TOPS - designing digital tools for personal and social interaction

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ABSTRACT

In this paper we describe the TOPS project, which aims to generate digital engagement tools to aid personal and social interaction between older adults and their care providers. TOPS focuses specifically on rural older adults who experience chronic pain – this responds to research priorities and to gaps identified in the health, social and technological literature. We outline the project's methods, strategy for technology design and present feedback from initial scoping research.

Categories and Subject Descriptors

H.1.2 [Models and Principles]: User/Machine Systems – human factors; J.3 [Life and Medical Sciences] – Health; K.4.2 [Computers and Society]: Social Issues – Assistive technologies for persons with disabilities

General Terms

Design, Human Factors

Keywords

Older adults, rural, chronic pain, interaction, participatory design

1. INTRODUCTION

It is estimated that one in every three girls, and one in every four boys born in 2011 will reach their 100th birthday [1]. By 2030, approximately 22 % of the UK's population will be aged 65 and over, compared with 16.5 % in 2010 [2]. The potential societal impact of these projected increases are stark, particularly for the delivery of healthcare. As people age they are more likely to develop long-term (chronic) disease (e.g. arthritis, diabetes), which may require complex management from a variety of providers (e.g. General Practitioners, condition specialists). This can be costly, particularly if a patient's condition deteriorates and they require unscheduled care, which may involve admission to hospital. Newer models for delivery of chronic care focus upon 'extitution' [3], which sees a shift towards care being delivered in the community, out-with expensive hospital facilities. This may result in cost savings.

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The implementation of telehealthcare technologies within the home forms a key part of extitution strategies. This includes fall/flood/gas leak detectors (telecare), and systems that monitor various aspects of patient health remotely (telehealth). The general concept is that improving monitoring within the home may help to identify deteriorations in medical condition earlier, preventing potentially unnecessary transport to, and institution in, hospital. Such 'assisted living' has been recognised by Government and initiatives are underway in the UK to expand the use of telehealthcare, previously restricted to small-scale, regional pilot studies. The UK Department of Health's 'Whole Systems Demonstrator' project was a randomized controlled trial of telecare and telehealth technologies, involving over 6,000 people across three UK sites [4]. 'DALLAS' is the next initiative, scheduled to commence in 2012 - Delivering Assisted Living Lifestyles At Scale (UK Technology Strategy Board). DALLAS, which is industry-led, will see technology rolled out to three to five communities with around 10,000 persons in each [5]. This represents a considerable up-scaling in the use of technology for health

However, there are concerns that the introduction of technology may lead to patients receiving fewer face-to-face, home visits by health and social care providers. This could mean less personal and social interaction, which older adults report as being central to their healthcare experience. These interactions are particularly important in rural areas where a health or social care provider may be the only person an older adult sees on a regular basis. Interfering with this interaction could be detrimental to older adults' well-being.

2. TOPS PROJECT

The TOPS (Technology to support Older adult Personal and Social interaction) project lies within the healthcare theme of the RCUK-funded dot.rural Digital Economy Hub.¹ TOPS is a collaborative, multi-disciplinary initiative involving healthcare researchers (University of Aberdeen, The University of the Highlands and Islands and the Institute for Rural Health, Powys), clinical specialists (University of Aberdeen Centre of Academic Primary Care), human geographers/social scientists (University of Aberdeen) and computing scientists (SiDE and dot.rural Digital Economy Hubs).

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The aim of TOPS is to develop digital engagement tools to aid personal and social interaction between rural older adults and their care providers. Personal and social interaction with providers is normally unplanned and as such is often overlooked in technology design. Specifically, TOPS focuses upon older adults with chronic pain. Persons with chronic pain may already be physically and socially isolated, so any change in their levels of personal and social interaction could affect them more than those without chronic pain. Chronic pain is also self-reported more often in rural areas, perhaps as rural lifestyles and occupations (e.g. farming, fishing) are more likely to result in long-term pain in middle and later life; pain services may also be more difficult to access.

The research questions addressed by TOPS are as follows:

- What types of personal and social interaction take place between rural older adults with chronic pain and their health and social care providers during home visits?
- What aspects of personal and social interaction do rural older adults with chronic pain value?
- What types of technology do rural older adults with chronic pain use within and out-with their home?
- What types of technology are necessary in order to enable the level of interaction required by individual rural older adult users?

3. METHODS

The first phase of the project will be qualitative, observing home visits to older adults with chronic pain by health and social care providers, then interviewing them separately. Some older adults included in the study will already have telehealthcare technologies in their homes, and others will have none. Following this, a larger-scale quantitative survey will be distributed to a sample of rural older adults with chronic pain. The survey will address a wider set of issues including economic factors. The data collected by qualitative and quantitative elements will be used to design cultural probes (e.g. short videos and/or storyboards describing personal and social interaction technology prototypes) for use within later focus groups with older adults.

Research will be conducted in two rural areas of the UK; the NHS Highland area in Scotland, and the Powys Local Health Board in Wales. Two levels of rurality will also be studied; 'accessible rural' and 'remote rural'. This variation is intentional - it will hopefully maximise the diversity of older adults' experiences of managing pain, care delivery systems and technology infrastructure.

4. TECHNOLOGY DESIGN

A shortlist of adaptations to products and implementation issues, which could impact upon personal and social interactions with health and social care providers, will be developed. Researchers will work intensively with a small number of older adults and their carers, some of whom use telehealthcare and some who do not. Working prototypes of some pervasive and ambient technologies that support lightweight, low-bandwidth social interaction will be delivered through a series of home meetings and participatory design workshops.

The design element will draw on methods and concepts developed by the SiDE Digital Economy Hub from work conducted with persons with early-stage dementia and Parkinsons disease, and on work with older adults on experience-centred design of health services.

5. RESEARCH CHALLENGES

The TOPS project addresses several research challenges:

- The user-interface must be suitable for older adults. Evidence indicates that employing technology familiar to older adults may be fruitful (e.g. digital television) [6]. There are also important ergonomic considerations.
- It is likely that a range of personal and social interaction tools will be required, to suit the diverse needs of individuals (e.g. digital immigrants vs digital natives [7]).
- The implementation of technology in health and social care inevitably involves service redesign. This is something that older adults, who may be very reliant on services, and carers, some of whose roles are currently under review, may be sceptical of. As such, TOPS needs to be sensitive to this.

6. INITIAL SCOPING RESEARCH

An informal focus group discussion was carried out with adults (including some older adults) living in a rural, island area as a 'scene-setting' exercise. Some individuals were very ICT-aware, using smart-phones, apps and social media. One couple, who had both experienced health problems including chronic pain, had chosen to relocate to the community. They reported that the sense of community had improved their well-being – also, the good broadband connection had allowed them to run a business from home, which improved feelings of self-worth. Most appeared to be aware of social media; however, not all participated directly. These results are only anecdotal, but, they provide an important initial insight into rural pain, community and technology.

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