Health information behavior research
with marginalized populations

ABSTRACT

As part of an increasingly vibrant area of research, information behavior scholars have shown that traditionally marginalized populations (e.g., older adults, LGBTQ people, people of color, low-income people, and people with chronic diseases or disabilities), may have distinct health information needs and information behaviors. These differences may arise from unique patterns in marginalized groups' life experiences, health risks and burdens, social networks, and available resources, as well as dynamics of social marginalization and exclusionary service design. This subfield of information studies that challenges established notions of health information seeking behaviours to further develop theories and models, as well as propose new models for information services and technologies. The unique characteristics of marginalized populations have necessitated the development of novel research approaches and methods, as well as interdisciplinary collaborations and community-based partnerships. This panel invites audience members to think critically about what it means to engage marginalized populations in research, and the methods and approaches needed to do so in a health context. It will also allow participants to broaden their understanding about the health information seeking behaviors of marginalized populations. Panelists will introduce and contextualize marginalized populations' health information seeking behaviours and explore potential or existing connections between themes from a variety of disciplines. Following a brief introduction and presentations from five panelists (who are themselves exploring marginalized populations health information seeking behaviours), there will be an open discussion session with the audience in a World Café format.

Keywords

Health information behaviors; marginalized populations; community engagement

INTRODUCTION

This panel focuses on the panelists' health information behavior research among different marginalized populations. We focus on marginalized populations for three reasons:

1. In recent years, the health sciences and medical practitioners have placed increasing importance on patient empowerment, individualized and contextualized care, and informed medical decision-making. All of these trends are predicated on by successful health information seeking;

2. Marginalized patient populations experience greater barriers to empowerment and medical decision-making;
3. Research in health information behavior is often disease-oriented, not population-oriented.

The panelists will discuss their health information behavior research with a wide variety of marginalized populations, including men who have sex with men, LGBTQ youth, young parents, parents of trans and gender creative youth, vaccine-hesitant parents, low-income families managing chronic illness, parents of individuals with Down syndrome and Autism Spectrum disorder, young Black women, adults on dialysis, and women with chronic pain.

BACKGROUND

Traditionally, research in health information behavior focuses on information seeking, often among groups of people who share a specific diagnosis (Lambert & Loiselle, 2007). This work emphasizes the motivations for and outcomes of information seeking behavior in health. These studies indicate that the motivations for seeking out health information are multifaceted and change over time; they include making choices about treatments, determining whether to modify a health-related behavior, learning what questions to ask the doctor, feeling in control of the illness, coping with the emotional impact of chronic disease, constructing a positive identity, and satisfying curiosity (Barbarin, Klasnja, & Veinot, 2016). Participants in these studies have a preference for getting health information from healthcare providers, but they typically consult multiple sources when they are experiencing health information needs. Source selection is impacted by factors related to the source, to the patient, the relationship between patients and sources, characteristics of the information need, and social norms (Zhang, 2014). Health information seeking is linked to positive and negative health outcomes, including sense making, decision making, uncertainty management, confusion, avoidance, and fear (Johnson & Case, 2012). Often, factors related to the patient (e.g., capacity for understanding health information, demographic characteristics) or to the information (e.g., quality of health information, presentation or format of information) are the focus of studies in this domain. We argue that conducting research with marginalized populations allows for a more comprehensive picture of the causes, conditions, and consequences of health information behavior. Focusing on marginalized populations highlights central issues in information behavior that are otherwise overlooked, including the social costs of information seeking, information access, and the ways in which social structures enable, enhance, or prevent information behaviors within and among communities.

We position our understanding of marginalized populations

using a conceptual framework of access to healthcare, considering approachability of healthcare resources, acceptability of seeking out and availing one's self of healthcare resources, availability and accessibility of healthcare, affordability of care, and appropriate fit between the services offered and the populations who will access those services (Levesque, Harris, & Russell, 2013). This dynamic perspective on access allows us to better define marginalization not as a static quality that can be easily quantified (e.g., "income below 200% of the poverty level") but as interwoven processes that relate both to individual characteristics (e.g., income level, social capital) and to the characteristics of healthcare services (e.g., their location and cost). We include both individuals with chronic diagnoses who must manage their illness over the course of their lifetime, and individuals who experience population-specific health information needs, in our understanding of marginalized individuals.

PANEL AGENDA

The purpose of this panel is to (1) examine issues surrounding health information behavior research with marginalized populations, and (2) consider the intersection of multiple disciplines in health information behavior research (e.g., public health). We will address the following topics:

- Why is health information behavior research with marginalized populations necessary?
- What are some useful methods for this research?
- How can researchers build relationships with marginalized populations?
- When and how should other disciplinary approaches be incorporated into this work?

The organization of our panel is as follows:
1. A brief introduction to marginalized populations and health information behavior research will be presented by the panel moderator, Blake Hawkins (5 minutes)
2. Five examples of health information behavior research with marginalized populations will be presented by the panelists Blake Hawkins, Amelia Gibson, Kaitlin Costello, Tiffany Veinot, and Devon Greyson (50 minutes).
3. Brief closing remarks and additional discussion of marginalized populations research will be presented by Blake Hawkins (5 minutes).
4. World Café discussions in small groups, with each panelist acting as a facilitator for discussions about the topics discussed in panel, giving participants the opportunity to share perspectives and discuss future research (Carson, 2011) (30 minutes).

To structure the World Café discussions, the following questions will be used as a starting point:

1. How do you work with marginalized populations in your research?
2. How can we address some of the challenges of working with marginalized populations?
3. Are there additional methods approaches to consider when studying marginalized populations? What kinds of methods have you used, either successfully or unsuccessfully?
4. How do researchers move beyond deficit-based

frameworks when working with marginalized populations?

PANEL DISCUSSIONS

Building relationships with participants
Blake Hawkins, MLIS, (moderator/panelist) is a doctoral student from the University of British Columbia iSchool and School of Population and Public Health interested in community-based research with LGBTQ youth and sex workers. Over the last four years he has had a variety of opportunities to collaborate with community groups in different capacities (as a researcher and community engagement roles with academia). As an academic and community member he has completed research on information behavior, online interactions, knowledge mobilization, and public policy impact on accessing health services. As a panelist he will discuss some of his master's research on LGBTQ health information seeking behaviours. This work involved a year of building partnerships and engaging with the community to understand their needs and what would be appropriate for a research project. He will briefly reflect on his experiences building relationships with community partners – this includes the power dynamics, managing expectations, and some myths both researchers and community partners may have about these relationships. Additionally, Blake will discuss the importance of being aware about the community context (e.g., location) and how this may impact the engagement process with community partners. In the case of his research project, Blake had to deal with some gendered obstacles when recruiting young gay, bisexual, and other men who have sex with men due to the legacy of masculinity in the community. By sharing his academic and professional experiences, in the context of this one project, he hopes to emphasize the importance of context with information researchers who are interested in building partnerships and complete research with marginalized populations.

Amelia Gibson Ph.D is an Assistant professor at the University of North Carolina at Chapel Hill where she studies health information behavior, and local communities and places as information systems. Her current work focuses on information poverty and how intersections of identity, place, space, and social and economic power/privilege influence information access and information behavior. She will discuss her work in information poverty, information access, and geographies of health related information seeking among parents of people with disabilities, and young Black women, as examined in two projects - Healthy Girls Know, and the Disability LINES project. Healthy Girls Know is a youth participatory action study that engages a pilot cohort of 6 Black teen girls (12-15) The Disability LINES project examined the information needs, information worlds of parents of individuals with Down syndrome and Autism Spectrum Disorder. The project encompassed two studies - an interview study that examined health information access and behavior among 41 parents of individuals with developmental disabilities, and a survey (n=935) of the information needs and information source choices of parents of individuals with Autism Spectrum Disorders (ASD) in the state of North Carolina. Together, the two studies informed an expanded understanding of information poverty as experienced by parents and caretakers who rely

on medical data and research (available on the internet), as well as local procedural and institutional knowledge.

Methods and approaches

Costello will discuss some of the methodological challenges in health information behavior research with marginalized populations by presenting the methods from her current study. This study employs a qualitative approach to interactive information retrieval research and employs home visits, semi-structured interviews, and retrospective think-alouds to uncover the causes and consequences of online health information seeking in the context of chronic pain. Although many studies evaluate how people use the Internet to interact with information, most of the research in this area cannot be generalized to adults diagnosed with chronic diseases, for several reasons: interactive information retrieval studies have not typically targeted health information needs; the studies are primarily conducted with college-aged students, who interact with the Internet differently than older adults diagnosed with chronic illnesses; and the studies usually impose search tasks on participants rather than allowing them to search for information that meets their own information needs. Previous research, which has been largely concerned with interactions during information seeking, also generally does not examine information *use*, a central component of information behavior. The current study aims to understand how real patients diagnosed with chronic conditions search the Internet for health information, what information they are interested in finding, how they understand and evaluate that information, and how it is used after their search session has concluded. Costello is an Assistant Professor at the School of Communication and Information at Rutgers, the State University of New Jersey. She studies health information behavior with a focus on how patients diagnosed with chronic conditions use social websites, such as Twitter, Facebook, online support groups, and other social websites to communicate with other patients about their health. She has conducted multiple qualitative studies in this domain, interacting directly with participants with various health information needs and often diagnosed with chronic health conditions.

Tiffany Veinot, MLS, PhD, is an Associate Professor at the Schools of Information and Public Health at the University of Michigan. Veinot will argue that health information behavior research with marginalized populations should incorporate study of the networks, families, and communities in which individuals are embedded. To do so, she contends that information behavior researchers should "make the 'meso' visible" in their research. The "meso" level of society includes small scale collectivities that fall between the micro level of individuals and the macro level of nation states, including entities such as families and communities. Research conducted at a meso level of analysis permits identification of emergent informational phenomena that are not reducible to individual behavior, such as differential patterns of access to information and connections between collective information behavior. Furthermore, multilevel analyses can permit rigorous modeling of the relationships between individuals and their meso-level contexts. This talk describes methods used in a

longitudinal study of the information activities and networks of low-income families in which at least one member has a chronic illness. In this study, the family was taken as the central unit of analysis, and individual participants were sampled by family group. This mixed methods study involved five contacts with 25 families (with 2-6 members each) over two years. The study used two family-centered interviewing methods: 1) individual interviews conducted using a "whole family methodology"; and 2) "family group interviews", which adapt the focus group method for people who know one another. Individual surveys, including family network items, were completed at each contact, and a "home tour" was conducted once. All data analyses were conducted at both the individual and group level. The value of these methods will be illustrated with examples of analyses of both individual and group-level information phenomena.

Incorporating multidisciplinarity

Devon Greyson, PhD MLIS, is a postdoctoral research fellow at the British Columbia Children's Hospital Research Institute and the University of British Columbia Department of Pediatrics, and instructor of Women's and Gender Studies at Capilano University. Greyson's research focuses on health-related information practices of youth and parents, and on the ethics and effectiveness of health information interventions. Greyson's work includes ethnographic research with young parents and vaccine hesitant populations; health services and policy survey research with parents of trans and gender creative youth, health care providers, and the general population; and normative-empirical analyses of population health information interventions with a particular eye to the distributive justice implications for marginalized populations. On this panel, Greyson will discuss adapting dimensions of health care access to apply to health information access, as well as the strategy of conducting interdisciplinary research in order to flexibly and appropriately "give back" to participant populations by co-creating research outputs that matter to their communities.

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