

# Pain in persons who are marginalized by social conditions

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## 1. Introduction

Pain is often poorly recognized, inadequately assessed, and unsuccessfully managed among people in mainstream society,<sup>7,40</sup> but this is particularly the case for people who have been historically, economically, and socially marginalized,<sup>39,46</sup> although access to pain management is considered a basic human right.<sup>10,53</sup> People who are indigenous, recent immigrants or refugees, of colour, LGBTQ2S, less well educated, living with mental health or substance-use challenges, or have experienced violence and trauma, among others, are vulnerable to a higher prevalence of painful medical conditions, relative to nonmarginalized people, as well as to experiencing barriers to pain management services.<sup>80,86</sup> This study addresses the challenges of providing access to pain management for people who have been socially and economically marginalized and emphasizes the need for care at the intersection of 2 bodies of knowledge: the broad biopsychosocial model of health, given that social determinants of pain are of conspicuous importance in these populations,<sup>8,21,22,54,87</sup> and the growing understanding of the intersections between trauma, violence, substance use, and pain.<sup>67</sup> Those who face stigmatization and marginalization are at risk for not receiving health and social benefits broadly available to the population at large.<sup>5,6,34,38,64,85</sup>

## 2. Identifying socially marginalized populations

The list of marginalized populations is extensive.<sup>59</sup> Social attributes related to culture, ethnicity, race, indigeneity, socio-economic class, gender, sexual orientation, incarceration, intellectual capability, and health that are not valued or are disrespected or disapproved by at least some segment of the general population<sup>55</sup> lead to discrimination and systemic

inequities, including, but not limited to, racism,<sup>38</sup> homophobia,<sup>69</sup> poverty,<sup>85</sup> and housing instability.<sup>55</sup>

Caution should be observed when characterizing people in terms of shared attributes. Use of labels creates a risk of stereotyping and overgeneralization—substantial individual differences can be expected in pain experience and its management within groups of people who share experiences of marginalization; in any group of people described as marginalized, many are healthy and resilient. As well, these social categorizations interconnect, often creating overlapping or intersecting marginalizing conditions that increase the risk of discrimination and disadvantage.<sup>68</sup> Co-occurrence of multiple challenging social circumstances is commonplace; refugees or asylum seekers may have religious, racial, or ethnic backgrounds, or sexual or gender identities, for which they have been persecuted and have suffered from trauma and violence. Or people who are homeless may live in social isolation, with risks of mental health or substance abuse problems.

## 3. Likelihood of pain in socially marginalized populations

There have been relatively few studies that have addressed prevalence of pain in people who are socially marginalized, reflecting the methodological challenges of identifying and assessing pain in these populations, and, perhaps, limited interest in these issues. Studies of chronic pain often examine patients in tertiary pain clinics.<sup>24</sup> Exclusion criteria for these clinics often screen out people who live with mental health issues, substance-use disorder, etc.; hence, exclusion criteria and recruitment approaches may skew data.<sup>3,24</sup> There is no reason to believe that, on average, people who are marginalized would not be exposed to the same types of painful injuries and diseases as the population at large, as well as being subjected to additional pain arising from environmental challenges, lifestyle, behavioral health practices, medical comorbidities, and inadequate care specific to a subpopulation.

The following provides illustrative data from selected socially marginalized populations:

- (1) People experiencing homelessness with a history of post-traumatic stress disorder and abuse had disproportionately high levels of persistent moderate to severe pain and pain interference.<sup>55</sup>
- (2) Torture survivors not only experience pain and other health concerns but may have numerous psychological and social problems that complicate care, including uncertainty about civil status, unstable accommodation, isolation from family, friends, and culture and means of support and access to work.<sup>2</sup>

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- (3) Studies of indigenous peoples in Canada indicate extreme health inequities, linked to historical and ongoing colonization, including higher incidence of pain and pain-related disabilities of all types (eg, musculoskeletal, throat, ear, and dental conditions). Yet, indigenous people are less likely to seek or access treatment,<sup>48</sup> in part because their pain is more likely to be misunderstood or minimized.<sup>56,57</sup>
- (4) Despite a paucity of research on the prevalence of chronic pain among people in LGBTQ2S communities,<sup>51</sup> there is ample research on the multiple barriers LGBTQ2S people experience accessing and receiving health care.<sup>4</sup> Emerging research highlights the burden of chronic conditions experienced in the LGBTQ2S community, including high prevalence of disability, mental health distress, and other chronic conditions.<sup>35,61</sup> Studies indicate that people who are transgender and older or have disabilities have higher rates of chronic pain than their cisgender counterparts<sup>31</sup> and Two-Spirit peoples' experiences of pain may be the embodiment of combined racial, sexual, and gendered discrimination, stress, and trauma.<sup>49</sup>
- (5) Refugees fleeing home countries have frequently been exposed to multiple traumas and often experience post-traumatic stress, in addition to chronic pain,<sup>78</sup> thereby presenting unique health needs.<sup>66</sup> Responses to pain and coping strategies vary across ethnic groups and there are wide disparities in provision of care and treatment decisions, leading to increased pain-related suffering in ethnic minorities.<sup>17</sup>
- (6) People living with human immunodeficiency viral disorder (HIV) experience pain, but there is limited understanding of social factors, including stigma, associated with this pain.<sup>71</sup>
- (7) Black veterans in the United States were found to be less frequently screened for the presence and severity of pain than white patients in Veterans Health Administration primary care.<sup>15</sup>

#### 4. Challenges of discrimination and bias

Socioeconomic and other environmental challenges complicate or compound pain and limit access to pain management. Conditions of poverty, isolation from family, friends, or health care professionals, inadequate accommodation, physically demanding labour, and limited access to support and work increase the likelihood of inadequately managed pain.<sup>13</sup> Lack of financial resources is often a key underlying problem. Poverty is commonly linked to social marginalization and is associated with disparities in provision and receipt of pain management.<sup>9,37</sup> People in marginalized populations are at risk of having been exposed to adverse childhood experiences,<sup>52,60,74,83</sup> including childhood and family violence and maltreatment associated with inadequate nutrition, sleep, or medical care, and severe or prolonged fear, or torture, all of which can increase the likelihood of acute and persistent ongoing and untreated pain.<sup>2,62</sup> In general, this aggregation of factors carries risks of additional and more severe medical comorbidities that complicate care and are known to precipitate personal stress, anxiety, and depression. Neurobiological mechanisms for relationships between adverse life events and pain are only beginning to be understood.<sup>19</sup> Comorbid medical conditions also can contribute to decline in social status and subsequent further disadvantage.

There is evidence of devaluing and discrediting practices directed at people with chronic pain who are socially marginalized.<sup>32,73,82</sup> Charges by patients of racist, classist, heterosexist, cissexist, transphobic, sexist, and ableist biases by health care

providers and others are not uncommon.<sup>33</sup> Biased behavior comes not only from people who could be characterised as antagonists or strangers, but also from friends, family members, employers, and health care professionals.<sup>26</sup> Uncertainty about sources of pain are likely when pain is not medically understood or diagnosable, leading to discounting reports of pain,<sup>28,50,76</sup> and health care providers report they are less inclined to help, feel less sympathy, dislike patients, and suspect deception under these circumstances.<sup>27</sup> How extensive or representative these interactions are in the experience of people who are socially marginalized has not been established empirically. It is noteworthy that patients concerned about injustices in the treatment they receive are vulnerable to greater emotional distress,<sup>75</sup> prolonged work disability, invalidating or stigmatizing reactions of others, and poor rehabilitation pain outcomes.<sup>18,70,72</sup>

#### 5. Access to care in socially marginalized populations

Access to best practice care for pain management is a general problem<sup>30,58</sup>; this is compounded by major disparities in access to health care that are widely acknowledged in both the traditional biomedical system and in services using a broader biopsychosocial model.<sup>47</sup> Efforts to understand and rectify disparities in care typically focus on health care funding and scarcity of limited resources. Access to publicly funded health services can be crucial, with private services often posing exorbitant costs. Some services have been developed specifically to meet the needs of disadvantaged groups, for example, programs for patients at low-income clinics.<sup>79</sup>

Socioeconomically disadvantaged groups often express unwillingness to access existing facilities and/or to be less likely to access, or have access to specialized care for persistent pain because of discrimination and bias.<sup>1,63,77</sup> When disadvantaged people do seek care, it is often reported to be inadequate and harmful.<sup>6,33,85</sup> Failure to access care may be a consequence of a history of unsatisfactory experiences or difficulty interacting with care providers.<sup>16,84</sup> Immigrant populations may have language barriers and require trained translators who are not readily available. Although systematic studies do not seem to have been undertaken, patients regularly complain about care services. People will express that they are not listened to or taken seriously with clinicians minimizing or denying the validity of complaints.<sup>23,38</sup> Some people also allege harmful treatment with statements that providers are enacting marginalization, stigmatization, racism, misgendering, sexual harassment, and more.<sup>88</sup> This can lead to patients avoiding services, pursuing non-regulated services, or relying on themselves. Denison et al.<sup>29</sup> found among indigenous residents of British Columbia, Canada, that women avoided care for themselves for fear of their children being apprehended, particularly if they were perceived to be “drug seeking.”

#### 6. Pain management for people who have been socially marginalized

Tailoring or customizing care to suit the culture and needs of people who have been socially marginalized is important. In general, management of pain and related disability should be delivered following careful biopsychosocial assessment and an interdisciplinary, multimodal intervention approach,<sup>81</sup> ranging through the spectrum of evidence-based pharmacological, other medical, and psychosocial pain management. Biomedical care should be provided while attending to the intersecting contexts of

social and other environmental factors that determine the experience and expression of pain and disability.<sup>42</sup> Given the likelihood of backgrounds of trauma and violence, it is important that this should be addressed.<sup>67</sup>

Assessment should be adapted to the population. When lack of familiarity with the local language represents a barrier to accurate assessment, translation reflecting both a need for a common language and sensitivity to cultural variations should be provided. All patients should be asked about current life conditions and ongoing health challenges, such as poor accommodation or homelessness, disrupted sleep, inadequate money for food, isolation, substance use, uncertain immigration and legal status, and other ongoing issues. Culturally safe care includes not assuming that all patients are heterosexual or cisgender and respecting LGBTQ2S patient sexual and gender identities and chosen pronouns. Care providers should be trained to identify stereotypes and prejudices they may subscribe to about people who represent socially marginalized groups. Assessment should include consideration of psychosocial factors that exacerbate disability and contribute to challenges in responding to interventions, including emotional reactions (eg, anxiety and depression), unhelpful coping and thinking patterns (eg, catastrophizing and maladaptive coping), behavioural maladjustment (eg, inappropriate avoidance of activity and inactivity), and deteriorating social relationships (eg, stress at work, home, or in the community, reinforcement for pain or illness behaviour and social isolation). Strengths and resiliency in people who face structural violence, discrimination, and chronic pain should be recognized and validated.

A framework based on Equity-Oriented Care<sup>11,12</sup> addresses 3 interconnected, research-derived dimensions: trauma and violence informed care (TVIC), harm reduction, and culturally safe care. This approach provides services that feel and are culturally safe, equitable, and accessible, based on understanding the effects of trauma and systemic interpersonal and structural violence, intersecting factors, and their links to health and behaviour. It explicitly addresses inequitable power relations, potential harms, and traumatizing effects of seeking health care, racism, discrimination, and ongoing effects of historical and current inequities by creating safe and trusting environments. The concept of cultural safety leads to training health care providers to more explicitly address power relations, institutionalized and interpersonal biases and other forms of discrimination, as well as the ongoing impacts of historical injustices on health and health care. Harm reduction also is prominent in aiming to provide services for people who use substances in a respectful, inclusive, and compassionate manner and to develop policies and services that minimize the harms associated with substance use, including addressing the criminalization of substances and people who use substances.

The TVIC framework seems to be of particular value in addressing unique characteristics of socially marginalized populations, including the structural conditions that often contribute to experiences of interpersonal violence and focusing on accessing supports to improve physical and emotional safety. During the past 10 to 15 years, there has been a movement to develop and implement policies and practices that are trauma-informed in sectors working directly with people impacted by violence, including in health, particularly in relation to mental health and substance use,<sup>20,69</sup> justice, housing, antiviolence, and social work sectors.<sup>25,44,45</sup> This movement developed largely in response to a growing understanding of the connections among violence, trauma, negative outcomes in physical and mental health, and substance-use problems, as well as to the need to

make systems more responsive to the needs of people who face these challenges.<sup>65</sup> Trauma and violence informed care builds on trauma-informed care to take into account how violence may be ongoing in a person's life, including structural forms, such as policy created and enforced poverty, disproportionate criminalization, or systemic discrimination.

In the absence of a TVIC lens, provision of pain care could lead to retraumatizing patients and limit access to the care that they urgently need. Many health care providers view trauma as a historic event and fail to recognize repeated encounters and their ongoing effects on patients. Providers often focus on individuals without recognizing the impact of ongoing interpersonal and structural violence, inequity, and conditions that continue to shape the lives of people living in marginalized conditions. A key component of treatment is the patient's trust of the health care provider. Care providers who do not demonstrate continued personal caring for patients threaten the potential that arises from close relationships with care providers. Equity-Oriented Care has been demonstrated to be associated with better mental and physical outcomes.<sup>11,34</sup>

Systematic guidelines addressing specific requirements for care have not been developed for populations experiencing pain and social marginalization. Best practices will be needed that specifically consider experiences of stigma, bias, and discrimination. An exception and illustration is provided by guidelines developed to provide care in survivors of torture.<sup>2</sup> Implementation of guidelines and related best practices is often challenging due to organizational and personal barriers (eg, resistance to change, insufficient organizational support, and resource limitations).<sup>36,41</sup> However, early evidence suggests that movement toward greater equity in care can be achieved with low-cost changes through organizational support to engage direct care providers in change.<sup>13,14,34,43</sup>

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The authors have no conflicts of interest to declare.

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