CARE-RATE: INITIAL DEVELOPMENT OF AN ARTIFICIALLY INTELLIGENT ONLINE TOOL FOR CONNECTING CAREGIVERS TO RELEVANT SUPPORT

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ABSTRACT

Providing care for someone living with dementia requires a wide variety of products, services, and other resources to support both people in the care partnership. There is a tremendous amount of information available online, however, knowing what to look for or where to find it can cause potentially helpful information to remain hidden. This paper describes the transdisciplinary participatory development of CARE-RATE, a web-based application that leverages cutting-edge artificial intelligence techniques to find personalized solutions to dementia caregiving problems.

INTRODUCTION

The average age of the global population is rising and, consequently, so is the prevalence of age-related conditions, such as Alzheimer's disease and other dementias. Family and other unpaid caregivers (hereafter referred to as 'caregivers') of people living with dementia provide the bulk of care, with an estimated 15.9 million people providing 18.1 billion hours of unpaid care in the United States in 2015 alone, which equates to an estimated economic value of $221.3 billion USD (Alzheimer's Association, 2016).

Caring for someone who has dementia is an intensive occupation that can be physically, emotionally, and financially difficult. Caregiving has been shown to result in higher levels of psychological and physical stress, which can increase a caregiver's susceptibility to illnesses, limit their ability to perform their own daily occupations and impact their ability to provide needed care (Fonareva & Oken, 2014; Gilhooly et al., 2016). Access to support, professional and otherwise, can reduce negative aspects of caregiving (Brodaty, Green, & Koschera, 2003; Tang & Chan, 2016). This includes products, information, and services to support dementia care as well as feeling socially connected and competent as a caregiver (Joling et al., 2015). While it is often up to caregivers to find the various forms of support that they need, locating appropriate support can be difficult, frustrating, and often futile, as caregivers may not know what they are looking for or how to find it.

In response to this need, we are leading the development of CARE-RATE, an artificially intelligent online tool that connects caregivers to products, resources, and strategies that they need. While CARE-RATE is cloud-based, it does not operate as current search engines do where the user must explicitly state what they are searching for (i.e., having to know what they are looking for prior to searching for it). Instead, CARE-RATE uses natural language processing to enable caregivers to have a back-and-forth dialogue to describe the problem they are having in a style akin to speaking with a knowledgeable human, including CARE-RATE recognizing when it needs to ask targeted questions to extract missing requisite information. We are building custom search and ranking algorithms that leverage IBM's Watson and BlueMix cloud to identify and sort online resources (e.g., websites, databases, social networks) that are relevant to the caregiver's particular situation. This paper presents some of the progress to date and outlines future work.

METHOD

CARE-RATE is being developed using a collaborative participatory approach. Computer

scientists, rehabilitation scientists, and engineers are working closely with caregivers through four focus groups and a standing advisory committee (which consists of eight family caregivers, two directors from private long-term care facilities, and members of the research team). To date, the data from the first two focus groups have been analyzed and the results are being used to inform the design of the initial CARE-RATE prototype, as discussed below. The third and fourth focus groups will be held in March 2017 and will be used to explore target design questions in more depth to extract information that will be used to further refine the prototype.

RESULTS TO DATE

Focus Groups

Ten caregivers participated in two semi-structured focus groups (n=10: 7 were women; 6 cared for their spouses and 4 cared for a parent). Participants were asked about sources of information, information they need, and features of resource providers.

Four themes emerged from the initial focus groups. The first is "How do we anticipate what we need to know?". Participants suggested that it is difficult to know what questions to ask, that it was difficult to be proactive as they had to be in the situation to recognize their needs. Terminology was a challenge, particularly in the early stages of the dementia progression.

They identified several features of an online resource that were important; most prominent was the desire to have a resource that was credible. Content, the third theme, seemed related to the disease stage, for example, information about the diagnosis is needed early on, while legal information is sought later in the progression.

The final theme related to feelings of isolation and the need to connect. Participants expressed a desire to interact with people in a similar situation, to share concerns and to learn from the experience of others.

System Development

These information from the focus groups is being used to prioritize how CARE-RATE identifies and sorts information as well as what types of information should be presented to caregivers, including how to design the user interface.

The back-end of the system uses a modern variant of artificial intelligence called "cognitive computing" which combines natural language processing and information retrieval. Through a simple dialogue, the tool gathers information about the caregiver's (and patient's) context and builds a more accurate picture of their needs. The tool then searches the web for products, strategies, and local resources to return possible solutions that avoid irrelevant solutions.

As a bootstrap, approximately 100 seed URLs of relevant, general websites on Alzheimer's were passed to Apache Nutch[1], which in turn crawled the web, producing approximately 100,000 PDFs, HTMLs, and TXT files. These were then indexed, based on their content, using an implementation of Apache Solr[2] for IBM BlueMix.

A module to perform relevancy ranking in BlueMix was then trained in a supervised fashion using a large matrix of queries, URLs, and scores representing the relevancy of the latter to the former. To produce this matrix, four volunteers each produced and posed 40 novel queries about Alzheimer's and Alzheimer's care to Google, and subsequently scored the top four results with regards to their relevancy.

FUTURE DIRECTIONS

The CARE-RATE project is entering its third of a projected five years of primary development. Future work includes conducting two more focus groups and the translation of focus group data to design criteria. The resulting prototype will be iteratively developed with input from the project advisory group then tested and refined based on feedback from caregivers of people who have dementia living

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[1] http://nutch.apache.org
[2] http://lucene.apache.org/solr/

in the community. The first fully-operational prototype is expected to be launched in Summer 2017. Up-to-date progress will be disseminated at the RESNA conference, including significant findings from the fully-analyzed focus groups and their impact on CARE-RATE's design.

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