Care provision expectations of remote adult children of ageing Parents

**Abstract:** The expectations of adult children about their elderly parents regarding their care provision was surveyed. We found that the needs and expectations regarding their elderly parents included better information on entitlements of their parents, how to access relevant aged care services, the challenges of remotely dealing with dementia and depression of their parents, accessing medical and non-medical services and access to respite care. The aim was to identify needs that ICTs could potential to assist with. While the majority of respondents (67.2%) stated that they were satisfied or very satisfied with the frequency of contact with their elderly parent(s), they also cited logistical/transport difficulties, lack of time and stress as potential barriers in being in regular contact with their parents. The responses also indicated a high level of interest in a service that could act as a case manager to assist the adult child in discharging their responsibilities, manage access to services and to monitor the well-being of the parent. There is a need for further research to explore how this might be accomplished, whether such a service was viable and what funding models could be applied.

**Keywords:** information technology, aged care, seniors, family concerns, remote care, telehealth.

1. **Introduction**

The expectations, needs and concerns of adult children about their elderly parents is a field that is under-researched. Anecdotally these children feel poorly equipped when confronted with issues of their elderly parents. This small project aims to assist in identifying a larger research agenda that focuses on the special healthcare needs of families where the generations are geographically separate, and in particular where technology might have potential.

The interest internationally in the adoption of ICT to assist in the delivery of care for the frail elderly [1] is shared in Australia although few home telehealth projects have proceeded beyond the pilot stage. Whilst there are care organisations with a commitment to using technology the aged and community care sector remains largely labour-intensive and often still using paper-based records. The sector in Australia is facing many challenges including those related to rising consumer demand, workforce availability and skill levels, and providing services across the vast geographical spread of the aged care population and location of services. These challenges promote the need to investigate and implement new models of care delivery through ICT.

Previous research has focused on professional carers [2] [3] or managers of care provider organisations [4]. There is interest in exploring the experiences of adult children of frail elderly people to gain a better understanding of issues that concerned them relating to the potential use of ICT.

An on-line survey was undertaken in 2011 of a convenience sample of people who were known to have or were considered likely to have, aged parents. The sample was
primarily located in Queensland, a geographically large area with particular challenges of distance for serving remote communities. The project involved:

1) a small-scale convenience survey and
2) telephone interviews of experience, attitudes and concerns about ageing parents.

This paper reports on part 1 – the on-line survey.

2. Ageing

Australia shares the concerns of most countries regarding the impact of an ageing population. Technology is anticipated to offer significant potential for equipping societies to respond to these pressures [5] [6], including assisting aged people in extending active and independent lives, maintaining consumer productivity and quality of life as well as better managing and supporting the healthcare workforce and in delivering and increasing the quality of care in home, community and residential care settings. Globally there is increasing adoption of telecare, telehealth, smart homes and assistive technologies by consumers and care provider organisations [7]. Technologies offer an array of benefits including a reduction in hospital admissions and length of stay [8] [9].

3. Technology

Technologies now exist that can monitor state of health, notice changes in activities, provide alerts to events such as falls and alert a carer, so reducing unnecessary emergency callouts [10]. Automation is expected to enhance security, safety and independence [11] which could help maintain quality of life and decrease the demand for carer support.

There is much research and demonstration projects that have the aim of promoting the adoption of ICT for care [12] [13] but little in terms of addressing the needs of adult children. In Australia a system of referrals away from hospital admission to community aged care is in use [14].

An indication of the extent of new technologies available to ageing services and related research is available from the Center for Aging Services Technologies [15]. The Technology Research for Independent Living (TRIL) in Ireland is using ethnographic approaches to better understand seniors’ attitudes to technology [16].

4. Residential and community aged care services

In Australia the frail aged can be supported in their own homes or in Residential Aged Care Facilities (RACFs) or nursing homes which offer multiple levels of care.
5. Methodology

A purposive sample design was employed and a convenience sample of 350 people was invited to participate who were selected from amongst colleagues and acquaintances of the researchers. The criteria for selection was the opinion of the researchers that the invitees were expected to be of an age where they may have elderly parents. The email invitation asked people to confirm they had elderly parents and if so, to complete a survey questionnaire. Sixty-eight people completed the survey. It is not known how many did not participate due to not having elderly parents or declined for other reasons.

The email invitation contained information about privacy, security, anonymity and the right to not complete or withdraw. Ethics approval was obtained from the USQ Human Research Ethics Committee.

6. Findings

Participants were asked about the frequency of contact with their elderly parent (Table 1). Most were satisfied or very satisfied with the frequency of contact with their parent and only 20% were dissatisfied.

![Frequency of Contact Table]

Asked about difficulties in making contact with elderly parents (Table 2) one-third reported no difficulties whilst others identified “time consuming or not enough time”, “stressful”, “logistical difficulties” and “difficult to resolve issues raised by parent”.

![Potential Difficulties Table]
In response to the question “How well are the needs of your elderly parent met?” (Table 3) the majority identified social needs as the greatest.

Information resources and access to services for elderly parents was a concern of adult children (Table 5).

Respondents were also asked how likely they might be to use a range of potential services to help them in caring for their parent (Table 6).
The last two questions of the survey were open-ended allowing respondents to comment on other services that might assist them and on anything else that might assist their elderly parent. Thirty-three comments were received which were analysed thematically. The need for better information was the most commonly expressed need. This included information about their parent’s entitlements, access to services and support, and knowing where to go for support. Respondents also reported challenges in organising to take their parent to non-medical appointments such as a hairdresser and in house-keeping. Difficulties were reported in dealing with challenging behaviours, dementia and depression and a need expressed for better information on how to manage these issues.

7. Discussion

Most people have become familiar with and have adapted to technologies that are now pervasive across industries. In ageing and aged-care there is a comparatively low level of use of innovative technologies, although that appears to be changing.

Ageing is a challenging period of life associated with physical and mental decline, increased incidence of chronic illness, challenges to remaining in the workforce or industry, difficulties in maintaining active and socially-connected lives. A recent survey of 500 residents of nine residential aged care facilities in Queensland, Australia found a disturbing level of clinically significant and poorly addressed issues. It can be presumed that the elderly living in the community might also have a high level of poorly addressed issues and needs. Anecdotally there are challenges for families when their parents become frail and need support from the aged care system. It is difficult to navigate the complexities of finding access to care and support services and a key issue appears to be a lack of knowledge [17].

The term “sandwich generation” is often used for those with demands from both their own dependent children and frail elderly parents. With the increasingly delayed age of mothers having their first child, smaller families and the baby-boomer generation beginning to reach the age of increasing frailty. The needs for supporting family carers and particularly the “sandwich” generation will increase over the coming years demanding that more attention is paid to meeting their needs.

8. Conclusions

The pressures on adult children that are geographically separated from their elderly parents are many; there is also the lack of the ability to directly monitor their mental and physical well-being. Not surprisingly, the respondents (n=68) of the survey we conducted cited logistical/transport difficulties, lack of time and stress as potential barriers in being in regular contact with their parents. The respondents identified better information on entitlements of their parents, information on accessing relevant aged care services, the challenges of remotely dealing with dementia and depression of their parents, accessing medical and non-medical services and access to respite care as their main needs.
The respondents to this survey also indicated they would value a case-management or advocacy service that could intercede face-to-face on their behalf. There is therefore a need for further research to explore how this might be accomplished, whether such a service is viable and what funding models could be applied.

The survey respondents were asked to indicate if they are willing to participate in a follow-up telephone interview. Nineteen out of the sixty-eight indicated their willingness and gave their contact details. This follow-up research will be undertaken during 2013 and the findings reported in a subsequent paper.

References