Consulting Online Healthcare Information: E-Caregivers as Knowledgeable Decision Makers

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ABSTRACT

Home caregivers provide multidimensional support to family and friends who are aged, disabled, and unable to care for self. Often experiencing the negative effects of caregiver stress, they face potential physical and emotional strain, changes in health requiring emergency treatment, and financial burden. Today, families are turning to mobile technology to lessen their burden and to cope with the stress of caring for members through activities including healthcare information searches. The purpose of this study is to explore how the Internet is helping caretakers to make decisions on the selection of doctors and treatment options. Multivariate regression analysis and individual level data from the Pew Internet and American Life Project is used. The authors’ findings suggest that while caregivers are using the Internet for making decisions on family health needs, they are not as likely to use it to protect their own health.

KEYWORDS
Caregiver Health, E-Caregiver, Homecare, Mobile Technology, Smartphones, Telehealth

INTRODUCTION

The act of home caregiving in the U.S. has grown in demand and scope. By 2020, it is predicted that there will be 16.2 million “non-institutionalized seniors” 65 years and over living in the U.S. with one or more health issues requiring caregiver aid (U.S. Department of Health and Human Services [USDHHS], Administration for Community Living, 2015, p. 100). Home caregivers, either family or friend, are providing multidimensional support to adults or children who otherwise would require institutional assistance. Often unpaid, they provide home safety, arrange nutrition, oversee finance and insurance, and assume medical tasks for the terminally ill (Pew Research Center, July 2012; Schmeida & McNeal, 2014). In providing medical care, home caregivers interface with the community medical system during all phases of disease, from diagnosis to discharge and transfer to home (Schmeida & McNeal, 2014; Cantekin, Kavurmac, & Tan, 2015). As a result, the home caregiver often faces physical and emotional strain from the result of looking after a loved one (USDHHS, 2015). Among the key stressors related to providing support is making decisions related to treatment options and doctor selection; these and other healthcare decisions require vast information and are driving online health information searches across the general U.S. public (Schmeida & McNeal, 2014). Considered a “core social impact of the Internet”, e-caregivers need the skill to find complex information for decision making on recipient care, turning to mobile technology to meet their needs quickly (Pew Research Center, July 2012; Pew Research Center, June 2013). Of particular concern is whether home caregivers are using these skills in protecting their own health. Do family members become focused on the wellbeing of other members under their care or do they also prioritize protecting their own health? This study explores these questions using multivariate regression analysis and individual level data from the Pew Internet and American Life Project.
BACKGROUND

Home caregivers provide support to family and friends who are aged, disabled, and unable to care for self. The number of U.S. adults providing unpaid care to an adult 18 years or older has increased from 27% in 2010 to 36% for August-September 2012 (Pew Research Center, June 2013, p. 8). In addition to assisting with activities of daily living, newer reports (National Conference of State Legislatures, 2014) show the scope of home caregiving has broadened as they assume traditional nursing tasks, such as medication management, wound care and working with medical equipment. This multitasking role requires both physical effort and informed decision making.

Online health searches are considered a form of telehealth; defined as the use of electronic information and advanced communication technology (digital technologies) to support institutional healthcare services, consumer and provider education, health administration and health research (H.R. 2157, 2001). Telehealth has been promoted as a means of improving accessibility to healthcare services, improve service quality, and promote efficiency by reducing service costs (Schmeida, 2005). For the home caregiver, telehealth primarily takes the form of online information searches, nevertheless it has proven vital in decision making on treatment modalities including medications, various hospitals and providers, and health insurance. According to the Pew Research Center (June 2013), the Internet plays an important role for home caregivers, with 59% claiming online resources helpful to support their functions as caregiver, and 52% using the Internet in coping with the stress associated with caregiving (p. 4). E-caregivers are connecting with government and non-government health service websites, such as the U.S. Department of Health and Human Services Administration on Aging National Family Caregiver Support Program website on caregiver support services; to find evidence-based medical treatment modalities using WebMD; locating public health service providers at the Centers for Medicare & Medicaid Services www.cms.gov website; and to participate in social health networks online (USDHHS, 2015; Centers for Medicare & Medicaid Services, 2015; Schmeida & McNeal, 2014). Caregiver activities also include searching health insurance online. Schmeida and McNeal (2014) found unpaid home caregivers (for adult or child) are downloading insurance forms and applying for insurance online.

Caregivers are not alone in accessing healthcare information online; the general population is also using the Internet as tool for managing healthcare needs. According to Pew Research Center (January 2013) approximately 35% of adult Internet users have connected online to “figure out what they or someone else might have” using the information to decide if a medical practitioner is warranted, self-care, or in-between. Using the Internet as a means of “triage diagnose” was led by females, 18 to 64 years, non-Hispanic white, annual household income of $35,000 to $75,000 and beyond, education level of high school to college graduate and greater (p.7). More specifically, 55% of Pew survey respondents affirmed searching online within the past 12 months for information on a specific disease or medical problem; 43% searched a particular medical treatment or procedure; 16% on drug safety or recalls; 15% on medical test results and 14% searched information on caring for an aging relative or friend (p. 10).

Although caregivers are not alone in turning to the Internet as a tool in managing their health needs, they are different from the general public in a number of ways including demographics and geography. Research (AARP Public Policy Institute, 2011; Pew Research Center, July 2012; Tong, 2007; Schmeida & McNeal, 2014), has found caregivers to be primarily middle aged, more affluent, married or living with a partner and in a rural region. As compared to those living in suburban and urban areas, persons living in rural America are more likely to take on the role of family caregiving. This is partly due to geography; individuals living in rural areas are more likely to have limited access to nearby providers and community resources. Many must rely on the Internet for their informational
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