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Title

Chronic struggle: a new framework for understanding chronic pain and marginalization

Priority 1 (Research Category)

Social determinants and vulnerable populations

Presenters

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Abstract

Medicine often ignores the social aspects of health experience. Applying the lens of social determinants of health has not fully mitigated the tendency of Western medicine to focus on biological causes and pharmaceutical solutions. Objective: We present the stories of 26 people living with chronic pain who have been rendered socially, economically, and politically marginal by existing systems and structures of inequity in ways that exacerbate suffering. We argue that their diverse and multi-faceted experiences are better understood by the term “chronic struggle” rather than “chronic pain”, thus de-centering the medical aspects of people's experiences. Study Design: Institutional ethnography (IE) is a sociological approach increasingly used in health studies. IE begins in the standpoint of people with lived experience and considers them as experts of that experience. IE analysis follows sequences of action, with one informant's interview leading the way to the next or to a text for analysis. Through this process, we linked participants' micro level experiences to macro level systems and structures. Setting or Dataset: Participants were recruited for in-depth telephone interviews in online spaces (e.g. Twitter and Kijiji) and through existing networks of our multi-disciplinary research team across several provinces in Canada. Population Studied: Our study focuses on people who are over the age of 18, speak fluent English and who self-identify as living with chronic pain and marginalization. Results: Our findings call attention to the complexities and ‘everyday emergencies’ (Millar, 2014; Mitchell, 2020) that come to shape and define one's experiences with chronic pain. Our themes capture the cascading and inter-related experiences of illness, mental illness, addiction and poverty as they are described and understood by people with lived experience. Combined, we are made aware of how chronic pain is not the key defining difficulty of one's life—a biographical disruption—but rather one additional difficulty in a life that is always already defined by health and social complexities. Conclusions: As these stories illustrate, while the social and the medical are managed as separate sectors within Western society, for patients they are intertwined and inseparable. Focusing on only one aspect of this experience – be it medical or social – impairs our ability to understand the experience of either or to offer meaningful relief.