

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.

PAGE: FREQUENCY OF CONTACT

1. Thinking about how often you contact your elderly parent, which statement best applies to you? (include all forms of contact, in person, phone, mail) [Create Chart](#) [Download](#)

	Response Percent	Response Count
I am very satisfied with the frequency of contact I have with my elderly parent	26.5%	18
I am satisfied with the frequency of contact I have with my elderly parent	39.7%	27
I am neither satisfied nor dissatisfied with the frequency of contact I have with my elderly parent	13.2%	9
I am dissatisfied with the frequency of contact I have with my elderly parent	17.6%	12
I am very dissatisfied with the frequency of contact I have with my elderly parent	2.9%	2
answered question		68
skipped question		0

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”.

PAGE: POTENTIAL DIFFICULTIES WHEN MAKING CONTACT







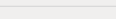
2. Thinking about potential difficulties you may encounter when making contact with your elderly parent, please select ALL those that may apply to you [Create Chart](#) [Download](#)

	Response Percent	Response Count
Time consuming or not enough time	35.4%	23
Stressful	30.8%	20
Logistical difficulties / lack of transport / far	35.4%	23
Difficult to resolve issues raised by parent	16.9%	11
No difficulty encountered	33.8%	22
Other (please specify) Show Responses	12.3%	8
answered question		65
skipped question		3

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.

3. In your opinion, how well are the needs of your elderly parent met?						Create Chart	Download
	Not met at all	Somewhat met	Well met	Very well met	Unsure	Response Count	
Social needs (contact with family/friends)	6.6% (4)	32.8% (20)	36.1% (22)	23.0% (14)	1.6% (1)	61	
Social needs (outings and other recreational needs)	11.5% (7)	41.0% (25)	32.8% (20)	14.8% (9)	0.0% (0)	61	
Personal hygiene and self care (e.g. hairdresser)	4.8% (3)	11.3% (7)	48.4% (30)	33.9% (21)	1.6% (1)	62	
Non urgent medical needs (e.g dentist, podiatrist)	8.3% (5)	6.7% (4)	56.7% (34)	28.3% (17)	0.0% (0)	60	
Home cleaning	5.0% (3)	20.0% (12)	48.3% (29)	25.0% (15)	1.7% (1)	60	
Shopping	3.3% (2)	30.0% (18)	41.7% (25)	23.3% (14)	1.7% (1)	60	
Cooking and nutrition	4.9% (3)	26.2% (16)	41.0% (25)	26.2% (16)	1.6% (1)	61	
						answered question	62
						skipped question	6

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

5. From all the statements below, choose the 3 statements that best apply to you when thinking about supporting/caring for your elderly parent "I would like"				Create Chart	Download
		Response Percent	Response Count		
To be better informed about the services that my elderly parent is entitled to		75.4%	43		
To get help to access services/assistance for my elderly parent		59.6%	34		
To be better informed about the issues faced by my elderly parent		35.1%	20		
To be better informed about the daily life of my elderly parent		15.8%	9		
To be reminded about things I need to do for my elderly parent		24.6%	14		
To have someone responsible for co-ordinating the services/assistance for my elderly parent		36.8%	21		
To speak to someone who can advise me on how to best support my elderly parent or resolve his/her issues		38.6%	22		
			answered question	57	
			skipped question	11	

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).

6. How likely would you be to use the following services to help you caring for /supporting your elderly parent						Create Chart	Download
	Not likely to use	Somewhat likely to use	Very likely to use	Unsure	Response Count		
A service providing me regular feedback about my elderly parent wellbeing and problems	20.8% (11)	35.8% (19)	39.6% (21)	3.8% (2)	53		
A case manager co-ordinating the delivery of all services to my elderly parent and checking quality of services	25.0% (14)	23.2% (13)	50.0% (28)	1.8% (1)	56		
A service to help me secure and establish the necessary assistance required for my elderly parent	5.4% (3)	23.2% (13)	71.4% (40)	0.0% (0)	56		
A service that can help me resolve the daily issues faced by my elderly parent	24.1% (13)	40.7% (22)	35.2% (19)	0.0% (0)	54		
A service that can do things for my elderly parent when I do not have time myself	7.0% (4)	29.8% (17)	63.2% (36)	0.0% (0)	57		
						answered question	58
						skipped question	10

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

- [1] Essen A and Conrick M. (2008) Visions and realities: developing 'smart' homes for seniors in Sweden, eJHI - electronic Journal of Health Informatics, Vol 2(1), e2
- [2] Eley, Robert and Fallon, Anthony Bruce and Soar, Jeffrey and Buikstra, Elizabeth and Hegney, Desley (2008) Nurses' confidence and experience in using information technology. Australian Journal of Advanced Nursing, 25 (3), pp. 23-35.
- [3] Eley, Robert and Fallon, Anthony Bruce and Soar, Jeffrey and Buikstra, Elizabeth and Hegney, Desley (2008) Barriers to use of information and computer technology by Australia's nurses: a national survey - Journal of Clinical Nursing, 18, 1151-1158
- [4] Soar, J. and Eley, R. (2010) Changing ICT for /Client/Patient Management and Clinical Information in Residential and Community Aged Care Services in Regional Australia: Structured Interviews with Service Managers, in Lee, Y., Zenn Bien, Z., Mokhtari, M., Kim, J., Lee, Heyoung, and Khalil, I. (eds.) Aging Friendly Technology for Health and Independence. Lecture Notes in Computer Science 6159, Springer, Berlin
- [5] Bowes A and McColgan G, (2005) West Lothian Interim Report, West Lothian Council and the Department of Applied Social Science, University of Stirling
- [6] Soar J (2008) Information Management in Modern Healthcare Organisations, Proceedings IBIMA, 4-6 January 2008, Marrakesh, Morocco
- [7] CSCI (2006) Time to Care? An overview of home care services for older people in England, report published by Commission for Social Care Inspection, London, www.csci.org.uk, October 2006
- [8] Jeffrey Soar, Anne Livingstone and Szu-Yao Wang (2009) A Case Study of an Ambient Living and Wellness Management Health Care Model in Australia, in Mounir Mokhtari, Ismail Khalil, Jeremy Bauchet, Daqing Zhang and Chris Nugent (eds.) Ambient Assistive Health and Wellness Management in the Heart of the City, Refereed Proceedings of the 7th International Conference On Smart homes and Health Telematics (ICOST2009) 1-3 July, 2009 – Tours, France, Springer.
- [9] Darkins, A., Ryan, P., Kobb, R., Foster, L., Edmonson, E., Wakefield, B., and Lancaster, A.E. (2008) Care Coordination/Home Telehealth: The Systematic Implementation of Health Informatics, Home Telehealth, and Disease Management to Support the Care of Veteran Patients with Chronic Conditions, TELEMEDICINE and e-HEALTH DECEMBER 2008 1118-1126.:
- [10] Soar J and Seo Y, (2007) Health and Aged Care Enabled by Information Technology, Annals of the New York Academy of Sciences, Volume 1114 Page 154-161, October 2007
- [11] Philipson G and Roberts J, (2007) Caring for the future: The impact of technology on aged and assisted living (Invited Paper), eJHI - electronic Journal of Health Informatics, Vol 2(1), e3.
- [12] Alison Bowes and Gillian McColgan, (2005) Smart technology at home: users' and carers' perspectives, Interim report February 2005, by Department of Applied Social Science, University of Stirling
- [13] SOPRANO - Service-oriented Programmable Smart Environments for Older Europeans, <http://www.soprano-ip.org/> (accessed 5 December 2012)
- [14] Soar J, Yuginovich T and Whittaker F (2007): Reducing avoidable hospital admissions of the frail elderly using intelligent referrals eJHI - electronic Journal of Health Informatics, Vol 2(1), e3.
- [15] CAST, Center for Ageing Services Technologies, www.agingtech.org (accessed 28 January 2013)
- [16] TRIL, Technology Research for Independent Living, <http://www.trilcentre.org/> (accessed 28 January 2013)

-
- [17] Stockwell-Smith G, Kellett U and Moyle W. (2010) Why carers of frail older people are not using available respite services: an Australian study. *Journal of Clinical Nursing*, Volume 19, Issue 13-14,