Non-Peer reviewed:

Patient Oriented Research: An Approach to Advancing the Addictions Arena

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Abstract: With the rising prevalence of substance abuse and overdoses across Canada, there is an ever-present need to address this growing trend. However, there is a knowledge to action barrier of putting evidence based research into practice in the Canadian Health Care System. Patient Oriented Research is an opportunity to close this gap by having patients involved as partners. This paradigm benefits patients, as they are able to further contribute to their own treatment and health care, and professionals, as they can focus their research and practice based on the account of the patient's experience. Valuing patients as experts in their own experience can improve the standard of care, create better continuity of care, and add to current knowledge of sustainable strategies for long term suppression of substance abuse.

Keywords: Addiction**,** Health Care, Patient Oriented, Canada.

Addiction in Canada

The Canadian Centre on Substance Abuse notes the estimated "cost of substance abuse totalled almost $40 billion in Canada in 2002 or $1,267 per capita" (Rehm et al., 2006, p. 3). Substance Use Disorders (SUD) have been a societal issue for generations, causing substantial socioeconomic burdens. An unbounded cycle of public policy has been both expensive and varied in effectiveness.

In a report prepared for the Mental Health Commission of Canada, it was estimated that "there are over 2.0 million people living with an SUD, of these approximately 72.5% are male. By 2041 the annual number of people living with an SUD is expected to increase by 10.1%, reaching over 2.2 million people or 5.1% of the total Canadian population" (as cited in Smetanin et al., 2011, p. 104). Results from the national Canadian Community Health Survey (2012) found that 6.4% of males and 2.5% of females self-reported symptoms consistent with SUDs (Pearson, Janz, & Ali, 2013). Today's headlines are marred with overdose fatalities. In 2012, Fischer and Argento found that "some 500,000 – 1.25 million people are estimated to use prescription opiates non-medically in Canada, of which 125,000 – 200,000 may be dependent" (p. 193). One in eight fatalities in 2010 throughout Ontario were attributable to opioids for ages 25-34 (McInnis, Robeson, Gereghty, & Porath-Waller, 2016). Recently, the Globe and Mail reported that "in British Columbia and Alberta, the two hardest-hit provinces, fatal overdoses linked to fentanyl soared from 42, in 2012, to 418 in 2015" (Howlett, Giovannetti, Vanderklippe, & Perreaux, 2016, para. 8).

In April of 2016, the province of British Columbia declared a state of emergency following more than 200 deaths in three months related to fentanyl use (Ellis & Lindsay, 2016).

While opiate addiction is at a crisis point, alcohol and tobacco abuse also remain a prominent issue across the country. Of the 76% of Canadians who reported drinking in 2013, 23% of male and 18% of female drinkers exceeded the chronic-risk guideline (Health Canada, 2013). In terms of smoking, 15% of Canadians reported smoking in 2013, with an average daily consumption of 13.9 cigarettes per day for daily smokers 15 years and older (Health Canada, 2013). Often individuals with SUD are addicted to multiple substances at once. Another study found 48% of alcohol-dependant respondents also reported nicotine dependence; these respondents were more than twice as likely to have at least one other lifetime addiction diagnosis compared to non-nicotine, non-alcohol dependent subjects when controlling for psychiatric and addictive disorder effects (Le Strat, Ramoz, & Gorowood, 2010).

The Knowledge to Action Barrier

Despite the problem of addiction in Canada, the spectrum of services ranges drastically and the term *evidence based* is loosely used across the continuum. The modalities of care range from unlicensed to underground housing networks promising hope beyond their delivery capability. Consistency and motivations amongst delivery providers remains divided. The juxtaposition between harm reduction and traditional abstinence-based facilities is borderline contentious. Advancing knowledge into practice within the addiction context is not immune to the larger system challenges facing the Canadian healthcare sector. Too often there is a fundamental gap between what we know and what we do. Despite a general awareness of this paradox, fewer than 60% of internal medicine decisions are made with adequate validation (Canadian Institutes of Health Research, 2011). Currently, 50% of Canadian patients do not get treatments of proven effectiveness, and up to 25% get care that is unnecessary, or potentially harmful (Canadian Institutes of Health Research, n.d.).

In 2015, the Canadian Institute for Health Information estimated that taxpayers would spend a total of $219.1 billion, or $6,105 per person on health care, over 10% of national gross domestic product (GDP). In light of the aggregate system costs to taxpayers and the availability of quality research, the divide remains prominent (Graham & Tetroe, 2007).

Researchers and practitioners alike have expressed similar sentiments of knowledge barriers in healthcare (Atwal, 2002; Brownson, Chriqui, & Stamatakis, 2009; Kohatsu, Robinson, & Torner, 2004; Meyer, 2000). In looking at the juxtaposition between research and practice, Sacristán (2013) notes that "the expression 'from bench-to bedside' accurately reflects the objective of translational research, a type of research frequently characterized by the lack of communication between basic research and clinical application" (p. 5).

The domain of Knowledge Translation (KT) for addiction service providers is layered with diverse professional bodies, public and private interests, competing priorities, and available resources crossing many epistemological boundaries. The process is both expensive and laborious. Given the system dynamics of public and private organizations and arguably low barriers to entry, the gap between the best available knowledge and the consistent application in treatment planning is a noteworthy issue. Due to the unfortunate rising publicity of substance abuse in Canada, much of the efforts have been focused on marginalized populations, originating in areas such as Vancouver's downtown east side. Addiction is far greater than the stereotypical understanding impacting millions from coast to coast. It is indiscriminate and consistently destructive to families and communities irrespective of socioeconomic standing. Yet we also know people can and do rehabilitate from SUDs, though our progressive lens often excludes these individuals. Our collective knowledge construction is perhaps so geared towards understanding intricate outcome factors that we forget to appreciate the value SUD affected individuals have to offer in helping.

Patient Oriented Research

One identified opportunity for enhancement is the realm of patient oriented research, which has also been noted for considerable underdevelopment in the Canadian healthcare context (Naylor et al., 2015). The patients, as partner models, provide an opportunity for stakeholders throughout the healthcare system to identify knowledge gaps, pursue knowledge aimed at improving care, and diminish the knowledge to action barriers. The framework for patients as partners taps into the ubiquitous purview of individuals and groups impacted by various health concerns to affect the entire research enterprise with a general target of improving patient care, public health, and the service delivery system. Other countries have found success in implementing this model. The United States initiated the Patient-Centered Outcomes Research Institute as a component of the Affordable Care Act legislation with an average annual budget of $650 million (Collier, 2011; Born & Laupacis, 2012). Founded in 1996, the United Kingdom's National Health Service has seen great improvements through their collaborative INVOLVE framework (Hayes, Buckland, & Tarpey, 2012)

In 2013, Canada announced the Strategy for Patient Oriented Research (SPOR), which the Canadian Institutes of Health Research (CIHR; n.d.) defines as:

> A national coalition of federal, provincial and territorial partners (patient advocates, provincial health authorities, academic health centres, charities, philanthropic organizations, pharmaceutical sector, etc.) dedicated to the integration of research into care – the right patient receives the right treatment at the right time. Patient-oriented research refers to a continuum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve health care systems and practices. It produces information for decision makers and health care providers that will improve health care practices, therapies and policies. And it ensures that new and innovative diagnostic and therapeutic approaches are applied when and where needed. (p. 1)

This patient-centric model operates through an integrated professional environment where patients are proactively engaged and potentially representing all facets of one's interaction with the Canadian healthcare system. The CIHR (n.d.) notes that patient involvement is essential to SPOR, as they collaborate in the governance, priority setting, production of research, and distribution of the knowledge while continually analyzing relevance of specific health related issues. The SPOR structure constitutes both a national research infrastructure facilitated by regional support units and a system of research networks driven by public health needs, including cardiovascular disease, cancer, and mental health (Rouleau, 2009).

The Value of Patient Oriented Research in Addictions

Implementing a patient engagement strategy in the addictions context has potential to ensure those most affected by substance abuse have a voice in the resolutions we strive for. It facilitates an expansion of the conversation that may augment the portrayal of success and perhaps even the definition of recovery.

In May 2016, the Canadian Centre on Substance Abuse launched a national survey aimed at gathering "information on the life experiences of individuals in recovery from addiction to alcohol and other drugs in Canada, including information on the personal journeys and different pathways that exist for Canadians" (Crowe, 2016, para. 2). This survey is merely one example of the methods that can be employed to begin engaging the thousands of Canadians living in recovery from addiction. Examples such as this provide the opportunity for understanding addiction in the context of lived experience of those affected across Canada, and similarly to initiatives put into place in the United States, the United Kingdom, and Australia.

The approach is not to advocate one aspect of care, but rather a spectrum. Patient-oriented pharmacological treatment has been applied to alcohol addiction, with primary clinical evidence showing considerable benefits to the approach (Addolorato, Mirijello, & Leggio, 2013). Similarly, in a biopsychosocial setting, applying a patient-oriented aim for alcohol addiction has been emphasized in order to re-evaluate goals over the course of long-term treatment (Jakubczyk & Wojnar, 2012).

While considerable pharmacological research advancements of addiction treatment continue to make strides, failing to research the lived experience of recovered individuals would underrate the extensive knowledge this cohort has to offer. Exploring all facets of addiction such as value of lived experience, intimate understanding of the challenges addicted individuals face, and factors of sustainable recovery have the potential to augment the work being done by communities, clinicians, and policy makers. Interacting with patients who have utilized various addiction treatment modalities can provide insight into successes along with an advanced understanding of their challenges.

For the many thousands who have had little or no clinical attention yet experience recovery, there is considerable value in understanding their path. Inquiry into factors that have sustained absence from substance abuse, how individuals have successfully navigated challenges while on the path to recovery, and how specific factors could be applied to the interventions of addicted individuals have potential to greatly aid our collective therapeutic treatment priorities. Communities and organizations that have been affected and have incurred first hand experience could critically influence the national discourse on addictions. Engaging larger system questions such as the role of societal connection, socioeconomic mobility, factors and forces influencing quality of life, determinants of sustained abstinence, and influences returning one to positive citizenry have the potential to significantly develop collective understanding of the issue.

Conclusion

It is short-sighted to believe addiction is formed overnight, yet more naïve to posit the existence of an acute solution to a visibly chronic health problem. There are numerous modalities and theories to support recovery from addiction, which this paper does not attempt to dispute. Rather, a call is put forth for treatment providers, clinicians, researchers, and stakeholders from all areas concerned with advancing the level of care in the addictions arena to consider engaging individuals who intimately understand the struggles of addiction and the tenants of a successful recovery. Valuing patients' perspective from lived experience can greatly contribute to and improve the standard of care. Supporting patients as partners in future research has potential to better the continuity of care and impact our knowledge of evidence based, sustainable strategies for long term suppression or remission in substance abuse.

This perspective is not to minimize the role of today's researchers and advancements that are being made. Rather, it is an opportunity to compliment the existing clinical research programs throughout the professional community, with a viewpoint that both acknowledges and more intimately incorporates those affected with the aim of turning more of what we know into what we do, for the benefit of those suffering. A greater patient engagement strategy will gain valuable insight into sustainable factors and forces of success in facing addiction. This enhanced understanding can better prioritize and homogenize treatment protocols germane to addiction treatment in both public and private practice.

Compliance with Ethical Standards Funding: This study was not funded by an external source.

Conflict of Interest: C. McPherson and H. Boyne declare that they have no conflict of interest.

Ethical Approval: All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000.

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