

Using Online Data in Health Co-Inquiry: A New Method

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Introduction

Abstract

This project develops a new, multi-method approach to Health Co-Inquiry. In health and mental health care and research, there are efforts toward person-centered and fully integrated care, along with carefully conducted research studies that can foster evidence-based practice. Health Co-Inquiry happens when person-centeredness, integrated care, and evidence-based practice are combined with collaboration between all stakeholders (including activation of persons with illness, caregivers, and health and mental health providers). In receipt of a grant from the National Science Foundation for institutional technological improvements in data collection, a research protocol was developed for pulling in large amounts of stakeholder information from online sources. The process includes focused online searches for URLs; developing computer code to search data from URLs for specific content; and researcher analysis of content for global themes. Safeguards include removing stakeholder monikers from quoted narratives and seeking stakeholder consent to quote them if a URL is accessed via a password.

Keywords: Health Co-Inquiry, patient-activation, person-centered, integrated care, evidence-based practice

Background

Managing chronic health conditions is a worldwide challenge, with tremendous suffering and expense being sustained (e.g., in days lost to disability, caregiver time and energy, treatment costs, and health and mental health provider effort; World Health Organization, 2001). Typically, such conditions involve health changes and management over a long period of time (WHO, 2014). So, planning, action, and evaluation of actions are essential for patient well-being. Some negative outcomes might be prevented when communication and collaboration improve between patients, caregivers, and health and mental health providers (International Collaboration for Participatory Health Research, 2016). In the most preferred models of fully integrated care, patients and caregivers are equal participants in information gathering, evaluation, planning and implementation of care plans (Frerichs, Lich, Dave, & Corbie-Smith, 2016). Health Co-Inquiry (Seifert, 2015) is a highly cooperative and multi-method approach. It includes stakeholder activation, person-centeredness, evidence-based practice, integrated care, and openness to subjective, as well as objective inquiry. Through Health Co-Inquiry, stakeholder collaboration can lead to improved outcomes.

Person Activation in Chronic Health Conditions

[In healthcare, the person with a health condition is generally referred to as a "patient", and in mental health practice, s/he is called a "client". So, here we will refer to the individual as a patient/client in order to honor each discipline's preferred term.]

An essential concept in the management of chronic health conditions is patient/client activation, or more broadly, "person activation". All stakeholders who are involved in chronic illness can benefit from being activated toward cooperation, collaboration, and positive outcomes. For all stakeholders, gaining relevant knowledge and skills, comprehending a particular person's predicament, and working for prevention, good treatments (when they are necessary), and competent health management are fundamental (e.g., Davis, Schoenbaum, & Audet, 2005). Traits of an activated person include seeking information, looking for help, and engaging in healthful thoughts and behaviors (Hibbard & Tusler, 2007). Presumably, the same sorts of activation might benefit caregivers and providers, too, and when all stakeholders are activated toward cooperation and positive outcomes, they can work together to achieve compromises.

Person-Centered Practices in Health Management

Collaborating toward compromises is vital to Health Co-Inquiry. A vibrant concept in healthcare today, person-centeredness originated in the field of psychology (Rogers, 1951). Yet, it is now in use in many fields and disciplines. Essentially, a person-centered approach takes into account the wants and needs of the individual, and while it is typically associated with the wants and needs of the patient/client in mental health and health care practice, a Health Co-Inquiry approach also links it to the wants and needs of other stakeholders, like caregivers and providers. When "reciprocal person-centeredness" is observed, each stakeholder can feel free to communicate about her or his wishes and needs in an open and accepting exchange—fostering mutuality and balance (Seifert, Flaherty, & Trill, 2013; Vaillot, 1966).

Evidence-Based Practice in Chronic Health Conditions

Having access to expertise and knowing the extant literature related to a specific health condition is absolutely necessary in the context of managing chronic illness. Usually, one's health or mental health provider is presumed to be the access point to such expertise. However, in Health Co-Inquiry, each stakeholder is highly regarded for his or her expertise, i.e., what knowledge the stakeholder brings to collaborative inquiry that is relevant to managing the chronic health condition. For example, a provider might know about the newest, approved treatments, a caregiver might have insights about what is possible within the patient's/client's ecology, and the person with the chronic condition might be aware of subtle nuances that are very individualized (e.g., personal habits and preferences). So, each stakeholder brings a kind of expertise that can be shared during treatment planning and evaluation. Each stakeholder's unique vantage should be treated as an *advantage* as another piece of the puzzle, which might lead the collaborative team to assemble the whole thing.

Fully Integrated Care in Chronic Illness

As a fourth component of Health Co-Inquiry, integrated care fits the spirit of the foregoing concepts and practices. Indeed, the best models of integrated care include descriptions of stakeholder activation, person-centeredness, and evidence-based practices, while incorporating expertise across different types of providers (e.g., physicians, healthcare associates, mental health professionals, other clinical staff) in order to optimize patient/client outcomes (Jones & Ku, 2015).

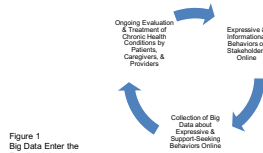


Figure 1
Big Data Enter the
Feedback Loop in
Management of Chronic
Health Conditions

Technology in Health Co-Inquiry: Online Resources and Data

The Online World: 2000+

Since the early 2000s there has been an explosion of online technologies and human presence on the internet. According to Internet Live Stats (2017), use of the worldwide web has increased from fewer than 500 million people in 2000 to more than 3 billion in 2016. As Oh and Lee (2012) have observed, the rapid expansion of internet use globally has enhanced access to information about disease and health management. In the 21st century, this can foster patient activation and aid the cooperative endeavor between patient/clients, their caregivers, and their health and mental health providers. One factor that seems to predict patient/client participation in health support online is an "intrinsic health orientation" (i.e., wanting health information and seeking prevention; Dutta & Feng, 2007, p. 181). Being at risk for, or being diagnosed with, a particular health condition seems to further predict an increase in seeking online support and information relevant to that condition (Dutta & Feng, 2007).

Online Health Support: Activating Health Co-Inquiry

In Health Co-Inquiry, persons with health conditions, their caregivers, and their providers collaborate toward positive outcomes (Seifert, 2015). As mentioned previously, part of the collaborative endeavor is person activation, and the internet can play a vital role. For example, persons with a cancer diagnosis who self-reported seeking support online also acknowledged that the greatest benefit of their health-related internet use was to equip them with knowledge (Seckin, 2011). For family caregivers of persons with pediatric cancer, Coulson and Greenwood (2011) found that the highest levels of perceived support from online activity were related to information gathering and emotional buttressing (see also, Cutrona & Suhr, 1992). So, caregivers, too, can be activated toward and report benefits from internet use.

Bifurcated Method

Step 1: Develop list of 13 chronic health conditions using WHO and US data about top 10 disabling and top 10 fatal ones.

Step 2: Develop a list of global, health-related search terms.

Step 3: Identify URLs related to the given health conditions via 4 common search engines.

Step 4: Vet the URLs by visiting all websites to be sure that they contain content related to the specified health conditions.

RESEARCHERS:

Step 5: Read and reflect on narratives posted at the various URLs.

Step 6: Identify the common themes across patient/client, caregiver, and provider narratives.

Step 7: Evidence converges on common themes.

INFO/TECH:

Step 5: Write code to pull down narrative into spreadsheets.

Step 6: Use global search terms and lists of specific search terms (by condition).

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