Research

‘They never talked to me about. . .’: Perspectives on aged care resident transfer to emergency departments

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Aims: To explore perspectives of three groups concerning transfers from aged care facilities to emergency departments. We sought to reveal factors influencing transfer decisions; how active each group was in making decisions; and to what extent groups ceded decision-making to others.

Methods: Semi-structured interviews of 11 residents, 14 relatives and 17 staff with content analysis of interview transcripts.

Results: The three groups substantially differed in their involvement with initiating, and attitudes towards, transfer. Residents were least likely to be involved in the decision, yet most likely to support transfer. Staff felt conflicted between their desire to provide optimal treatment for one ill resident, and their obligations to other residents under care. Staff perspectives were largely consistent with published data, but we describe new results for other informant groups.

Conclusions: Group expectations and preferences differ substantially. Service delivery to meet all preferences presents a challenge for health service design.

Key words: emergency medicine, frail elderly, patient transfer, qualitative research, residential facilities.

Introduction
For every 100 older people living in residential aged care facilities (RACF), there are between 30 and 150 transfers per annum to hospital emergency departments (ED) for clinical care [1]. Such transfers occur predominantly in very unwell people with serious illness or injury [2]. Nevertheless, it has been consistently argued that some transfers to ED from RACF are avoidable, either because they are for ‘minor’ problems that are able to be managed outside of ED, or because of inadequate advance care planning [3,4].

We previously systematically reviewed the literature pertaining to decisions to transfer residents to ED from RACF and found that two overarching themes classify these: decisions taken to support improved clinical outcomes or quality of life in residents (the ‘resident dominant’ theme); and decisions taken with no expectation of resident benefit but influenced by other factors (the ‘resident subordinate’ theme) [5]. Data from this review are important but much of it was derived from primary studies with RACF staff as the respondents. Only a small number of studies have examined the views of other important respondent groups such as residents or their relatives [6–8]. No studies have thoroughly evaluated how the views of different stakeholders converge and diverge regarding ED transfer. This is important because for RACF residents, the decision to attend ED and who makes the decision is complex. By definition, people living in RACF are no longer able to live independently in the community. In many circumstances, they have lost the capacity to make autonomous decisions about their own health, but even when they retain capacity there are often other stakeholders that influence choice [9]. In any one transfer situation, a resident, their relative or a staff member may be the sole or dominant decision maker, or it may be a negotiated situation between two or more of these parties. Understanding the main influences for each group, and how these influences interact, is an important step in design of health services that are responsive to the needs of all decision makers.

The objectives of this study were therefore to capture and interpret the perspectives of three important decision-making groups (residents, relatives of residents and RACF nursing staff) concerning the transfer of residents from RACF to ED; to understand how the perspectives of these converge and diverge; and to explore shared decision making and the extent to which there was delegation of transfer decisions to others.

Methods
Institutional ethics approval was obtained (Sydney University Human Research Ethics Committee no. 10653).

We conducted semi-structured one-on-one interviews with consenting residents of RACF, relatives of residents and RACF staff. The interviews were conducted by interviewers (AP and GA) at a time and place of the respondents’ choosing. Participants were made fully aware of the reasons for the research and gave written informed consent.
Sampling was purposive [10] with snowball sampling techniques [11] additionally used for staff recruitment. Resident participants were identified with the assistance of clinicians in the ED of hospitals. We sampled only those residents that ED staff indicated had no life- or limb-threatening reason for transfer and were identified as being cognitively able to participate in the study. The residents were approached by research staff in the ED, given written information about the study and verbal consent was obtained to contact the resident post discharge from hospital to seek their formal consent for participation. Interviews with consenting residents were subsequently conducted within the RACF. Relative participants were similarly recruited from ED. Staff participants were from local RACF around participating hospitals and were recruited with the assistance of facility managers that acted as champions of the research.

Interviews were conducted using a semi-structured interview guide that had contextual, evaluative and strategic questions (see Appendix I for basic interview guide). Interviews were recorded and transcribed in verbatim. Field notes were taken, and the transcribed interviews were read and edited while listening to audio and consulting field notes. Interviews within each group were continued until data saturation was reached.

Edited transcripts underwent qualitative content analysis using NVivo software (version 9, QSR International, Burlington, MA, USA). Two investigators (DH and GA) were involved in coding. We initially developed a coding tree with nodes based on the interview content and coded transcripts accordingly. Subnodes were created where required to disaggregate data. The initial coding framework was a conceptual model based on the hypothesis derived from our prior literature review that staff decision-making would be predominant, with minimal shared decision-making. This coding tree was iteratively adjusted as additional transcripts were coded. Coded transcripts were reread to confirm all data were included for analysis, and major themes were identified although progressively sorting and collapsing. Data from each stakeholder group were initially analysed independently before results were compared across the three groups.

Results

Interviews were conducted until data saturation with 11 residents, 14 relatives and 17 RACF staff members (nurses or nursing assistants). Residents had a mean age of 88 years and nine of the 11 were female. They were residents of six facilities. Staff informants were all female and drawn from the same six facilities.

Residents

Resignation

Resignation emerged as a key theme in the responses of residents to their ED transfer and their own health needs. Residents reported that they were not consulted on key decisions, understood that someone else would be making the decisions and hospital transfer was inevitable. Most residents expressed no dissatisfaction with this state of affairs or any desire to change it. Less commonly, resignation is met with resentment where residents indicated a desire for change but with no expectation that change will occur.

If the decision was mine, I wouldn’t go [resident 7]

When residents were asked to describe the decision-making behind their transfer to ED, in most cases no consultation with the residents occurred.

They never talked to me about it. The first thing I knew I was in the ambulance and going. They never even told me I was going [resident 4]

Someone’s got to make decisions when you’re not up to it and that’s what I’m in here for [resident 10]

However, one resident expressed a view that they not be transferred only for it to be overridden by staff. Additionally, one resident was involved in initiating transfer.

I said to my son, best thing that you call for the ambulance [resident 3]

Security

Residents overwhelmingly described a sense of security associated with ED transfer. Implicit in this is the sense of insecurity associated with becoming ill within their RACF.

I knew I was in safe hands. You were there, there’s somebody near you to help you [resident 8]

I felt, well I’m here where there’s doctors and everybody here [resident 6]

The residents’ lack of faith in the capacity for medical care to be delivered in the RACF was also evident.

I think they’re mainly to do with aged care and not so much with sick care. I mean, they haven’t even got a bloody thermometer here. How the hell are they supposed to look after someone like me? [resident 9]

Despite this perception of security, residents also often viewed the ED as busy, chaotic and demanding. Some residents were particularly concerned if, among this environment, they felt ignored or forgotten. However, to some extent this sense of busyness also reassured some residents, and added to the sense of security that if something particularly bad was to happen there would be someone at hand to assist. Even where they may not have wanted transfer, no resident volunteered any alternative to ED transfer unless a doctor could have come immediately to see them. By and large, informants viewed the ED as imperfect but still the only viable alternative in many situations. For example:
Well, there’s nowhere else. If it’s bad enough go into the emergency, get some treatment what you can get [resident 5]

Although most perceptions of ED staff were positive, one resident described feeling unvalued by the ED physician attending her, to the point that she would be afraid to return to that particular ED again.

Well, he turned around and he said, oh, what are you doing here? All this sort of thing. He said, no, we can’t accept you. He said, we do some good things here but we’re not miracle workers. Which quite hurt my feelings [resident 9]

Waiting times and the physical comfort of the ED environment were also mentioned by individual residents as negative aspects of ED care.

Relatives

Partnership

There was great diversity among relatives regarding their involvement in transfer decisions; which reflected the rich spectrum of relationships that relatives have with both the RACF and the resident for whom they care.

Overall relatives saw themselves in partnership with the facility staff or, less commonly, the resident, regarding transfer decisions. How active the relative was in that partnership, and the state of amicability of the relationship with RACF staff, varied widely. In some circumstances relatives expressed a desire to avoid hospitalisation where possible, while recognising it was often necessary. This ambiguity around ED transfer is well summarised by one informant:

She’s been quite happy with her experience – apart from not wanting to be there [relative 4]

Interestingly, several relatives reported that the resident had indicated directly they did not want to go to hospital, despite this not being a dominant theme from the resident respondents themselves.

She doesn’t want to go to hospital. That’s one thing she hates going [relative 3]

He said to me, no, nothing more. I said what do you want done, how do you want to be cared for now, what do you want done? Just kept out of pain and comfortable. That’s all he wants [relative 13]

However, some also expressed an alternative view:

Dad realises when he’s crook, if he’s got to go to hospital, then that’s the best place he can be. So he’s always quite happy to go [relative 12]

Frequently, the relatives used words such as trauma to describe hospital-related experiences of their relatives.

She's been quite happy with her experience – apart from not wanting to be there [relative 4]

Because she’s within her environment and she doesn’t have to go and sit in the middle of the night at [hospital name]. Even two hours for them, out of their environment, is a big issue [relative 14]

A common aspect was the disorienting effect associated with transfer.

If things can be done there, obviously that’s preference. When they’ve got to get out of their comfort zone, I think it can be distressing for them. If they don’t have a familiar face around or familiar sounds, yeah [relative 7]

Because she’s within her environment and she doesn’t have to go and sit in the middle of the night at [hospital name]. Even two hours for them, out of their environment, is a big issue [relative 14]

On the other hand, there was clear recognition that hospitalisation was unavoidable, and in fact desirable, in
many circumstances. Sometimes this was acknowledged in a
matter-of-fact way.

When they have to go, they have to go [relative 10]

Relatives also recognised that the motivations for transfer are
sometimes because of the lack of availability of staff within
the RACF, or because of the RACF staff taking a risk-averse
approach to resident care.

Those poor nurses. In there they’ve got too many patients
and not enough nurses. The staff is not enough in that
place [relative 3]

But see, [facility name] has to cover themselves. Overreaction
is probably the wrong word but they’re overcautious
[relative 9]

A large number of relatives expressed the view that having a
medical service available to visit the RACF would be an
alternative to transfer, but were also realistic that this is often
not available.

Well, I would think if a doctor would come, which they
don’t these days, but I mean if a doctor would come and if
they had a doctor there on call that would come and make
that decision it would save them taking them off to hospi-
tal. But that doesn’t happen. Doctors don’t do that, I don’t
think [relative 9]

ED care was often perceived as providing reassurance that
was not otherwise available in the RACF.

We feel comfortable that she has had some professional
care. There’s nothing that might go missing sort of thing
and put off. She does get good care. . . . The doctor is
not always on call over at the care facility. He’s not there
to do something at that time so who knows how long it
might take for him to get there. So it’s best that I think
she goes to the hospital and gets the emergency care
[relative 5]

Lost property or medication, waiting times and aspects of the
physical ED environment (such as the lack of privacy and cool
ambient temperature) were all cited as negatives of ED care.
However, an additional key concern to emerge from relatives
was the periods where they were excluded from being in the
same clinical area or cubicle as the resident. Relatives saw
multiple roles for themselves in the ED – as a calming and
reorienting influence, a companion, and an advocate for the
health care requirements of the resident.

I still feel like I am protective towards him and I just
want to make sure that they understand what’s happen-
ing with him. Because I don’t know. I just think some-
times it’s easy, some just may not take the time with him
[relative 13]

Staff

Fidelity
There is a diversity of processes for involving other parties
before staff will initiate transfer. Different staff informants
variably report consultation with a resident, relative, facility
manager, extended practice nurse, general practitioner (GP),
hospital or telephone advice line before transfer. Staff value
and see purpose in established procedures that have been
developed with residents and relatives to inform transfer
decisions. Particularly when it comes to relatives, staff placed
importance on honouring the wishes of relatives and involv-
ing them in any transfer decision process if that was desired.
Fidelity arises from the sense that staff have that they are part
of the residents’ lives, as in this staff informant talking of a
resident who had recently died.

They were part of our family here. . . . they weren’t just a
patient who paid fees and paid your wages; they were part
of a broader picture [staff 15]

Consistent with findings from the relative group, facility staff
report that they are sometimes empowered to make judgement
calls on hospital transfer without consultation, although they
will usually still inform relatives of any decision.

More commonly, the staff described transfer decisions as
being made in consultation with the resident or family. The
most common situation was that the staff saw themselves as
facilitators and advisors to families, rather than final arbiters.

Sometimes, however, staff would use strategies to try and
influence family members to avoid transfer, described as a
‘selling strategy’ by this informant.

Part of the thing that we try to tell them is we can do this
here, however, the decision is yours. We can treat mum
here, we can treat dad here, but if you want them to go to
hospital we will ring the ambulance on your behalf. Trying
to get that message across, whether they feel that hospital
or the word hospital means better care, treatment as
opposed to aged care facility, this is where they live, there’s
lots of things that both parties have to sell themselves on
[staff 16]

Similar strategies are used with residents reluctant to follow
staff advice to go to hospital.

They’ll say I don’t want to go to hospital. But, I mean if it’s
a crunch time we go to them and say look, if you go this is
what might happen and it might benefit you in this way.
Then if they’re very desperate . . . . sometimes they’ll say
yes [staff 1]
She had to go into the hospital against their wish. She was bleeding so she had to go in. They just felt that she’d been through enough but again you can’t have them haemorrhaging here [staff 15]

The inverse is also found.

It wasn’t us that was actually wanting the resident transferred, it was the family. On this occasion it was the family who were insistent [staff 14]

**Professional burden**

A major finding that emerges from our analysis is the burden staff felt as the custodians of care for their residents. ED was seen as but one component of a health system to access for their residents and staff have a clear view that ED transfer was appropriate some of the time. Staff resisted the idea that ED care should be denied to RACF residents solely on the basis that they are in a facility.

A resident has a right to go. . . even if not sick, just like you or I would if we were living in our home, we could call an ambulance – they’re not going to question us [staff 14]

Nonetheless, this view of transfer was tempered by a number of concerns.

We always worry – to tell you the truth we always worry – and we do not want to send them there [staff 5]

I have to say I’m quite fearful of sending any of my residents to Emergency [staff 13]

The following succinct quote summarises the burden that staff feel.

We’d rather look after them here if we can [staff 8]

The overwhelming view of staff in our study was that the residents are best cared for where possible at the facility. But the important words in this response are ‘if we can’. Clinical need will result in hospital transfer. However, staff also suggested that much ED transfer was clinically unnecessary yet the only viable option available due to the lack of alternatives.

Sometimes it can get a bit frustrating and you think this person really doesn’t need to be hospitalised but I do need some care. Some advice, some other direction [staff 3]

The ED was perceived as providing a safety net service.

At Christmas, we had one GP left. So therefore, that puts pressure on the system doesn’t it; on A&E or – because they’re our only back up [staff 1]

A large number of negatives associated with ED care were referenced by staff including mixing frail older people with other ED clientele; excessive noise and lighting; time spent on stretchers; lack of attention to basic care needs such as food, fluid and changing continence pads; excessive time that residents spend alone with no reassurance; incorrect medication timing and dosing; and lost property.

Staff also described a number of episodes of suboptimal clinical care provided by ED, such as iatrogenic injury or residents being returned to the RACF with the problem for which they were sent to ED not rectified.

Nonetheless, staff were cognisant of the difficulties ED staff face and appreciative of their work as fellow health professionals.

You do have to marvel at the stuff that goes down there and they get through it. You might have a wait. There’s only two pairs of hands. We don’t have trouble with emergency [staff 11]

Professional burden was also apparent in other responses. Staff highlighted the difficulty they face when a resident becomes ill, as their obligation is not only to that resident but to the rest of their facility. This is contrasted with the perspective of a relative by this informant:

They’re looking at this one human; not the one human out of eighty and the load on us [staff 1]

Staff did reference, and frequently use, a number of existing services that provide advice and care for residents within the RACF. These services were valued but perceived as somewhat limited in their scope of practice, times of availability, or promptness. There was variation noted in the interpretation of clinical necessity among staff. For example, some staff reported being very happy to have residents with a laceration requiring suturing or chest infection treated in the RACF, whereas other staff describe conditions such as these as requiring ED transfer.

**Discussion**

We have found noteworthy differences among the three informant groups regarding the transfer process. At the heart of these differences is the profile of a vulnerable older person as the typical RACF resident. All informant groups in our study recognised this vulnerability, yet how this informs their views on the desirability of ED transfer differs from group to group.

Residents perceive themselves as disempowered in the decision-making process, and yet were reassured by hospital transfer and derived a sense of safety from it. While recognising that the ED is not a pleasant place to be, the predominant finding here was residents themselves viewed ED transfer as necessary and reassuring in many circumstances. Of all three respondent groups, residents were least likely to equivocate over whether transfer was desirable.
It is not clear to what extent these findings represent the phenomenon of ageing related acquiescence whereby older people who recognise the relinquishment of control in their own lives are likely to acquiesce as a means of preserving dignity [12]. Irrespective of whether this is an influence, the findings suggest that residents as a group are least likely to be active participants in the decision-making process and most likely to accentuate positives of ED care. Our data is consistent with findings that frail older people are likely to believe that recurrent hospitalisations are unavoidable, even desirable, and to be appreciative of the care received, even if the care does not meet all of their needs [13–15].

For relatives, the vulnerable older person in a facility carries a number of emotional responses well described in the literature, most notably loss and guilt [16,17]. The ambiguity that featured prominently in relatives’ decision-making in our study mirrors the uncertainty and decision-making stress found previously among relatives making a range of decisions about a resident’s life [18]. Relatives perceive and are responsive to shortfalls in care both within ED and within the RACF and, as such, can see themselves as having to choose the ‘lesser of evils’ rather than choosing a positive pathway for the resident. It could be argued that the feelings of guilt associated with RACF placement leads to a desire for exceptional care among relatives which is unrealistic, yet we found relatives attached value to the advice of staff and were grounded in their expectations. No relative in our sample volunteered that they had initiated or insisted on transfer against the advice of RACF staff, despite this being a feature of staff responses in this study and others [7].

Staff had a clear view of, and take pride in, their professional obligations. While responsive to the desires of residents and relatives, it appeared that staff saw themselves as making decisions not only in the interests of one resident that is unwell, but in the interests of all residents under their care and the facility as an institution. These findings are congruent with the results from our systematic review of prior literature [5]. In this review, we found a large number of decisions to initiate transfer are taken with no expectation that they will improve outcome for the resident transferred. In this study, we have confirmed that staff are more likely than other groups to express the idea that transfers are unnecessary but nonetheless occur because of many factors such as inadequate planning and communication. This is consistent with other published data. For example, it has been found that 77% of professional respondents (RACF directors) believe that there are too few do-not-hospitalise orders in RACF [19].

We did find, as reported elsewhere [9], that on rare occasions, staff adopt a variety of tactics to deny other stakeholders their choice over whether to be transferred despite being respectful of relative and resident choice. Bauer has previously reported that there is a ‘rhetoric’ of partnership with families in facilities, yet the relationship is much more complex and frequently tension arises because relatives have a sole focus on their resident family member and believe that person should always ‘come first’, whereas staff have to cater for the needs of a large number of residents [20]. We found that partnership with staff was highly valued by relatives although the guise of partnership varied from one situation to the next. Tension, as described by Bauer, was occasionally found in our study, but we also found that each of these groups was sympathetic to the difficulties faced by the other in the care of residents.

Previous work looking at general life in RACF has found that the priorities of residents, families and staff diverge [21], hence it is not surprising to find differences between respondent groups in our study. The source of this divergence is multifactorial but largely expected. In Ben Natan’s study, residents most valued comfort and support; family most valued information and an ongoing role in the life of the resident; and staff most valued proficient professional care including fulfilling their obligations not only to the resident but the employer [21]. The differences do pose a theoretical challenge for policy makers seeking to design programs that meet the needs of stakeholders in reducing transfer, especially if the programs are calibrated towards meeting the needs of one group over another. Disagreement between relatives and staff around goals of care is reported elsewhere [22]. For this work, we conceptually explored the idea that shared decision-making would be infrequent. While our results do not support that one group is always dominant, residents and relatives were both more likely to cede decision-making to staff than the other way round. Formal shared decision-making and ‘an equal say’ is not common.

Our study is limited by the fact that resident informants by necessity were drawn from the population of residents with non-life threatening illness who were cognitively capable of providing informed consent and participating in the research. It is recognised that at least half of all RACF residents have significant cognitive impairment [23]. Because staff and relative informants were not restricted to talk about cognitively able residents, we cannot know whether the responses of these two groups would have differed if such a constraint had been imposed. The fact that it took longer to reach thematic saturation point with staff than other groups is indirect evidence that experienced staff develop a greater range of informed perspectives in working with many residents across the spectrum of co-morbidity. Funk has found that a number of variables predict the degree to which residents in long term care may wish to be involved about autonomous or joint decision-making regarding a range of life choices, although not including ED transfer [24]. As we did not collect this information, we do not know to what extent our resident population reflected the variables identified in Funk’s work. We did not find evidence of collaborative coalitions, as reported in other settings [25], whereby two parties in the resident-relative-staff triad arrange to conspire against the wishes of the third party. Because we concentrated on acute
episodic medical care and ED transfer, our study did not directly address issues around palliative and end of life care that are recognised by many authors as being important in examining hospitalisation from RACF [26–30].

In conclusion, our study found that aged care residents have a number of special circumstances that require consideration in the ED setting. These include an understanding of the dominant decision-maker when it comes to initiating transfer, the motivation for transfer and the desirability thereof. In this study, we have highlighted substantial differences between three important groups regarding transfer. Understanding these differences, and the fluidity of relationships between stakeholders, is the first step in designing acute medical services that are better aligned with the requirements and preferences of each group.

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Key Points
- Concerning the transfer of aged care residents to ED, the qualitative literature contains a wealth of data derived from staff informants, but comparatively little from residents themselves or their relatives.
- Understanding the preferences of each of these respondent groups, and whether one or more groups are dominant in the decision-making process, will aid the design of responsive health services. Even if programs are designed to provide alternate medical care for residents, these will not be well utilised if they do not meet the preferences of dominant non-resident decision-makers.
- In this paper, we show that the expectations, experiences and preferences of staff, relatives and residents concerning ED transfer decisions do differ substantially. Residents are most likely, and staff least likely, to cede decision-making to other parties. Formal shared decision-making arrangements, and an ‘equal say’, are uncommon but most informants are supportive of the processes they have in place to decide whether transfers should occur.

References
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Appendix I

Interview guide (for residents)

1. Introduction of the nature and aim of the project (reiteration of study participant information statement)
2. Explore the participant’s recent experience with the system (contextual)

Can you begin by describing your recent trip to the hospital emergency department?

What are your most vivid recollections of being in the emergency department of the hospital?

Who made the decision that you should go to emergency that day?

3. Seek participant’s views on what is working well with ED on the basis of their experience (evaluative)

4. Seek participant’s views on what is not working well with ED on the basis of their experience (evaluative)

5. Re-evaluation of this episode of care

Thinking back now, do you think it was important that you went to the ED when you did?

What factors do you think most influenced (you/other decision maker) deciding that you should go to ED that day?

How did you feel about going to the hospital emergency department that day?

Would there have been any other way you could have received the medical care you needed that day?

Thinking of the care you can currently receive in your nursing home, what things would need to be different for you to have received the treatment you needed there?

6. Seek participant’s views on what would be the features of an ideal system? (strategic)

If you had your way, how would you change things to improve the way you get treatment when you become ill?