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Involving older people in research to examine quality of life in residential aged care

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Introduction

Residential care in Australia has long been subsidised by Federal Government funds, and since the mid 1980's, the Australian Government has introduced and refined strategies for assessing quality in residential care facilities, eventually evolving into a mandatory accreditation system (Gray, 2001). Implicit in such systems is the understanding that the ultimate outcome of these standards should be improved resident quality of life (QoL). However, it cannot necessarily be assumed that receipt of good quality clinical care results in heightened life quality. The exact aspects of QoL that are important to residents must thus be understood so that residential care providers and clinicians can target them.

Quality of life is not easily defined, it means different things to different people, and as such is equally difficult to measure (Arnold, 1991; Ball *et al*, 2000; Bury & Holme, 1993; Byrne & MacLean, 1997; Courtney *et al*, 2003; Guse & Masesar, 1999; McDowell & Newell, 1996). However, it is largely agreed that the construct comprises both objective and subjective elements (Arnold, 1991; Ball *et al*, 2000; Bury & Holme, 1993; Byrne & MacLean, 1997; Fletcher *et al*, 1992; Guse & Masesar, 1999; McDowell & Newell, 1996), and recent research concedes that the subjective elements (i.e. the person's own perceptions) are paramount (WHOQOL Group, 1993).

Much research into QoL has emerged from the health related quality of life (HRQoL) field, so there has been a tendency for substantial emphasis to be placed on health status as an indicator of QoL (McDowell & Newell, 1996). As people age, health and physical functioning tend to deteriorate, but despite such changes, older people have been found to score more highly on psychological aspects of QoL and may rate their overall QoL more highly than their younger counterparts (Frytak, 2000). Thus, traditional HRQoL scales are not always appropriate for the older population (Courtney *et al*, 2003). Moreover, the nature of residential care presents further paradoxes for the researcher; residents are physically frailer than even the general older population and institutional life is markedly different to life at home (Bury & Holme, 1993; Byrne & MacLean, 1997; Cohn & Sugar, 1991; Coons *et al*, 1996; Fiveash, 1998; Guse & Masesar, 1999; Kane, 2001), thus different factors become important for the maintenance of optimal QoL (Kane, 2001). Furthermore, resident perceptions of their own QoL have been found to differ markedly from the perceptions of staff and researchers (Ball *et al*, 2000; Byrne &

MacLean, 1997; Cohn & Sugar, 1991; Fletcher *et al*, 1992; Kane, 2001; Rai *et al*, 1995). It is being increasingly acknowledged that such concepts as autonomy, control and choice are important for resident QoL (Ball *et al*, 2000; Byrne & MacLean, 1997; Coons *et al*, 1996; Harrington *et al*, 1999; Kane, 2000; Kane, 2001; Kane & Kane, 2000). The above suggests that, as much as possible, research into resident QoL should be conducted from the residents' perspective. This paper discusses a study that used focus groups to develop insights into QoL issues for aged care facility residents. These insights could then be used to help determine an appropriate QoL measure for use in a later study.

Method

Focus groups use a structured interview process utilising open-ended questions to determine the feelings and opinions of small groups of participants about a specific topic (Krueger, 1994). In total, eight focus groups were conducted, each containing 4-12 participants; all occurred within residential facilities from the same aged care provider in and around the Brisbane metropolitan area. Residents were asked about their perceptions of quality of life, including factors which enhance and impede QoL outcomes.

Results

Subsequent to content analysis, a number of themes were identified; each is described briefly below.

Circumstances

Residents largely stated that their circumstances were beyond their control, particularly in regards to the decision to move into residential care in the first place. Most agreed that while their surroundings might be quite comfortable, they still did not equate to being at home. However, most participants also expressed a desire not to be a "burden" on family and friends, which somewhat offset any dissatisfaction with their circumstances. Also present was a well-articulated determination to make the most of their situations. Thus most stated that they had adjusted to the move and were quite happy where they were, although some expressed ongoing dissatisfaction with their circumstances.

Choice & Autonomy

The ability to make meaningful choices was regarded as an important contributor to quality of life. Facilities enabled this in a variety of ways, for example through choice of meals, and contribution to decisions about activities and bus trips. It was generally considered that the nature of resident circumstances (i.e. institutional living) limited autonomy. However, facilities were able to encourage some autonomy (e.g. through allowing freedom of movement into and out of, and within the facility).

Activities

Participation in activities – both individually and as a part of a set program - was generally considered to be important to quality of life. However, comments about participation in the activity program were not always positive – with a need for activities to be perceived as meaningful and purposeful.

Physical status & health

This theme was especially important to residents of high care facilities, as it was usually declining physical health that necessitated the move into residential care. On a day-to-day basis, health status was considered a significant contributor to QoL, as was being free of pain and discomfort. Related to physical status was mobility, which was a major discussion-point. Limited ability to move from place to place was considered to impact on many aspects of QoL, particularly independence. When residents were able to do things for themselves, it was described in substantially positive terms, whereas loss of independence appeared to be felt acutely. Participants emphasised the need to maintain some level of independence for as long as possible, further noting that being able to assist others was very rewarding.

Socialisation

The ability to socialise and have meaningful contact with others was considered important. Being in a residential facility contributed to loneliness for some, due to isolation from family and difficulties interacting with other residents. However others stated that being in a residential facility alleviated loneliness, as it enabled contact with other people, as opposed to being at home by themselves. Contact with family and friends was a particularly important form of

socialisation to the participants. Numerous participants also described the inability to have regular or frequent contact with family members as a significant loss.

Security

The importance of feeling safe and secure within their environment was a recurring theme. Nearly all described feeling an increased sense of security and personal safety since moving into care. For some participants, feeling "unsafe" in their home was a direct contributor to the decision to move. Financial security was a related theme. Most felt secure in their financial situation. Many had their finances tended to by someone else and expressed relief at not having to worry about this aspect of their lives.

Environment

Residents expressed much sadness over the necessity to sell their homes in order to raise the funds required for their move – this tended to be experienced as a profound loss, and some spoke of associated resentment. Related to this was having to give up possessions when moving into the institutional environment. This was alleviated somewhat by facilities allowing personalisation of rooms. However, a single room only allows for a limited number of possessions, and a shared room considerably less.

Room size and the sharing of rooms and bathrooms all had a bearing on quality of life. This was most strongly expressed in relation to bathrooms, with hygiene issues, privacy, and dignity being the salient factors when bathrooms had to be shared. Those who had their own rooms were grateful or described it as a determining factor in their choice to live where they did. Those who did not have their own rooms mostly expressed a desire to have their own, although one participant described the social aspect of sharing a room as positive.

Staff

Because staff played a major part in the lives of residents, they were often referred to. Discussions about staff tended to fall within the following two categories.

Staff Interactions

Positive interactions with staff were considered important contributors to quality of life. There was acknowledgement that this varied from individual to individual, with different residents

getting on better with different staff members. Descriptions of staff were generally very positive, usually related to the notions that “they always do their best” and “give their all”. However, this was not always the case, and negative staff interactions were considered to contribute to poor QoL outcomes.

Staff Numbers

There was also much discussion about perceived staffing limitations and their negative impact on quality of life. This was expressed in terms of staff not having enough time to spend with residents, being unable to respond in a timely manner, and no longer being able to do “special extras” for the residents.

Summary

Despite being somewhat reticent, the participants were able to provide some useful insights into what quality of life meant to them. Much of what was discussed was ultimately related to control and autonomy. Moving into residential care was largely viewed as a choice that was out of their control, with the only possible contribution from them being choice of facility. However, some indicated that they maintained control by being proactive in deciding to move before their health significantly deteriorated. Autonomy was further limited by declining physical function and the realities of institutional life, although it was acknowledged that facilities made efforts to address these problems. Contact with families was clearly important for quality of life, with participants speaking at length about the joy of seeing family and the loneliness felt when contact was limited.

Also prominent within their discussions were environmental factors – the human environment of the staff and the physical environment of the facility. Staff members were clearly significant factors within their lives, which is not surprising given the amount of contact between residents and staff inherent in institutional life. Most were of the opinion that staff worked very hard and that they were sometimes in short supply. However, as the residential facilities were their homes, they were most interested in the *quality* of interactions with staff members; quality staff interactions were described as demonstrating that they cared, creating feelings of friendliness and warmth, and spending time with residents. A number of comments suggested, with some sadness, that staff members seemed to have less time to spend with residents than in the past.

However, simply knowing that there were people around to assist them where necessary engendered a sense of security that many expressed was lacking when they were living in the community.

The physical environment was discussed at length, particularly in relation to privacy. Again, this is not surprising considering the residential facility is their home environment. Single rooms were most coveted, particularly those with their own ensuite. Many considered sharing bathrooms less than ideal, more because it exposed them to varying standards of hygiene than because of privacy issues. Having enough space for personal possessions and being able to personalise their own space were also important to the participants. The physical environments were also considered secure and many participants mentioned feeling safe within the facility.

Discussion

The results described in this paper confirm recent research into QoL of nursing home residents, which suggests that factors such as autonomy, choice, the physical and social environments, and social needs are vital for maintaining resident QoL (Byrne & MacLean, 1997; Coons *et al*, 1996; Harrington *et al*, 1999; Kane, 2000; Kane, 2001). Physical health was discussed as an influence on QoL, but it was not the primary factor, rather it was simply one of a number of factors impacting on resident QoL. This reflects findings in the literature that, despite poorer physical health, older people often score more highly than younger adults in psychosocial aspects of well being, as well as for subjective impressions of QoL (Frytak, 2000). It appears that residents were, for the most part, adapting to their changed circumstances and "getting on with it".

Implications for Care Providers

Given the comments made by study participants, the following would be worthy of consideration by providers of residential aged care services.

- As much as is possible, enable choices – big and small - to help facilitate a sense of control and autonomy in the residents.
- Encourage participation in activities, and more importantly, allow access to a wide variety of activities, both group and individual. For participation to have meaning, the activity must match the individual, not vice versa.

- Ensure optimum health care, especially regarding pain management, and facilitate resident independence. The latter has implications for the availability of allied health professionals such as physiotherapists and occupational therapists.
- Facilitate meaningful and appropriate social contacts, such as through groups of shared interest (e.g. "Scrabble", craft). Of particular importance is that family are encouraged to maintain involvement in the resident's life, given the emphasis placed on family contacts as a source of joy.
- Surroundings do matter. A sense of safety and security enhances peace of mind, and enabling residents to personalise their own space adds to their comfort. Privacy was considered very important for QoL, particularly when it came to shared bathroom facilities. It thus appears that the current Australian trend for individual rooms and ensuites within aged care facilities is an appropriate one.
- As much as the physical environment is important, a positive social environment is vital. As well as receiving good care from them, residents appear to need to develop a positive rapport with staff members, and to feel that staff will be available to them when needed. Stresses on residential care staff related to the ever-increasing need to do more with less could potentially interfere with this. It is essential that it not be forgotten that, as well as being nursing care facilities, these places are also homes and residents need to feel they are more than just a patient on a nurse's list.

Conclusions: The Advantages of Consultation with Residents

The focus group consultations facilitated an understanding of QoL issues from the residents' perspective. In so doing, it enabled choice of an appropriate QoL tool for quantitative exploration of resident QoL. The tool eventually chosen was the WHOQOL 100 (Murphy *et al*, 2000; WHOQOL Group, 1998), which covered many of the same issues discussed in the focus groups, thus ensuring that data gathered was relevant to the residents[1]. Such "real world" research enables greater application and uptake of the findings, ultimately benefiting residents of aged care facilities through enhanced QoL outcomes. As researchers, it is imperative that we consult the group being researched and consider them a part of the process, rather than making assumptions about what is relevant for them, thus enabling research to truly benefit those on whom it focuses.

[1] More information about the WHOQOL 100 and other QoL measures is contained in Courtney et al. (2003); results of the quantitative QoL survey will be the subject of a later paper.

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