

THE IMPORTANCE OF REVISITING: RETRACING FAMILY CAREGIVERS' EVERYDAY INFORMATION WORK (Lightning Talk)

Abstract or Résumé:

Information is a key tool that enables care providers to be involved in the health and wellbeing of older adults in their care. While recognizing care providers' information practices as *work* has slowly received scholarly attention, there has been little corresponding scholarly effort to frame family caregivers' data practices as *work*. In this paper, I revisit an earlier study to determine whether family caregivers' information work and data work are sufficiently different so as to be distinguished as different forms of work.

1. Introduction

Information is a key tool that enables care providers to be involved in the health and wellbeing of older adults in their care. Caring for a community-dwelling older adult is an intricate information practice as family caregivers are increasingly encouraged to actively and independently seek out information as part of their care work, finding, translating, balancing, storing and mediating information received from a number of different sources in different formats, making judgments regarding the degree of usefulness and pertinence of the information found.

While recognizing care providers' information practices as *work* has slowly received scholarly attention (e.g., Dalmer, 2020; Hogan & Palmer, 2005; Souden, 2008), there has been little corresponding scholarly effort to frame family caregivers' data practices as *work*. In this paper, I revisit an earlier study to determine whether family caregivers' information work and data work are sufficiently different so as to be distinguished as different forms of work.

2. The Earlier Study

The first study sought to bring a lens of *work* to family care providers' information activities in order to acknowledge and draw attention and visibility to the complex effort, time, affect, and resources required in seeking, locating, sifting through, interpreting and dealing with the implications of information found. The term *information work* is used to underscore the information-related care activities, ranging from manual labour to highly abstract decision making, that family caregivers engage with in their everyday and every night lives. This includes both the intellectual and emotional qualities of using information. Families' information work might include, for example, looking up side effects of a new medication, or deciding which family members to contact to share information after attending a doctors' appointment.

In order to make family caregivers' work more visible and to understand how family caregivers actually experience information work in their daily lives, I spoke to 13 family caregivers of community-dwelling older adults living with dementia – seven wives, one husband, and five daughters ranging in age from 50 to 77 years of age.

In these interviews and in a visual mapping exercise (taking inspiration from Sonnenwald's information horizons [1999]), I asked family caregivers to speak about as well as doodle and sketch out their information activities, patterns, sources and, ultimately, their worlds. As participants spoke to me and sketched, they began to share and tease out the many people, places, tools, schedules, organizations, and devices that they engaged with, avoided or negotiated in order to inform themselves about dementia diagnoses or the many associated changes and symptoms that manifested and evolved over the course of providing care.

3. The Importance of Revisiting

Since the conclusion of this first study, I have gravitated towards socio-gerontechnology, a field of study that joins age studies with Science and Technology Studies (STS) and that stresses that technologies, older people and care networks are co-constituted in a social field comprised of actors, discourses and power relations (see, for example, Peine, Marshall, Martin, & Neven, 2021). I explore how age studies intersect with communication, media, and critical data and information studies, discerning how our data-driven society and digital data-gathering practices impact and govern how we grow old in our communities.

As Sousa argues, it is crucial “to make visible the ways in which care for older people is (re)constituted through shifting conceptions of care” (p. 134). As prompted by this conference's call of *Leaps and Stumbles*, I have revisited my earlier study to think through the relationship between information work and data work within care contexts as well as to think through how to continue to make visible the many and changing facets of care work – and of particular focus for me, data work. In alignment with this newer line of questioning, I am curious how data work is transforming experiences of care work. This strikes me as being quite crucial – the keeping track of the changing work that family and friend care networks are asked to do, implicitly and explicitly - work that is increasing in scale and complexity with the continued introduction of technological devices, gadgets, and apps.

As I have begun rereading my earlier interview transcripts and revisiting participants' information world maps with this new lens of seeking out instances of families' data work, I am struck by the presence of data. Multiple and intersecting appearances of data, both digital and analogue. Throughout this paper, I will question whether I unintentionally simplified participants' experiences and expressions of their information work in my earlier study by not considering or taking up many of their care-related information-related needs and activities as data work.

Ultimately, this reflective paper brings information and data into conversation within care contexts, reveals the labour that data require in familial care relationships, and, finally, considers the utility of bringing a lens of work to familial care in order to shape our understandings of data and its entry into our everyday lives.

References

Dalmer, N. K. (2020). 'Add info and stir': An institutional ethnographic scoping review of family care-givers' information work. *Ageing & Society*, 40(3), 663-689.

Hogan, T. P., & Palmer, C. L. (2005). "Information work" and chronic illness: Interpreting results from a nationwide survey of people living with HIV/AIDS. *Proceedings of the American Society for Information Science and Technology*, 42(1).

Peine, A., Marshall, B. L., Martin, W., & Neven, L. (Eds.). (2021). *Socio-gerontechnology: Interdisciplinary critical studies of ageing and technology*. Routledge.

Sonnenwald, D. H. (1999). Evolving perspectives of human information behavior: Contexts, situations, social networks and information horizons. In T. Wilson & D. Allen (Eds.), *Exploring the contexts of information behaviour* (pp. 176-190). London: Taylor Graham.

Souden, M. (2008). Information work in the chronic illness experience. *Proceedings of the American Society for Information Science and Technology*, 45(1), 1-6.

Sousa, I. (2013). New technologies and concepts of care. In P. Armstrong & S. Braedley (Eds.), *Troubling care: Critical perspectives on research and practices* (pp. 129-142). Canadian Scholars' Press Inc.