A WEB-BASED COMMUNITIES OF PRACTICE SUPPORT SYSTEM FOR CAREGIVERS

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INTRODUCTION

CareNet is a web-based system to support informal caregivers (called herein "caregivers"), ordinary citizens engaged in the health care of their families and friends in their homes, developed in a partnership of the Victorian Order of Nurses (VON), Waterloo Institute for Health Informatics Research (WIHIR) and the Computer Systems Group (CSG). It uses concepts from work on Communities of Practice (CoP), software engineering, particularly Web-based systems design, content authoring, and knowledge management to create a supportive environment for caregivers. CoP are groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly [3].

The objectives of the CareNet project are: (1) To create a highly effective interactive environment that addresses the needs of caregivers: (1a) to obtain information and guidance (1b) to achieve efficient communication with professional healthcare workers with whom they collaborate and with other caregivers from whom they can gain advice, emotional support and solace (1c) to access other information and physical resources that are needed for proper care, and (1d) to document their observations, interventions and insights that can in turn become a knowledge resource for other caregivers. (2) To demonstrate the beneficial impact of CareNet on caregivers who collaborate with professional care providers of the VON. Information that is made available directly to caregivers through CareNet should be authoritative, comprehensive, up-to-date and relevant to the caregiver's locale.

THE NEED FOR CAREGIVER SUPPORT

With the aging of the "Baby Boomers," it has become clearer that the health care system faces challenges that require innovative approaches and alternatives to institutional solutions if care is to remain affordable and accessible. Today, patients are often discharged from institutional care at a higher level of acuity than they were admitted just a few decades ago. In fact, the home has become the locus of care for those recovering from major interventions and those with chronic conditions.

Organizations like the VON deliver and co-ordinate specialized care services in the home environment, making the home an extension of the care system. Although much can be and is done by such external care providers, complete care usually depends on the patient's family members or friends, transforming these individuals into caregivers, without whom care in the home would not be sustainable. This imposes many challenges on these individuals who generally lack adequate care-related knowledge and skills, and already have full, independent lives.

Many in-home care providers, such as aging spouses, are further challenged by their own limited mobility or other conditions. CareNet is intended to provide caregivers access to "support channels" such as care-related information resources, communication with professional care providers and other caregivers, the experience-based insights of other caregivers and providers, community-based resources (such as pharmacies and other suppliers), event co-ordination via booking and scheduling, and other capabilities that reduce the burden of caregiving. In our view, capabilities like these are essential if we are to realize a sustainable health system.

METHODOLOGY AND APPROACH

Our methodology includes the following steps:

(1) The Definition of Requirements and Desired Effects: We have created a joint team with the VON to define the needs of caregivers that can be addressed with Web-based tools, and to assess their effects.
(2) The Configuration of the Web-based Informatics Development Environment (WIDE) to serve as a basis for CareNet: CareNet is based on our WIDE Web-based software toolkit (described later) which has been tested and extended in approximately 30 similar

applications [5],[7] to the point that it addresses many of the requirements of a caregiver CoP.
(3) The Development of the Functions and Content of CareNet: We used WIDE in consultation with the VON to create a system to address caregiver needs.
(4) The Creation of the Knowledge Transformation Component: We are extending WIDE to enable the capture of knowledge and experience provided by caregivers for sharing with other caregivers. This work initially is taking the form of a series of discussion forums wherein the content is indexed under a controlled vocabulary.
(5) Deployment and Improvement: As the CareNet pilot is created, it is reviewed/approved by VON staff.

The Definition of Requirements and Desired Effects

Our approach here has been to document initial user requirements and then demonstrate a fully usable pilot implementation quickly to obtain user approval. As users have the opportunity to use the pilot, they soon determine new requirements or refinements. Our robust development environment allows us to respond quickly to the needed changes as it supports a process of "requirements discovery." Such an approach is needed when exploring new applications, particularly in settings where advanced information and communications systems have rarely been used.

The WIDE Basis and Content for CareNet

The configuration of WIDE to support caregivers has been relatively straight-forward. It involved the selection and assembly of a set of WIDE toolkit capabilities to create a webspace similar to many others we have created. The capabilities of WIDE have been documented by Cowan [4],[5] and are summarized here. WIDE is a collection of services that support the following capabilities.

- Searching (via a built-in indexing and search engine with thesaurus capabilities).
- Rapid (forms-based) database application and report development.
- Work flow modelling, presentation and management.
- Booking appointments and event management.
- Interactive messaging.
- Targeted announcements and group management.
- The definition of appropriate role-based security.
- Creating data-bases of multimedia information.
- Pull and push software agents [6] to acquire data from or send data to other databases and web servers automatically.
- Mapping of geo-referenced information along with map annotation and geographic querying.
- Built in asynchronous education software to provide on-line instruction and guidance.
- A competency assessment tool.
- A natural language generation service that supports customization of information to user characteristics, and many other features.

The model of the CareNet webspace is created using the WIDE toolkit and then the operational system is generated from the XML representations of the model using XSL transformations.

The Creation of the Knowledge Component

Our approach to this work is multi-component. First, we are extending WIDE to incorporate both moderated and open discussion forums (advanced forms of web-log "blog") that allow caregivers to record any thoughts, observations, interventions, insights and experiences (which we refer to as "tacit knowledge") that they believe may have value to others. This logging capability is complemented with the ability to enter or retrieve structured messages that can be annotated by staff. The structured message and annotation capability is built on an XML tagging system developed locally. To provide the basis for aggregating information, a taxonomy (a carefully managed vocabulary) suited to the care environment is under development. This vocabulary will be used for structuring and annotation purposes. An editor that allows the retrieval of tagged materials based on the logical combination of tags will be used to support retrieval of material that may be of interest where it can be distilled into guidelines by professional care providers. A long term research goal is the creation of a care ontology with a degree of semi-automatic production of informative messages.

Deployment and Improvement

This work is proceeding through a series of successive stages. The initial stage has been the creation and demonstration of a pilot which has served as the vehicle for demonstrating system capabilities that conform to requirements (the pilot is a fully functional prototype). Once the basic satisfaction of requirements was demonstrated, actual content was

entered into the pilot system. The pilot provides the basic functionality and enough content to demonstrate the system to users. The pilot will gradually evolve into a full-service system with all required content and usability features. This process will continue, resulting in the gradual refinement of CareNet. Given the nature and challenges of care, the ability of our toolset and approach to configure to specific needs and to support such evolution is a significant strength and attractant.

The WIDE toolkit has been developed to generate web-based systems rapidly. One of its most important characteristics is that domain experts, rather than programmers, can be taught quickly to use the toolkit to manage system evolution and maintain content.

RESEARCH BASIS

CareNet is built on the following research: the innovative application of WIDE; research by C. Yang [1] in authoring educational documents; our previous work on the tagging of content to support reuse and repurposing; and knowledge management based on the research of Abidi, et al. [2]

Our approach to the application of the WIDE toolkit to the support of caregivers is essentially to configure a series of capabilities that support the activities of caregivers, treating them as a Community of Practice. We are creating an environment that facilitates interaction with other caregivers and enables natural support groups to emerge, enhances their communication with professional care providers, and provides the means for the sharing of various information and physical resources.

Our approach to transforming tacit to explicit knowledge is multiphased. First, we defined a standard message framework for caregivers to record their observations, insights, etc. This message framework assists the caregiver by providing headings, including:

- Situation (existing conditions, preceding events, patient status, patient problem(s) and the like);
- Importance (seriousness of situation);
- Interventions (treatment, care process, etc.);
- Observations (symptoms, patient response, insights, thoughts, etc.);
- Results (effects of the intervention);
- Reason for Recording (possible guidance, general information, lesson learned, etc.);
- Security (private [self-only], open to all, open to caregivers only, restricted to care professionals).

The caregiver is asked to document as many of these as possible, each of which serves as an index to the message. The index terms are captured as XML tags associated with the text message. This process leads the caregiver through the creation of a structured note that can be retrieved by logical combinations of the indices. The messages can be directly retrieved as a related group of messages by others according to security constraints. Groups of messages can be distilled into suggestions, topics for further education, guidelines or other distillations by professional staff. All indices are selected from the controlled vocabulary that is presented to the individual entering or retrieving information within a message creation and retrieval interface. Initially, knowledge distillation will be performed manually, and the results will be made available in the system as meta-messages linked to the underlying messages that were used to create them. As we move forward, we will experiment with the automation of aspects of this distillation using the framework proposed by Abidi, whereby we map between messages and scenarios that are primitive pre-guidelines or knowledge frames, often still requiring a degree of human interpretation and summarization.

This work has been undertaken with the realization that tacit-explicit knowledge transformation is in its infancy and that approaches at this time are partial. However, our team has also recognized that a vast raw resource of tacit knowledge can be found within any group of care providers, whether informal caregivers or professional care providers. This evolving approach will begin the process of capturing and transforming this raw resource into shareable knowledge that is highly relevant, the product of thoughtful consideration, useful, and valuable to others regardless of the source. The raw knowledge also serves as an indicator of problems, misunderstanding, incomplete appreciation of the total picture, fears, etc. that can be remediated. These remediations, in turn, can be summarized, documented and made available as an evolving resource that emerges from the countless interactions between and among caregivers, patients, and care professionals.

Our assessment of the systems impacts will address both caregiver and professional care provider acceptance (by measuring actual use by individuals) and satisfaction (via on-line surveys), and management satisfaction (by periodic survey), as well as the achievement of the specific impacts defined in the requirements phase (by manual assessments performed

by a research assistant on a six-month basis during the test and full deployments.

RESULTS TO DATE

The development of the infrastructure to support the CareNet pilot is an ongoing activity. Concepts are tested with an expert caregiver support team, suggestions for improvements are made, and then rapidly incorporated into the operational pilot.

Parts of the pilot have been deemed ready for public use and are being moved to an operational implementation. Current plans include:

- Separate sections containing information for caregivers based on category (caring for spouse/partner, caring for child, caring for an older person, caring for myself)
- Ask a VON Expert
- Frequently Asked Questions (FAQs)
- Community resources
- Index of disease specific information
- Search

A key issue that arises and is under constant discussion is the sustainability of information, in this case information about the community and about specific diseases. Questions arise such as: Does the portal just refer the caregiver to a community site that may or may not have current information? What are the authoritative information sites in a community? How seamless is the access to community information? Does the portal just point to the local bar association (lawyers) or does the portal provide some form of seamless access? How much expertise is needed to maintain the section on "disease specific information?" Finally how can information technology assist with sustainability? For example, software agents can be configured to consult various authoritative sources and report on discrepancies thus using exception reporting techniques to minimize human intervention in data maintenance. As part of these efforts there is an ongoing discussion on how to maximize benefits to the caregiver while minimizing the cost of data maintenance to the VON.

The work on knowledge management has not yet left the research laboratory because tools are not robust enough for normal use. However research is continuing on tacit knowledge capture and tacit-explicit knowledge transformation as well as personalized health and caregiver information [8].

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