

MORE THAN A BROKER: A CASE STUDY OF KNOWLEDGE MOBILIZATION IN A DIGITAL ERA

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ABSTRACT

This research described here examines the role of e-health and medical informatics through the lens of one e-health knowledge broker in Canada. Eating disorders are an important issue in Canadian health and it is difficult to find accurate information online. Theoretical models examined include those which describe the roles of health knowledge brokers, including those who advocate for critical social change. A case study is presented of one Canadian agency which brokers knowledge about eating disorders. This agency has a highly complex role which employs multiple technologies: telephone help lines, a website, and webinars. The help lines and email supports are designed to respond to questions about eating disorders and to refer individuals to service providers. When compared to the oft-cited role of the knowledge broker to disseminate research information, the key roles of this agency move beyond this, providing reliable and consistent information; brokering spaces for capacity-building; promoting critical health literacy and advocating for health equity.

KEYWORDS

e-Health, Knowledge Brokers, Eating Disorders, Health Equity, Critical Health Literacy

1. INTRODUCTION

The role of the e-health knowledge broker agency has not been fully explored in the literature, leaving gaps with respect to both theoretical considerations and rigorous research studies. This paper presents a case study of one health knowledge brokering institution which maintains both e-health and traditional knowledge brokering practices. A case study is provided which introduces the complexity involved in measuring the impact of health knowledge exchanges in general and e-health knowledge brokering in particular which is designed to support the prevention, intervention, and treatment of eating disorders in Canada. This research is presently in its initial phases.

First, some key questions help increase the focus on the issues. In the present digital era, where do individuals turn to find information when they suspect that their own health or the health of someone who is close to them is in jeopardy? How does this change if there is a culture of silence or shame attached to this ailment? What are society's imperatives if this particular health condition can be fatal? In these circumstances, what are the key roles of the health knowledge broker and how can we measure the impact of the knowledge broker?

In the case of the provision of health information for eating disorders, the role of the e-health knowledge broker takes on a significance and immediacy that may not be experienced by other knowledge brokers or knowledge mobilization intermediaries. The role of the knowledge broker in this case is imbued with a sense of urgency to provide current, helpful, and factual information to support the efforts of the individuals seeking help to connect with health care providers, but also carries a responsibility to educate society.

According to their website, www.nedic.ca, The National Eating Disorder Information Centre (NEDIC) is a Canadian non-profit organization providing resources on eating disorders and weight preoccupation. NEDIC defines clinical eating disorders as medical conditions which require treatment from health professionals and these include anorexia nervosa, bulimia nervosa, binge eating disorder, and eating disorders not otherwise specified. Traffic to the NEDIC website is reported to be very high, and in addition to this, approximately 1,600 individuals annually contact the NEDIC helpline by phone or through email. This paper begins to explore the work of NEDIC in the context of research on the role of knowledge brokers in general, and e-health knowledge brokers in particular, recognizing that they provide a vital health education space.

1.1 Eating Disorders – the Canadian Context

Within the past year, one of the reports of a Canadian parliamentary committee has raised serious, multiple concerns with respect to the rising incidence and lack of treatment for Canadians with eating disorders, especially girls and women (House of Commons, 2014). According to the expert witnesses, eating disorders are described as a serious form of mental illness impacting the health of 600,000 to 990,000 Canadians at any point in time. One expert witness testified that anorexia nervosa and bulimia nervosa are fatal for 1,000 to 1,500 Canadians annually and this rate of incidence may possibly be underreported (House of Commons, 2014).

Eating disorders are also an equity issue; anorexia has the highest rate of mortality of any mental illness but treatment wait times in Canada for eating disorders are not responded to with the same urgency as other life-threatening health crises (House of Commons, 2014). Four out of five persons affected by eating disorders are women, which may reflect that society pressures girls and women in numerous ways to obtain a certain ideal body type. Perceptions of body size and shape are impacted by society's stereotypes, including the marginalization and stigma surrounding weight which can prompt disordered eating. Expert Canadian witnesses identified that fat stigma, which encourages food regulation and dieting, and a national culture of blame for individuals with eating disorders and their families are barriers to treatment (House of Commons, 2014).

According to Jasper (2005) if the generally-accepted and relatively unchallenged messages of a society state that the ideal body *is achievable with effort*, when in fact this body type is generally unattainable for the average population, this contributes to weight preoccupation. Schools are particularly problematic environments for messages about weight and appearance because peers can reproduce societal stigma against obesity, and they can also encourage individuals to pursue diets and persist with them. There is, in addition, an overall focus on *healthism* in schools (Rich, Holroyd and Evans, 2004) which focuses on a person's individual responsibility for their health and size. If this discourse around personal responsibility and health is not interrogated and deconstructed for students, it can help to build anxieties about body size and shape (Rich et al., 2004).

There is, in addition, societal pressure and stigma associated with fat. Schools have been identified as "potentially toxic environments" for weight and appearance messages (House of Commons, 2014; Robertson 1 & Thomson, 2014). Peer messages can reproduce stigma against fat, but they can also encourage those who are dieting to continue to lose weight. If students are perceived to be overweight, they are more likely to experience bullying and teasing (Fox & Farrow, 2009; Puhl, Luedicke & Heuer, 2011) which can, for example, impact their participation in physical education programs (Puhl & Luedicke, 2012). Research has also shown that teachers and in particular, physical education teachers, hold stereotypes around weight; holding lower expectations for students who are overweight in both their cognitive and physical areas of potential (Greenleaf, Martin & Rhea, 2008; O'Brien, Hunter & Banks, 2007).

These kinds of oppressions occur more easily in a society which focuses on individual responsibility and lifestyle change to look a certain way rather than looking at how society is influencing or determining health. Canadian health policy has been criticized for drawing too heavily on lifestyle change or a neo-liberal focus rather than examining societal determinants of health (Mikkonen & Raphael, 2010) and also for pursuing a medical anti-obesity model which promotes consumerism through diet foods, regimes, and self-discipline (Rail & Beausoleil, 2003).

In summary, then, eating disorders in the Canadian context present a very real health risk, but the prevention, intervention and treatment of eating disorders has been compromised by health care systems and education systems that promote efforts to lose weight, and equate health with certain sizes. The key implication for a health knowledge broker in this particular context is that their messages are, essentially counter-cultural. The health knowledge broker needs to convince both the medical practitioner community and society that food and weight preoccupation are harmful and potentially fatal to certain populations.

2. THEORETICAL CONSIDERATIONS

2.1 Knowledge Brokers

The transfer of health research to practice has been described as a slow and complex process (Graham et al., 2006). Knowledge brokers are people or organizations who help to package the knowledge and create connections between the researchers and their audiences (Meyer, 2010). Knowledge brokering is growing in the postmodern era and because new knowledge and brokering spaces are growing, in particular in the healthcare sector, this health research can have immediate implications for patient care and treatment. While earlier descriptions of the role of knowledge brokers include the facilitation of the “creation, sharing and use of knowledge” (e.g., Svarrisson, 2001), Meyer provides other examples of knowledge brokering in healthcare which delineate additional roles for knowledge brokers:

- Identifying knowledge
- Redistributing and disseminating knowledge
- Rescaling knowledge
- Transforming knowledge

According to Meyer, in order for health knowledge to be used, it is not just moved along but it is re-packaged to meet the needs of the users. In order to do this, Meyer theorizes that knowledge brokers need to live and work at the peripheries of both the research world and the world of the knowledge user, working behind the scenes in collective and interactive ways. The end product is “brokered knowledge” (p. 123) which is knowledge “made more robust, more accountable, more usable; knowledge that ‘serves locally’ at a given time; knowledge that has been de- and reassembled” (Meyer, 2010, p. 123).

The Canadian Health Services Research Foundation (CHSRF) (2003) see knowledge brokers as go-betweens and they emphasize the human aspects of that role. Brokering means bringing people together who share common issues in order to share their experiences and to hear about new evidence. In their words, “Getting the right mix of people and information together to tackle the right issue at the right time is the essence of brokering” (p. 9). Brokering also involves building networks and relationships both to share current research and to stimulate future research (CHSRF, 2003).

CHSRF concludes that health knowledge brokering is not a commonly found role in Canada. Good brokers are curious, flexible, well-informed and able to handle a range of information and ideas. They are also the ones who will resist quick fixes until they have seen that the research-based evidence has been reviewed. CHSRF advocates that the tasks of the broker include the following:

- bringing people together to exchange information and work together;
- helping groups communicate and understand each other’s needs and abilities;
- pushing for the use of research in planning and delivering healthcare;
- monitoring and evaluating practices, to identify successes or needed changes;
- transforming management issues into research questions;
- synthesizing and summarizing research and decisions (CHSRF, 2003, p. i)

While the CHSRF report sees multiple roles for knowledge brokers, the report also acknowledges gaps in the research. For example, networking is a key function but much more research is needed on how knowledge brokers set up networks, provide information and train individuals within their organization. Ward, House and Hamer (2009) concur, stating that more needs to be investigated as one challenge to knowledge brokering is a lack of understanding of how it works based on different contexts.

Early research and concept development on the role of the health knowledge broker indicates that more specific research is needed to understand the contexts within which knowledge brokers operate. Early theoretical frameworks focused on knowledge producers and users as two camps, linked by the knowledge brokers. More recent models indicate that knowledge brokers transform the knowledge to specific contexts, and that they work with a presence in both the world of the researcher and the world of the knowledge user. In the section which follows, e-health knowledge brokering is explored, opening up new aspects of the role of the e-health knowledge broker.

2.2 E-Health Knowledge Brokers

The term and concept of e-health has been defined by Eysenbach (2001) as the provision of health information and health services enhanced by utilizing the internet and other technologies. He theorizes that access to multiple sources of information and research can not only inform but empower patients, give them more choices, and encourage more patient-centered medicine. It can also extend health care to persons who may be geographically distant, or who seek information during off hours. E-health provisions are especially important for persons who perceive a stigma associated with their illness. An extensive US study of internet use for e-health concerns indicates that the internet information can be a valuable tool for education about health, particularly when the health concern is a stigmatized illness (Berger, Wagner & Baker, 2005).

Connecting health care practitioners to persons who are potentially at risk is a key role in e-health provision today. An e-health information broker can be a repository for practitioners and provide access to current research. An e-health information broker can also create an interface that encourages people seeking help to connect with health care practitioners. Health care practitioners also have a role in helping their patients identify reliable e-health information websites, or teach them how to critically assess the health information which is on the web.

Adolescents, in particular, can be at risk for health concerns where there is stigma attached (such as mental health) because of their reluctance to reveal their concerns and seek out a health care professional. One Canadian study of how adolescents use the internet for health information reveals that topics of body image and nutrition are very important to adolescents and these are some of the most frequently accessed spaces on the internet. Participants in the Canadian study indicated that adolescents frequently access websites for health information and they value the anonymity provided by a webspace to share their health concerns (Skinner, Biscope, Poland and Goldberg, 2003).

Early research on the internet and its impact on the provision of health care knowledge indicated that even at the turn of the century, literally millions of biomedical research articles were put online annually, creating concerns for information overload and questions surrounding how knowledge users can determine the quality of online information, prompting a call for more formal evaluations of e-health websites (Christensen & Griffiths, 2000). More recently, studies have focused on examining how health users make use of the website information, resulting in new understandings about the factors which contribute to trust in health websites (Sillence, Briggs, Harris & Fishwick, 2007).

One study which evaluated web-based information on eating disorders created a scale of evidence-based clinical practice statements and then analyzed websites based on this scale. They found that in general the quality of information available online about eating disorders left room for improvement, and more research was needed to determine the types of information and quality indicators that health users would find to be the most helpful (Murphy, Frost, Webster & Schmidt, 2003).

2.3 Measuring Health Knowledge Outputs

Very little has been written about how to measure the impact of a health knowledge information on the web (Murphy et al., 2003) and in addition, little is known about how to measure the impact of a health knowledge broker. One output tool which as designed to measure health research (not broker) impact has been proposed by Kuruvilla, Mays, Pleasant and Walt (2006). Its four dimensions are areas of research impact: research, policy, service and society.

- *Research*-related impacts include publications and papers;
- *Policy* impacts include, for example, policy networks, and participation at various policy levels;
- *Service* impacts include quality of care, and evidence-based practice; and
- *Societal* impacts include, for example, health literacy, equity and human rights, social capital and empowerment

Health literacy in this context is described as as a broad range of skills which can help to locate, understand, assess and utilize health information for informed choice, reduced risk, and increased quality of life (Kuruvilla et al., 2006). This impact framework has not yet been applied to outputs of health knowledge brokers or e-health knowledge brokers but it could be potentially helpful in examining and reporting the effectiveness of e-health brokers.

Nutbeam (2000) also argues for health literacy, finding that health education programs which focus on telling people what to do or not to do have not been successful in producing health behaviour change, and transmission has not been an effective way to moderate health outcome gaps between different groups. He describes health literacy as a set of skills that lead to enablement. *Basic or functional* health literacy encompasses knowledge and skills; *communicative* health literacy includes more advanced skills which can be applied in new situations and communicated. The third level, *critical literacy*, involves the critical analysis of information which empowers individuals to take more control over their health and to influence society (Nutbeam, 2000). As Kuruvilla et al. (2006) note, human rights and equity include the rights of individuals to shape health decisions that impact their lives.

In summary, theorizing on the role of the knowledge broker in health knowledge translation indicates that the role is both complex and critically important. At stake is the empowerment and enablement of the users of health research knowledge, the building of community and capacity surrounding health knowledge exchanges, and improvement of the health and life chances of individuals.

3. RESEARCH DESIGN

This paper describes proposed research using the lens of a descriptive case study. Lichtman (2012) describes the case study as a research approach which involves a specific and detailed study of an entity. Qualitative case study research is described by Merriam (2009) as a distinctive form of research design within the critical epistemological perspective which assumes that there are multiple realities, dependent on different individuals' world views and experiences, which involve the privileging of certain realities. For example, within a case study approach in the critical paradigm, there is an examination of those whose interests are protected and preserved at the expense of other perspectives (Merriam, 2009). Similarly, Guba and Lincoln (1994) explain that the reality in a case study which is described to the researcher(s) is shaped by forces such as "social, political, cultural, economic, ethnic, and gender values" (p. 109).

By design, the methodology proposed here is distinctively dialectical and hermeneutical, seeking information and refining it through the interactions which occur between and among participants and investigator and become refined as a result. The voice of the researcher is considered to be both advocate and activist, "transformative and intellectual" (Guba & Lincoln, 1994, p. 112).

Data collection for the case study presented here will employ multiple sources such as online offerings, webinars, interviews, observations, e-documents, and artifacts. These multiple sources allowed for deeper understandings and confirmation of findings. Data will be analyzed through the identification of key themes across the compiled data (Cresswell, 2012). Rather than employ the structure of the entry and closing vignette (Cresswell, 2012, p. 106), this planned research is introduced through a case study which outlines the context, the issues and theoretical conceptions of the role of the e-health knowledge broker. A discussion of selected issues and assertions follows.

3.1 NEDIC: A Descriptive Case Study

NEDIC identifies itself online as, "Canada's leading source of information and support in the field of eating disorders and related issues" (www.nedic.ca). It is a not-for-profit organization that has been working since 1985 to promote health and raise awareness of the complexities surrounding food and weight preoccupation. They provide a first point of contact. Of the individuals who contact NEDIC over the course of a year, approximately 60% will be individuals who have an eating disorder but their parents, friends and teachers will also call for information.

Education, outreach and client support are three of the central roles that NEDIC undertake as an e-health knowledge broker. They maintain a presence through email, phone lines and their website, as well as through webinars and events. NEDIC provides information to school counsellors, teachers, psychologists, psychotherapists, family doctors and researchers, among others, but central to their mission is to give timely information to individuals who need more information about eating disorders and their families. It is important that individuals who contact NEDIC for support are met with consistency, with hope and with an expectation that NEDIC can empower them to navigate to seek answers.

NEDIC connects individuals with information on service providers in their vicinity; they maintain the Service Provider database with just under 800 program providers, including those who are provincially funded, fee-for-service or free. Because the number of institutional beds for individuals with severe eating disorders is inadequate in Canada (House of Commons, 2014), many individuals between early identification and tertiary care are not having their needs met. In some of these cases, because individuals have multiple concerns when they have an eating disorder, NEDIC may be able to help them to connect with service providers in order to meet another of their health needs.

A key issue for maintaining the centre is funding – they have limited resources and a huge mandate. Approximately 20% of their funding comes from the Ministry of Health. Other sources of income include fund-raisers, the biennial conference and grants from foundations and sponsors who are carefully selected based on hospital criteria and philosophy.

NEDIC maintains a database of information on eating disorders based on references to peer-reviewed material. While their funding permits access to eating disorder journals, they do not have the funds or personnel to scan journals in other areas such as clinical psychology or school counselling. To broaden their understandings, NEDIC gathers information through listservs, seminars that they attend and many informal conversations with clinicians, teachers and other activists in the field.

NEDIC offers a biennial conference which takes months of planning. Significant time is given to the identification of key researchers and cutting edge research in eating disorders and related areas. NEDIC also provides information through an internal listserv and gives and receives information through the individuals who present webinars for them. Each of these webinars sold out within two days of opening the enrolment. They organize communication efforts by considering different populations – universal populations for prevention, an early intervention group and those who identify as having eating disorders who need to find help.

Two projects undertaken by NEDIC for universal populations have been directed at schools through the Beyond Images curriculum, and at Girl Guides through the Love Yourself badge. Beyond Images is a body-image and self-esteem curriculum designed for students in Grades 4-8 – a time of vulnerability for student populations because their bodies are changing. This curriculum was designed in 2009 and since 2013 is available free of charge through the NEDIC website. NEDIC estimates that, conservatively, more than 10,000 students have undertaken this curriculum. Similarly, the Love Yourself badge, which NEDIC developed with Girl Guides, is the 2nd most popular challenge badge in Guiding with approximately 1,000 guide members undertaking it annually.

At the present time, a key focus for NEDIC as an e-health care provider is to undertake rigorous research to document their role and their impact as an e-health knowledge provider. To that end, an investigation has begun to interview key personnel who access NEDIC as an e-health knowledge broker to better understand the roles that NEDIC provides and examine how researchers, practitioners and the public use the e-spaces and physical spaces for knowledge brokering that NEDIC creates.

4. DISCUSSION

Health knowledge brokering functions can include linkages and partnerships, awareness, capacity-building, support, and policy influence (Cooper, 2012). While NEDIC performs many of the recognized roles of the knowledge broker; this organization also places an emphasis on e-health brokering in non-standard areas. For example, they appear to be more client-centered than research-centered, but maintain deliberate standards for dissemination of research knowledge. They also maintain a focus on collective knowledge without privileging one type of information at the expense of another. Dede (1999) has identified that collective learning is facilitated when knowledge mobilization efforts are supported by digital technologies. NEDIC uses digital technologies through email, webinars and websites for the stated goal of capacity building, but are seeking ways to measure the outcomes of their health knowledge brokering.

This review of the literature and presentation of the initial case study indicate that there is much to be gained from research which examines the role of e-health knowledge brokers in general, but, in particular, in examining the role of an e-health knowledge provider who maintains a deliberate equity stance both by its funding imperatives, but also prompted by the specific needs of Canadians with eating disorders who are experiencing inequities in health care and health outcomes. Much more needs to be understood about the role

of an e-health provider which expresses a commitment to building critical health literacy understandings. While hope and empowerment are not often found in the literature as knowledge brokering outcomes, they are indications that findings related to this particular e-health knowledge broker will influence the present field in new ways.

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