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The invisibility of ruling texts: An institutional ethnographic scoping review of family caregivers' information work

1. Introduction

To make visible how different facets of family caregivers' eldercare work are highlighted or obscured in academic writing and research, this scoping review examined the conceptualizations and portrayals of family caregivers' information work in scholarship and the degree to which this type of work is recognized. In doing so, this study deepens our understanding of the complex relationship between information and care by exploring how texts come to regulate our understanding about and research surrounding information-related care work.

2. Context

As the proportion of older adults will more than double in the next 20 years (Statistics Canada, 2010), the aging of Canada's population necessitates innovative supports from familial, societal and governmental institutions. The federal government's endorsement of aging in place (the ability to live at home for as long as possible) combined with a shifting away from institutionalization and decreasing availability of government-funded home care programs is increasingly transferring responsibilities and demands for unpaid care work onto families. Keefe (2011) reports that between 70 to 80 percent of care provided to older adults is done by family members and friends.

The provision of, access to, and ability to navigate and use information enable family caregivers to be involved in the care and wellbeing of aging family members. Policy documents from the United Kingdom's Department of Health (2012a; 2012b) typify the emphasis on the centrality of information to carers' lives, with information as fundamental to good care, enabling and empowering carers to make better choices and to take control. This expectation that family caregivers will 'do' information work is confounded, however, by a significant number of studies "indicating that extensive unmet caregiver information needs persist" (Washington et al. 2011, p. 39). Barnes and Henwood (2015) critique the 'informatization of care', a trend in which information may marginalize or replace care, and draw attention to the distinction between informing *to* care and informing *with* care; the latter indicative that information is neither separate nor outside care, but is instead inextricably linked to care (p. 159).

Corbin and Strauss (1985) first described ‘information work’ as a form of work done by people living with chronic illness. Within LIS, Hogan and Palmer (2005) and Souden (2008) have taken up the concept, both characterizing information-related activities as part of the work of managing one’s own chronic illness. This present study aims to advance the conceptualization of information work by focusing on the additional work of searching on behalf of or because of another. In alignment with Corbin and Strauss (1988), I assert that care work “has an information component and presumes some degree of information processing whether the work is manual labor or highly abstract decision making” (Huvila, 2009, p. 3). Characterizing caregivers’ information practices as *work* brings attention to the time, effort, resources, etc. that are often made invisible in literature and policy, owing to the construction of caregiving as a gendered concept of social and familial responsibility. Harris (2009) speaks to this hidden and underarticulated form of work: “the information-seeking work involved in taking responsibility for one’s ... family members’ health involves much more than simply looking for and locating data relevant to a specific condition ... it means sifting through, interpreting and dealing with the implications of the information one finds” (p. 78).

3. Framework of Inquiry

Institutional ethnography, developed by Canadian sociologist Dorothy E. Smith in the 1970s, is a method of inquiry intended to uncover invisible forms of work. While notably implemented in the health sciences and other human services, IE is not yet “widely taken up by library and information science researchers” (Stooke & McKenzie, 2009, p. 660).

By mapping how the everyday world of people’s experiences is “put together by relations that extend vastly beyond the everyday” (Smith, 2005, p. 1), the many influences on a caregiver’s every day and every night experiences are made visible. In the case of the everyday lives of family caregivers of community-dwelling older adults, one such ‘influence’ is how scholars or researchers come to study, know and write about the work, and more specifically, the information work done by these caregivers. These extralocal influences, called ‘ruling relations’ by Smith, are invisible, networked linkages of control and coordination that exist outside of individual people but shape their local experiences. Networked across time and space, ruling relations might include corporations, government bureaucracies, mass media and of focus in this study, academic texts and discourse.

Texts in an IE study are broadly construed as “material objects that carry messages” (Smith & Turner, 2014, p. 5), that is, “words, images, or sounds that are set into a material form of some kind” (Smith, 2006, p. 66), and include paintings, music, television and writing. Smith (2005) outlines two key features of texts that enable institutional ethnographers to go beyond peoples’ everyday experiences to reveal ruling

relations: the replicability of texts and their ability to be read or heard by any number of individuals in identical form across time and place. While texts are ubiquitous in academia and academics engage with textual materials on a daily basis, these textual events, that is, the engagement with texts go “almost entirely unnoticed” (Smith, 2005, p. 122). The pervasive, yet undetected use of texts ensures a standardized framework and a particular way of knowledge production that is replicated for other academics to read and take up. How caregivers’ information work is framed in scholarly writing becomes replicated in other studies, and may shape or distort what is highlighted or obscured in subsequent studies.

Smith (1999) describes the regulatory hierarchy of texts as ‘intertextual hierarchy’, that is, higher-order (‘ruling’) texts that control or standardize other texts. In analyzing scholarly articles, this present study builds on the concept of intertextual hierarchy by examining the chronology of publication for instances of texts that project organization of knowledge surrounding information work into subsequent texts, and will strive to make visible “what lurks below the water line” ... that what is “largely unconscious and unarticulated, even by its practitioners” (Bates, 1999, p. 1043).

4. Methods

A scoping review was used to make texts “ethnographically visible”, bringing to light texts’ coordination of caregivers’ local experiences. Scoping reviews, an assessment of the extent and nature of research activity to convey the breadth and depth of a field, are lauded for their ability to provide a “comprehensive and panoramic overview” (Davis et al., 2009, p. 1388) of the literature. Following the five stages outlined by Arksey and O’Malley (2005) (identification of research question; identification of relevant studies; selection of included studies; data extraction and charting; and summarization and dissemination of findings), this scoping review captured what information work ‘looks like’ in a variety of academic disciplines’ research literature. Databases from social sciences, health sciences and library and information sciences were searched for terms relating to information, caregiving and work. Articles meeting inclusion criteria were read thoroughly. In keeping with an institutional ethnographic analysis, articles were read to identify ruling relations present in the coordination and organization of caregivers’ information work. Specifically, articles were analyzed for texts’ use of language (and power), organizational interests, indications of unstated assumptions, and the portrayal of and assumptions relating to informal caregiving and information work, including tasks studied and how work was described.

5. Findings

From an initial 2043 articles retrieved, a total of 72 articles were included for full analysis in this scoping review. The information work of family caregivers of community-

dwelling older adults was, save for one article, invisible in the articles analyzed within this scoping review. Perhaps unsurprisingly, the construction of caregiving as work was also invisible. One contribution to this invisibility may be due to the ways in which information was conceptualized, studied and shared in these academic writings. Information was rarely defined and was narrowly construed, considered simply as new knowledge, support, or education. There lacked an acknowledgement that “information is dependent on the individual user and that ‘best’ information, as an objective reality, does not exist” (Harland & Bath, 2008, p. 468). Moreover, the frequent classification of information as an ‘intervention’ to be delivered by a technological tool and to be used by caregivers impinged a clinical tone to the construction of information (an example of the biomedicalization of caregiving [Hooyman & Gonyea, 1995]). The articles included for analysis generally positioned information externally to caregivers, not giving recognition to experience, previously-known information or other, more internally-located loci of information. As introduced earlier, Barnes and Henwood (2015) articulate and label this tension between the external and internal location of information within the information-care relationship. The ‘inform *to* care’ approach, dominant in policy and research (and as observed in this study), positions good care as a result of the availability of good information, with information as “separate and outside of care, while nevertheless acting upon it to provide care” (p. 147).

6. Discussion

This is the first institutional ethnography study to incorporate a scoping review and is in attempt to recognize how concepts and theories explored in LIS and caregiving research may legitimize the boundaries placed around the methods and ways we think about and study the information work of family caregivers (and ultimately, how these ruling texts might organize the everyday lives of family caregivers of older adults).

Despite the promise information interventions are purported to afford caregivers (decreased stress, empowerment, etc.), articulating the information-care relationship remains elusive. The positive, enabling effect information has on the caregiver and their relationship with the care receiver is discussed in the literature as an assumed cause and effect relationship. There lacks, however, an exploration of how and why this relationship is able to develop. This may be due to the inconsistent application of theories or models in the sampled studies, the paucity of critical or feminist angles and the glaring absence of contributions from LIS scholars who may be able to better speak to the complexities of grappling with information and explaining why more information is “not a panacea for uncertainty” (Barnes, Henwood, & Smith, 2014, p. 14). Adopting an understanding of informing *with* care may be a means by which to elevate information within care as more than a practice, a skill or a passive occurrence, but as a complex and visible form of work.

7. References

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