Discharge-planning for long-term care needs: the values and priorities of older people, their younger relatives and health professionals

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Discharge-planning decisions about long-term care (LTC) can be difficult and distressing for older people, families and discharge-planning health professionals. Retrospective research suggests that despite good intentions and a shared focus on the best interests of the older person, stakeholders may hold very different values about good outcomes and how to decide them. We aimed to compare the opinions and values of frail elders living at home, younger relatives and health professionals experienced in discharge-planning, prospectively: before, not after, a LTC decision. We interviewed three types of stakeholders (10 older people, 8 relatives and 18 health professionals) using a hypothetical vignette about a frail elder leaving hospital. In a mixed methods design, we quantitatively compared the discharge plans and decision-makers that stakeholders suggested, and qualitatively analysed the 36 interview transcripts for participants’ articulation of underlying values during these discussions. Older participants often suggested safe restrictive options (residential care, proxy decision-making) for the hypothetical frail elder, while advocating autonomy for themselves. Younger people generally endorsed autonomous decision-making and less restrictive discharge options especially if the elder was mentally competent, but reported difficult ethical tensions between safety and autonomy. Individual personality and preferences, mental capacity, and the importance of personal care in supporting autonomy were central themes consistent with the Ecological Theory of Aging. Accordingly, discharge planners can usefully articulate the balance of safety and autonomy, conceptualizing home care as maintaining independence rather than accepting dependence. Ethical training should incorporate sophisticated models of practice specifying both psychological and physical safety as components of beneficence. Few elders adopt a consumer approach to LTC: health professionals can encourage mid-life adults to consider later care needs when planning for retirement.

Keywords: discharge-planning, qualitative research, aged care, ageing in place, ethics of care, dementia, homes for the aged, home care services.

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Introduction

Globally, families are shrinking while more people reach extreme old age (1) and, increasingly, will need formal long-term care (LTC): personal care provided by nonrelatives in residential institutions or at home (2). Rather than operating as consumers and researching options in advance, many elders defer LTC decisions until prompted by their environment (3, 4). In Australia, as elsewhere, this often occurs during hospital discharge-planning (5, 6) because hospital admissions can be markers for declining function and increasing care needs, identified by health professionals who have ethical responsibility for patient care (7–11). Older people do not always accept home LTC (12) even though this can delay residential placement (13). The Ecological Theory of Ageing or ETA (14–15) suggests that with reducing capacity, elders are vulnerable to environmental pressures, and their responses vary individually and over time. Elders may either tolerate high environmental press in the service of values such as autonomy and self-responsibility or surrender...
independence in return for LTC, safety and reduced environmental press.

Accepting formal LTC, especially residential LTC, marks a transition often characterised by distress, grief and crisis for older people and their families. Research (11, 16–21) supports the importance of timely collaborative LTC transitions, but retrospective accounts by all three major types of stakeholder – older people, relatives, and health professionals – feature themes of powerlessness, lack of control, time pressure and conflict (13, 22–25).

The ethical theories and frameworks developed within acute medical contexts or nursing homes have quite limited applicability to these transitions (26–28) during which personal values and narratives appear to have more influence than principle-based ethics (29). In the discharge-planning context, the traditional medical ethics framework appears too narrow because relatives, as well as the patient, have legitimate interests in the outcome (27), and because along with physical safety, psychological safety is also highly salient (30). Avoiding physical risks may increase psychological risks and vice versa (31): in preventing physical harm to older people, relatives and health professionals may inflict psychological harm through the loss of autonomy and other valued attributes of life (home, neighbourhood, privacy). Planning, timing and balance emerge from this literature as psychological rationales or meta-values used by stakeholders to determine, explain or legitimise decisions particularly when interests and ethical values conflict (24, 32–34).

Accordingly, it may be that participants in LTC decisions have common goals – the best outcome for the older person – but differing values and conflicting ethical priorities, as well as different beliefs about good discharge plans and how they should be decided.

Retrospective studies of stakeholders’ experiences provide rich information. In a data-driven study, McCullough et al. (35) compared values expressed by older people, their relatives and health professionals, interviewed separately after LTC decisions. They concluded that when considering LTC decisions, professionals expressed health-related values and relatives focussed on care, whereas elders prioritised values like self-identity and autonomy. Similarly, Forbes and Hoffart (36) interviewed 27 elders who had recently accepted residential or home-based LTC and identified seven important values underlying interviewees’ beliefs and attitudes. Most strongly expressed were independence and sense of self, followed by security, work ethic, privacy, quality of life and trust. The value of independence was expressed equally strongly by all participants, but those in residential LTC also expressed acceptance – interpreted by the authors as a psychological buffer assisting elders to cope.

Psychological research suggests that attitudes and values need to be studied before as well as after major decisions. Attitudes often shift to support decisions that have been implemented (37), whereas in advance, people demonstrate optimistic bias – the belief that their outcomes will be better than average (38) – potentially reducing their receptiveness to information (37). Prospective studies of stakeholders before LTC decisions, and direct comparisons of the views and values of all three stakeholder groups, are rare in the published literature.

Using a convergent parallel mixed methods research design that integrated quantitative and qualitative data collection and analyses (39), we interviewed three types of stakeholders about a hypothetical future of LTC decision. We hypothesised that suggested discharge destinations and decision-makers would differ significantly between stakeholder types, as would the values and meta-values they articulated when discussing what should happen: elders would prioritise autonomy, relatives would focus on safety, and professionals would be guided by ethical principles primarily described as duty of care.

**Method**

Thirty-six adults were recruited in an Australian city using snowball processes through an outer suburban medical practice, a large city hospital, other health agencies and personal contacts. Diverse cultural backgrounds, opinions and viewpoints were explicitly sought, and to guarantee that professionals could not be identified, recruitment occurred within several health agencies. To ensure voluntary participation, potential participants were given information sheets and they contacted the interviewer. The study was approved by the Royal Adelaide Hospital and University of Adelaide Human Research Ethics Committees.

Ten older people – five men and five women – from varying socioeconomic and ethnic backgrounds participated. Their mean age was 77 years (range 70–83 years). Two lived alone, eight with spouses. They had numerous medical co-morbidities indicating high risk for residential placement (40). Exclusion criteria were being in residential LTC or being cognitively unable to consent. Eight younger relatives – four men and four women – were recruited: aged 45–69 years (mean age 51). Each had a frail older parent or parent-in-law not in residential LTC. Because respondents’ own age could potentially influence values, spouses and sibling caregivers were excluded. Eighteen experienced health professionals actively involved in discharge-planning for older people participated. Most had spent 4 years or more (range 1–20 years) working intensively with elders. Six were men. The mean age was 37.9 years (range 23–56 years): three medical doctors specialising in geriatrics, four nurses, three occupational therapists, four psychologists and four social workers. These are the professions most involved in discharge-planning.

All 36 participants were able to speak English, read and summarise the vignette. They were interviewed at their preferred locations: home, work or the university.
Individual semi-structured face-to-face interviews centred on a vignette which described a hypothetical frail and isolated older woman, ‘Mrs Smith’, with declining cognition, limited mobility and several medical problems common in older people. Living alone at home, she refused both residential and home-based LTC at the end of a hospital admission. The vignette was based on the literature, constructed by discharge-planning health professionals, and presented with pilot data at an Allied Health conference. Open-ended questions were the following: What Mrs Smith’s discharge destination should be, who should decide, what would make a difference, and a request for any other comments?

Interviewees’ specifications of destination and decision-maker were quantitatively compared across stakeholder type using SPSS Crosstabs (chi-square tests). Qualitatively, the 36 interview transcripts were searched for unprompted expressions of values or meta-values which were coded using thematic analysis, a qualitative approach for studying ‘the social distribution of perspectives on a phenomenon or process’. Research-based thematic analysis was selected as intermediate between data-driven and theory-driven analyses, appropriate to the early stages of research. Rather than being grounded in study data, this qualitative method searches for themes and codes identified from existing research, thus developing knowledge rather than re-inventing the wheel. There is some risk of influence by others’ assumptions or biases but reduced risk of influence by one’s own: important because interviews were conducted and coded by the first author, who worked in a discharge-planning environment.

The prospective literature was small so the retrospective literature was searched for configurations of values using PubMed, PsycInfo, ISI Web of Science, Australasian Medical Index, Health Business, Health Source Nursing, Sociological Abstracts, Social Work Abstracts, Expanded Academic Index, Academic Search Elite and ProQuest. Key words included discharge-planning, institutionalisation, placement, patient admission, facility admission, nursing homes, homes for the aged, residential care, institution, LTC, attitudes, public opinion, family, caregiver, medical, physician, elderly, hospital patient, decision and autonomy.

We identified no relevant ethical theories, and only one comprehensive values of framework, that of McCullough et al. Their 15 values categories were adopted and supplemented with values reported in other retrospective studies, in particular Forbes and Hoffart, totalling 33 values specified in the study codebook (the basis for the analysis). Table 1 shows a sample codebook entry, and the 33 values are listed in Table 5 that reports this analysis. Transcripts were coded for the presence or absence of a value, rather than frequency, of each value being spontaneously expressed. Values were coded as ‘negative’ if a value was explicitly rejected or an opposite value expressed. Abstract values (e.g. ‘independence’) were coded at the lowest most specific level possible (e.g. autonomy, decisional capacity, identity, physical capabilities or work ethic/self-responsibility). Meta-values of planning, timing and balance were also coded. To maximise the rigour of the qualitative analysis, we utilised the accepted guidelines.

For each stakeholder type, recruitment ceased once sample size exceeded 6 and novel values were no longer being recorded, indicating that saturation was reached. For professionals, more interviews were conducted, attempting to encompass more discharge-planning disciplines. Older participants and relatives appeared confident and unselfconscious, rarely passing to seek reassurance or agreement. In contrast, some health professionals’ responses suggested constraint and a need to express correct professional views. They were aware that the interviewer (a clinical psychologist) knew their names and in some cases was their colleague, but that confidentiality was guaranteed. They expressed a wide range of values, but their practical suggestions were almost unanimous. Particularly initially, some spoke formally and impersonally (‘You would need to do…’), but this was usually followed by informal and more frank conversation. It appeared that once they had expressed the ‘correct’ view, they felt able to critique it, expressing more individually held values.

Table 1 Value coding example from the study codebook

<table>
<thead>
<tr>
<th>Care (personal care)</th>
<th>Definition</th>
<th>Personal care is available for the elderly person. Personal care includes (if required) meals, housekeeping, help with ADLs and IADLs, available within a short enough time.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicators/Flags</td>
<td>Care, caregiver, help</td>
<td>Help in an emergency – code as Safety/security Monitoring of person’s well-being – code as Safety/security Institutional/residential care – code as Institutional care Professional/medical/nursing care – code as Professional care</td>
</tr>
<tr>
<td>Qualifications/Exclusions</td>
<td>‘She must have a caregiver, or someone who can look after her properly’ (OP02). ‘The best outcome might be, if she could stay [at home], with a caregiver that’s there quite a bit, or pops in and looks after meals and that sort of thing’ (REL09).</td>
<td></td>
</tr>
</tbody>
</table>
A parallel community survey (47) not reported here, and later reflective discussions with some participants, served as triangulation. Ten per cent of each subgroup’s transcript was re-analysed and coded by an independent researcher: Cohen’s kappa (46) was 0.76 (p < 0.01), confirming the coding procedure was robust.

Results

Where should Mrs Smith live?

Despite the small sample size, Table 2 depicts statistically significant relationships between stakeholder role (older person, younger relative or health professional) and suggested discharge destination (home or elsewhere). Role explained 29% of the variance in suggested destination ($\chi^2 = 10.8, \text{df} = 2$, $N = 36, p = 0.004$, two-tailed). Cramer’s $V$ – an effect size measure for chi-square tests, analogous to Pearson $r$ (48) – was 0.54, indicating a large effect. Whereas 60% of the older people suggested residential care, only 6% of health professionals did so. Relatives were divided: half said that Mrs Smith should be discharged home, half to residential LTC.

Who should decide?

Few elders suggested that Mrs Smith should decide her own discharge destination (Table 3). Most nominated a guardian, relative(s) or next of kin, or her hospital team or doctor, or a meeting of all concerned. In contrast, most relatives and health professionals said that Mrs Smith should decide, sometimes dependent on her mental capacity. The groups differed significantly in whether they nominated Mrs Smith, with group membership explaining 42% of variance ($\chi^2 = 15.4, \text{df} = 2$, $N = 36, p < 0.000$, Cramer’s $V = 0.65$, two-tailed).

Participants who recommended substitute decision-making were also more likely to suggest residential LTC, perhaps because cognitive impairment influences both decisorial capacity and care needs (Table 4: $\chi^2 = 7.62, \text{df} = 2$, $N = 36$, Cramer’s $V = 0.46$, Fisher’s exact probability $p = 0.009$, one-tailed). Variance in decision-maker – self or proxy – explained 21% of variance in destination.

Underlying values

Group differences were also evident when interview transcripts were qualitatively analysed for the presence or absence of the 33 values specified in advance (see Table 5).

Elders’ values. As a group, the elders mentioned 28 of 33 listed values – a mean of 8.8 each. The value mentioned most was personal care, often home LTC: ‘She must have a caregiver, or someone who can look after her properly’ (OP02 – the second older person interviewed). Mental ability to carry out everyday activities was mentioned by 60% of elders: ‘So even if you were fit and you were starting to forget, how can you run an establishment of any sort?’ (OP02 – the second older person interviewed). Mental ability to carry out everyday activities was mentioned by 60% of elders: ‘So even if you were fit and you were starting to forget, how can you run an establishment of any sort?’ (OP05). Autonomy was mentioned by 50%: ‘I still go with the theory people can decide for themselves’ (OP03), as were safety ‘Now she could collapse again and she could lie there for some time and die’ (OP04), beneficence ‘Someone should step in and do what’s best for her’ (OP08), health ‘It all depends on what state she’s in’ (OP10), and the personal value of living at home:

She’d be in familiar surroundings. She can potter around to her heart’s content, as long as somebody can bring in some food, and I mean the supermarkets

<table>
<thead>
<tr>
<th>Table 2 Where should Mrs Smith live after leaving hospital? Responses (%) by group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Where should Mrs Smith live after leaving hospital?</strong></td>
</tr>
<tr>
<td>Home</td>
</tr>
<tr>
<td>Unqualified</td>
</tr>
<tr>
<td>With supports</td>
</tr>
<tr>
<td>Residential care</td>
</tr>
<tr>
<td>Hostel</td>
</tr>
<tr>
<td>Nursing home</td>
</tr>
<tr>
<td>Unspecified</td>
</tr>
<tr>
<td>Smaller house/ Home unit</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 3 Who should make the decision? Responses (%) by group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Who should make the decision?</strong></td>
</tr>
<tr>
<td>Mrs Smith</td>
</tr>
<tr>
<td>Unqualified</td>
</tr>
<tr>
<td>If competent</td>
</tr>
<tr>
<td>Relative(s)/Guardian/ Next of Kin</td>
</tr>
<tr>
<td>Hospital/Doctors</td>
</tr>
<tr>
<td>Consensus – meeting of all involved</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 4 Relationship between suggested decision-maker and suggested destination</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequencies</strong> (N = 36)</td>
</tr>
<tr>
<td>Mrs Smith should live in her own home</td>
</tr>
<tr>
<td>Mrs Smith should live in residential care</td>
</tr>
</tbody>
</table>
will deliver if you phone an order. It’s a lot to be said for familiar surroundings. If she’s able to shower herself even… Familiarity with your own home and what you know and probably a few people around that you know (OP03).

Relatives’ values. Younger relatives mentioned the most values, an average of 11.9. As a group, they mentioned 25 of 33 listed values. Every relative mentioned safety or security: ‘She’s a danger to herself. She can’t cope’ (REL01). The personal (psychological) value of living at home was mentioned by 87.5% of relatives: ‘If she really wanted to stay in her home I wouldn’t want to take that from her’ (REL07) and ‘But whether I’d be like that when I’m 76 or something who knows. I might think I want my dining-room table, I want my house I’ve lived in all this time’ (REL03). Finances were also mentioned by 87.5% of relatives:

What would be put in around her, what it would cost. Whether anyone would be able to pay for this and whether that would really be something she’d prefer to do, to pay those costs, if what is happening is a deteriorating condition (REL02).

Health was mentioned by 75%: ‘Well, again, it’s not in her interests in terms of her health’ (REL03), and ‘Maybe she might actually live longer being in her own home in terms of being happier there or whatever. And she might just give up if she goes into a nursing home’ (REL03), as was the value of relationships:

She may not be able to be placed into the sort of residential placement that would allow the niece to visit as often and probably Mrs Smith values her niece’s contact. It doesn’t say anything about neighbours or anything else. Can’t tell whether that’s a factor. It doesn’t say anything about pets, but of course they would be a very important consideration. (REL02).

Autonomy was mentioned by 62.5% of relatives: ‘You have to respect Mrs Smith’s right to stay in her home’ (REL06), as was personal care: ‘The best outcome might be, if she could stay, with a caregiver that’s there quite a bit, or pops in and looks after meals and that sort of thing’ (REL09).

Caregiver burden was also mentioned by 62.5% of relatives: ‘I know how frustrating the distance can be, especially if the phone’s out of order, or off the hook’ (REL10), ‘the feelings of the son, how he feels about her being on her own’ (REL01), and:

It’s of course very distressing for all the family. Mrs Smith of course, and her son, the niece is obviously closely involved. It has ripples in a lot of ways… it matters enormously in people’s lives (REL02).

Other values often mentioned by relatives were as follows: the best interests of the elder ‘The son and niece, even if there is a friend who visits, does it mention a friend, have got to encourage her for her own good, for everybody else’s peace of mind as well’ (REL01); better functioning at home ‘She has routines. If there is any cognitive dys-

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Table 5 Research-based thematic analysis: percentage of each stakeholder type mentioning each of the 33 values and 3 meta-values

<table>
<thead>
<tr>
<th>Values &amp; Meta-values</th>
<th>% of Older people (N = 10)</th>
<th>% of Younger relatives (N = 8)</th>
<th>% of Health professionals (N = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Acceptance/Stoicism</td>
<td>30.0</td>
<td>0.0</td>
<td>16.7</td>
</tr>
<tr>
<td>2a Autonomy good</td>
<td>50.0</td>
<td>62.5</td>
<td>94.4</td>
</tr>
<tr>
<td>2b Autonomy bad</td>
<td>10.0</td>
<td>12.5</td>
<td>0.0</td>
</tr>
<tr>
<td>3 Best interests older person</td>
<td>50.0</td>
<td>50.0</td>
<td>33.3</td>
</tr>
<tr>
<td>4 Care (personal care)</td>
<td>100.0</td>
<td>62.5</td>
<td>94.4</td>
</tr>
<tr>
<td>5 Caregiver autonomy</td>
<td>10.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>6 Caregiver benefits</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>7 Caregiver burden</td>
<td>30.0</td>
<td>62.5</td>
<td>61.1</td>
</tr>
<tr>
<td>8 Decision-making capacity</td>
<td>0.0</td>
<td>0.0</td>
<td>16.7</td>
</tr>
<tr>
<td>9 Decision-making process</td>
<td>20.0</td>
<td>12.5</td>
<td>33.3</td>
</tr>
<tr>
<td>10 Environment (quality)</td>
<td>0.0</td>
<td>0.0</td>
<td>5.6</td>
</tr>
<tr>
<td>11a Filial responsibility Yes</td>
<td>10.0</td>
<td>12.5</td>
<td>0.0</td>
</tr>
<tr>
<td>11b Filial Responsibility No</td>
<td>20.0</td>
<td>12.5</td>
<td>0.0</td>
</tr>
<tr>
<td>12 Finances</td>
<td>30.0</td>
<td>87.5</td>
<td>66.7</td>
</tr>
<tr>
<td>13 Health</td>
<td>50.0</td>
<td>75.0</td>
<td>61.1</td>
</tr>
<tr>
<td>14a Home valued</td>
<td>50.0</td>
<td>87.5</td>
<td>66.7</td>
</tr>
<tr>
<td>14b Home function better</td>
<td>10.0</td>
<td>50.0</td>
<td>27.8</td>
</tr>
<tr>
<td>15 Identity of older person</td>
<td>10.0</td>
<td>0.0</td>
<td>16.7</td>
</tr>
<tr>
<td>16a Institutional care good</td>
<td>10.0</td>
<td>12.5</td>
<td>0.0</td>
</tr>
<tr>
<td>16b Institutional care bad</td>
<td>30.0</td>
<td>12.5</td>
<td>22.2</td>
</tr>
<tr>
<td>17 Logic/Pragmatism</td>
<td>20.0</td>
<td>12.5</td>
<td>0.0</td>
</tr>
<tr>
<td>18 Mental abilities</td>
<td>60.0</td>
<td>75.0</td>
<td>61.1</td>
</tr>
<tr>
<td>19 Neighbourhood</td>
<td>0.0</td>
<td>12.5</td>
<td>16.7</td>
</tr>
<tr>
<td>20 Physical abilities</td>
<td>30.0</td>
<td>75.0</td>
<td>50.0</td>
</tr>
<tr>
<td>21 Privacy</td>
<td>0.0</td>
<td>0.0</td>
<td>5.6</td>
</tr>
<tr>
<td>22 Professional care</td>
<td>30.0</td>
<td>25.0</td>
<td>5.6</td>
</tr>
<tr>
<td>23 Professional opinion</td>
<td>20.0</td>
<td>0.0</td>
<td>11.1</td>
</tr>
<tr>
<td>24 Psychological wellbeing</td>
<td>30.0</td>
<td>75.0</td>
<td>61.1</td>
</tr>
<tr>
<td>25 Relationship</td>
<td>20.0</td>
<td>75.0</td>
<td>22.2</td>
</tr>
<tr>
<td>26 Safety/Security</td>
<td>50.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
<tr>
<td>27a Social contact good</td>
<td>30.0</td>
<td>37.5</td>
<td>55.6</td>
</tr>
<tr>
<td>27b Social contact bad</td>
<td>30.0</td>
<td>37.5</td>
<td>16.7</td>
</tr>
<tr>
<td>28 Work ethic</td>
<td>40.0</td>
<td>50.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Self-Responsibility</td>
<td>30.0</td>
<td>62.5</td>
<td>0.0</td>
</tr>
<tr>
<td>Planning</td>
<td>50.0</td>
<td>25.0</td>
<td>16.7</td>
</tr>
<tr>
<td>Balance</td>
<td>20.0</td>
<td>37.5</td>
<td>38.9</td>
</tr>
</tbody>
</table>

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aValue derived from Forbes & Hoffart (36).  
bValue derived from McCullough et al. (35).
environment (REL02); and self-responsibility ‘I wouldn’t want to be dependent on my family that much’ (REL03).

**Health professionals’ values.** As a group, they mentioned 25 of the 33 listed values; on average they mentioned 10.2 values each. All mentioned safety: ‘She could be at risk of serious injury or calamity, there’s a need to reduce the risk’ (HP04), and ‘A very at-risk little lady’ (HP14). Autonomy was mentioned by 94%: ‘The person in the centre should decide’ (HP04), as was personal care ‘If she had just a little bit more assistance with certain things’ (HP12).

Finance and the personal value of living at home were mentioned by 67%: ‘Home is precious’ (HP14) and:

> How much money am I going to spend for the future? Even though I’ve got a condition that is going to probably lead to institutional care at some time in the future. What’s the value of, to her, of still being in a home that she knows well? It’s a very hard judgment to make (HP03).

Caregiver burden was mentioned by 61%: ‘It’s a worry for the family, the neighbours see her as being at risk. A strain for the family and an uphill battle for service providers’ (HP04) and ‘The niece lives across town, so that’s a long way away, has a job and a family, and visits after work, and does the shopping. So that’s an enormous burden’ (HP03).

Health was also mentioned by 61%: ‘If she continues to lose weight, it could cause a lot of trouble. Malnutrition, infection, pressure ulcers’ as were mental abilities ‘I guess in this case the short-term memory is of concern as well, and whether that’s affecting her looking after herself’ (HP01) and psychological well-being: ‘If we were able to institute reasonable supports and she was able to stay at home… not having to move out. That could be important in terms of her self-esteem as well’ (HP10).

Social contact was mentioned as desirable by 56%: ‘She may not see it that way, but she’s isolated from her… family… If she went into care, she would quite likely make some friends’ (HP08). Physical abilities were mentioned by 50%: ‘So I would be doing some kind of activity of daily living assessment to see what she was capable of doing for herself’ (HP06).

Ethical conflict between beneficence and patient autonomy was clearly expressed: ‘It’s a dilemma, a complex situation. The decision that’s best for the person can mean standing back. It can be difficult in a professional situation… Why’s it difficult? The professional responsibility of duty of care’ (HP04) and:

> Then to actually decide ‘Yes, I think this should go to the Guardianship Board’, or… I don’t like handing over someone’s... power in a way. I think ‘Oh I don’t want to have to do that’. But then the social workers emphasise it is our duty of care, and we can’t just send someone home because you don’t want to take away their independence and things (HP05).

The importance of personal care was also acknowledged by professionals who, like relatives, often suggested home LTC – ‘Everything would snowball in a very short amount of time if she didn’t have those supports’ (HP12) – articulating that this might resolve conflicts between safety and autonomy:

> I think she should go home. I don’t think she should just be discharged – ‘See you later and thanks very much’ (laughs). Because there is obviously a duty of care, there are some problems. Yes, there needs to be some work done. There needs to be some discussion with her which is... sort of couched in ‘How can we help you to stay home?’ rather than ‘You can’t stay at home, you need to go into care’. It’s about ‘We can provide you with supports in order for you to stay at home...’ And I would probably try and get the support of her family and friends as well. Without it appearing like some major exercise to do her over. Of course it’s not. Yes, I think that should be the aim. If that’s what she wants... to keep her at home (HP08).

Meta-values too were introduced differently across stakeholder types (Table 5). The meta-value mentioned most by elders was balance – usually family members balancing caregiving with other commitments. Relatives, however, mentioned planning most:

> You are going to have a few signs where you probably need to start thinking, is this the long-term spot that I should be... You are going to get to that point probably before this situation, where you really should be moving, and moving when you are still quite well (REL03).

Professionals were most likely to mention timing: ‘If she goes home and declines support she is at risk. It’s better to get caregivers in earlier while she can get to know them’ (HP14), and:

> So she might have some years if she lived at home, rather than just a few weeks. Of course the other side of that is, it is also going to be easier to move her into a new environment at this time and not later, and it is always tricky that one (HP03).

**Additional emergent values**

Participants introduced some values and topics not listed in the study codebook and thus outside the planned analysis (Table 5). These were recorded as ‘emergent values’ of which the commonest was the older individual’s personality and preferences: ‘She seems as though she’s a very independent person and wants to stay that way’ (OP08); ‘We don’t know what sort of person she is, whether she is a solitary person who really does push people away’ (REL06); and ‘A lot depends on that person’s personality, and sense that she needs to be taken care of, or sense that she wants to be autonomous. That is really a very important dimension. Given an equal level of physical feasibility’ (HP07).
Several relatives and professionals mentioned issues of isolation and distance:

When you’ve got family that lives interstate, or a great, you know, far country or something. I often find that they are more extreme either way for what they want done to their parents. I guess because they are not there to be able to help at all on a regular basis and they really want everything either, I mean, either they want them placed, no debate entered into, or at home, no debate entered into. I often find that the absent family is the one that’s got stronger points of views (HP06).

For the son, I think that it would be really good that he could be contacted because he must be very worried and living interstate... So there’s probably some guilt. And he may also have some unrealistic expectations because he is interstate, and isn’t seeing the day-to-day things for Mum (HP18).

Some professionals indicated that relatives should support professionals’ opinions, and some relatives said that professionals should keep relatives informed and support their stances: ‘It would help if the Occupational Therapist and the Social Worker confirmed what the family were saying. Instead of just being totally impartial’ (REL01).

Responsibility to maintain property was mentioned by relatives ‘Moving out before things get too run down’ (REL06) and elders:

Quite frankly I don’t know what the answer is, but I do know this, for me I couldn’t have a place that’s falling down around my ears, where people are saying ‘Oh she is old, and she can’t manage’ you know (laughs). I wouldn’t like that. Some people don’t care, they say ‘Well this is my home and I’m staying’. But for me I have to do something else (OP05).

Potential risks to the community if Mrs Smith caused a major accident at home, or to the hospital through litigation, were suggested by some professionals: ‘We’d get in big trouble if you sent somebody home and then something happens. The hospital wouldn’t be... (laughs) so thankful, I don’t think. Especially with all this public liability and things happening at the moment’ (HP05).

Relatives too mentioned the community’s interest in discharge-planning: ‘It’s not in the interest of society to be funding I think, even with hospitals or whatever, but is it really, like you are sort of draining the tax payer dollar by... I think the additional risk if you like’ (REL03).

One relative mentioned death as a potential resolution: ‘Well, I don’t want to sound callous but if she died that would solve everybody’s problem wouldn’t it? But you wouldn’t wish that on anybody’ (REL08). No elder or professional mentioned death. The value of living alone was mentioned by elders and health professionals: one elder also mentioned altruism.

Many health professionals, and most relatives, observed that the vignette story was common or ‘a classic case’ (REL01) but no older respondent said this. Conversely, most elders spontaneously mentioned their own future LTC needs, but other stakeholders did not. One elder emphasised that unlike Mrs Smith, she would accept help. Another explained that while recommending residential LTC for Mrs Smith, he would not want it himself: ‘I’d probably think more of what I want, than what’s best for me. I’ve always said I’ll go out feet first with a label on my big toe! Probably not practical though is it?’(OP09).

Discussion

To summarise, our quantitative and qualitative findings supported each other, the ETA and the broad hypothesis that given the same discharge-planning vignette, different types of stakeholder would make different recommendations and express different values. Older people recommended safe and restrictive options for a less able elder, but autonomy for themselves. Younger people acknowledged the rights and autonomy of frail elders but struggled with protecting them. Values analysis revealed more complex patterns than we had predicted. All stakeholder groups acknowledged the centrality of individual person-ality and preferences. Beyond this, elders prioritised personal care and mental capacity; younger relatives talked about safety, finances and the value of living at home; health professionals focussed most on safety, then autonomy and personal care.

Some values reflected local culture. Most Australian elders live alone or in couples. Australia has high home ownership levels and low population densities: hence, the relevance of property maintenance, distance and isolation. Basic residential LTC is Government-funded for all Australians, but home LTC is poorly resourced; thus, wealth shapes LTC choices.

Interestingly, although elders focused most on personal care and individuality, they often suggested residential LTC and proxy decision-making for Mrs Smith whom they described as ageing less successfully than themselves: being at more risk, requiring more support and being capable of exercising less independence and autonomy. There was some objective support for this. Interviewees were not cognitively impaired or facing imminent placement. Few lived alone.

Alternatively, Mrs Smith’s situation represented a possible future. Psychologically, elders may have distanced this by highlighting individual differences and her relative incapacity. Nygren and Iwarsson (16) described a similar cognitive strategy as ‘benchmarking... relocation did not have to be considered as long as their situation did not become as bad as that of other persons of their age they knew of’ (p. 183). Unlike the other stakeholders, elders were being asked about someone uncomfortably like themselves, so the questions may have held deeper and more personal meanings for them. This could explain why
older participants usually introduced their own potential LTC needs, whereas other stakeholders did not.

Younger respondents (relatives and professionals) emphasised safety although many suggested discharge home. Most believed the hypothetical elder should decide her destination, but only if she had mental capacity. Discharge-planning becomes most ethically complex (49–51) when issues of mental capacity and proxy decision-making are raised (25) in the ‘grey area’ between competence and incompetence, as in this vignette.

Values analysis revealed a clear tension between beneficence (duty of care/safety) and autonomy in discharge-planning. Rather than being oblivious to elders’ autonomy and psychological needs, younger respondents seemed painfully aware that safeguarding physical health produced ethically difficult outcomes. Few seemed able to resolve this: none suggested that physical and psychological safety could be considered together as beneficence. Instead, relatives sought affirmation from health professionals and vice versa. Recent dementia research (29) suggests that for family decision-makers, beneficence supplants autonomy over time, consistent with our finding that support for autonomy was often conditional. Further development of a transitional theory or model of ethics for discharge-planning may utilise an ‘ethics of care’ philosophical approach: this acknowledges both individuality and connectedness (52, 53), while informing and being informed by qualitative research (54).

Many conversations focussed on acceptance of home LTC, often described as the key to maintaining autonomy. As Nygren and Iwarrson (15) also suggest, LTC conceptualised in this way rather than as dependence offers a useful framework for some discharge-planning discussions. This discourse, with the strong related theme of individual differences, highlights the potential utility of the ETA for predicting and explaining elders’ choices (14).

Few elders mentioned the planning meta-value, echoing previous findings (3, 4) that elders rarely apply consumer decision-making to LTC. Discharge-planning health professionals work most with patients needing immediate LTC. Younger relatives were most likely to mention planning: for them, the LTC decision-making process may commence long before a decision is made or even discussed.

Despite common accounts of caregivers juggling others’ needs and their own, the elders mentioned balance most. The literature offers some explanations. In the bioethical debate, relatives’ needs are sometimes classed as conflicting and external interests (25): relatives may have been inhibited from mentioning them. Elsewhere, older people have expressed balanced and ethical stances about their own and their families’ needs (23, 27).

Unsurprisingly, timing as a meta-value was mentioned most by discharge-planning professionals. Focus on timing is appropriate to their short-term or intermittent involvement: LTC offered too early or late has costs. Increasingly, however, health care is provided by community-based nurses, doctors and allied health professionals (55) who can potentially help patients anticipate and plan for LTC (4).

Physical independence inevitably ends in death or dependence but only one participant mentioned death as eventually resolving the LTC issue. Perhaps, respondents did not want to appear insensitive; without specific prompts they did not raise the topic.

Socially desirable responding was a potential confounding influence, as in most survey and interview research. However, responses, values and meta-values varied within and between stakeholder groups in this study, reducing the likelihood that participants were merely repeating a socially accepted consensus. The open-ended nature of the interview, and the question – What would make a difference? – seemed to encourage expansion and deepening of responses.

Another limitation of the current study was that identical interview questions had differing levels of personal relevance for the different stakeholders. Future researchers could consider asking all participants directly about their hypothetical future selves, as well as about others, because people considering proxy decisions may make more conservative suggestions (56).

It may also be useful to collect data anonymously, possibly online (as the ageing population becomes more computer-literate, this will be more feasible within discharge-planning and LTC research); to vary vignettes addressing differences in gender, culture and health status; and to recruit spouse and sibling caregivers and more professionals, for example physiotherapists, family doctors and community nurses.

Although the study was geographically limited and small, significant quantitative effects were observed, qualitative research guidelines were followed, and saturation was achieved. Stakeholder values and meta-values largely resembled those reported elsewhere, supporting use of the larger retrospective literature to understand the discharge-planning experience for elders, their families and health professionals. Specifically, the differing values that different stakeholders have described after LTC decisions are also articulated in advance and may well operate throughout the discharge-planning episode.

Clear suggestions emerge from these data for improving the discharge-planning experience through theory development, professional training and community education. Ethical care models can specify psychological and physical safety as components of beneficial discharge-planning and acknowledge transitions and relationships. Trainees can learn that balancing patient safety and autonomy is central to ethical practice and that timely acceptance of LTC can represent autonomy. It may be possible to educate mid-life adults – who acknowledge elders’ need to plan – to consider their own later LTC when planning retirement.
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Author Contributions

All authors contributed to study design and recruitment and critically reviewed the manuscript. The first author collected and analysed the data and drafted the manuscript.

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