perception of safety and evoke intense emotions in individuals and in the community. This rupture provokes a struggle of interpretation within the human mind, as images imprint unpleasant feelings, shadow, and a diminution of power. Uncertainty allows suspicions to smoulder and give way to fear. As we strive to persevere in our own being (conatus), we are compelled to remove what causes us pain, and our desires are active and effective in this process. The central desire for a safe and familiar social environment is thwarted by the mystery of Kiesha's disappearance. Uncertainty allows imagination of too many possible threats to control, and incites an overwhelming desire to 'know'. The community and the media use suspicion as a means of organising images and ideas (emphasising some ideas and avoiding others) in a way that produces what is desired; a perception of safety for the collective.

This activity includes differentiating Kiesha's family (and especially her mother) from the community and then constructing them as responsible. The article skids slanderously towards explicit accusations by describing Kiesha's mother as "*scarcely… seen*" since "*fronting up to a media conference in dark glasses and barely able to speak*"; and indicating how "*almost everyone has solved the case in their minds*".[13] Blaming the family for Kiesha's disappearance is an available option as the family already occupies a marginalised social position. The low socioeconomic status of the family is established through descriptions of the "*dismal*" and "*forgotten*" neighbourhood.[13] Kiesha's family members are portrayed as vagrants for "*staying in various motels*", despite the police having completely undone their home (ripping out carpets and unhinging doors) for forensic investigation.[13] While Kiesha is constructed as innocent and vulnerable, her mother is portrayed as fully responsible for the failure to protect her, suggesting child safety can and should be managed by mothers. Establishing the inadequacy of Kiesha's mother functions to display and contain the tragedy to an individual failure instead of a community threat.

Erosion of Kiesha's mother's worth and moral character improves the believability and effect of these images; a task Devine accomplishes. Kristi Abrahams is described as young, unmarried, and living with a man who is not Kiesha's biological father, inferring she has had several partners. Devine mentions that Kiesha's family is known to the Department of Child Services, but there is no mention that another child of Kristi's has previously died, nor is there mention that Kristi identifies as an Aboriginal person; these aspects of the story sit as commonly known background from other news reports.[22] Kristi's actions are placed like shadows in a sequence to develop certainties where there are none. The article reports her, "*barely able to speak*",[13] without contextualising this within the fact that she delivered another baby a few weeks ago. Her abject openness and vulnerability is met with intolerance as she spills raw unbounded inarticulate emotion.[23] Kristi's inability to keep herself together to address the media is offered as evidence of her guilt. Kristi's vulnerabilities and marginalisation are concealed and her ability to keep her children safe is assumed, even within a society that positions her with little relative power.

The community members "… *discuss their theories endlessly, analysing the body language of Kiesha's mother, Kristi Abrahams, and stepfather, Robert Smith, on TV*".[13] Ideas "not clear and distinct enough for us to be able to draw any certain conclusions with regard to the matter under consideration",[19] have led to "*unprintable*" suspicions implicating the family. Suspicions offer a tempting alternate to displace images of fear with family guilt. These ideas are imagined as knowledge; "*almost everyone has solved the case in their minds*"; and "*they know where the ice addicts live, and they know in which families children are safe and in which they aren't*".[13] From Spinoza's perspective it is both natural and necessary for the human mind to imagine knowledge of what happened to Kiesha in a way that follows a desire to decrease distress. In this case, this process is so strong that the community (and the columnist) ventures to claim that they knew all along that Kiesha was not safe and they know what happened to her, despite the lack of evidence from extensive police investigation (even months later).

Safety for the collective is also produced through reconstructing perceptions of the community as close, connected and safe. The fact that Kiesha is missing has interrupted this perception, but Devine employs heavy use of rhetorical imagery to dampen any confusion. Kiesha had not been to school and no one other than her immediate family had seen her for three weeks. Devine's "*kind hearted locals*" did not know Kiesha ("they talk non-stop about a little girl they never knew"), nor did they notice her presence or absence in the community.[13] Kiesha was unknown and invisible. It is only in her public absentia that she has evoked a "*heartfelt outpouring of concern*".[13] While the community knows "*where children are safe*" and "*anyone would have taken her in*", no one said or did anything to protect her.[13] The responsibility to protect her, after all, is not theirs. Social ideologies of 'family values' and 'parental rights' allocate responsibility for children's welfare solely to parents, within legislated boundaries. Even with legal mandates to report violence against children, there is a particular assignment of responsibility that results in absolution at social, community and individual levels, except, as in this case, the assignment of full responsibility and blame to mothers. It might also be argued that in our societies, no one wants to get involved in the private matters of families, that it takes too much time or trouble. However, that argument obscures the overwhelming social desire to get involved in selective and intrusive ways, and oversimplifies very complex social and political interests in maintaining ideologies of family and childhood.[24] In reference to a review of media representations of individual missing children in the United States, Conrad observes, "As much as punishing individuals served to displace collective guilt and responsibility, so too did the emphasis on institutional concern over individual abused or missing children deflect attention away from the fact that all children are voiceless, powerless and 'missing' in American policy."[24 p331]

The desire to preserve the status quo in power relations for children and families also may be behind the distracting production of "*public grief*".[13] Kiesha's neighbours linger outside her family home and build a shrine as a symbol of caring, and in effort to "*forge a strong sense of community and purpose*".[13] Rhonda, a mother of six children (and unlike Kristi, an expert mother), is "*proud*" to live in a community that "*pulls together*".[13] Devine interprets community concern out of images of members building a teddy bear shrine, lighting candles, and releasing balloons. However, the community's decision to blame Kiesha's family and then hold vigils outside their home reminisces of something more sinister. Conrad argues,

> The political and social responses to child abductions and murders in different 'communities' are based on an implicit level of 'contamination' and reflect an underlying class and race determinism: 'deviant' victims and their families come under increased surveillance and institution control, whereas in the case of crimes against children from 'idealized' families there is increased parental protection and the criminalization of the assailants – the protection of childhood (sexual) innocence being equivalent to the protection of family and political order and serving to affirm the existing and arguable patriarchal power structure. [24 p337]

Violence against children persists despite considerable investments in research and in social services.[3,6] Deeply held social and political values which position children with little power might be threatened with critical examinations of child abuse and neglect. While Devine scapegoats politicians and child protection systems for abandoning this community, this blame obscures collective social responsibility for the broader issues of poverty and racism. Disrupting imagination with rational knowledge might appreciate the depth and breadth of these social problems. However, this might also elicit despair, which, by its very nature, the human mind must avoid. While Miranda Devine's story distances us from the pain of Kiesha's disappearance, there are some rational minds that resist these images. In the online comment section one reader replies,

> Get a grip Miranda, aren't these "kind" people the same people who gathered to throw rocks and hurl abuse at the family last week as they arrived home from the police station? Leaving teddy bears and sobbing over tealight candles is not indicative of a caring community. They come together to gossip and give thanks its [sic] not their child whose [sic] missing.[25]

As of March 2011, Kiesha's disappearance continues to be a mystery. The community has dispersed to carry on with their lives, and there are few traces of Kiesha, with the exception of one young filmmaker planning a documentary about Kiesha's story.[26]

Implications for suspicion

Responses to child abuse and neglect which centre on suspicions must, from Spinoza's point of view, recognise the vulnerability of the human mind as an idea of the body, and as affected by emotion and the collective. News of Kiesha's disappearance motivates a strong productive desire to eliminate threat to community safety. The liminal social positioning of Kiesha's family leaves them open to accusations of guilt, and powerless against the slanderous utterances of the media and community. The community actively constructs a more tolerable version of events, described and experienced as 'knowledge'. While their ideas are certainly real, they do not contain direct truths or true ideas as they might believe, and as suggested by Devine. Instead, it can be argued that Kiesha's disappearance threatens to reveal the oppressive nature of social values of childhood and family, or the effect of issues of poverty and racism on many children. Instead of moving towards painful ideas, the display of rhetorical images in mass media fiercely defends social values and norms. This case offers a poignant illustration of how emotion and sociability become entangled in knowledge in ways that reinforce social norms and assumptions, and reproduce social inequities.

This analysis highlights the problem of 'suspicion' in child protection interventions; specifically, the problem of basing predominant nursing responses solely in legal obligations to suspect and report to authorities. If suspicion is to be used as a mechanism to keep children safe, it is important to first acknowledge the limits of the human experience of suspicion in relation to knowledge. A new, more critical perspective towards understanding and interpreting suspicion requires integration of, and careful attention to, the necessary persistence of images that improve our sense of wellbeing; the powerful and productive nature of desire in the context of imagination; and the strong influence of the collective. By attending to the vulnerabilities and possibilities of a conceptual understanding of suspicion, different responses to children and families can begin to be conceptualised by nurses. Analysis of the human experience of suspicion in situations of child abuse and neglect may reveal patterns which, when considered carefully and rationally, have the potential to shift its light from an angle which casts shadows, to an angle which reveals the underlying structures of suspicion and their effect on nursing responses.

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Abstract
Few studies have assessed healthcare workers' understanding and use of a women's health approach (WHA) in practice, specifically with regards to cervical cancer treatment. Given the dominant biomedical approach, it is important for healthcare workers to be aware of, and feel capable of addressing the gender-specific needs of their patients. The purpose of this study was to assess healthcare workers' understanding of a WHA in a cervical cancer treatment centre in western Canada. Using a feminist case-study method, semi-structured interviews were conducted with nine healthcare professionals of the multidisciplinary team, including: nursing, social work, medicine and radiation therapy. Findings from interviews indicate that healthcare workers did not use a WHA. Analysis brought forward three main barriers to the implementation of a WHA, which stimulated the creation of seven recommendations towards implementation of a comprehensive WHA. The goal of this paper is to disseminate research findings in a way that honours the contribution of the participants from the clinical milieu, and acknowledges the need for creativity, innovation and a 'rethinking' of care delivery for women with cervical cancer.

Key words case-study, cervical cancer, women's health

Exploring the Presence of a Women's Health Approach in Cervical Cancer Care

KRISTEN HAASE &
ROANNE THOMAS-MACLEAN

Introduction

Cervical cancer is the second most common women's cancer in Canada.[1] This cancer is an especially complex condition because of its duality as a chronic disease, and its link to the sexually transmitted infection human papillomavirus (HPV) as the primary risk factor.[1] Treating women with sexually transmitted illnesses has been historically problematic because of the associated stigma, which is said to be linked with delays in treatment, poor health outcomes, guilt, isolation, fear and denial.[2-4] Initial testing for sexually transmitted infection/disease (STI/D) often takes place at a community clinic or other medical delivery centre specializing in sexual health. Such centres often provide counseling and referral services for women needing further treatment. However, women requiring further treatment of irregular pap test results are usually treated in non-community health settings, most often a cancer clinic or day procedures area of a hospital (5). In these facilities, healthcare workers may not be aware of the nature of HPV transmission, the sensitivity of the issue, and the psychosocial concerns of women receiving treatment. In addition, health professionals have not been asked to think critically about the sociopolitical context in which they practice, and how this may affect patients.

A women's health approach (WHA), is defined as one that focuses on "epidemiological differences, and highlights the specific health needs of women and girls. WHA includes a focus on female sexuality and reproduction within a holistic approach to addressing health needs across the lifespan".[6] Although a WHA seems to be central to sensitive and appropriate cervical cancer care, prior research has not examined healthcare workers' perspectives of such an approach.

A WHA acknowledges that when women seek treatment for physical concerns, such as cervical cancer there are psychosocial, contextual, and sociopolitical factors that cannot be overlooked. The goal of this study was to begin the important task of assessing healthcare workers' understanding, perceptions and approaches to gender sensitive care. The findings of this research also stimulate questions for further study of gender sensitive healthcare.

Literature review

Two key domains provide the context and rationale for this research. The first addresses incidence and treatment of cervical cancer and HPV. The second domain positions the research within multidisciplinary discussions surrounding women's health and Gender-Based Analysis (GBA).

Cervical cancer and HPV

Examining the provision of care for cervical cancer is an important contribution to the literature because cervical cancer has become one of the most common cancers affecting women around the world.[7] According to the Canadian Cancer Society[1] since the advent of ad-hoc screening programs in 1977, incidence rates have dropped 50% and death rates by 60%. In addition, women with HPV are at greater risk of developing cervical cancer.[8] In a study by Sellors and colleagues, the highest rate of HPV was among 19-25 year olds, who have a 24% infection rate.[9] This has led to the development and deployment of a national vaccine program for cervical cancer that targets young women.[10]

In addressing cervical cancer arising from HPV, there are two factors that need to be considered. These present a challenge for those who carry out treatment and education. First, cervical cancer is a chronic disease, which entails a special set of considerations, such as chronic disease management and long-term implications of diagnosis, treatment and survivorship. Second, HPV is a sexually transmitted infection. Problems related to the treatment of chronic disease are thus amplified when associated with a sexually transmitted infection.[11,12] While safe sex and community-based harm reduction programs are working to reduce the overall incidence of sexually transmitted infections, treatment of invasive and non-invasive cervical cancer normally take place in traditional hospital or medical settings - usually cancer clinics.[13]

Women's health

Women have historically accessed the healthcare system more than men, both for themselves and as primary caregivers of their families. Economic status has a significant impact on health, as Spitzer states, and average lifetime earnings of women are only 67 percent of their male counterparts.[14] Spitzer also points out that male life expectancy is 76 years, while females can expect to live until 81.[14] This means that women have more years than men in which they can access the system. Moreover, the additional years lived by females are more likely to be plagued with chronic illness; 11 percent of women suffer from chronic conditions, compared to only 4 percent of men.[14]

To rectify the disparity in women's health, Health Canada has rolled out two strategies to address gender differences: the Women's Health Strategy[5] (WHS) and Gender-Based Analysis (GBA).[15] The WHS was released by Health Canada, and outlines how the healthcare system has failed to address women's health specific needs. The document also provides a plan for departments to address these imbalances. GBA was first developed in 2003, and re-released in 2007 by Status of Women Canada.[15] GBA is a tool designed to assist federal departments in systematically integrating gender consideration into policy, planning and decision-making. Various components of these strategies set out specific parameters for policy development regarding women's health.

The purpose for both the WHS and GBA is to shed light on past inequities in the healthcare system that devalued, misunderstood and then misrepresented women's health.[16] While the WHS provides a recap of what types of differences women have (and may continue) to experience in the healthcare system, GBA focuses on gender, rather than women only. GBA also goes beyond the impetus of healthcare, with the goal of integrating strategies into any relevant social departments in the Federal government.[15]

It is important to note that GBA was developed outside of a biomedical/health focus, from the Department of the Status of Women. Within the biomedical, a reductionist model based on biological sex differences tends to dominate.[16] A biomedical lens usually reduces women to their biological disposition to reproduce, focuses on binary opposition of men and women, and overlooks the socially derived aspects of gender that create unique circumstances for both men and women.[17] GBA, at its most basic, attempts to shed light on the numerous complex social factors that interact with the biological to create the person. A women's health approach, focuses specifically on gender and biological differences, and suggests strategies to meet these within a predominantly biomedical healthcare system.[18]

The implementation of GBA and the emphasis on women's health policy in government research and policy-making is promising. However, while women's health has evidently become an issue considered by government agencies, research has not translated into subsequent practical action in the clinical domains. The most recent federal guidelines—the Programmatic Guidelines for Screening for Cancer of the Cervix in Canada,[19] do little to address the psychosocial challenges associated with diagnosis and treatment.

The need for attentiveness to psychosocial needs prior to cancer diagnosis and during cancer screening (pap testing) have been well-documented.[20,21] Nevertheless, a lack of attention to psychosocial concerns by healthcare workers when informing women of abnormal pap test results is evident in the reviewed literature. Several studies on communication of pap test results describe women as feeling anxious or confused about abnormal findings and not being given thorough or conclusive information from their physician.[22-25]

Feminist literature problematizes the procedure as well. For example Dietch and Davies'[26] phenomenological study explores the harmful experience of waiting for treatment after being informed of an abnormal pap test and women's experience of being given little information or support during communication of results. Another study explored the longitudinal experiences of women following abnormal pap testing and found that a woman's experience with her body changes.[27] Women interviewed in this study felt the cervix was an area of the body they did not pay attention to prior to their diagnosis. As a result of the abnormal pap test and subsequent follow-up, women paid more attention to their bodies, and felt their bodily boundaries changed.

Few research projects have talked specifically with healthcare workers to elicit their opinions on gender-specific care and whether a women's health approach is present in their day-to-day practice. Healthcare workers are central to understanding the health care system because they are the primary actors who carry out policy, provide care, and interact directly with patients. It is also imperative to understand that policies in a book, or best-practice guidelines are different than what actually takes place in practice.[29] Herein, this article seeks to address that oversight by examining the opinions of healthcare workers of the multidisciplinary oncology team treating women with cervical cancer.

Method

In this study, a case-study method was chosen to gain a comprehensive view of the sum of the perspectives of the individuals who provide care at one cancer clinic. Reinharz states that case studies are "used to illustrate an idea, to explain the process of development over time, to show the limits of generalizations, to explore uncharted issues by starting with a limited case, and to pose provocative questions".[28] Due to the paucity of research on WHA in the specific context of cervical cancer this presents a starting point to begin exploring women's health needs.

According to Letherby, "feminist research is feminist theory in action".[32 p62] Further, Letherby states that the political aims of feminist theory are grounded in, and celebrate the experiences of men and women- thereby challenging the experiences of mainstream knowledge. Therefore, using a feminist approach meant focusing critically on one specific case, and the experiences of a few, rather than on the comparative analysis of multiple cases.[28] For this research, the focus was on understanding experiences of healthcare workers at one clinic. Through these many voices the authors tried to generate a comprehensive understanding of WHA and gender-specific care.

Nine semi-structured, open-ended interviews were conducted with policy-makers, practitioners, and healthcare workers employed at the clinic. Of the nine interviewees, two were radiation therapists (both female), two were nurses (both female), two were social workers (both female), and three were physicians (two males, one female); there were seven female participants in total. The rationale for interviewing those who work at the clinic, rather than those who attend it, is to provide insight into the perceptions of those who carry out treatment and interact with the women who access services.

Discussions were initially held with the clinic director to ensure interest in participating in the study. Ethics approval was received from the affiliate University Research Ethics Board. Written consent from the director, as well as contact information for several employees at the clinic, was obtained. Primary data collection was then initiated.

All interviews took place during the fall of 2006. Seven of the nine interviews were conducted at the cancer clinic, while two were conducted off site at participants' private offices. Participants were mostly female (seven of nine), and all had some type of post-secondary education. The length of the interviews ranged from approximately 25 to 45 minutes.

A semi-structured interview guide was developed for the purpose of this research. Questions were developed to probe participants about their thoughts about WHA at the clinic, their professional role, and gender-specific needs. A conversational approach was utilized to allow the researcher to be reflexive, with the participants guiding the conversation.

The nine interviews were transcribed verbatim and checked for accuracy by the first author. Content analysis, described by Patton as "any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings" was conducted with all transcripts.[31 p453] Making sense of the core concepts and identifying major themes was not a process separate from transcription; rather, it was an integrated and continuous process that was informed by a feminist perspective. Interviews were conducted with attention to talking, writing, editing and listening from a feminist viewpoint.[32] The main themes and patterns that emerged linked back to the initial review of the literature in meaningful ways.

Findings from this study are presented below and incorporate relevant literature throughout as described by Thomas-Maclean.[33] Although an attempt was made to present the findings in a linear fashion, the nature of the research findings necessitates more of a 'messy' back and forth approach between the literature and the participants' responses. This approach to presenting research findings is one not often accepted in positivist scientific journals, however, this approach has garnered support from researchers and students who learn that research is certainly not a linear process (34). Both authors feel this format illustrates a more accurate representation of the findings in this feminist case-study.

Findings

According to participants, a WHA, as defined above, was virtually non-existent in the clinic. However, participants expressed a general understanding of some of the tenets of a WHA. Interviews revealed a number of important barriers to healthcare workers' ability to implement a WHA in clinical practice. These barriers include: 1) Medicalization; 2) Lack of evaluation; and 3) Understanding women's health and gender-specific needs. Each of these barriers is contextualized within literature relevant to a women's centered approach to healthcare.

Medicalization

Drawing upon early work on the conceptualization of medicalization (e.g., Ivan Illich, Irving K. Zola), Kohler Riessman expands the concern with medicalization to include feminist understandings of this phenomenon.[35] Medicalization has been defined to mean, first, that conditions and behaviours are "given medical meaning" and understood through the lens of health and illness and, second, that medical institutions are seen as being responsible for the elimination of said conditions and behaviors.[35] Kohler Riessman asserts that medicalization is also involved with social control and the construction of deviance, in a variety of ways, and awareness of social context is diminished, as power relations are perpetuated.[35] Such a definition sees the process of medicalization taking place primarily at the conceptual level; the research findings from this study show how medicalization manifests in various processes at an interpersonal level, well beyond the doctor-patient relationship.

Despite differences in degree of formal education and work experience, all interviewees tended to revert to medicalized language when discussing aspects of client care. This tendency to revert to "medical speak" and to medicalize interactions with patients was not limited to the physicians. Medicalized language was also employed by nurses, psychosocial oncologists and radiation therapists. These findings suggest that medicalization is not the sole purview of physicians, but is rather a general by-product of the biomedical model influencing the clinic's overall practice.

The following quotations were elicited when participants were asked questions about a change in patient demographics, and about services that cater to the unique needs of women. One radiation therapist stated:

> I don't believe there has been a lot of change in numbers we have seen. I think it has been fairly steady, maybe slightly younger…. If a patient has not had a hysterectomy, the uterus is an excellent organ to be able to insert catheters into to allow us to give a higher dose to that actual organ.

In response to a question about checking in on patients during their treatment, one nurse stated:

> "Well, we do follow-up, especially when they are getting the first treatment, and we will call them a couple of days after the first treatment, not to be too narrow but to see if there are any side effects—as far as nausea and vomiting—and there is a follow-up phone call and checkup with them and then there is a lot of stuff related to side effects.

Focusing on the physical symptoms and treatment of cancer are a demonstration of medicalization. Health care workers routinely referring to women as the physical site of their cancer which emphasizes the problematic parts of the physical body, rather than the existence of a whole, embodied person. Also, while physical symptoms are often the most problematic post-chemotherapy side-effect, there seemed to be little attention to the relationship of the physical symptoms to the holistic experience of being sick.

Nonetheless, there are positive practices that should also be acknowledged in the context of the clinic, and the cervical cancer screening program in particular. There is invaluable benefit to utilizing uniform and non-individualized approaches to screening; even though it suggests medicalization. That is, the cervical cancer screening program utilized by the province and cancer clinic operate on the basis of findings which indicate that women over the age of 35 were generally under-screened while women between the ages of 18 and 34 were generally over-screened, this attempts to target screening towards those who need it most. One physician indicated this stating:

> There is a of angst in the younger generation to talk about and to access care and women things. Whether it be for pap smears or contraception. …I think that attitude is a healthy attitude and I think the screening program has promoted that attitude.

Lack of evaluation

Another barrier identified in the interviews related to the need for evaluation of the current program. When discussing whether women's needs were being met at the clinic, one nurse stated:

> I am not sure but I guess in order to find out you could do some sort of survey with women to find out.

Although each participant was asked about current evaluative strategies (such as questionnaires, surveys, program reviews, etc.), none of the participants were familiar with any. Some were aware of internal evaluations that had been done, but even those operating at the management level were not aware of the findings. Also, the scope of the few evaluations done was limited. One participant spoke of an evaluation to assess the current hours of operation and whether clients were satisfied with them. She too was unaware of the results. One radiation therapist stated:

> Surveys are done every once in awhile. A patient survey—and I don't know what the frequency of those or how they are assessed. Some have come from us because of accreditation, sometimes. When that comes around we have to do that. Some have come from other areas in the hierarchy.

Facilitating the opportunity for evaluation provides women with the ability to share their experiences, improve services for other women, and to strengthen areas where services are lacking. Evaluations might also provide healthcare workers insight into the needs of women with cervical cancer and how these are unique to other clients. This exercise would allow women to provide feedback in an anonymous way, allowing them to share their opinions without fear of it affecting their care.

Understanding women's health and gender-specific needs

Participants in the study were aware of women's specific health needs, but did not label their understanding as a WHA. When probed regarding such things as childcare for women, family support, and sexual health counseling, each of the participants emphasized that these were important aspects of care. However, few were aware as to whether these needs were met. Participants were aware of gender issues, but described several limitations in implementing gender sensitivity into their practice. They were not ignorant of the implications of gender difference, but often simply overlooked them due to other constraints. Some participants also seemed to be unsure whether cervical cancer qualified as women's health. One social worker stated:

> Umm probably there is more of that in breast cancer, women's health, I mean certainly with the women's health center … not anything at our cancer center here. We have always had support groups for women with breast cancer clinic here though.

During the course of the interviews, many initiatives conceived by the cancer clinic were mentioned. One strategy remarked on quite often was the cancer agency's agenda to decrease "wait times." Most participants felt that wait times were of central importance, because it is crucial for women to get timely treatment upon diagnosis of cancer. A diagnosis of cancer is a life-altering experience, however, so to imply that the only concern for women with cancer is wait times oversimplifies a very complex issue. The focus on wait times seems to be an extension of the process of medicalization, because it addresses only the need for physical treatment and overlooks the need for psychosocial care or anxiety associated with the process of 'waiting'.

Almost all of the interviewees deemed childcare to be imperative for this type of cancer centre. Women often come every day of the week for less than half an hour for radiation treatments. For immigrants, new Canadians, marginalized persons and those with limited support, there are few options for childcare for such a short period of time. One of the participants suggested that women could bring their children to the cancer centre and leave them in the waiting room, where the receptionist could watch them. However, this did not seem like a reasonable solution to the problem given that there is no formal program in place. The issue of childcare is greater for those clients who travel long distances to obtain treatment and already face a major geographic barrier.

Participants also expressed concern about women from rural and remote areas who must travel for treatment. Participants felt the travel was a great burden, especially when they had families and jobs. The uncertainty of the length of time of treatment was seen as a significant factor. One physician stated:

> If we have a patient coming from the North we know we can't do blood work, chemo and check-up all in the same day because some treatments are really long and if we do bloodwork in the morning and see that the counts are too low, then we have to cancel all the appointments in the afternoon.

Participants also felt that there were problems associated with screening the rural and remote populations. The participants indicated that many of their patients from the north are Aboriginal, and living on reserves in variable social and economic conditions. One nurse stated:

> Lots of them [the patients] don't have telephones, so the challenges of getting them here and compliant with these appointments if they can be sometimes people who aren't compliant with other areas of their care, then they might not be compliant in coming to see us.

Another participant explained that the shortage of services in rural and remote areas might hinder screening for women not being comfortable with personnel. One physician stated:

> There was some gender preferences toward women as opposed to men [doing the screening] in some of the areas and so there was some issues to the screening program itself and how to make it more effective… so long as we are aware that anybody can take a pap smear. It can be a nurse, it can be a nurse assistant.

Sexual health counseling was another topic that generated participant comments. Many participants mentioned that sexual education was a major need for women at the clinic. There was not a designated professional responsible for addressing sexual health education, so when patients would ask questions, staff often said they did not know the answer and did not know who to ask. The two radiation therapists stated that it was the psychosocial oncologist's area, while the psychosocial oncologist said it was a nursing issue. Nursing staff was unaware of whose area it was, but to the best of their knowledge it was not a nursing issue. Sexual health was therefore an area demanding attention; a comprehensive women's health approach would ultimately address this. One radiation therapist states:

> It [sexual health] is an area that most people are not comfortable talking about…but younger women, I mean they have got a long life, a long sexual life ahead of them and perhaps even childbearing if it doesn't sterilize them and um you are young…but they need somebody to talk to them about what is safe, what is not safe, how to enhance these situations you know.

The lack of knowledge of a WHA was a barrier that affected the staff's ability to meet women's needs. However, even though some staff indicated a lack of knowledge in certain areas, such as sexual health, others were seen to have expertise; therefore, information sharing would greatly benefit provision of information about sexual health.

Recommendations towards a WHA

The barriers identified through informant interviews outline why a WHA was not implemented at this clinic. This section provides strategies and several recommendations for the constituent parts of a WHA. All of the suggestions below arose from comments derived from interviews with participants.

Evaluation of patient experience

Several participants revealed that patients were occasionally surveyed about their experience at the cancer clinic; however participants were unaware of the purpose and outcomes of these evaluations. The rationale for evaluation surely is to ensure that patients' needs are being met. While participants felt strongly that patients were overwhelmingly satisfied with the treatment and services they received, it would be beneficial to have women with cancer directly report on their treatment experience.

The first recommendation is to seek input from women about their patient experience. Evaluation methods could include surveys, focus groups, and one-on-one interviews focusing on gender-specific treatment, experiences, and issues. Surveys targeted only at issues like "hours of operation" are important to patients, but not sufficient to capture women's personal experience of cancer treatment.

From the interview, it seems that additional focus areas could include family issues, difficulties in health maintenance, and sexuality and psychosocial concerns. Examples of family issues mentioned during interviews include, childcare, family planning, and traveling/relocating for treatment.

In order to ensure that appropriate issues are evaluated, collaboration among disciplines would be necessary. Psychosocial oncologists, who work directly with patients to overcome social challenges, could take a central role in identifying areas needing evaluation. Evaluation will only be successful if it focuses on holistic issues identified by women themselves. Once data has been collected, findings should be summarized, disseminated to staff and other relevant personnel, and potentially published in practitioner journals. The dissemination of this information within practice and professional circles will facilitate ongoing discussion within the oncology community. Sharing the information within these forums can only serve to enhance the care received by women with cervical cancer.

Thinking about implementation

From this research, it is evident that the personnel who provide direct patient care to women with cervical cancer are aware of gender-specific needs. However, there was limited, incorporation of gender-based strategies taking place at the clinic. While this is a case study of only one clinic, other research demonstrates that it is likely the rule and not the exception. For example, a report released by the Prairie Women's Health Centre of Excellence,[6] "Invisible Women: Gender and Health Planning in Manitoba and Saskatchewan and Models for Progress," indicates that gender-based analysis and planning is absent in most regional and provincial health authorities. The report recommended that regional health authorities move away from a reproductively focused view of women's health, and consider broader gender specific care for women. Proposed in 1999, this recommendation is still pertinent nearly ten years later. Arguably, a strength of the researched clinic is the recent consolidation of services in the province, which makes cancer care more centrally managed and distributed. Implementation of gender-based analysis could be done province-wide and each centre could pilot gender-based analysis in one specific treatment.

If GBA strategies were to be implemented into practice at the clinic, it would be important to incorporate evaluation as a way of measuring the success or failure of the program. As per the guidelines laid out above, women should be directly involved in the evaluation process. Moreover, if gender-based analysis strategies are to be implemented, it needs to be targeted at individuals providing patient care at all levels, including reception and volunteers.

Patients on the board

Perhaps one major reason that medicalization is so pervasive is the lack of women's input into treatment processes and clinic policies. Two participants mentioned the presence of a lay advisory board. This board is comprised of selected professionals from the clinic, as well as "lay people" from the community who have experienced treatment or are family members of those who have had treatment. This is a positive step toward incorporating patients into the development of patient care. To take this further, it could become clinic policy to incorporate women and men undergoing treatment into the development of policies that affect their care. This would provide patients and survivors with an active role, rather than being fixed in a passive role.

In keeping with the idea of inclusivity, it would also be advisable not to label non-healthcare professionals on the committee as "lay people," which suggests that they know little about the issues. People who have undergone treatment and join the board should be regarded as experts; perhaps not in the specifics of evidence-based treatment protocols, but definitely in the area of patient care.

Expert consultation

In order to facilitate gender-based analysis, a position should be created to ensure the successful and continuous application of gender-based principles. The person filling this role could: serve as a liaison between patients and healthcare workers if gender-based concerns are identified; work with those conducting evaluations to come up with solutions to gender-based barriers/issues; participate in meetings within all departments of the cancer clinic; and act as an agent of change to promote more gender-based analysis at the clinic.

The duties of the proposed position would include raising the profile of women's health and gender-based analysis. This could include distributing literature to clients about the attempts at incorporating a WHA, public relations activities and putting up literature posters around the clinic.

Staff Education

Many staff members identified their own knowledge gaps in a number of areas. In the discussions, there was a lack of knowledge about how to address women's health needs. Furthermore, it was evident that there was confusion at the clinic about who was responsible for certain patient education needs.

The issue of role confusion recurred in interviews, especially regarding women's need for sexual health education. In general, clinic leadership needs to identify knowledge gaps and determine who will address them. Rather than continuing to be unsure about who should do what, a proactive approach should be adopted to address concerns affecting the care of women with cervical cancer. The clinic is clearly passive in identifying who should cover issues such as sexual health. This issue is probably thought to be 'mainstreamed', or part of everybody's role. Sexual health, due to its private nature, is not something patients generally bring up to the healthcare worker. This is a case where the organization needs to be very clear about who is responsible for sexual health, especially in a disease that is associated with HPV.

Rather than hiring new personnel to deal with the problem, program heads need to take the lead. Knowledge gaps first need to be identified. Staff committees should research best practices and present these to the staff to ensure unanimity. Education should be implemented into client care. It must be emphasized that this does not necessitate treating sexuality and other sensitive issues like "any other thing." Discussions about so-called "embarrassing" matters such as sexuality, intimacy and drug-use should be conducted in a value-free and sensitive manner.

When healthcare workers identify knowledge gaps, these gaps are often shrugged off due to cutbacks and politics. If a knowledge gap is identified, healthcare workers can act as advocates for patients. As powerless as healthcare workers often feel, they have access to resources and information that many patients are not privy to. Furthermore, if healthcare workers feel empowered to take an active part in patient education, it is plausible that they may find more satisfaction in their job. Past studies have shown that nurses satisfied with their job, are more likely to have satisfied patients.[36,37] Findings from these studies may be applicable to other caring professions working within the same healthcare system. These findings are important because they don't minimize the political and sometimes oppressive bureaucracy of the healthcare system, but instead suggest a road map to work within it.

Promotion of dialogue

Healthcare workers should be encouraged to dialogue regarding the shortcomings identified in the case study and also to exchange concerns identified before this research took place. Providing a place to express concerns may well help to establish the recommendations already mentioned. A significant number of the ideas in the research came directly from those working in the clinic. Perhaps the research provided an outlet for the healthcare workers that they never had, or perhaps they never previously cared to share their ideas. Whatever the case, their ideas have the ability to transform the clinic.

Time is the crucial factor in facilitating dialogue. Time needs to be allocated for healthcare workers to talk about significant issues related to patient care. They do not all have to engage in daunting academic work; they just need to dialogue regarding their concerns.

Psychosocial concerns

Arguably the single most important finding from this study concerns the fact that more research needs to be done with women who have cervical cancer to investigate the disease's psychosocial implications. There is some overlap of this recommendation with others, but it does warrant a separate discussion because of its importance. Cervical cancer is less common than breast cancer, but it brings with it a unique set of challenges for women. Issues that seem to be pertinent are silence, stigma, sexuality and education. A great deal of work is being done in the area of cervical cancer, but much of it targets issues such as how to get more women into screening programs, non-attendees and the physiology of the disease. There are myriad other psychosocial issues that accompany all women with cancer. Notably, given its connection with HPV, the issue of social stigma affects many women. Such topics need to be studied in depth. Furthermore, guidelines for assessment of psychosocial needs in the adult patient were revised and released in 2009.[38] Theses guidelines suggest the need for comprehensive and focused assessment, screening for distress, education of health care providers, and the importance of considering the patients social context.[38] The point on social context emphasizes the significance of family life stage, and the need for healthcare workers to be aware of the far-reaching implications of a cancer diagnosis. In this study patients were aware of these issues, but seemed somewhat limited in their perceived ability to assess and implement psychosocial interventions.

Of similar importance would be research with women from rural and remote areas, as well as First Nations, Aboriginal and Métis women. Participants often identified these groups of women as having additional challenges regarding both screening and treatment, and labeled them as "high risk." Also, although not widely cited, research provides evidence regarding other barriers to treatment for Aboriginal women. One study assessed a group of minority women in Northern Ontario. The findings indicated that about 33% of Ojibwa and Cree women refused internal exams, compared to zero and 8% among other minority groups (39). Findings of this sort indicate the need for greater consultation with Aboriginal women to discuss strategies for creating and disseminating culturally sensitive educational material.

At the clinic where the research was conducted, the experiences and opinions of women clients were not informing treatment in any way. This confirms the findings of Thomas-Maclean[40] that such settings divorce treatment of the disease from the self-perceived needs of the ill person. It also points to the fact that medicalization subverts resistance, or "resistance comes to look increasingly irrational since health—an intrinsic good—cannot reasonably be called into question".[18] The interviewees' perception of the program as doing fine without evaluation and their belief that patients are not interested in involving themselves illustrates the degree to which medicalization is firmly entrenched within the clinic.

Limitations

Some of the limitations of the study pertain to those inherent to a qualitative approach. However, the goal of this study was to understand and explore rather than generalize findings, therefore a qualitative approach was the most design to answer the research question. In addition, owing to legal and ethical concerns, the clinic director had to approve the participation of the clinic personnel. This may have affected the demeanor of participants: if they participated only at the request of a superior, they may not have been sincerely interested in or comfortable taking part in the study.

Conclusion

This study revealed that while a women's health approach was not specifically present, many healthcare workers identified constraints impeding their ability to attend to women's specific health needs. Further research is needed to explore these constraints specifically and their impact on implementing a women's health. More work is also required in the area of healthcare workers' understanding of a women's health approach and their capacity to implement such an approach. For example, it would be valuable to assess the capacity of oncology nurses to implement and manage women's health strategies into their practice with women undergoing cervical cancer treatment. Studies also need to be completed involving women receiving cancer treatment to understand their level of satisfaction with care approaches, their willingness to be involved in care, and their perceptions of the need to move towards a WHA in cancer care.

This research also emphasizes the need for knowledge translation on the part of researchers and practitioners working in the area of women's health and gender-based analysis. There is scant literature available assessing WHA and how it affects care, how it is conceptualized by healthcare workers and patients alike. Given the pertinence of this topic and its ability to affect care it is important to emphasize the need for turning research findings into changes in clinical practice.

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Résumé
À partir des résultats d'une enquête exploratoire sur l'expérience de l'entrée en maternité de douze primipares francophones de la région d'Ottawa, au Canada, cet article présente les écarts observés entre le vécu attendu et le vécu réel des participantes et offre, selon une perspective féministe, une réflexion critique sur les effets néfastes de ces écarts sur la santé des femmes. Enfin, l'auteure tente d'illustrer comment l'expérience de l'entrée en maternité, surtout en ce qui concerne l'allaitement maternel, tend à être médicalement et socialement encadrée de manière telle que le bien-être des nouvelles mères devient un aspect secondaire de leur expérience.

Mots clés allaitement, attentes, maternité, réalité, santé des femmes

L'expérience de devenir mère : entre les attentes et la réalité

DENISE MOREAU

Introduction

> Ce que j'espère, c'est que celles- et ceux- qui se diront féministes à l'avenir auront compris qu'il faut, certes, aider les femmes à ne pas être mères quand elles ne veulent pas l'être, mais qu'il faut aussi les aider à l'être quand elles le souhaitent.
>
> Yvonne Knibiehler, Le Monde 2007

Devenir mère est un changement mémorable et irréversible dans la vie d'une femme. L'entrée en maternité est un processus éprouvant qui affecte la santé des femmes. Avant la naissance de leur enfant, les femmes ont une perception de l'expérience de la maternité fondée sur les mythes qui entourent cette expérience dans notre société. Cette perception est également influencée par l'expérience de maternité de leurs amies, leur mère et toutes les femmes de leur entourage. La plupart des femmes ont des attentes et des aspirations quant à leur futur rôle de mère. Or, lorsqu'à la naissance de leur enfant, les femmes vivent une réalité très différente de ce qu'elles avaient imaginé ou anticipé, elles se retrouvent dans une situation qui se rapproche d'une perte de contrôle pouvant mener à la détresse. Plusieurs recherches ont démontré que plus l'écart est grand entre les attentes et la réalité de la maternité plus grand est le risque que ce conflit soit associé au développement d'une fatigue physique et émotionnelle que les femmes tenteront de surmonter pendant des mois sinon des années.[1] Chez certaines femmes, cette grande fatigue peut même se transformer en dépression postnatale.[2-3]

Une enquête exploratoire proposée par une infirmière et une sociologue, visait à croiser, dans une même étude, l'approche infirmière et l'approche sociopolitique de la maternité. Cette étude avait pour but de recueillir et d'analyser le témoignage de primipares sur leur représentation de la maternité avant et après l'arrivée de l'enfant, montrer l'écart entre les attentes et la réalité de ces femmes vis-à-vis la maternité et à mettre en évidence la présence de signes de fatigue physique et émotionnelle[1] durant cette transition à la maternité.

Cet article vise à présenter la méthodologie utilisée dans cette étude, les caractéristiques des femmes rencontrées ainsi qu'une brève recension des représentations de la maternité d'hier à aujourd'hui, suivie du différentiel constaté entre la représentation dominante actuelle et l'expérience des participantes pour terminer avec une réflexion critique sur les effets pervers de ces écarts sur la santé des nouvelles mères.

Les représentations de la maternité

La maternité est une expérience singulière et sociale. La représentation personnelle de la maternité est une façon intime de concevoir et d'imaginer le rôle de mère influencée par la famille d'origine et le milieu social de la future mère. La représentation sociale de la maternité est constituée d'une réalité commune élaborée et partagée par un système social fondé sur l'autorité du père, en l'occurrence le patriarcat.[13] Car, même si la maternité est de plus en plus représentée comme une expérience personnelle inscrite au plus intime de la vie privée de chaque femme, elle n'en demeure pas moins une construction sociale patriarcale dont les coûts et les responsabilités sont toujours dévolues aux femmes. [14]

D'hier à aujourd'hui

Mettre au monde des enfants et être disponible pour les aimer, les nourrir, les soigner, les éduquer et s'en séparer, telle semble avoir été pendant fort longtemps la seule véritable contribution sociale attendue des femmes, tout comme leur seule raison d'être.[15] À différents moments de l'histoire, des femmes se sont révoltées contre l'unique modèle de féminité (mère épouse ménagère) qui leur était imposé, mais leurs revendications ont trouvé peu d'échos aux siècles passés.

Il a fallu attendre la fin des années 1950, pour que le mouvement des femmes qui émerge alors, devienne un point de ralliement pour exprimer haut et fort leur volonté de changement et leur désir d'être reconnues comme citoyennes à part entière.[15] Durant les années 1960, les femmes envahissent plus massivement le marché du travail et obtiennent enfin la possibilité de choisir le moment pour devenir mère ou celui d'exister sans être mère grâce à l'arrivée de la contraception. Toutefois, les difficultés, les ambivalences et les contradictions inhérentes au passage du modèle de la mère - ménagère à temps plein des années 1950-1960 à celui de la femme orchestre des années 1970-1980 déroutent de nombreuses femmes. Pour la majorité des femmes de cette période, cette quête d'égalité par le contrôle des naissances et l'indépendance financière est vouée à l'échec tant le poids des contraintes matérielles et structurelles de l'articulation travail - famille est déterminant dans le fonctionnement de leur vie quotidienne.[15] Les représentantes de cette première vague du féminisme contemporain prennent conscience qu'il est illusoire de croire que toutes les femmes pourront, sans changements majeurs des institutions sociales et des rôles parentaux, se réaliser et s'épanouir pleinement.

Durant les années 1980, les femmes sont plus nombreuses à s'instruire et à entrer sur le marché du travail. Certaines font carrière dans des domaines anciennement réservés aux hommes. Elles sont également plus nombreuses, même à l'arrivée des enfants, à conserver leur emploi que ce soit à temps plein ou partiel. En somme, les femmes de cette décade continuent la lutte déjà entreprise pour le contrôle de leur vie personnelle et professionnelle.[16]

Maushart[17] qualifie d'hyper - caféinée la vie des mères des années 1990. C'est la naissance des super mamans, des super épouses, et des super femmes.[2] Ces femmes tentent de tout concilier : la maternité, la vie de couple et la carrière, certaines s'épuisent et abandonnent, d'autres y arrivent mais souvent au détriment de leur santé. Devant l'irréalisable, une envie de tout lâcher s'installe et plusieurs femmes renoncent à travailler pour devenir mère au foyer et élever leurs enfants. Cette façon d'exercer le métier de mère en tentant de tout maîtriser plutôt que d'exiger des changements sur le plan de la société est la marque de fabrique de cette super génération.[16]

La mère parfaite

Depuis le milieu des années 1990, les mères sont atteintes du syndrome de la mère parfaite, qui n'est pas sans rapport avec le culte de l'enfant roi. Les valeurs de performance et de réalisation de soi véhiculées par notre société entraînent le désir d'être des mères parfaites. Les médias ont en partie contribué au mythe de la mère parfaite, c'est ce que relatent les auteurs Douglas et Michaels (18) dans leur livre *The Mommy Myth : the Idealization of Motherhood and how it Has Undermined Women*. C'est à coups de reportages et d'entrevues avec des vedettes qui affirment avoir connu la félicité le jour où elles ont expulsé leur placenta que les médias, magazines féminins en tête, ont contribué à créer une image romantique et totalement idéalisée de la maternité. Bien entendu, les mères trouvent parfois ce discours ridicule, mais en même temps, elles se laissent prendre.

De nos jours, il ne suffit plus qu'une femme livre son âme à la maternité, elle doit aussi donner son corps, son esprit, son couple. On attend d'elle qu'elle se fonde dans la maternité en faisant tout ce qu'il faut durant la grossesse pour avoir un bébé en santé, accoucher naturellement, allaiter sur demande au moins un an et établir un lien fusionnel avec son bébé. Les mères sont tenues responsables du bébé à naître et de ce qu'il deviendra.[19] La mère lui doit tout, son temps, son énergie, son lait, elle doit s'oublier pour son enfant.[16,19,20] Le contexte social actuel pousse les mères à se transformer en mère parfaite à plein temps plus que complet.[16] C'est l'ère de la maternité totale. En somme, au cours du XX^{e} siècle, différentes représentations sociales de la maternité se sont succédées : la mère maternelle pour les disciples de Freud, la mère branchée prescrite par Dr. Spock, la mère libérée des années 1970, la mère qui se réalise des années 1980, la mère sacrificielle des années 1990 et la mère parfaite des années 2000.[16]

Méthodologie

Les approbations éthiques ont d'abord été obtenues afin de permettre le recrutement des participantes et la collecte des données sous forme d'entrevues. Ainsi, pour réaliser cette étude, douze femmes francophones résidant dans la région d'Ottawa, en couple avec un homme et enceintes pour la première fois ont été rencontrées. Chaque rencontre a duré un peu plus d'une heure, au domicile de la participante. Les participantes ont été recrutées dans une classe de pré admission à l'hôpital et dans un cours prénatal offert par les services de la santé publique d'Ottawa. Les femmes francophones de la région qui ne suivaient pas un cours prénatal ont donc échappé à notre investigation. Il est important de mentionner ici cette limite parce qu'au vu des caractéristiques socio-économiques des femmes rencontrées, nous pouvons considérer que la participation à des cours prénataux offerts en français dans la capitale nationale du Canada suppose d'appartenir à une catégorie de la population supérieure à la moyenne.[4] Pour saisir l'expérience de ces femmes quant à la maternité, des entrevues semi dirigées ont été conduites en 3 temps par les deux chercheuses : au 8e mois de leur grossesse, 2 mois après la naissance et 6 mois après la naissance.

Au début de chaque visite, les femmes étaient invitées à compléter l'Échelle de Dépression Postnatale d'Édimbourg (EDPE) de Cox, Holden et Sagovsky (1987).[5,6] L'EDPE a été traduite et validée dans plus de 23 langues par des chercheurs de différentes disciplines. Cette échelle se compose de 10 questions auxquelles la mère est invitée à répondre en indiquant la proposition qui correspond le mieux à son humeur de la dernière semaine. Chaque question présente des réponses sur une échelle de 4 points (de 0 à 3). Le score total s'établissant de 0 à 30, les chercheurs estiment qu'un total de 13 et plus indique la présence de symptômes de dépression majeure. La complétion de cette échelle par chacune des participantes au début de chacune des entrevues a permis l'évaluation des émotions de la cliente au cours des sept derniers jours précédant la visite. L'échelle d'Édimbourg (EDPE) de Cox, Holden et Sagovsky (1987) a été grandement utilisée pour évaluer les symptômes dépressifs au cours de la grossesse et de la période postnatale dans les cultures occidentales et orientales.[7] L'EDPE a été validée pour être utilisée en période prénatale et cette version a été traduite dans plus de 12 langues dont l'arabe et le vietnamien.[8,9] Plusieurs recherches ont révélé que bon nombre des femmes dépressives après la naissance de leur enfant l'étaient également pendant leur grossesse. Aujourd'hui nous savons que 10 % des femmes enceintes souffriront de dépression, de là l'importance du dépistage.[10]

L'entrevue avant la naissance avait pour but de recueillir les données sociodémographiques : âge, niveau de scolarité, emploi, type d'union, durée de l'union, des informations sur la décision de devenir mère ; l'importance de cette décision à ce moment de la trajectoire de vie ; le soutien du conjoint et de l'entourage dans cette décision ; la préparation physique et psychologique à l'accouchement, le plan de naissance (s'il y a lieu) ; les changements anticipés par cette naissance sur sa vie et celle du couple, la projection de l'organisation de la vie quotidienne après la naissance ; le vécu de la grossesse et le projet d'allaiter.

L'entrevue réalisée 2 mois après la naissance visait à recueillir les impressions de la nouvelle mère sur son accouchement, sur son expérience d'allaitement (ou non) ; sur son vécu de nouvelle mère ; sur ses impressions sur son nouveau-né ; sur les réactions du conjoint et des familles à la naissance, à l'allaitement ; sur l'organisation quotidienne de la vie à trois (partage des tâches avec le conjoint ; transformations observées) ; sur le soutien matériel des familles; et sur les transformations de sa vie sociale.

L'entrevue réalisée 6 mois après la naissance insiste sur l'organisation quotidienne de la vie à trois, les transformations observées, le suivi médical s'il y a lieu et les perspectives d'avenir immédiates (retour au travail ; garderie) et à plus long terme.

La possibilité de réaliser trois entrevues sur une durée de sept mois s'est révélée riche d'enseignements. Les 36 entrevues ont été enregistrées, puis transcrites mot à mot, le plus fidèlement possible. Les dires des participantes ont ensuite été organisés en deux thèmes pour faciliter l'analyse des données selon les objectifs de la recherche : les représentations de la maternité et les signes de fatigue physique et émotionnelle.[11,12] Puis, les écarts émergeants entre les attentes et la réalité des participantes vis-à-vis la maternité ont été identifiés et classifiés en fonction des similarités (les écarts communs) et des différences (les écarts distincts) entre les participantes. Enfin, les expressions de fatigue physique et émotionnelle ont été relevées dans le discours de chacune des participantes afin de permettre la comparaison de ces expressions aux scores obtenus à la complétion de l'Échelle de Dépression Postnatale d'Édimbourg (EDPE) de Cox, Holden et Sagovsky (1987).

Caractéristiques des femmes rencontrées

Au moment de l'enquête, les douze participantes sont âgées de 26 à 35 ans. À l'exception de l'une d'entre elles, toutes sont mariées. Quatre participantes vivent avec leur conjoint actuel et père de l'enfant depuis plus de 5 ans. Onze femmes sur douze ont un diplôme universitaire dont dix d'entre elles ont un emploi à temps plein et une des participantes ayant un diplôme collégial a aussi un emploi à temps plein. Une seule est sans emploi, bien que détentrice d'un diplôme universitaire de droit dans son pays africain d'origine où elle travaillait avant de venir au Canada. Pour six d'entre elles, le revenu du couple s'élève à plus de 100 000 $ et varie plutôt entre 40 et 90 000$ pour quatre des participantes, (deux n'ont pas répondu à la question). Dix grossesses sur douze étaient activement programmées. Deux participantes, inquiètes de ne pas devenir enceintes au moment choisi, ont consulté un gynécologue, aucune toutefois n'a eu recours à la procréation médicalement assistée. Dans les dix cas où la grossesse était programmée, il s'agit, aux dires des femmes (leur conjoint n'a pas été interrogé), d'un « projet parental » mis en branle à un moment précis du parcours respectif des deux partenaires. Après les études, les voyages, la carrière et la stabilité financière, ils n'attendaient plus qu'un enfant et s'y sont préparés, notamment en s'inscrivant à des cours prénataux. Plus de la moitié des femmes[8] ont rapporté vivre un partage équitable des tâches avant l'arrivée du bébé. Ces mêmes femmes croyaient que ce partage serait adapté et maintenu à l'arrivée du nouveau-né.

La réalisation des trois entrevues a été très bien accueillie par les participantes. Certaines se préparaient au rendez-vous et se réjouissaient de « parler entre adultes », comme plusieurs l'ont exprimé. Ce qui constitue sans doute un indice de la relative solitude dans laquelle elles vivent les premiers mois de leur maternité. Il faut noter que la plupart d'entre elles sont venues vivre dans la région d'Ottawa en raison de leur travail, mais qu'elles n'y sont pas nées et leur famille est restée dans leur région d'origine. Parmi toutes les participantes, trois ne sont pas nées au Canada. Enfin, six couples n'étaient pas entourés de leurs familles au moment de la naissance.

Neuf des participantes avaient droit à un congé parental d'un an, ce qui est en liaison avec leur statut professionnel. Ce dernier aspect a échappé à notre vigilance lors de la phase préparatoire de l'enquête. Nous avions prévu réaliser trois rencontres avec chacune des participantes. Nous visions, lors de la troisième rencontre, à recueillir des données sur l'organisation de la vie familiale après le retour au travail de la mère, ce qui s'est révélé impraticable puisque la majorité des mères n'était pas de retour au travail à la troisième visite. D'autant que si plusieurs, avant la naissance, envisageaient de partager le congé parental avec le père, elles y renoncèrent par la suite ou réduisirent le temps dévolu au père en raison des difficultés rencontrées avec l'allaitement.

L'expérience des participantes

La grossesse

Les femmes rencontrées dans le cadre de cette étude sont des femmes de leur temps. Dès la première rencontre, elles expriment vouloir faire ce qu'il y a de mieux pour l'enfant qu'elles portent, puisqu'elles se sentent responsables de sa santé. Parmi les principaux changements et malaises physiques de la grossesse rapportés par les mères, toutes ont exprimé avoir vécu une plus grande fatigue que celle anticipée, surtout durant les trois premiers mois. Au niveau psychologique, la grossesse a semblé être un temps propice à la résurgence de conflits familiaux non résolus. Des manques affectifs ont été exprimés par certaines participantes. La relation de la gestante avec sa propre mère est reconsidérée au regard des prises de conscience et des nouvelles émotions que lui apporte l'expérience de la grossesse.

L'accouchement anticipé et l'accouchement vécu

Pour les participantes, l'accouchement demeure une expérience méconnue et angoissante, même après avoir suivi des cours prénataux. Selon leurs dires, l'expérience physique de l'accouchement est démontrée et quelque peu expliquée dans les cours prénataux, mais la préparation psychologique est oubliée.

> Catherine (les prénoms choisis sont fictifs) : « au cours prénatal, on nous a montré une vidéo sur dif-

> férents types d'accouchements (…) moi j'ai trouvé ça (sourire) pas très beau(…)j'en ai parlé avec mon amie qui a trouvé ça complètement horrible(…)on ne comprend pas pourquoi on nous fait voir ce genre de vidéo. Ça nous fait peur ! »

Toutes les femmes de cette étude avaient choisi d'accoucher à l'hôpital et toutes souhaitaient donner naissance « naturellement », soit sans épidurale. L'unanimité semble indiquer que telle est la valorisation mise de l'avant. Elles étaient néanmoins conscientes de la douleur reliée à l'accouchement et ne trouvaient pas nécessaire de souffrir à tout prix, c'est pourquoi elles demeuraient ouvertes à l'option de l'épidurale. Au final, seulement trois ont accouché sans anesthésie, huit ont fini par recourir à l'épidurale et une a subi une césarienne après de longues heures de travail. Toutes ont trouvé l'accouchement beaucoup plus difficile et douloureux qu'elles ne l'avaient imaginé.

Le rôle de mère

Au huitième mois de grossesse, l'arrivée du bébé et la transition à la maternité semblent difficiles à imaginer pour la majorité des participantes. Elles ont une vague idée des exigences liées aux soins du bébé et de ce que son arrivée va changer dans leur vie. Certaines craignent de ne pas être à la hauteur pour prendre soin de leur enfant parce que sans expérience ou presque avec les bébés.

À la deuxième rencontre, toutes insistent sur le fait que c'est exigeant de s'occuper d'un bébé. Alors que certaines craignaient trouver le temps long d'être à la maison, elles trouvent maintenant difficile de trouver du temps pour elles.

> Martine : « C'est certain qu'au tout début, j'étais surprise de la quantité de temps que je passais à prendre soin de ce bébé là (…) au travail (cette participante est médecin de famille), je pouvais pas croire les femmes qui me disaient qu'elles n'avaient pas le temps de prendre leur douche. Là, je le sais ». Stéphanie: « Je me sens un petit peu (…) pas prisonnière mais (…) c'est que je ne peux pas le laisser ».
>
> Hélène : « Oui, ben, ma vie tourne autour de l'allaitement (…) c'est sûr que changer des couches ce n'est pas extraordinaire (…) ».
>
> Catherine : « Ça prend vraiment du temps (…) s'occuper d'un enfant (…) je trouve qu'il prend quand même beaucoup de place, j'ai l'impression d'avoir perdu un peu de ma liberté quelque part ».
>
> Danielle : « La semaine passée j'étais tannée, pas tannée du bébé, mais tannée d'être à la maison… changer des couches, pis d'allaiter ».

Toutes sont unanimes sur le fait que ce n'est pas très intéressant un bébé durant les premiers mois. Plusieurs ont rapporté ne pas être devenues instantanément amoureuses de leur enfant dès sa naissance.

> Catherine : « J'avoue qu'au départ, c'est pas intéressant un bébé, ça prend de la place quand même. J'étais pas si attachée (…) c'est venu à partir de 4 mois (…) ».
>
> Bénédicte : « Il ne souriait pas, j'avais pas de (…) j'attendais cet instinct maternel (…) c'est juste depuis les dernières trois semaines que vraiment je… je suis en amour ».
>
> Véronique : « Des fois je me dis que c'est pour tout le temps ce bébé, ce n'est pas comme du baby-sitting, je me suis dit c'est vrai on est trois et c'est pour toujours! ».

La fatigue physique et émotionnelle

À la visite du deuxième mois, elles sont nombreuses à se dire très fatiguées et à manquer de sommeil. La plupart des participantes présentaient des signes de fatigue physique et ont rapporté avoir vécu des moments difficiles dans la ou les dernières semaines. Pourtant, les résultats à l'échelle de dépression postnatale d'Édimbourg ne reflètent pas les dires de ces participantes. Rappelons que le score obtenu à la complétion de cette échelle devait permettre une évaluation de l'état émotif de la cliente dans la semaine précédant la visite.

Si Martine obtient un score de 1/30 qui indique un état de bien-être idyllique, elle déclare pourtant au cours de l'entretien :

> Psychologiquement, ça m'a pris du temps à me remettre de l'accouchement. J'ai arrêté d'allaiter la semaine passée (soupir) il avait 7 semaines, ça n'avait pas de bon sens (…) j'avais pas de plaisir (…) il me semble que j'avais perdu confiance en moi (...) peut-être que je ne suis pas assez calme (…) je trouvais que j'étais pas compétente ».

Malgré son score de 7/30, Hélène dit :

> J'ai eu les blues (…) j'étais comme dépassée par les événements (…) je n'arrivais pas à gérer toutes ces nouvelles émotions (…) je pleurais tout le temps pour rien, j'étais super émotive (…) je voyais mon bébé et je pleurais (…) j'étais parfois angoissée d'être seule avec bébé.

Catherine quant à elle, obtient un score de 4/30 ce qui ne l'empêche pas de constater :

> Des fois c'est vrai que je me réveille le matin, je me dis bon ben, ça va continuer encore longtemps (…) l'allaiter et tout ça, le point de non retour (…) quand on réalise ça, ça fait un peu peur.

Chantal avec un score de 7/30 déclare :

> J'ai eu les blues (…) pendant les premières semaines,

> j'ai trouvé ça dur, j'avais la larme à l'œil tout le temps. Les deux premières semaines, j'étais épuisée, je déprimais, j'avais l'impression de ne pas être une bonne maman.

Évidemment, il faut noter que l'expression d'une importante fatigue physique et émotionnelle se concentre généralement dans les 10 à 15 jours suivant l'accouchement alors que la complétion de l'échelle s'est faite à la huitième semaine. Toutefois, il est tout de même important de rapporter que l'expression de leur vécu de nouvelle mère à la huitième semaine ne correspond pas aux résultats obtenus à l'échelle d'Édimbourg.

À la visite du sixième mois, les scores obtenus à l'échelle d'Édimbourg indiquent encore une santé physique et émotionnelle excellente. Stéphanie va parfaitement bien puisque son score est de zéro. Elle dit pourtant :

> C'est lourd par moment (…) des fois j'aimerais ça avoir une pause, pis que lui prenne la relève (…).

Alors que Catherine (5/30) établit un bilan globalement positif, mais nuancé :

> J'avais envie de savoir ce que c'était d'être mère, euh, d'être enceinte et tout ça. Bon, bien, je l'ai su là, puis, bon, je ne suis pas sûre de vouloir tout de suite recommencer quand même.

Cette incohérence entre les résultats obtenus à l'échelle d'Édimbourg et le discours des participantes révèle peut-être un certain malaise chez les nouvelles mères, à se donner le droit de reconnaître leur fatigue et leur détresse.

Changements anticipés et changements réels dans le couple

Pour la plupart des participantes, les principaux changements anticipés à l'arrivée du nouveau-né se résument ainsi : Comme couple, nous serons certainement moins libre et spontané, nous aurons moins de temps pour nous deux, la priorité sera l'enfant, même si une participante a dit à plusieurs reprises lors de la première entrevue : *« on a pas envie que bébé prenne toute la place »*.

À la visite du deuxième et du sixième mois, certaines ont exprimé leurs frustrations vis-à-vis leur conjoint :

> Stéphanie dit : « il arrive du travail souvent tard après souper (…) il se demande pourquoi j'ai pas fait le lavage (…) il ne réalise pas ce que ça représente de s'occuper d'un bébé ».
>
> Quant à Hélène : « On dirait que sa vie à lui n'a pas vraiment changé ».

Toutes les participantes rapportent que leurs moments d'intimité sont limités.

> Chantal précise même : « J'ai couché avec la petite au sous-sol pendant les 6 premières semaines pour qu'il puisse dormir ».

Avant la naissance de l'enfant, la majorité des participantes interrogées avait indiqué que leur conjoint partageait les tâches domestiques, surtout au niveau de la préparation des repas. Cependant, après l'arrivée du bébé, plusieurs femmes ont avoué prendre sur elles plus de tâches qu'auparavant et assumer la majeure partie de la charge mentale liée aux responsabilités familiales. En somme, le nouveau-né prend beaucoup de place, toutes les activités de la mère gravitent autour de lui. La solitude des mères se fait sentir pendant que le couple semble se retrouve en suspens.

L'allaitement : l'expérience la plus difficile dans la transition à la maternité

Selon les données recueillies auprès des participantes de l'étude, c'est au niveau de l'allaitement que l'écart est le plus grand entre le vécu attendu et le vécu réel de l'expérience de la maternité. L'expérience de l'allaitement rapportée par les mères rencontrées est loin de l'idéal promu par l'OMS, l'UNICEF, relayés par Santé Canada, l'Agence de la santé publique du Canada, la Société canadienne de pédiatrie et les diététistes du Canada.

Depuis plus de 30 ans, l'allaitement maternel fait l'objet d'une promotion institutionnalisée en matière de santé maternelle et infantile. Les organismes internationaux comme l'OMS et l'UNICEF et Santé Canada considèrent l'allaitement maternel comme la méthode optimale d'alimentation des nourrissons en raison de ses effets bénéfiques sur la croissance, l'immunité et leur développement cognitif.[21-23] L'Agence de la santé publique du Canada, Santé Canada, la Société canadienne de pédiatrie et les diététistes du Canada recommandent l'allaitement exclusif pendant les six premiers mois du nourrisson né à terme et en bonne santé, l'introduction d'aliments complémentaires ensuite tout en poursuivant l'allaitement jusqu'à deux ans et plus.[22] Il est également mentionné que l'allaitement permet le développement et le maintien d'une « relation spéciale » ou « relation d'amour durable » avec son bébé.[24,25] Enfin, l'allaitement maternel est présenté comme faisant partie de l'« expérience complète » de la maternité puisqu'il est tenu pour avoir des effets bénéfiques sur la santé physique et psychologique des mères.[21-23]

Le choix d'allaiter

Au 8^{e} mois de grossesse, toutes les participantes de l'étude étaient déterminées à allaiter leur enfant. Ce choix semblait naturel. Aux questions sur leurs motivations, elles répondaient, avec une belle unanimité, qu'on leur avait dit, aux cours prénataux, que « *c'est bon pour le bébé* ». Dès lors, deux futures mères exprimaient le sentiment d'avoir subi une certaine pression des professionnelles de la santé pour allaiter.

> Selon Sandrine : « Je pense qu'on nous a assez rempli l'esprit que c'est la meilleure des choses (…) alors, c'est ce que je vais faire. »
>
> Quant à Hélène, son dire est plus radical : « Il faut que je parle de la mafia de l'allaitement (…) je trouve que dans les cours prénataux, on a énormément de pression pour allaiter (…). »

La promotion de l'allaitement maternel et la participation aux cours prénataux les avait persuadées que pour « *être une bonne mère* », elles devaient allaiter leur enfant parce que c'est ce qu'il y a de mieux pour leur bébé.[26,27]

Selon les lignes directrices nationales de Santé Canada (2000), pendant la grossesse les professionnels de la santé doivent expliquer aux futures mères que :

> L'allaitement et les préparations lactées pour nourrissons ne constituent pas des choix équivalents. Ils doivent s'assurer que les femmes et les conjoints connaissent les avantages de l'allaitement et les risques liés à l'utilisation de préparations pour nourrissons.[28]

Ainsi pour plusieurs femmes, la décision d'allaiter ne constitue pas un « véritable » choix ou une décision complètement « délibérée ». Car même si la majorité des femmes sont d'avis que « donner le sein est meilleur »,[29] elles sentent néanmoins une pression sociale pour allaiter et croient qu'elles seront perçues comme une « mauvaise mère » si elles choisissent de nourrir leur bébé autrement.[29] Sans considération pour leur situation particulière, les futures mères sont donc contraintes de choisir l'allaitement pour se conformer aux attentes sociétales.[30]

La préparation à l'allaitement

Pour la plupart des femmes y compris les participantes de la présente étude, la préparation à l'allaitement consistait à s'informer et à se documenter sur le sujet auprès des professionnels de la santé surtout dans le cadre des cours prénataux, mais aussi par des lectures et des discussions avec des amies ou des femmes qui ont déjà allaité.

> Bénédicte raconte : « j'ai décidé de nourrir (…) ça m'inquiète un peu, je connais personne qui a allaité dans mon entourage (…) j'ai regardé la vidéo de Dr. Newman, pis j'ai lu le livre (…) je suis allée à une rencontre de la ligue La Lèche. »
>
> Stéphanie semble moins convaincue : « allaiter c'est mon premier choix, par contre je ne me fais pas d'idée (…) étant donné mon historique (…) ma mère n'a jamais été capable d'allaiter. »
>
> Hélène veut essayer : « je veux essayer, mais j'essaie de ne pas trop me mettre de pression parce que je trouve que dans les cours prénataux ils nous en mettent beaucoup (…) je vais faire ce que je peux (…) mais je ne sais pas vraiment à quoi m'attendre. »

Dans le matériel promotionnel, l'allaitement maternel est généralement associé à tout ce qu'il y a de plus facile et naturel et ce, en dépit des difficultés, souvent minimisées, auxquelles des solutions donnant toujours l'impression d'être très simples, sont apportées.

D'ailleurs, le thème choisi pour la semaine de mondiale de l'allaitement en 2010 est révélateur : « Seulement 10 petits pas! L'allaitement rendu facile ».[31] Depuis 2006, le ministère de la santé et des services sociaux du Québec [32] publie chaque année dans des journaux locaux, un guide sur l'allaitement maternel dont le titre tout aussi éloquent est : « L'allaitement, c'est tout naturel ! »

Le fait d'associer l'allaitement à un geste naturel a pour effet de le délier d'un apprentissage. Ainsi, lorsque les femmes reçoivent le message que l'allaitement est naturel certaines croient qu'elles n'ont pas besoin d'apprendre à allaiter. Pourtant, même si toutes les femmes de notre étude étaient bien documentées, les premières semaines de l'allaitement ont exigé un apprentissage important et parfois difficile pour toutes les participantes.

L'apprentissage de l'allaitement durant les premiers jours de la période postnatale

Afin de favoriser le succès de l'allaitement maternel, les lignes directrices nationales de Santé Canada [28] recommande d'adopter les mesures suivantes : Allaiter tôt, soit dans la première demi-heure après la naissance, encourager des tétées fréquentes sans restriction, et guidées par le bébé, réveiller le bébé somnolent au besoin, encourager la cohabitation mère enfant durant tout le séjour à l'hôpital, aider à trouver une position adéquate et à prendre le sein et favoriser l'allaitement exclusif. Les bébés nourris au sein ne devraient recevoir aucun aliment ni aucune boisson autre que le lait maternel, sauf si des conditions médicales l'exigent. Les sucettes et les tétines devraient être évitées surtout durant l'établissement de la lactation. Toutes ces mesures démontrent que l'on semble d'abord préoccupé par le bien-être du bébé plutôt que par celui de la mère.

> Pour plusieurs, les débuts ont été difficiles, Sandrine : « le plus difficile c'était les premiers jours de

> l'allaitement (…) ici, on essaie de nous mettre en boîte (…) y sont trop rigides dans leur façon de voir l'allaitement (…). »
>
> Quant à Geneviève : « ça dépend des infirmières (…) elles ne disent pas toute la même chose (….)».
>
> Et Chantal : « c'est qu'à l'hôpital à chaque trois heures, il te réveille pour allaiter la petite (…) pis y en a une autre qui arrive pour prendre ta pression (…) ça finit que t'a vraiment hâte de partir. »
>
> Enfin Véronique : « j'ai trouvé que j'ai pas assez eu d'aide à l'hôpital (…) elle me le mettait au sein pis elle disait : c'est bien, c'est comme ça qu'il faut faire, pis elle partait tout de suite. »

Le séjour abrégé à l'hôpital des nouvelles mères influence grandement le succès de l'allaitement et le suivi. Il faut généralement compter jusqu'à quarante-huit heures pour que l'allaitement d'un nouveau-né en santé soit bien établi. La durée moyenne du séjour à l'hôpital a été de 48 heures pour presque toutes les participantes. Toutes les femmes ont trouvé leur séjour à l'hôpital peu reposant, parfois même stressant et avaient hâte de retourner dans la tranquillité de leur foyer. Leur court séjour à l'hôpital, le manque de personnel et/ou son indisponibilité n'ont pas permis aux participantes de bien démarrer l'allaitement.

L'expérience de l'allaitement telle que vécue par les participantes

Toutes les participantes de l'étude ont allaité leur enfant et elles sont unanimes, même si certaines ont eu un accouchement laborieux et douloureux, à considérer que l'allaitement est l'épreuve la plus marquante dans la transition à la maternité. Cette épreuve se décompose en plusieurs sous - épreuves difficiles à surmonter. Il y a d'abord les malaises physiques et l'inconfort.

> Écoutons Martine : « J'ai trouvé ça difficile (…) j'avais extrêmement mal aux mamelons après le boire ».
>
> Hélène : « J'avais peur de la mettre au sein (…) j'avais mal aux mamelons (…)».
>
> Danielle : « Le début était pas facile (…) ça faisait mal (…) mes seins coulaient beaucoup (…) je dormais avec une serviette autour de moi (…) c'était ridicule (…). »

Il y a ensuite la technique de l'allaitement qu'elles maîtrisent mal au début et qui atteint leur confiance dans leur capacité d'allaiter.

> Ainsi Geneviève : « L'allaitement a été terriblement difficile (…) je suis revenue avec les attentes de l'hôpital qui étaient : il faut que ça soit 15 minutes d'allaitement par sein (…). Mon petit, il fait peut-être ça maintenant (à l'âge de deux mois), pis pas tout le temps, donc pour un bébé naissant, c'est vraiment pas réaliste (…) la panique par rapport à ça était plus grande que nécessaire (…) ».
>
> La même précise encore : « (…) quand tu allaites en football, tu ne vois pas la lèvre inférieure, la lèvre inférieure rentrait tout le temps, je pense que c'était ça mon plus gros problème, ça m'a pris du temps avant de réaliser ça (…) c'était souffrant en attendant ».
>
> Quant à Chantal : « Au début, j'avais de la misère, elle ne prenait pas bien le sein. L'infirmière a été me chercher une téterelle. Des fois, ça marchait, des fois, ça ne marchait pas ».

D'autres s'inquiétaient pour le bébé qui avait une faible succion, buvait trop lentement ou s'endormait au sein. Ou encore qui consommait une quantité de lait trop faible à chaque tétée.

> Ainsi Stéphanie : « J'avais l'impression que je n'avais pas assez de lait. On n'était pas sûr s'il faisait pipi ».
>
> Et surtout Véronique : « Il a perdu 8 % de son poids. Là, ils m'ont dit : ''vous savez, il faut lui donner un complément, parce que 8 %, c'est la phase critique, après 10 %, l'enfant est hospitalisé.'' Donc évidemment, j'ai commencé à pleurer, voilà, là, j'ai trouvé que (…) je n'ai pas été entourée à ce moment-là. On m'a fait peur. (…) et puis j'ai dû lui donner un biberon, ce que je ne voulais pas. Donc, ça fait un peu beaucoup, pis, après, j'ai trouvé que je n'ai pas bien été suivie, quoi (…) ».

L'allaitement est évidemment « chronophage ». Pour respecter et faire respecter les normes de l'OMS et de l'UNICEF (1990), à l'hôpital, une infirmière doit enjoindre la nouvelle accouchée de commencer à allaiter dans la première demi-heure qui suit la naissance, d'encourager des tétées fréquentes sans restriction et sur demande.

> Écoutons une autre fois Geneviève : « La quantité de temps qu'on passe à allaiter dans une journée ! Au début, je passais peut-être 14 heures de ma journée à allaiter. C'est fou, là. Je n'ai pas le temps de manger, j'ai pas le temps d'aller à la salle de bain, j'ai pas le temps de me laver une pomme, j'ai le temps de rien, rien, rien. Ça c'était un choc ».
>
> Chantal n'est pas mieux lotie : « J'ai trouvé ça extrêmement difficile dans le sens que ça lui prenait à peu près une heure à boire. Il fallait que je le nourrisse aux heures ».
>
> Quant à Bénédicte : « Les boires sont très rapprochés, aux 2 heures, parfois même aux heures. (…) Ça n'a pas de sens. J'étais frustrée. J'ai commencé la bouteille avec mon lait à 4 mois (…) j'ai pu sortir un peu ».
>
> Danielle a tranché un peu plus tôt : « Il mangeait beaucoup (…) ça n'arrêtait pas. Il y a des jours où je l'avais au sein tout le temps (…). Là, cette semaine, (à huit semaine de vie) j'ai décidé d'introduire de la formule (…) pour avoir un plus de liberté ».
>
> Une participante exprime même l'impression d'être

> réduite à être un biberon. Comme le dit Stéphanie : « je me sens prisonnière ».

Le « choc de l'allaitement » à l'hôpital et surtout lors du retour à la maison quelques heures plus tard est important. Les participantes n'étaient pas préparées à ce qui leur arrivait, bien qu'elles aient suivi des cours prénataux. D'ailleurs, aucune des participantes ne fait référence aux cours prénataux comme source valable de préparation à l'allaitement. En termes de préparation, certaines participantes avaient fait des lectures et/ou regardé une vidéo à propos de l'allaitement, d'autres avaient assisté à une rencontre de la Ligue La Lèche. Lors de la première rencontre, au 8e mois de la grossesse, elles paraissaient plus angoissées par l'accouchement proche que par l'allaitement. Si plusieurs se disaient un peu inquiètes : « on n'a pas de modèles » c'est que d'une part, elles n'ont pas eu la chance de voir, dans leur entourage, des mères allaiter leur enfant et que d'autre part seulement 2 % de leurs mères, dans les années 1970, ont choisi l'allaitement maternel.[33]

> Stéphanie: « J'ai surtout lu (…) je connais personne autour de moi qui a allaité. Je suis confiante. Ce n'est pas quelque chose qui m'angoisse (…) c'est quelque chose de beau. Je trouve ça beau ».
>
> Quant à Véronique, elle souhaitait faire d'une pierre deux coups : « Je veux allaiter parce que c'est bon pour le bébé et (…) ça va me faire perdre du poids ».

Face au « choc » de l'allaitement, plusieurs participantes ont tenté d'obtenir des conseils et de l'aide auprès de « spécialistes de l'allaitement ». Le jugement d'Hélène est sans doute le plus sévère, parce qu'il exprime d'un seul tenant ce que d'autres rapportent par bribes. Lisons le :

> Quand j'allais voir les consultantes en allaitement, des fois, elles nous aident, mais des fois elles nous font énormément de pression pour qu'on continue, pour qu'on pousse, je n'ai pas l'impression d'être tout le temps soutenue dans mon choix, mettons d'arrêter. Je trouve que ça manque un peu, beaucoup d'ouverture. L'allaitement mixte est mal vu (…).

Hélène poursuit en reprenant un terme qu'elle a déjà utilisé à la rencontre précédente :

> Il faut que je parle de mafia de l'allaitement (…) on a énormément de pression pour ne pas lâcher (…) pis, même des fois, ma marraine d'allaitement disait : '' Tu ferais tellement une bonne marraine d'allaitement !'' Mais moi je ne veux rien savoir de ça !

Quatre participantes ont cessé l'allaitement avant les 6 mois prescrits. Les unes l'attribuent à un manque de capacité de leur part.

> Ainsi Stéphanie : « Je pense que c'est juste moi là-dedans : le fait que je ne produisais pas assez de lait.
>
> J'ai cessé de l'allaiter à deux mois et demi. »

D'autres ont le sentiment de ne s'être pas acquittées de leur devoir.

> Ainsi Martine : « Je suis contente d'avoir allaité jusqu'à 6 semaines (…) j'étais tellement convaincue et je voulais tellement le faire (…) Je n'étais tout simplement pas capable d'arrêter avant. Je le faisais par obligation (…) Je ne pouvais pas me permettre de ne pas allaiter (…) j'ai l'impression d'avoir échoué ».

Les effets pervers de l'écart entre le vécu attendu et le vécu réel de la maternité

Donner naissance est un événement marquant dans la vie d'une femme. C'est une expérience corporelle et émotive intense dont elle se souviendra toute sa vie. Dans le milieu de la santé, on oublie trop souvent qu'accoucher est d'abord un événement personnel et intime avant d'être un événement médical. Les participantes de l'étude se sont dites bien informées sur la physiologie de l'accouchement mais insuffisamment préparées, psychologiquement. La plupart ont révélé avoir été anxieuses, ne sachant pas comment réagir et composer avec la douleur au moment de l'accouchement. L'anxiété affecte souvent et de façon négative le déroulement du travail et de l'accouchement, l'expérience médicale l'emporte alors sur l'expérience intime. Les témoignages des participantes sur l'expérience de l'accouchement soulèvent le besoin d'une meilleure préparation aux émotions de la mise au monde au moment de donner naissance.

Aucune des participantes de l'étude n'avait imaginé qu'il soit si exigeant et épuisant de s'occuper d'un nouveau-né, ni à quel point son arrivée allait changer sa vie. Face à un tel constat, les mères se retrouvent confrontées à une impasse : soit elles ont le sentiment d'avoir été dupées par rapport à tout ce qu'on leur avait fait miroiter sur la maternité et qu'elles ne peuvent réaliser, soit elles ne se sentent pas à la hauteur de leur nouveau rôle. Dans un cas comme dans l'autre, cette impasse entraîne une fatigue psychologique que plusieurs femmes tenteront de surmonter pendant longtemps, trop longtemps. La maternité est devenue une obligation de compétence et de performance. Trop de femmes se donnent à leurs enfants au détriment de leur santé.[16] De plus, encore aujourd'hui, les mères continuent non seulement de porter leurs enfants, mais continuent également d'en porter quotidiennement, la « charge » mentale, bien plus largement que les pères. Les mères se sentent écartelées, divisées, épuisées et culpabilisées. Dans le monde du travail, on fait comme si les femmes n'étaient pas aussi des mères, et partout ailleurs on fait comme si les mères n'étaient plus des femmes. Les femmes réclament l'espace, le temps et les mesures sociales pour vivre positivement et de façon équilibrée leur double inscription dans le privé et dans le social.[15] Il faut secouer l'institution de la maternité et exiger une organisation sociale plus humaine, une harmonisation des rythmes professionnels et personnels et un allègement des stéréotypes masculins et féminins.

Parmi les données recueillies à l'issue des entretiens qui se sont échelonnés sur sept mois pour chacune des participantes, l'allaitement semble constituer l'expérience la plus dévastatrice dans l'apprentissage de la maternité. Aujourd'hui, l'allaitement est considéré comme un droit de l'enfant, la mère n'a donc pas son mot à dire. D'ailleurs les hôpitaux qui prônent l'allaitement sont « amis des bébés » pas forcément « amis des mamans ». Pour reprendre ici les mots d'Yvonne Knibiehler : « La grossesse et plus encore l'allaitement constituent des moments privilégiés de moralisation ».[14] Contrairement à la grossesse, l'allaitement n'est pas obligatoire pour la mère en devenir, ce qui déstabilise la société qui compense par une pression encore plus forte.

L'allaitement en soi n'est pas à critiquer, ses bienfaits sont incontestables tant pour l'enfant que pour la mère. Ce qu'il faut critiquer ce sont les pressions, les injonctions et les normes qui sont imposées aux femmes et qui les culpabilisent. Les femmes méritent de pouvoir accéder à des informations nuancées, objectives et non culpabilisantes afin de décider si elles allaiteront ou pas, de la même manière qu'elles peuvent aujourd'hui décider si elles ont ou non des enfants.

Selon Penny Van Esterik, Américaine féministe et militante de l'allaitement, les groupes féministes devraient intégrer l'allaitement dans leurs luttes pour plusieurs raisons : l'allaitement suppose des changements sociaux structurels qui amélioreraient la condition des femmes; l'allaitement affirme le pouvoir de contrôle de la femme sur son propre corps et questionne le pouvoir médical; l'allaitement s'oppose à la perception du sein comme étant d'abord un objet sexuel; l'allaitement exige de redéfinir le travail des femmes en tenant compte à la fois de leurs activités productives et reproductives d'une façon plus réaliste; enfin, l'allaitement encourage la solidarité féminine et la coopération entre les femmes d'ici et d'ailleurs.[34]

En conclusion, les témoignages des femmes interrogées dans cette étude révèlent que l'expérience intime de l'accouchement est troublante, que les exigences liées aux soins du nouveau-né sont sous-estimées et que l'expérience de l'allaitement est culpabilisante. Les témoignages des participantes de cette étude nous forcent à reconnaître que l'entrée en maternité est socialement et médicalement encadrée au détriment du bien-être de la femme dans cette expérience si personnelle et intime.

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