Development and evaluation of a consumer's guide to residential aged care

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Abstract

This three-phase study aimed to develop and evaluate an information guide for potential consumers of residential aged care. Phase 1 consisted of a series of six focus groups with 41 seniors to determine the information needs of potential consumers. Phase 2 comprised a 2 round Delphi survey in which a panel of 10 industry stakeholders prioritised the themes identified by the focus groups. Phase 3 consisted of a pilot test and evaluation of the prototype information booklet by 19 seniors and their families. A feature of the guide is that its contents were identified by seniors themselves as information they wanted to know about residential care.

Aged care service provision

The provision of services to the nation's aged represents a significant financial impost on the Australian taxpayer. The Federal Government's total expenditure on aged and community care in 2001-2002 is estimated to be $5.4 billion, of which $4.2 billion relates to residential care subsidies (DH&A, 2002). Other major elements are Community Aged Care Packages ($248 million) and the joint Commonwealth/State Home and Community Care program, to which the Commonwealth contributes $615.5 million and the State/Territories contribute an additional $396.7 million. The Federal Government pays for residential care at eight different levels of resident dependency. The average national cost per utilised place in 2000-2001 was $28,194. These costs apply only to direct services designed specifically for the aged; the total of indirect and hidden costs is estimated to be significant.

A related issue concerns the rise in the number of elders as a proportion of the whole population. The National Strategy on an Ageing Australia (1999) indicated that the ageing of the Australian population has accelerated in the past two decades, and is projected to rise further over the next 30 years. In addition, the greatest increase is occurring in the very old (those aged 85 years and over). Mason et al (2001) stated that while only 7% of women aged 65 years and 3% of men were residents in an aged care facility on any one day in 1999-2000, the probability of entering an aged care home after turning 65 is actually 0.42 for women and 0.24 for men. Further, Liu (1998) commented that almost all women over 90 years and many extremely old men will do so. Therefore aged care policy makers, managers of residential facilities, and members of the wider community need to be prepared for future increases in service demand.

Literature review

The decision-making process that accompanies nursing home placement is complex, as Groger (1994) and Freudenberger-Jet et al. (1996) demonstrate. Less well-documented are the experiences of the people who undertake the search and selection of a nursing home for themselves or a loved one, and the outcomes they encounter.

Freudenberger-Jet et al. (1996) identified two types of individuals likely to be engaged in investigating nursing homes. The first consisted of those who anticipated being involved ultimately in such a process, either because they were currently engaged in long term care giving, or they had perceived a gradual deterioration in the functional status of a care recipient of their acquaintance. The second category of searchers comprised those for whom there was no prior warning about the need for nursing home care - for example as a consequence of a sudden deterioration of their own or a loved one's health. For those in such situations their task is potentially more urgent and therefore more likely to be hurried.

Salmon and Rosenthal (1990) suggest nursing home decisions are easier for family caregivers of individuals who experience gradual decline in physical or mental functioning, and who prepare for eventual long-term placement. However, they also indicate that, for some, even being aware of deterioration in their care recipient does not necessarily equip searchers in advance of their need, because they are too busy attending to their daily duties to consider the longer term.

Travis and McAuley (1998) extend the notion of a behavioural dichotomy and distinguish between anticipatory or non-anticipatory searchers in their approach to the task. They describe searchers as being either time-pressured or not time-pressured, and attribute the quality of the experience at least in part, to temporal influences. They also indicate that the relationship between the caregiver and the care recipient is likely to influence the degree to which the search and selection process generates stress in the searchers. They indicate that siblings, for example a sister searching on behalf of another sister, were found to be the least disturbed group, while time-pressured children, searching on behalf of ailing parents, were found to be the most distressed.

Jordan and Lindsay (1998) report that the amount of involvement in the decision-making process by the potential resident influences the degree to which they are satisfied with their ultimate move and outcome. Those who perceived that they lacked choice because someone else decided for them, they were not involved in the search process, or for some other reason, were the most likely to express dissatisfaction with the relocation experience.

A variety of sources of information are available to potential consumers of residential services to assist the preparations for their own, or a loved one's, admission into care. Various instrumentalities associated with the Commonwealth Government, including the Aged Care Assessment Teams (ACAT) of the Department of Health and Ageing, and the Standards and Accreditation Agency are important sources of information. In addition, each state administration has an Office of Ageing or equivalent seniors-related unit. Furthermore, not-for-profit organisations such as the Alzheimer's Association, and the Council on the Ageing also produce documents and advice on this topic, as do special interest groups such as the Ethnic Communities Council. The major limitation to the availability of this information is its multiple sources and access points, necessitating approaches to several organisations and facilities to gain access to the total resource.

Aims of the study

This study aimed to develop and evaluate an information guide for potential consumers of residential aged care. It also planned to present the consumer information guide in the most user-friendly format possible, and make it accessible in locations where it could be of optimal benefit to the client group.

It aimed to achieve this goal by first asking potential consumers what information they considered would assist their decision making about nursing home placement. Second, in order to rationalise the probable large number of items identified by consumers, it proposed to ask an expert panel of industry stakeholders to prioritise topics identified by consumers.

Methods

We undertook a three-phase project that used both qualitative and quantitative methodological approaches. Following approval from the Queensland University of Technology Human Research Ethics Committee, Phase 1 began with a series of six focus groups, hosted by a variety of aged care organisations such as Council on the Ageing. They were conducted in urban, regional, and rural centres throughout the state. Between 6 and 12 seniors and their family members in each group were asked to indicate what information they considered would

aid their decision-making and search and selection processes. They were also invited to suggest the most appropriate format in which this material should be presented. Finally, they were asked to nominate the locations in which the proposed resource should be available to ensure its optimal use. Focus group proceedings were recorded verbatim by a court reporter using a shorthand machine. A preliminary thematic analysis was conducted on the qualitative data. In accordance with Patton (1990), the focus group transcripts were analysed manually, line-by-line, and basic themes relevant to the three focal questions were identified.

Phase 2 comprised a two-round Delphi survey conducted among a convenience sample of 10 industry stakeholders, established as a Reference Group to support the project. The most frequently occurring responses to the questions posed in the focus groups were configured into a four-section questionnaire of 44 items. The only inclusion criterion was that the topic must have been mentioned at least once in each one of the six focus groups. Section 1 addressed general issues such as the types of facilities and levels of available care. Section 2 considered aspects of living in supported accommodation, and matters which individuals should clarify when conducting site inspections of residential facilities. Section 3 examined the preferred format for the proposed guide, and section 4 requested information about its location and availability. Reference Group members were invited to prioritise each set of items commencing with priority 1 representing the most important issue. Respondents were also invited to suggest additional matters which did not emerge in the focus groups, but which they, as experts in the field, considered important. The questionnaires were posted to participants with a reply paid envelope for ease of return. Non-responders received a phone call a fortnight after posting as a follow-up strategy.

Round 1 raw data were transformed using the recode command in SPSS 10.1 (2000) in which answers were classified into categories according to the rankings they had achieved. Votes were aggregated in each category and the top 50% of items from the combined results were incorporated into the round 2 questionnaire.

After the analysis of the second round results of the Delphi survey and their incorporation into a draft guide, the third phase of the project consisted of a pilot test of the completed handbook. It comprised a review of the booklet by 20 potential consumers drawn from host organisations but who had not participated in any of the previous strategies. The booklet was distributed by mail, with a reply-paid envelop and participants were invited to respond by a nominated date. Those who had not done so received one follow-up phone reminder call, one week after the recommended reply date. Suggestions and recommendations from the pilot test were incorporated into the definitive version of the consumer guide.

Phase 1 results - the focus groups

41 people contributed to the discussion in six focus groups. Two themes emerged in relation to information required to assist in the search and selection process. The first focused on matters which could be described as 'general information' and which revolved principally around the processes of service availability and/or delivery. The second theme concerned site inspections, and what potential consumers should look out for, or ask about, when visiting residential facilities.

Three themes emerged from the second question concerning the format that the consumer guide should adopt. These included that the guide could be paper-based, electronic, or adopt some other form, such as a series of lectures delivered at seniors' organisations. The third question related to where the guide should be made available, and responses were divided evenly between a range of community locations. However, all of the suggestions pertained to the consumer's immediate geographic vicinity. Table 1 summarises the focus group results.

Table 1: focus group responses in order of priority (N=41)

Information Needs		Format	Location
General Information	Site Inspections		

1. Types of facilities	1. Interaction between staff and residents	1. Paper-based - one or more of the following:
		  o Single sheet brochure
		  o Multiple brochures
		  o Booklet
		  o Newsletter
			1. GPs' waiting rooms

2. Levels of care	2. Meal preparation		2. Community centres
3. Fee structures	3. Special diets		3. Public libraries
4. Admission processes	4. Meal times and places		4. Chemists shops

5. Nursing home waiting lists	5. Allied Health services	2. Electronic
		  o Audio
		  o Video
		  o Web
			5. Mobile libraries

6. Role of GPs	6. Social well-being services	3. Other (speeches etc.)	6. Post offices
7. Merits of inspection in advance	7. Activities programs for individuals and groups		7. Links to web sites
8. Legal issues	8. Languages		
9. Community-based services	9. Availability of private rooms		
10. Temporary accommodation	10. Opportunity to choose room mate		
	11. Opportunity to change rooms		
	12. Dementia care		
	13. Palliative care		
	14. Talk to current residents		
	15. Spiritual care		
	16. Proximity to public transport		
	17. Facility's own transport		

Ten items of general information were raised at least once in each of the six focus groups. These included the need to clarify the differences between types of facilities available, such as nursing homes and hostels. Focus group participants were also interested in the different levels of care, fee structures and funding arrangements and the admission process including the composition of the assessment teams. They also wanted to know about nursing home waiting lists, the role of the General Practitioner, any benefits associated with inspecting facilities in advance of their actual need and legal issues such as Advanced Directives. Furthermore, they requested that community based services be described in detail and temporary accommodation alternatives such as respite, step-down units or serviced apartments be outlined as well. This final issue arose because at least one participant in each of the six focus groups expressed surprise that patients are obliged to be discharged from acute care after a specified period - usually 32 days, irrespective of their recovery rate or ongoing care needs.

The next area of concern to focus group participants encompassed what to look for when inspecting aged care facilities. Seventeen items were raised in this regard at least once in each focus group. They comprised: the interaction between staff and residents, meal preparation, culturally appropriate meals or special diet availability and meal times and places. Informants were also interested in the availability of allied health services such as podiatry and specialist services to support social well-being such as hairdressers, together with activities programs for individuals and groups of residents. What languages were spoken in the facility was another question of importance to some focus group participants.

Three matters pertaining to rooms were raised: the availability of private rooms, the opportunity to choose one's room mate(s), and the possibility of changing rooms if the original occupants could not live harmoniously together. The availability of dementia services and palliative care were important, as was the facility's own quality indicators. In addition the opportunity to talk to other residents or their families in advance of admission and resources for spiritual care of family members as well as residents were seen as being valuable. Two issues pertaining to transport also featured in the focus groups: what access was there to public transport from the facility, and did the facility have its own transport - important to convey residents to and from appointments and outings.

At least one member in every focus group meeting proposed the following options for the format of the consumer guide. They included a single sheet brochure with the minimum of details, multiple brochures on different aspects of residential care, or a comprehensive booklet. Some focus group participants in each meeting nominated electronic formats. They included audiotapes of the relevant information, videotapes and web pages. Other formats suggested included a series of speeches at Seniors' Centres and community organisations, and dedicated columns in Seniors' newsletters.

The final matter addressed in the focus groups concerned the location and distribution of the proposed information guide. Seven sites were considered appropriate: community centres for seniors, public libraries, mobile libraries, General Practitioners' waiting rooms, chemist shops, post offices, and links to seniors' organisations web sites. Although several sites were put forward, the most important issue was that the guide be available in close proximity to where older people live.

Phase 2 results - the Delphi survey

Eight of the 10 Reference Group members returned both questionnaires from the 2 round Delphi survey. Due to the smallness of the sample, tests of statistical significance were not applied in the analysis of the Delphi survey results. Table 2 illustrates the final outcomes of the survey concerning general information and site inspection issues recommended to be included in the information guide.

Table 2: Delphi survey round 2 results (N=8)

General Information	% (Rounded)	Rank
Types of facility	88 (n=7)	1
Fee structure and financial arrangements	75 (n=6)	2
Levels of care	63 (n=6)	3
Residents Rights	38 (n=3)	=5
Community based services	38 (n=3)	=5
Benefits of early inspection	25 (n=2)	6
Site Inspection Guide	**% (Rounded)**	**Rank**
Interaction between staff and residents	75 (n=6)	=1
Availability of private rooms	75 (n=6)	=1
Choice of room mate or opportunity to change rooms	63 (n=5)	3
Specialised care - dementia, palliative	50 (n=4)	4
Allied Health Services	38 (n=3)	5
Activities program	25 (n=2)	=6
Diet and food related matters	25 (n=2)	=6

The format for the guide that achieved majority support, following analysis of the complete Delphi survey, was that of a booklet. The two major needs nominated by focus group participants and supported by Delphi survey respondents - the need for general information, and a guide to site inspections - were adopted as the foundation for this document. The first section was dedicated to General Information, and incorporated material on the six items which achieved the highest ranking following the second Delphi round. They were included in rank

order and described: types of facilities, fees, levels of care, residents' rights, community-based services, and the benefits of early inspection of residential facilities. Three new items that survey respondents recommended be included in the guide were also added. These were an account of the accreditation process, an explanation of the role of the aged care assessment teams (ACAT) and issues pertaining to quality of care. The description of accreditation was incorporated into the first section of the Guide on general information, as was the role of the ACAT. The third item on quality of care was raised in the second section, with matters to look for or ask about, when undertaking a site inspection.

The second section of the guide focused on site inspections and contained 26 questions related to the seven areas recommended by Delphi survey respondents. These comprised: the interaction between staff and residents, matters pertaining to bed rooms and co-residents, the availability of resources for dementia and palliative care, allied health services, activities programs, diet and food and quality of care. This final issue included questions about clinical care, safety and security and quality monitoring procedures. The questions and observations were repeated as a 'tear-off' section at the end of the booklet. This permitted the guide to act as an interactive resource, without the need to compromise the integrity of the overall document.

In recognition of the fact that it is not possible to incorporate a comprehensive account of all the relevant issues into a single booklet, a third section was added to the guide. It included a list of 30 relevant organisations and their contact details to assist potential consumers in expanding their knowledge of residential aged care.

Phase 3 results

The prototype guide comprised a monochrome version of the 16-page A4 size document and 20 participants drawn from the host organisations but who had no previous association with the study were invited to review it. The sample consisted of 10 seniors over the age of 65 and 10 family members between the ages of 35 and 60 years. Nineteen participants responded and one declined as a result of deterioration in his health.

The monochrome format was adopted to minimise any potential bias a visually appealing appearance may induce or detract from the text. The definitive version of the guide will be produced in full colour on mat paper for ease of reading by potential consumers.

None of the seniors requested any changes. Each expressed satisfaction or appreciation for the opportunity to participate and all nine indicated that the document contained at least some information about which they had no previous knowledge. Three family members suggested minor grammatical changes, for example in the structure of some of the questions proposed for site inspections. In addition, respondents recommended the inclusion of a further four contact organisations in section 3.

Discussion

Health care policy makers, Treasury officials, and residential aged care managers, among many others, could derive considerable benefit from the findings of this investigation. The study demonstrated that, among seniors who currently reside in the community, there is considerable demand for information about services to support the frail aged. Focus group members illustrated that knowledge of even the most fundamental aspects of aged care, such as the role of the ACAT, is not widespread. Furthermore, when invited to indicate whether or not they would use a resource such as the consumer guide, all focus group participants agreed they would. This finding should be interpreted with caution however because, as Cooper and Jenkins (1998) demonstrate, informants may give researchers answers that they believe the researchers want to hear.

Another, perhaps unsurprising, finding is the importance both focus and Reference Group members placed on the availability of private rooms, or at a minimum, the opportunity to choose a room mate or change rooms if harmonious living could not be achieved. This knowledge will be beneficial to architects and facility designers as well as policy makers. That these results are unsurprising may be partly a function of the sample selection process. For convenience, participants were recruited from established senior citizens groups and industry practitioners. However, as Spencer (2000) noted, the preference for privacy, and solitary sleeping arrangements, is not universal. Some cultures, such as that of the Australian Aborigines, claim a marked preference for sleeping

in communal settings, and are prepared to tolerate the idiosyncrasies of neighbours, even those who are cognitively impaired, to achieve this communality.

A further noteworthy finding of this study is the preference for information to be delivered in a printed rather than electronic form. This applied notwithstanding that informants' recognised electronic formats permit the data to be updated as frequently as is necessary. It is suggested that this is a generational approach, the result of a lack of familiarity with electronic technology. Future generations of seniors, more experienced in the use of interactive data delivery, such as the World Wide Web, may opt for other solutions.

There were several limitations to this study that should be identified. First, each stage of the investigation was conducted with the use of a small convenience sample. By doing so the ability to test the validity and reliability of the prototype consumer guide and the generalisablity of the results must be questioned. A second limitation concerns the use of the prototype guide by seniors and its impact on them. Postal surveys are widely recognised to have inbuilt limitations such as difficulty in understanding questions as Hugo et al (1987) and Herzog and Kaulka (1989) reveal. Furthermore, phase 3 participants had minimal dealings with the investigators. While they received details of contact numbers in the letter that accompanied the guide, none of them phoned the research team for any further information or advice. To overcome these limitations, the following recommendations are made.

Recommendations

The study should be replicated as a randomised control trial, in multiple centres, and with an increased sample. This will aid the elimination of any possible skewing in the present results.

Second, a randomised control trial will also provide the opportunity to introduce the notion of an intervention, in which half of the participants receive the guide, and the other half could receive a generic publication on aspects of ageing. This would enable the efficacy of the guide itself to be tested.

A further refinement is recommended, and this is an increased role for the researcher to act as an aged care services broker. This role would include the provision of a comprehensive explanation of the guide and its uses. It would also permit ongoing advice and information about all aspects of residential aged care to be available to members of the intervention group. Participants in the control group would be encouraged to make contact with their medical adviser to provide this support. Such a strategy would enable outcomes between specialist aged care broker services and those of the general practitioner to be compared.

Conclusion

Many seniors do not undertake preparation for admission into residential care, despite the likelihood that some will ultimately use this service. One of the reasons to explain the lack of groundwork derives from the problems of access to information on the subject, a consequence of its wide dispersal. To help alleviate the dilemma this study used seniors who dwell in the community to identify matters related to aged care services about which they would like to be informed. Participants were also able to develop and evaluate a guide to residential care services and recommend where it should be made available, to ensure its optimal use. In aiding potential consumers, the study also captured an information source of value to policy makers, industry practitioners and members of the general population.

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