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Looking through a Different Window: Chronic Disease Management in Public Health. Application of Symbolic Interactionism and Institutional Ethnography

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Abstract

Chronic diseases are defined as illnesses that are prolonged, do not resolve spontaneously and are rarely cured. They constitute 46% of the global burden of diseases and are responsible for 59% of deaths in Canada, tallying billions of dollars in annual medical expenditures. Regardless of the variety of available treatments, a vast majority of patients with chronic conditions report they do not receive the care they need or expect. The efficacy of chronic disease management (CDM) has been proven effective for the general population; the focus of this paper, however, is around populations who are less responsive to mainstream behaviour change interventions. Alternative conceptualizations of CDM could lend support for the development of models that target hard-to-reach populations who often have complex needs and for who typical interventions are reported to be less effective. This paper will explore two theoretical perspectives which provide the basis for alternative conceptualizations, symbolic interactionism (SI) and institutional ethnography (IE).

Keywords

Chronic Disease Management, Public Health, Conceptualizations, Interpretivism, Critical Social Theory

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Looking through a Different Window: Chronic Disease Management in Public Health. Application of Symbolic Interactionism and Institutional Ethnography

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Chronic diseases are defined as illnesses that are prolonged, do not resolve spontaneously and are rarely cured. They constitute 46% of the global burden of diseases and are responsible for 59% of deaths in Canada, tallying billions of dollars in annual medical expenditures. Regardless of the variety of available treatments, a vast majority of patients with chronic conditions report they do not receive the care they need or expect. The efficacy of chronic disease management (CDM) has been proven effective for the general population; the focus of this paper, however, is around populations who are less responsive to mainstream behaviour change interventions. Alternative conceptualizations of CDM could lend support for the development of models that target hard-to-reach populations who often have complex needs and for who typical interventions are reported to be less effective. This paper will explore two theoretical perspectives which provide the basis for alternative conceptualizations, symbolic interactionism (SI) and institutional ethnography (IE). Keywords: Chronic Disease Management, Public Health, Conceptualizations, Interpretivism, Critical Social Theory

Introduction

Chronic diseases constitute 46% of the global burden of diseases and are responsible for 59% of deaths in Canada, tallying billions of dollars in annual medical expenditures (Wagner, Austin, & Von Korff, 1996). Chronic disease management (CDM), systematized by Wagner et al., (1996) is recommended in primary health care as: “*pro-active, population-based approach to prevent disease progression and reduce potential health complications*” (Russell, Dabrouge, Geneau, Muldoon, & Tuna, 2009; Turner, 1996).

However, recent research evidences contradictory effectiveness when CDM is applied to populations experiencing complex needs, mainly explained by the variations in service delivery and individual or organizational deficiencies (Wagner et al., 1996). In this paper I will outline an alternative path, arguing that this contradiction stems from a theoretical conceptualization of CDM informed by the dominant in health bio-medical model. The bio-medical model with its focus on objectivity and universal reality does not allow for the examination of how context and structural forces impact chronic care, revealing a critical need for different epistemologies. My intent is not to dismiss the available research on CDM, but rather to offer alternatives for situations where mainstream CDM strategies are less effective. In this paper I will apply two theoretical approaches, namely symbolic interactionism (SI) and institutional ethnography (IE), which are informed by interpretative and social critical theory to the phenomenon of CDM. Here, the purpose is to demonstrate what different insights alternative conceptualizations may bring into our understanding of the CDM. I will also demonstrate the clinical relevance of theoretical applications for health care practices. In order to do so, I will present a hypothetical clinical case of a fictional client to explore how the phenomenon of CDM can be viewed and approached differently from alternative theoretical positions.

Situating CDM

Chronic disease management (CDM) is a field in which debates concerning theoretical affiliations are relatively new and distant from everyday life. Carter & Little (2007) argue that three fundamental facets of research -epistemology, methodology and method -should provide a framework for planning, implementing and evaluating the quality of any research. In this context, a few words are needed on the relevance of theory to research in CDM. Medical research is often seen, defined and expected to be value-free, atheoretical and neutral. Although theoretical assumptions in research are rarely explicit, they nonetheless frame the questions to be asked, how these questions are answered and what is considered as valid knowledge (Green & Thorogood, 2007). The same is true for medical practices in the way knowledge is constructed, defined and incorporated into everyday service delivery. Therefore, *theory* is central to any research. It arises out of a larger conception of social life (*ontology*) and belief of what knowledge is and how knowledge can be produced and constituted (*epistemology*) (Guba & Lincoln, 2005). While this is generally accepted in sociology and philosophy, it is not as explicit in health; given the rise in the current prevalence of one epistemological position referred to as “positivism” which emphasizes rationality, empirical study and belief in a single knowable reality (Guba & Lincoln, 2005). CDM constructs of *self-management support, delivery system design, decision support, clinical information systems, community resources, and health care organization* gained increased popularity in public health given their clarity and simplicity (Ministry of Health and Long Term Care and the Ontario Medical Association, 2005). CDM and its focus on scientific and unified knowledge reflect the dominant post-positivist perspective in medicine which views the world as independent of and unaffected by perceptions. However, CDM strategies are complex and challenging, especially when applied to populations experiencing compound and often conflicting needs. Approaching complex phenomena, such as CDM, from a singular lens of post-positivism may result in an over-simplistic understanding of the phenomenon which does not reflect the everyday reality of clients. CDM currently employs an individual and rational-based focus which makes it particularly difficult to follow for the socially disadvantaged, who are disproportionately represented among people affected by chronic diseases, given the variety of structural constraints they face in everyday life. Therefore, we need to supplement strategies derived from the prevalent post-positivist position with alternative theoretical perspectives. These alternatives may help us to gain insight into how social structures, political and socio-economic contexts impact clinical practices for people with chronic conditions.

My Social Location

To begin with, it is important to position myself as a researcher. I come into this project with multiple insights and perspectives on the phenomenon of chronic disease management, having been a psychiatrist working with people diagnosed with severe mental illnesses, a clinical social worker at the inpatient unit of one of the major psychiatric facilities in North America, and a PhD student in public health. As a psychiatrist I developed knowledge of medical practice and acknowledged common challenges in compliance with the prescribed regime among populations experiencing complex needs. Through my clinical work as a social worker I developed an understanding of the complexities surrounding care provision for people with complex conditions and challenges of circumstantial constraints. Subsequently, I carried my knowledge in health and behaviour with me into my PhD program in public health, wherein questions and concerns surfaced regarding the increasing number of people with life-long chronic conditions and the inability of the system to address their

complex needs. Gradually, in the course of an immersion in my doctoral work throughout courses and reflective discussions with my supervisors and colleagues, I came to realize that all research is inherently subjective, and all researchers regardless of their affiliation, have a particular world-view which underpins and shapes their projects and findings (Green & Thorogood, 2007; Guba & Lincoln, 1994). Thus, I surmised that the human world must be studied by means which allow one to view individuals as having the “capacity to interpret and construct reality” (Patton, 2002, p. 96), where linear cause-effect models are not equipped to fully understand the complex and intersected phenomenon within the context it is embedded.

In order to understand complex phenomenon, an approach which focuses on a process and goes beyond personal experiences is required. As a first step towards constructive dialogue on the possible re-conceptualization of CDM, this paper will explore how two different theoretical positions, such as interpretivism with its claim of multiple but equal realities, and critical social theory positing that reality is manipulated by certain powerful interests (Smith, Mitton, & Peacock, 2009) bring different insights into CDM practices. These alternative conceptualizations, while theoretical in nature, may lend support for the development of models for hard-to-reach populations with complex needs where typical interventions have been reported less effective.

Constructivist/Interpretivist CDM: Symbolic Interactionism application

During the 19th century, as opposition to the dominance of positivism, a new approach emerged known as “*interpretivism*” or “*constructivism*” (Guba, & Lincoln, 1994, 2005; Mohr, 1997) which acknowledges the existence of multiple realities of equal value implying that all knowledge is co-constructed. The major divisions within interpretive research are categorized as phenomenology, ethnographic interpretative, symbolic interactionism, ethnomethodology and grounded theory (Lowenberg, 1993). Phenomenology, grounded theory, ethnomethodology and ethnographic interpretative research are well established in health care and employed to understand processes, policies and practices (Starks & Trinidad, 2007). Blumer’s Symbolic Interactionism (SI) is of particular interest for CDM because it

- 1) views knowledge construction as a result of symbolic interactions between active agents (that is humans);
- 2) emphasizes a human being as a key change agent, and
- 3) is relatively less well utilized in health research compared to grounded theory or ethnomethodology (Denzin, 2008).

Symbolic interactionism is a social-psychological approach derived from the pragmatism tradition which emphasizes an alliance between the theoretical and practical, and stresses human beings as key agents of change (Denzin, 2008). It lends significance to meaning and interpretation as essential human processes in reaction to behaviourism and mechanical stimulus-response psychology (Burbank & Martins, 2010). The SI perspective postulates that people create shared meaning through their interactions with others and themselves, and that those meanings become their reality (Denzin, 2008; Patton, 2002). SI posits that all social phenomena are symbolic and hold different meanings for different individuals (Prasad, 2005). In short, from the SI perspective, human beings create the world they live in by acting on things based on the meaning they assign to them; these meanings emerge from interactions, which in turn are shaped by the self-reflections individuals bring to their situation (Denzin, 2008).

From the SI perspective, in CDM meanings of what chronic diseases are and ways to manage them are established through historical development and social interactions throughout the process of negotiation between human actors (that is patients, professionals, and society in general). Following on SI, the understanding of CDM is influenced not only by the social context, but also by the client's initial self-image formed through meaning constructions in the course of interactions with others and society; and symbolic meaning of the phenomenon, constructed within a particular socio-historical context. Actions employed will reflect this understanding framed by internally and externally derived meanings. To illustrate, one's inner image of incapability will influence the meaning assigned to the medical condition (e.g., not manageable). In turn, if reinforced by a similar vision from society (e.g., chronic diseases are not curable) and interactions with health professionals (e.g., persons with a chronic condition are incapable, need control and monitoring), from SI perspective, these factors will inform a client's actions (e.g., giving up, not bothered), which in turn, will sustain the inner image of incapability, reinforcing existent symbolic meanings through this meaning construction cycle. Two important conclusions are derived from the SI conceptualization of CDM. First, CDM is not fixed, and therefore amenable to change, dynamic and negotiable. This re-conceptualization of CDM as a constantly evolving, changing process holds important practical implications that could shift medical practices regarding CDM, requiring different strategies at different stages and tailoring to a particular client's need. Second, the SI perspective on human beings as active actors and knowledge co-constructors provides valuable grounds for interventions targeting self-perceptions, self-image and empowerment. On a broader scale, by employing the SI concept of symbolic interactions, which implies that human beings have complex ways of communicating through language and symbols, CDM can be conceptualized as not intrinsic, that is, as having different meanings for different people. Therefore, if there is no neutrality and universality regarding CDM as no action is possible on its own, the most effective strategies would be those targeting the symbolic representation of CDM in society through media and policy changes. From the SI perspective, as social beings we do not live in a vacuum, and therefore, our actions are related to and influenced by those around us. Thus, CDM strategies targeting broader socio-economic and political contexts may garner the most effective results.

Hypothetical Example

To illustrate what implications a reconceptualization of CDM may have on clinical practices, I will build on a hypothetical, although commonly seen in practice, "complex" clinical case. A hypothetical patient named Marry is a single female suffering from a number of chronic cardiovascular conditions, who lives on social disability assistance (ODSP) in social housing in the impoverishing area of an urban city. She has been recently diagnosed with diabetes type II and requires a prolonged and complex medication regime along with lifestyle changes. Marry visited a physician and was prescribed medication, diet and exercise, but she has a hard time keeping up with her appointments and the medical team is frustrated with her non-compliance, referring to her as "difficult." If we follow the traditional post-positivist approach, we would draw from demographic, biological, psychological, and some environmental factors to explain Marry's non-compliance. However, a more nuanced interpretation is possible by adopting the SI lens. In SI, meaning is important. Therefore, we would start by determining what it means for Marry to be diagnosed with diabetes. Marry tells us she feels overwhelmed with her new diagnosis and considers it to be "disastrous" as it is coupled with other existing constraints on her life. SI posits that one's perceptions and meanings determine further actions. Therefore, the meaning of diabetes as "disastrous" may result in despair leading to her "giving up" or wanting "not to be a bother." Next, SI views

human being as an active agent capable of and engaging in self-talk to make sense of the world around them, while knowledge is seen as co-constructed and shared through common symbols and interactions between individuals. This has direct clinical implications as it suggests that perception can be changed and symbolic meaning delivered through language impacts individual perceptions. For example, viewing individuals as capable of change and maintaining this optimistic outlook towards recovery could lead clients to engage in an active lifestyle and follow CDM recommendations, while conversely a pessimistic view where clients are referred to as “difficult” and lacking in agency could result in them becoming less interested in participating in lifestyle change interventions. Therefore, the SI notion of multiple equal realities has the potential to open up space for consensual and meaningful collaborative work through all layers of care.

Limitations

While SI may provide strong grounds for a variety of empowerment strategies at all levels, given that the historical and philosophical roots of SI are aligned with the politics of a liberal-minded status quo, there is a danger that participants may be turned into moral heroes who are capable and dedicated to change, and this change is expected to be generated from within, leaving behind the whole complexity of structural forces of power and dominance.

Critical Social Theory CDM: Institutional Ethnography

CDM requires life-long involvement where tasks are carried out by clients within everyday constraints; nonetheless, neither interpretative nor positivist traditions adequately focus on how structural factors shape peoples' lives. From a critical social perspective, what we do and how we do it is not neutral, because it is impossible to separate knowledge from the individual and wider societal interests and, therefore, all fields of knowledge creation (e.g., health) are mediated by power relations that are socially and historically constituted (Guba, & Lincoln, 1994, 2005). This distinction is central to the critical perspective as it implies that existing reality is greater than empirical domain which is comprised of structures and mechanisms independent of our perceptions (Kontos & Poland, 2009). Among other critical theories, Smith's (1987) standpoint theory, while initially developed to address the exclusion of women, is particularly relevant to CDM because its core concepts such as

- 1) *objectified knowledge*,
- 2) *ruling*, and
- 3) *standpoint* specifically address “...a silence, an absence, or nonpresence” (p. 20).

To Smith (1987) knowledge is objectified in the course of dominant practices through the employment of textual materials (e.g., regulations, guidelines, policies) manifesting throughout particular sets of social relations, called *institutions* with the aim of organizing objective, extra-local methods of control. These social relations have largely remained unacknowledged, which is especially troubling for CDM since they in fact define how everyday practices are carried out. Moreover, while these extralocal forces structure how CDM services are delivered, these may not be in line with a service recipients' reality. This process of formation of commonly accepted CDM strategies refers to “objectification,” where what knowledge is and how it is expected to be extracted reflects on dominant medical discourse informed by post-positivism. Post-positivism envisions knowledge as being atheoretical, however dictates what and how is viewed as scientific. To illustrate, academic

and clinical work on CDM reflects post-positivism, attracting research which is in line with its philosophical position, while rejecting that which is not. This ultimately results in the development of surplus practices attuned to the dominant ideology that through replication and recirculation are naturalized and seen as objective knowledge. In practice, while remaining largely hidden, CDM is informed by broader policies which define and ensure accurate implementation of clinical practices that are attuned to the dominant ideology; reinforcing the already existent order.

Institutional Ethnography (IE), a theoretically informed empirically based approach derived from standpoint theory, aims to make these hidden relations visible and elucidate the socially coordinated character and organization of people's lives (Smith, 1987). There is a clear kinship between the conceptual core of IE with its focus on

- 1) ideology;
- 2) institutions; and
- 3) the concept of work and the forms of social relationships structured around living people (Smith, 1987).

To examine CDM through IE means to accept CDM as being grounded in ideological discourse. From IE, CDM can be conceptualized as a set of claims informed by an ideological position prevalent in medicine which emphasize the biological nature of chronic conditions. To illustrate, aligned with the bio-medical model, CDM asserts that while people have "agency," that is, the capacity and ability to self-care, because the nature of chronic conditions is biological, management requires expert knowledge in order to achieve optimal control. Building on IE, one way to achieve this control is to ensure the appropriate tools are in place, such as a particular way of collecting and evaluating evidence, defining what constitutes evidence and what does not, which results are reliable vs. which are not. These sets of social relations, *institutions*, would "make some things visible, while others, as much a part of the overall work organization that performs the institution, do not come into view at all" (Smith, 1987, p. 162). This specific coordination of social relationships not only informs clinical practices, but also subordinates clients' experiential understanding of their condition prioritizing expert-based knowledge over experiential knowledge.

Hypothetical Example

Based on our hypothetical case, I will continue with a theoretical exploration applying IE to CDM. Marry is diagnosed with diabetes and comes for regular checkups with her GP. She meets with the nurse first as a part of routine primary care practice. Nurse takes her "history" and performs medical assessments in order to proceed further with the GP appointment. GP appointment lasts 15mins and is structured around her diabetes symptoms. The GP provides Marry with recommendations she is expected to follow and encourages her to comply with the prescribed regime. Marry finds it challenging to follow her GP's recommendations, so she quits. Both Marry and her medical team are frustrated by her lack of the progress.

From the IE perspective, Marry is drawn into a set of relationships which are set up by "someone else somewhere else" and are detached from Marry's everyday reality (Smith, 1987). To demonstrate, information presented by Marry is not neutral or objective, but is guided by the clinician, whose actions, in turn, are guided by a particular "text" which is often a type of intake/assessment form asking for particular types of information, such as demographic, brief medical history and complaints. These are not questions defined by a nurse or by Marry, but rather brought into practices through administrative and bureaucratic

processes. Marry's story is "written up" into a paper, where categories are pre-defined by somebody else somewhere else, developing a textual representation of who she is. Next, this "textual representation" is constructed into a "file" or "case" health professionals work with. The "file" or "case" obviously contains features of the person, but is an incomplete picture and, in fact includes only information deemed to be important as it is defined by experts. Such "files" are accumulated transforming people into reportable to the higher bureaucratic institutions "conditions," forming a pool of specific knowledge about this particular chronic state. Then, based on this pool of knowledge about this particular condition, general claims are made about what the condition is and how it is supposed to be managed. These general claims manifest in policies, strategies, and guidelines parachuting back to front-line clinical practices. The assumption behind is that an actual person and "textual representation" of this person are identical. What is missing here is the understanding that textual representations of the individual forms a hypothetical "ideal" which may not map onto actual individuals, as real individuals are not the same as textual "representations" which are detached from the local reality. Marry becomes a "patient with diabetes" where some information (e.g., demographic, medical complains, life history, etc.) is prioritized over the other (e.g., social conditions, relationships, emotions, etc.), and this dominant information continues to serve policies and treatment strategies. However, what is important to remember is that Marry's living with a chronic condition did not happen in a nothingness; it is embedded within particular socio-economic and historical contexts that shape and change her life significantly. This hidden dominance of particular types of knowledge results in strategies that are developed for "textual, ideal patients" making some of CDM goals and strategies irrelevant or unattainable for those diagnosed as they do not reflect their everyday reality. According to IE, chronic disease management should be seen as a set of ideological claims informed by particular socio-economic and historical contexts, which are sustained by both experts and participants, are governed and directed by organizational policies and practices, and are powerfully influenced by the setting in which they are deployed.

Limitations

While IE can significantly contribute to CDM practices based on its ability to provide comprehensive marcosocial analysis on organizational and policy levels, it may be challenging to implement given its openly political stand and challenges regarding translation into everyday practices.

Summary

The pursuit of quantifiable interventions and outcomes of care has become the sine qua non of health care research, bringing a struggle between the agendas of funding agencies and everyday realities of patients and clinicians to the forefront (Russell, Dabrouge, Geneau, Muldoon, & Tuna, 2009). Contemporary neo-liberal logic of management practices with its focus on profitability and standardization seeks to contain healthcare within discrete tasks (Mykhalovskiy, & McCoy, 2002). Irrespective of the elegance of CDM, it will be prone to failure if this approach means little to patients, or if interests served are those of funding agencies not those of clients. Alternative conceptualizations, such as SI and IE, may provide a useful option for CDM practices when mainstream bio-medically informed interventions are less effective.

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Presently, Yuliya is a PhD candidate at the Dalla Lana School of Public Health, University of Toronto and a Clinical Fellow in Neuropsychiatry with the Centre for Addiction and Mental Health, Toronto. Her area of specialization is diabetes management, people with severe mental illnesses, and critical social theoretical inquiries.

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