Patient Advocacy, Drug Promotion, and the Feminist

Paradox: An Analysis of the Canadian Pain Coalition

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Abstract

Healthcare has changed significantly over the past few decades with the emergence of neoliberalism as a dominant ideology informing policy. This paper examines the Canadian Pain Coalition's (CPC) conceptualization of chronic pain and its treatment in the context of neoliberalism. Through content analysis of the CPC's online materials, we show how the advocacy group constructs pain as an individual's responsibility and a physical disease that can be managed primarily with pharmaceutical medication. Drawing on insights from the social determinants of health and feminist literatures, we suggest that the CPC's construction of pain as a physical disease, an individual responsibility, and its emphasis on pharmaceutical treatment is inadequate in addressing the complex social, economic, and physical needs of people living with chronic pain. Taking up Susan Markens' concept of the "feminist paradox," we suggest that there is a necessary tension in the construction of pain as disease. On the one hand, it is constructed in terms of providing access to treatments, while on the other, it potentially medicalizes people living with chronic pain. Finally, we discuss how the CPC does not adequately address the side of the tension concerning medicalization, given the strong association between the CPC and the pharmaceutical companies.

Key words: neoliberalism, feminism, social determinants of health, chronic pain, pharmaceuticals, patient advocacy groups

Introduction

Healthcare has changed significantly over the past few decades with the

emergence of neoliberalism as a dominant ideology informing public policy. This

perspective encourages a market approach to health, commodifying healthcare

and constructing patients as health "consumers" who freely choose which treatment or cure is most appropriate for their illness. In this context, people are represented as individual, autonomous actors, separated from their relationships to their work and social lives. The market-based approach to health in the context of neoliberalism conflicts with support for public social infrastructure and neglects the social determinants of health. The market-based approach promotes the privatization of aspects of health determinants, such as water, education, housing and waste, and unemployment protection (Armstrong and Armstrong, 1996). This approach also supports an increasing influence of the pharmaceutical industry in healthcare services as part of a broader trend towards public-private partnerships in the delivery of health services. Because neoliberal policies emphasize a marketbased and individualistic approach to health and healthcare, illness tends to be depoliticized and reduced to treatable diseases rather than to be seen as a public health problem influenced by a myriad social forces.

Through an examination of a Canadian-based patient advocacy group that receives funding from pharmaceutical companies, we seek to explore an organization's conceptualization of chronic pain in the context of neoliberalism. According to results from the 2007/2008 Canadian Community Health Survey, about 1 in 10 Canadians aged 12 to 44 – 9% of males and 12% of females, an estimated 1.5 million people—experienced chronic pain. The prevalence of chronic pain increased with age and was significantly higher among people in households where the level of educational attainment was low and among the Aboriginal population (Ramage-Morin and Gilmour, 2010). This statistic demonstrates first, that chronic pain is a widespread problem in Canada, and second, that chronic pain affects people disproportionately according to their gender, race, and class. The feminist literature on chronic pain supports this contention that it is gendered, raced, and classed (e.g., Bendelow, 1993), but this fact has not translated into some of the most prominent advocacy work done on chronic pain, such as that of the Canadian Pain Coalition (CPC). We find this concerning given the history of women's health issues being ignored or misrepresented and given that people living with chronic pain may be treated as a captive market for corporations that aim to make a profit from treating illness. This paper examines the online written content of the CPC's website (including promotional and pain management materials). The CPC's written materials suggest that pain is an individual responsibility and a physical disease that can be managed primarily with proper medication. The organization's materials do not recognize the social determinants of pain, nor do they sufficiently address gender and chronic pain. Despite this omission, they receive significant funding from the pharmaceutical industry. We will address the complexity of these features of the CPC in relation to chronic pain with the use of feminist literature, and we will raise concerns about this form of patient advocacy.

Methods

We conducted a content analysis of the Canadian Pain Coalition's (CPC) website in 2010 (<u>www.canadianpaincoalition.ca</u>). We analyzed all available material on the CPC website during the months of September and October in 2010, including "Home," "About," "Grants," "Participate," and all materials related to "National Pain Awareness Week." We also analyzed materials posted on the website, including the CPC Charter (<u>CPC, 2010, "The Charter</u>"), and a booklet entitled "Conquering Pain for Canadians" (CPC, 2010, "Conquering Pain booklet").

Literature Review

There is little sociological literature specifically dealing with chronic pain. We draw on literature from the Social Determinants of Health, critiques of medicalization, and feminist literature on gender and pain to argue that chronic pain cannot be understood solely as a physical phenomenon – that understanding the social factors causing chronic pain and influencing the experience of this condition are key to providing useful advocacy for those living with chronic pain. This literature challenges us to question how chronic pain has been constructed by the CPC, and what impact this construction can have on patients.

Pain as Disease

Since the 1960s and 1970s, critical health scholars (e.g., Illich, 2002; Zola, 1972) have written about the expansion of medicine's control over the everyday

lives of people through the transformation of social conditions into medical problems. A key critique within the medicalization literature is that the reduction of complex social, cultural, and environmental conditions to conditions of individual pathology effectively upholds medical authority and the pre-eminence of the biomedical model of disease. A biomedical model of disease, which assumes a mechanistic body and an objective physical location of disease, is further challenged by phenomenological accounts of disease (Kleinman, 1988; Good, 1992; Good, 1994) and social constructionist approaches to illness (Lorber and Moore, 2002). The assumption that all diseases should have objective physiological indicators renders conditions or symptoms that lack a physiogenic cause questionable. In order for pain to be understood and expressed within this biomedical model, the subjective experience of pain must be transformed into an objective medical problem (Good, 1992). Kleinman (1988) and Good (1994) argue that a biomedical model which reduces illness to a physical condition or disease is not only inadequate in scope, but also focuses attention on the physical condition rather than on the person.

Furthermore, Lorber and Moore (2002) argue that illness is a social condition rather than a medical one; that is, while they do not deny the physiological changes that often accompany an illness, they argue that what constitutes illness or disease is not a physiological change or marker, but the inability to maintain social functioning. This social constructionist definition of

illness recognizes that social context and environment have as much to do with constituting illness and disease as does individual physiology or pathology. Feminist and critical scholars have also shown how medicalization is exercised in gendered, racialized, and classed ways (e.g. Lorber and Moore, 2002; Markens, 1996). Moreover, Bendelow (1993) has demonstrated how gendered assumptions regarding pain tolerance have resulted in women receiving inadequate treatment by physicians. This literature foregrounds the various social factors that shape conditions of health and illness.

Social Determinants of Health and Chronic Pain

The Social Determinants of Health (SDH) literature has challenged the singularity of the biomedical model's focus on the individual body. Scholars writing in this field argue that a reductive biomedical model does not account for social factors that contribute to health inequalities and illness (Raphael, 2006; 2008). According to Raphael (2006), the term "social determinants of health" emerged as scholars sought to understand the mechanisms underlying the health disparities among different socioeconomic groups in a given population. Social determinants of health refer to social and economic resources available to different groups including: income, food, housing, education, employment, and working conditions. Despite the abundant evidence that decreasing disparity among socioeconomic groups improves health for the population, Raphael (2006) argues that health policy makers in Canada have been slow to address these

societal factors. He suggests that this reticence by policy makers is related to the individualist approach of public health strategies which are based on biomedical and epidemiological traditions that conflict with a structural approach to understanding health and its determinants.

To date, there is little SDH research that focuses specifically on chronic pain. One exception is Goldberg and McGee's (2011) insightful work in which they make important links between chronic pain and social determinants of health such as employment, socioeconomic status, neighbourhood, and education. Drawing on broader SDH literature, the authors argue that the severity and frequency of chronic pain are more pronounced for disadvantaged or marginalized groups. Rather than viewing chronic pain solely from a biomedical model, the authors argue for addressing the social factors that contribute to this condition. They suggest that without broader social policies that address things such as proper nutrition, secure employment, and safe housing, the needs of people living with chronic pain will continue to go unaddressed. While the field very usefully points to the social factors affecting health, it is often uncritical of the way in which diseases come to be constructed as a medical issue. While the SDH literature can be useful in arguing that there should be better recognition of health problems and better access to health services based on social location, other critical scholarship has investigated the implications of labeling conditions 'diseases' and thus bringing them under medical expertise.

The Feminist Paradox

Feminist health scholars have explored the advantages and disadvantages of having a condition named as a disease and thus medicalized. This work is helpful in critically addressing the CPC's construction of chronic pain. Susan Markens (1996) introduces the idea of the "feminist paradox" in her analysis of the medicalization of premenstrual syndrome. She writes:

"That accounts of women's experiences of PMS figure prominently in the rhetorical legitimation of PMS as a medical phenomenon poses a challenge to feminists because they critique the lack of attention to women's health problems by the medical establishment and are, at the same time, skeptical of how women and the female body are understood and described when the complaints of women are taken seriously. It is this paradox that causes conflict among feminists" (p. 43).

We suggest that both sides of this feminist paradox must be considered when examining the work of the CPC and it's scholarship on chronic pain. On the one hand, feminists writing on chronic conditions with parallels to chronic pain argue for a biomedical diagnosis for chronic conditions in order to have women's pain legitimated. Similarly then, we suggest that the construction of chronic pain as disease provides women and marginalized others living with pain, access to medical attention and treatment.

While there is no specific feminist work on chronic pain, feminists have examined conditions such as chronic fatigue syndrome (CFS), fibromyalgia (FMS), and endometriosis. While endometriosis is a condition diagnosed in biological females, CFS and FMS are highly gendered conditions in which

women receive diagnoses in greater number than men. All three conditions also have chronic pain as a key symptom. Much of the feminist work on these conditions emphasize the need for women's accounts of chronic pain to be taken seriously by physicians and the biomedical legitimacy of their pain accounts. Feminist theorists have noted that women have often had their pain symptoms under-recognized, dismissed, or posed as 'natural.' Women have had the credibility and legitimacy of their self-reports of pain and discomfort questioned in the case of conditions such as fibromyalgia (Werner and Malterud, 2003), chronic fatigue syndrome (Asbring and Narvanen, 2002), undefined forms of pain (Johansson et al., 1999), and endometriosis (Denny, 2009). Many feminist scholars writing in response to the dismissal of women's subjective reports of physical pain have foregrounded women's experiences and have shown the effects of their dismissal on women and their health. Caplan (2001) and Cahn (2003) provide first-hand accounts of living with CFS, thus challenging those, including other feminists, who argue that CFS is solely a psychogenic condition and not a physical one. Cahn (2003) describes how lack of acknowledgement of CFS as a physical disease led others to identify her as "mentally ill" and Caplan (2001) experienced judgment and alienation by co-workers and friends. In some cases, because many physicians assume that CFS or FMS are psychogenic conditions, the therapeutic treatment that women receive is limited to psychotropic drugs (Caplan, 2001).

Many feminist scholars also emphasize how obtaining a medical diagnosis enables women to access treatment and services that were previously denied. For example, White, Lemkau and Clasen (2001) recognize the ambiguity of the diagnostic criteria for FMS; however, they argue for its application because the medical legitimacy granted by a diagnosis improves access to medical treatment and insurance benefits for women. Crooks, Chouinard and Wilton (2008) show that women actively negotiate an FMS diagnosis and identity in order to access ODSP, disability insurance in Ontario, Canada. An FMS diagnosis establishes the woman as "disabled enough" and entitles her to state benefits linked to recognition of her inability to maintain paid employment. Conversely, without this diagnosis, women lack the basis on which to make claims on the state and thus are not eligible for benefits based on their physical pain. While this body of feminist literature is effective in arguing for the need for the medical community to take women's accounts of chronic conditions and pain seriously, it neglects to provide a critique of medicalization or of the marketing of treatments for women's illnesses.

Broader feminist critiques in health argue against medicalization, overmedication, and the erasure of subjective experiences of illness. Applying the other side of the feminist paradox to chronic pain we suggest that when gender, race, class and ability are ignored, the experiences of pain are falsely universalized and treatment approaches can be reductive and inappropriately

simplified. In the context of neoliberalism and the political clout of large pharmaceutical companies, universalized treatment often means prescription drugs.

Feminist scholars critical of medicalization argue that women's health and bodies have been objectified and pathologized by the medical establishment. This has not necessarily resulted in better health for all women. Moreover, they argue that medical technologies have been used to control and govern women and their bodies. There is an extensive and troubled history of pharmaceutical remedies for women's health issues. The pharmaceutical industry has also profited greatly from defining conditions, such as PMS and menopause, as diseases that need to be cured with pharmaceutical remedies. While in some cases pharmaceutical solutions for women's health conditions have been helpful, in many cases they have had contradictory repercussions. For instance, while the contraceptive pill has been welcomed by many women as an effective and even liberating method of birth control, it's early and even some recent compositions such as Yasmin and Yaz have had serious adverse side-effects for some women (Johnson, 2011).

Analysis

The CPC was formed in May 2002 as a partnership of eight patient groups and individual patients. It is associated with the Canadian Pain Society – a 900member professional organization of clinicians and researchers. According to its website, its mission is to "promote sustained change and improvement in pain

management in Canada," (CPC, 2010, "About Pain Awareness Week") and its primary goal is to have the public and professionals recognize chronic pain as a disease in order to increase funding for research on pain, specifically on new treatments for intractable or chronic pain (CPC, 2010). The CPC Charter states, "pain in Canada is an epidemic" (CPC, 2010, "The Charter") and that patients are; entitled to have their reports of pain taken seriously, receive compassionate and sympathetic care, have treatment/care, follow-up, and periodic reassessment, actively participate, or have their parents or caregivers participate in their treatment plan development, gain timely access to best-practice care, and gain adequate information in order to consent to their treatment (ibid). While these entitlements do not necessarily seem to be at odds with those argued for by critical social scientists, a closer examination of how they construct chronic pain and the types of treatment they recommend suggest that the CPC's conceptualization of pain is reductively physical with an emphasis on pharmaceutical treatment.

The CPC offers information and education on its website in the form of a booklet titled, "Conquering Pain for Canadians" (CPC, 2010, "Conquering Pain booklet"). This booklet is made up of seven topics, each posed as a question. Three of the seven topics deal with healthcare professionals and/or medication. The question, "How should I talk to healthcare professionals about pain?" instructs patients not to ignore their pain, but to establish a "partnership" with a

healthcare professional. They establish that a physician is the first person to approach regarding pain management and they suggest describing pain according to single word adjectives such as "throbbing, stabbing, burning" and an intensity scale ranging from 0-10 (CPC, 2010, "How should I talk to healthcare professionals?"). The question, "Are there things I can do besides taking medication that can help my pain?" is itself phrased with the assumption that medication is the first response to pain. In their response to this question, the CPC writes that pain is best managed when medication is combined with nonpharmacological options such as "massage, heat, cold, and topical analgesic creams." Not only are these non-pharmacological options solely focused on the individual body, but the CPC is advocating for alternative treatments in addition to, not instead of, medication (CPC, 2010, "Are there things I can do?"). Lastly, in answer to "What about pain medications?" there is a clear emphasis on taking medication for pain. They write that a patient should not wait until the pain is "really bad" before taking medication, because "pain medications are an important part of treating your pain" and "it is important to treat your pain as early as possible." They write that pharmaceutical medication can be used for mild to severe forms of pain. In other words, medication is not the last, but the first line of treatment for all pain. For those concerned about addiction, the website claims not only that addiction to opioids used to treat chronic pain is uncommon, but that, "A physical dependence on opioids for pain relief is not

addiction." This is perhaps the most compelling 'push' towards medication. Until very recently, in order to allay widely held concerns regarding addiction to pain medications, the CPC has defined addiction so that physical dependence on opioids no longer signals addiction (CPC, 2010, "What about pain medications?").

The remaining three questions are not focused on medications. They outline how pain can affect a person's mental wellbeing, sleep patterns, relationships, ability to work, posture, mobility, and lifestyle choices. The CPC's description of how pain can influence a person's life is very individualized, and emphasizes 'lifestyle' as a personal choice. In answer to the question "What are the Effects of Pain on my body? Can I do anything myself?" the CPC suggests an exercise routine such as swimming or yoga. There is no mention of the kind of work a person does and whether this might be contributing to chronic pain, the person's role as a caregiver, the person's access to an exercise facility, or even to basic health services (CPC, 2010, "What are the effects?"). In answer to, "Is there a connection between pain and stress and depression? What can I do myself to lower stress?" the CPC tells the patient to sit in a quiet room and take deep breaths, then think of what colour the pain is and see how "the colour shrinks down to a smaller size as you breathe in and out" (CPC, 2010, "Is there a connection?"). In answer to, "How can I have good sleep hygiene" the CPC suggests using extra pillows, avoiding caffeine before bed, and only going to bed

when sleepy (CPC, 2010, "Sleep hygiene?"). The options proposed as additions to medication are personal lifestyle choices aimed at the individual level; they do not consider how broader social or institutional contexts such as employment or extended health benefits might impact their ability to manage living with chronic pain.

In the "Conquering Pain for Canadians" booklet, the CPC defines chronic pain as "pain that persists over three months, beyond when an injury should have healed. Chronic pain can be intermittent (occurs in a pattern) or persistent (lasting more than 12 hours daily) and can be considered as disease itself." (CPC, 2010, "Is all pain the same?"). To further distinguish between acute and chronic pain, the booklet continues: "It is important to understand that chronic pain is not just a continuation of acute pain. Unlike acute pain, which alerts your body to injury, chronic pain serves no purpose" (CPC, 2010, "Is all pain the same?"). Constructing chronic pain as disease involves producing a new category of pain and differentiating between acute and chronic pain. Thus, while acute pain serves as the symptom or sign of some other underlying cause of pain, chronic pain does not. The construction of chronic pain as disease is a shift from understanding pain as primarily a symptom of another underlying cause or disease. The definitions of acute and chronic pain offered by the CPC and its construction of chronic pain as disease fit squarely within a biomedical model.

While the CPC draws on the language of population health by describing pain as an epidemic, their website offers no further discussion of the broader social determinants of health that may contribute to developing chronic pain and the experiences of living with it. The absence of a larger structural view of chronic pain limits the political scope of the CPC and neglects to acknowledge socioeconomic and other differences among people living with chronic pain. The organization emphasizes individualized solutions to chronic pain and prioritizes medications; this is an approach that complements the industry that stands to profit from medicating chronic pain, but does not address the causes of chronic pain or fully address the complex needs of people living with chronic pain.

According to the CPC's website, both FMS and CFS are conditions that are included under the larger umbrella of chronic pain and thus, in some respects, this can be considered a move to reduce some of the ambiguity associated with these conditions. As a patient advocacy group and an organization aimed at increasing public awareness of chronic pain, their move towards stabilizing chronic pain as disease may be viewed as an effort to legitimize chronic pain and to take seriously the experiences of people living with chronic pain. The emphasis on chronic pain as disease and the recognition of the physical basis of chronic pain conditions (e.g., Richman and Jason, 2001) seems to fit with one side of the feminist paradox that argues for medical attention to chronic pain. It is easy to see how the label of "disease" can be important for those living with chronic pain and

struggling to have their experiences recognized and may provide access to treatment and services. On the other hand, however, the construction of chronic pain as a disease itself and not a symptom of a disease or syndrome raises concerns regarding medicalization and the efforts of pharmaceutical companies in producing a market for their drugs. This side of the feminist paradox has received less attention in the feminist literature on conditions associated with chronic pain and is completely absent in the work of the CPC.

Discussion

The CPC welcomes memberships from corporations including pharmaceutical companies within Canada, for a fee of \$500.00 (CPC, 2010, "Membership"). Pfizer seems to be closely associated with this coalition in several ways: the CPC Healthcasts present discussions on key topics related to neuropathic pain, and are funded through an unrestricted educational grant from Pfizer Canada (CPC, 2010, "Healthcasts"); the CPC's Pain Resource Centre, a resource about pain and pain management for Canadians is sponsored by Pfizer Canada (CPC, 2010, Pain Resource Centre, "Sponsors of this Site"); several members of the CPC's Board of Directors have a relationship to Pfizer, as researchers who are receiving funding from Pfizer, as a member of a Pfizer awards committee, or in one person's case, as Pfizer's National spokesperson for Fibromyalgia (CPC, 2010, "Board of Directors"). The CPC recently commissioned "The Report on Pain" exploring "the patient journey of Canadians

living with chronic pain" with support from Pfizer Canada Inc. (CPC, 2011, "Report on Pain"). Pharmaceutical corporations such as Pfizer have a vested interest in what they call "Community Investments." An investment entails some sort of profitable return. Pfizer is a leading pharmaceutical company that markets dozens of pain medications, some requiring long-term use which means substantial profits. As the CPC claims on its website, chronic pain is Canada's "silent epidemic" affecting approximately 6 million people. For Pfizer, instilling Canadians with a sense of entitlement to pain treatment and narrowly defining treatment as long-term pharmaceutical use is an intelligent business move. If, as reflected in the CPC website, chronic pain is a disease, pain medication the primary means of treatment for all levels of pain, and physical dependency not addiction but long-term pain management, then this supports the production of a large market for pharmaceutical drugs.

The close association between coalitions such as the CPC and the pharmaceutical industry is a growing phenomenon linked to the increasing influence of the pharmaceutical industry in healthcare in a context of neoliberalism. This profit-driven industry dedicates considerable resources to marketing in direct and indirect ways. Direct-to-consumer advertising is one way that the industry directly promotes drugs to consumers. In a more indirect fashion, pharmaceutical companies sponsor medical research and analyses that are developed to influence the opinions of researchers and practitioners about the

efficacy of their drugs (Sismondo, 2009) and outsource medical writing to agencies that produce favourable medical reporting on drugs (Healy, 2004). Sponsoring patient advocacy groups with a proclivity for recommending treatment in the form of pharmaceutical drugs could be considered yet another form of marketing. The CPC represents an apparent mobilization of patients to demand recognition of pain in particularly biomedical terms.

A number of social scientists have critically examined the relationship between the pharmaceutical industry and patient advocacy groups (Batt, 2005; 2010; Jones, 2008; Ball, 2006; Marshall, 2006; Toiviainen et al., 2004; Tuffs, 2006; Perehudoff and Alves, 2011). In a recent exploration of the debate over partnerships between patients' groups and pharmaceutical companies in Canada, Batt (2010) argues that "pharmaceutical companies are problematic funding sources for [patient groups] because they often have a direct interest in the outcome of the group's advocacy, which in turn can cloud the judgment of decision makers within the organization" (p. 72).

Some argue that organizations that accept industry funding seem to spend their efforts pressing for access to the newest and best drugs on the market, rather than asking 'tough' questions about the safety and efficacy of these drugs (Batt, 2010; Mintzes, 2007). This concern is particularly pressing with reports of over prescription of drugs such as OxyContin, Purdue Pharma's formulation of oxycodone. A study by Gomes et al. (2011) found that prescriptions for opioid

analgesics have risen by 16.2 per cent between 2003 and 2008. Among patients for whom high or very high doses of opioids were dispensed in 2004, 19.3 per cent of deaths during the subsequent 2 years were opioid-related (Gomes et al., 2011). According to Ontario's Health Ministry, between 300 and 400 people die each year in the province from opioid-related overdoses and that the opioid most frequently found during autopsies in recent years is oxycodone (Kirkey, 2012). Purdue Pharma is now phasing out OxyContin and replacing it with OxyNEO, which is apparently more difficult to crush or liquefy, for snorting or injection purposes (ibid). Six provinces have already said they will restrict access to the new formation (ibid). As we discussed above, until the recent media attention paid to OxyContin addiction, the CPC website emphasized the safety of opioids and made no mention of studies that suggest otherwise. According to a February 21, 2012 new release, members of the Canadian Pain Society have participated in the National Dialogue on Prescription Drug Misuse, sponsored by the Canadian Centre on Substance Abuse, "to develop strategies that can reduce the harms of prescription pain medication misuse in a way that does not harm people with pain who require these medications as an essential part of their treatment." In the release, the Canadian Pain Society states: "We cannot let people with serious pain become the collateral damage of the war on prescription drug misuse." At the same time, in the context of the discussion of provincial restrictions for OxyNEO, Dr. Roman Jovey, a past president of the Canadian Pain Society said "Putting any

medication on exceptional access creates a huge barrier to its use because of the paperwork and 'hassle factor' involved for doctors." (ibid). While spokespersons for the Canadian Pain Society have stepped up to condemn misuse of opioids, they continue to stress access to pain medications for their patients.

A recent study of 22 patient and consumer organizations, and pharmaceutical funding by Perehudoff and Alves (2011) from Health Action International Europe, found that "a financial relationship between commercial and civil society groups could jeopardize the uniqueness of the patient and consumer perspective and threaten the integrity of the multi-stakeholder format and the policy formulation process" (p. 5). Both Jones (2008) and Batt (2005) acknowledge that health consumer groups or 'patient groups' are often motivated by the intention of representing the voices of their constituents as part of a social movement for patients' rights. Patient groups find themselves in a situation where they do not have the funding to do their work effectively and must rely on industry for financial support. Disease and consumer groups have played an increasingly powerful role in health policy since the 1990s (Batt, 2005). Governments have cut back on support for community-based advocacy over the past two decades, leading advocacy groups to seek funding elsewhere, and the pharmaceutical industry is all too eager to provide this support. Partnerships between non-profit groups and the private sector are a funding strategy that has emerged from the 1990s climate of deficit-reduction and privatization (Batt,

2010). Governments in the UK, Canada, the US, and elsewhere have facilitated this trend by supporting "partnership" projects between advocacy groups and the private sector.

The relationship between patient advocacy groups and the pharmaceutical industry is complex, and we do not argue that there is a simple uni-directional relationship of power that moves from industry to patient groups (e.g., Novas, 2007 and Werner et al., 2004). What is concerning, however, is that these patientled movements that advocate for medical attention for conditions such as chronic pain may be unduly influenced by pharmaceutical companies that are driven by a fiduciary responsibility to their shareholders to increase profits. We suggest that this influence may be reflected in what we suggest is the indirect marketing of medication as the primary means of treating chronic pain. The effectiveness of this marketing is achieved by the erasure of the paradox and complexities of chronic pain from a condition that is at once physical, social, and psychological, to one that is solely physical. The CPC's website demonstrates how their rendering of chronic illness supports a particular perspective on health and medicine which does not explicitly endorse a corporation or drug, but does support an ideological and political model of health that is consistent with a neoliberal approach to health. When we consider the history of the pharmaceutical industry's efforts to market drugs and technologies to women, a feminist analysis of the CPC seems imperative.

Conclusion

We suggest that in the context of neoliberalism, advocacy groups have come to play an important role in drawing attention to specific health conditions. In the case of chronic pain, the CPC's online materials appear to reduce chronic pain to a biomedical disease and to emphasize pharmaceutical treatment as the most effective and long-term method of treatment. We suggest that this does not address the concerns of critical social scientists discussed above. While the attention that the CPC brings to the condition of chronic pain appears to address feminist arguments for increased medical attention to conditions of chronic pain, its erasure of the specificities of people's lives, absence of broader social structural concerns, and a lack of critique of the pharmaceutical industry does not address concerns raised by the SDH and feminist literatures. We suggest that the feminist paradox can be productive within critical analyses of health movements and advocacy groups. While the work of the CPC is effective in bringing legitimacy to the physical experience of pain, its lack of engagement with concerns related to medicalization and its emphasis on pharmaceutical medication is problematic. That is, while it is effective in addressing one side of the feminist paradox it does not address the other side, the critique of the medicalization and corporatization of health issues. In order to more fully address the complex health needs of gendered, classed, and racialized people, both sides of the paradox must be considered.

References

- Armstrong, A. & Armstrong, H. (1996). Wasting Away: The Undermining of Canadian Health care. Toronto: Oxford University Press.
- Asbring, P. & Narvanen, A. (2003). Ideal versus reality: physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Social Science and Medicine*, 57, 711-720.
- Ball, DE, Tisocki, K. & Herxheimer, A. (2006). Advertising and disclosure of funding on patient organisation websites: a cross-sectional survey. BMC Public Health, 6:201.
- Batt, S (2002). You, Your Breast Cancer Group and Prescription Drug Ads. The Newsletter of the Massachusetts Breast Cancer Coalition.
- Batt, S (2005). Marching to Different Drummers: Health Advocacy Groups in Canada and Funding from the Pharmaceutical Industry. Women and Health Protection.
- Batt, S (2010). Who pays the piper? Industry Funding of Patients' Groups. In Rochon Ford and Saibil (Eds.), The Push to Prescribe: Women and Canadian Drug Policy (pp. 67-93). Toronto: Women's Press.
- Bendelow, G. (1993). Pain perceptions, emotions and gender. *Sociology of Health and Illness*, 15(3), 273-294.
- Cahn, S. K. (2003). Come Out, Come Out Whatever You've Got! or, Still Crazy after All These Years. *Feminist Studies*, 29(1), 7-18.
- Canadian Pain Coalition. (2010). www.canadianpaincoalition.ca.
- Canadian Pain Society. (2012, February 21). Canadian Pain Summit Media Statement Prescription Drug Addiction is a Complex Societal Problem. National Pain Strategy Provides a Blueprint Solution. Retreived from: http://www.canadianpaincoalition.ca/index.php/en/about-us/mediaroom/?&news_id=178
- Caplan, P. J. (2001). Chronic Fatigue Syndrome. *Women & Therapy*, 23(1), 23-43.

- Crooks, V. A., V. Chouinard and R. D. Wilton (2008). Understanding, embracing, rejecting: Women's negotiations of disability constructions and categorizations after becoming chronically ill. *Social Science & Medicine*, 67(2008), 1837-1846.
- Denny, E. (2009). I Never Know From One Day to Another How I Will Feel": Pain and Uncertainty in Women With Endometriosis. *Qualitative Health Research*, 19(7), 985-995.
- Goldberg, D. & McGee, S. (2011). Pain as a global public health priority. Biomed Central Ltd., 11(770). Retrieved from http://www.biomedcentral.com/1471-2458/11/770.
- Gomes, T., David, N., Juurlink, I., Dhalla, A., Mailis-Gagnon, A., Paterson, J.M., Mamdani, M.M. (2011). Trends in opioid use and dosing among socioeconomically disadvantaged patients. *Open Medicine*, 5(1): E13-22.
- Good, B. (1994). Medicine, Rationality and Experience: An Anthropological Perspective. Cambridge: Cambridge University Press.
- Good, M-J. DV. (1992) Pain as human experience: an anthropological perspective. Berkeley: University of California Press.
- Healy, D. (2004). Shaping the Intimate: Influences on the Experience of Everyday Nerves. *Social Studies of Science*, 34(2), 219-245.
- Illich, Ivan.(2002). Limits to medicine: medical nemesis, the expropriation of health: with a new introduction by the author. 2nd Edition. London: Marion Boyars Publishers.
- Johansson, E., Hamberg, K., Westman, G. & Lindgren, G. (1999). The Meanings of Pain: An exploration of women's description of symptoms. *Social Science and Medicine*, 48, 1791-1802.
- Johnson, Erica. (2011, January 20). Marketplace looks into alleged Yasmin risks. In Tassie Notar's *Marketplace*. Toronto, Canada: Canadian Broadcasting Corporation.
- Jones, K. (2008). In whose interest? Relationships between health consumer groups and the pharmaceutical industry in the UK in Sociology of Health & Illness, 30(6), 929-943.

- Jureidini, J., Rochon Ford, A., Lexchin, J., Ramos, J., Raven, M. (23 September, 2008). "Letter to David Learmonth re 'consumer' speaker.' Retrieved from: http://www.healthyskepticism.org.
- Jureidini, J., Rochon Ford, A., Lexchin, J., Ramos, J., & Raven, M. (2009). Durhane Wong-Rieger: Associations with the pharmaceutical industry. Retrieved from: <u>www.healthyskepticism.org</u>.
- Kent, A. (2007). Head to Head: Should patient groups accept money from drug companies?: YES. *British Medical Journal*, 334, 934.
- Kirkey, Sharon. (2012, March 1). Rush to remove OxyContin called misguided; While some warn the fallout may be more harmful, others say the new limits can't come fast enough. Vancouver: The Vancouver Sun.
- Kleinman, A. (1988). *The illness* narratives: suffering, healing, and the human condition. New York: Basic Books.
- Lorber, J. and L. J. Moore. (2002). Gender and the social construction of illness. Lanham: Rowman & Littlefield.
- Markens S. (1996). The Problematic of "Experience": A Political and Cultural Critique of PMS. *Gender & Society*, 10(1), 42-58.
- Marshall J, Aldhous P. (2006). Patient groups swallowing the best advice? *New Scientist*, 19-22.
- Mintzes, B. (2007). Head to Head: Should patient groups accept money from drug companies?: NO. *British Medical Journal*, 334, 935.
- Mosconi, P. (2003). Declaration of competing interests is rare in Italian breast cancer associations. *British Medical Journal*, 327:344.
- Novas, C. (2007). Genetic advocacy groups, science and biovalues: Creating political economies of hope (pp. 11-27). In P. Atkinson, P. Glasner, and H. Greenslade (Eds.). New Genetics, New Identities. London: Routledge.
- Perehudoff, S. K. & Leonardo Alves, T. (2011). The Patient and Consumer Voice and Pharmaceutical Industry Sponsorship. Amsterdam: Research Article of Health Action International (HAI) Europe.

- Ramage-Morin, Pamela L. and Gilmour, Heather (2010). Chronic Pain at Ages 12 to 44 in Statistics Canada.
- Raphael, D. (2006). Social Determinants of Health: Present Status, Unanswered Questions, and Future Directions. *International Journal of Health Services*, 36(4), 651-677.
- Raphael, D. (2008). Grasping at straws: a recent history of health promotion in Canada. *Critical Public Health*, 18(4), 483-495.
- Richman, J. A. and L. A. Jason (2001). Gender Biases Underlying the Social Construction of Illness States: The Case of Chronic Fatigue Syndrome. *Gender, Age and Health*, 49(3), 15-29.
- Rochon Ford, A., & Saibil, D. (2010). The Push to Prescribe: Women and Canadian Drug Policy. Toronto: Women's Press.
- Sismondo, S. (2009). Ghosts in the Machine: Publication Planning in the Medical Sciences. *Social Studies of Science*, 39:171.
- Toiviainen, HK., Vuorenkoski, L., Hemminki, E. (2004). Survey on Finnish patient organizations shows economic and other interactions with drug industry. First annual meeting of Health Technology Assessment International, Krakow, Poland, 30 May-2 June.
- Tuffs A. (2006). Sponsorship of patients' groups should be made more transparent. *British Medical Journal*, 333:1238-d.
- Werner, A., Malterud, K. (2003). It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. *Social Science and Medicine*, 57, 1409-1419.
- White, M. T., J. P. Lemkau and M. E. Clasen. (2001). Fibromyalgia. Women & *Therapy*, 23(1), 45-58.
- Zola, Irving. 1972. "Medicine as an institution of social control." *Sociological Review*, 20(4), 487-504.