

# A Qualitative Exploration of Preferences towards Restraint before Loss of Capacity

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## Abstract

**Discussion:** Perspectives towards care in declining health consistently highlighted maintenance of choice and dignity. This study identified starting-points for better alignment between care planning initiatives and people's needs and preferences.

## Keywords

Access to Care, Falls, Qualitative, Restraint

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## 1. Introduction

Falls are one of the most frequent and serious problems facing older adults. Older adults with cognitive impairment are more likely to fall than their peers without cognitive impairment [1] [2]. Restraint is a well-known and controversial care practice sometimes used to prevent falls and to control behaviour, with the intent of minimising risk of harm [3]. However growing evidence indicates that restraint is not effective in the prevention falls or fall-related injuries in hospital or aged care facilities [4] [5]. Other directions are now being explored in this space, with person centred care approaches (PCC) which tend to minimize restraint use being increasingly recognized as best practice for the treatment of dementia [6] [7] [8] [9].

The use of restraint is controversial due to the restrictions on personal liberties related to freedom of movement, emerging evidence that use of restraint may directly cause harm, and the common absence of patient consent to receive this intervention. Many older adults with cognitive impairment are vulnerable and unable to advocate for their preferences [10]. In response, restraint-free care is emerging as an indicator of quality care with local and international guidelines

and polices outlining decision making processes to ensure restraint is used as a last resort [11]. Despite this, the prevalence of restraints remains high and particularly so in nursing homes [12] [13]. Establishing a true estimate is made difficult by methodological variances across studies however, a cross-national study by Feng *et al.* (2009) reported that between 6% and 31% of aged care facility residents had documented evidence of restraint use in their clinical assessment notes [14].

Different forms of restraint have been cited in the literature. Physical restraint may include the use of wrist and ankle shackles, vest restraints, or lap belts [15]. Chemical restraint involves use of sedative medications [16]. Both chemical and physical restraint use has been the focus of previous research and policy, though consistent approaches to use across jurisdictions are not yet apparent [17] [18] [19]. A less commented upon form of restraint is the use of covert restraint practices such as: tucking bed clothes in tightly, blocking movement with furniture, locking doors, and placing older adults in low chairs and beds that are difficult to get out of [18]. Potential harms include physical or psychological harm, loss of dignity, and death [20] [21] [22]. Negative consequences of restraint use include: 1) physical effects of a device in contact with the body (e.g. bruises, skin tears) and 2) physical effects of being immobilised in a prolonged sitting or lying position such as ulcers, respiratory complications, urinary incontinence and constipation, under-nutrition, increased dependence in activities of daily living, impaired muscle strength and balance; decreased cardiovascular endurance [23] the psychological effects of being trapped such as depression, fear, discomfort and anxiety [20]. Serious injuries and death have been known to occur when people try to remove themselves from restraint such as strangulation and falls resulting in fracture or head trauma [21]. Moreover, clinicians acknowledge that use of restraints is not favoured by patients and has a negative impact on maintaining a therapeutic alliance [24].

Growing research demonstrates that older adults in residential care setting value shared decision-making, choice and control regarding their physical and social environments [25]. Policies that foster resident autonomy, choice and control have been associated with physical and psychological health benefits [26] [27] and enhanced quality of life [28]. The current best model for shared decision making in aged care is possibly the Advanced Care Planning (ACP) initiative. This involves a process of formal decision-making aimed to help patients establish decisions about future care that take effect when they lose capacity, providing a range of options and services whilst still maintaining a duty of care [29]. However little work has examined how people feel about use of restraint for themselves (in future) or their family, what circumstances they feel may justify it, and other concerns they may have with its application.

This study aimed to explore attitudes towards restraint across a diverse set of stakeholders either directly involved or impacted by restraint practises now or in the future. The research question underpinning this study was: what are the community dwellers perceptions toward acceptability and feasibility of restraint

and participation in decision making about use of restraint, before cognitive decline?

## 2. Design and Methods

Qualitative social research investigates the relationships between individuals and the institutions and society in which they live [30]. We employed the use of semi-structured interviews and vignettes to address our research aim. Vignettes are frequently used in social research as a tool for framing complex or sensitive topics [31]. For pragmatic reasons we used purposive sampling to identify participants of varying ages with differing experiences of the health system in order to capture a diverse range of perspectives within the scope of study resources. We sought to recruit the first four responding participants into each of the following groups: 1) People (>65 years) who have been admitted to the hospital within the past year; 2) People (<55 years) who have had no exposure to the acute care system (personally or for their parent) in the past year; 3) People (<55 years) who have a parent who has received acute care within the past year; and 4) Health professionals. Potential participants within the aforementioned groups in Victoria, Australia were accessed via e-mail advertising by the researchers across their personal (e.g. facebook) and professional (e.g. professional list serve) networks. Responding participants identified the group they best fit with and provided written informed consent. Recruitment occurred between March and June 2018. Approval for this project was obtained from the Monash Health Human Research Ethics Committee.

### 2.1. Data Collection

Interviews, ranging from 30 to 60 minutes, were conducted by a single researcher (JW) in mutually convenient locations (e.g. café, participant's home). All interviews were conducted using an interview schedule (see **Table 1**), incorporating vignettes and open-ended questions [32]. However, there was participant freedom to express views and experiences in their own words and diverge from the interview guide and cover important topics that would not have otherwise surfaced [32]. To begin with, participants were shown pictures of and provided with a vignette of different restraint scenarios commonly used in health care including: physical restraint, use of a sitter, sedation, low lying beds, low chairs, furniture placement. Subsequent questions explored how participants felt about the potential for use of restraint, whether this was impacted by whether the individual involved had delirium or dementia; and perceptions towards being given the opportunity to be involved in planning for their future care before they might experience cognitive decline.

### 2.2. Data Analysis

Semi-structured interviews, ranging from 30 - 60 minutes, were recorded with the participant's permission and transcribed verbatim with identifying data re-

moved. Two authors (JW, TH), one an occupational therapist and the other a physiotherapist, independently coded data using an inductive thematic approach [33]. At the level of initial coding both authors read the transcripts multiple time and made notes. Transcripts were then coded line-by-line, describing and interpreting emerging categories and searching for differences and similarities. Following team discussion, the primary author developed a single codebook and each code was issued with a four letter label or code to facilitate data retrieval between the transcripts (for example, symptoms of confidence was labelled "CONF"). The next step involved examining the relationship between codes in the context of the research question in order to form themes. Consistency of findings was upheld through discussion of interpretations between researchers to confirm codes and categories. Any differences in researcher perspective were resolved by negotiation and, if necessary regrouped and recoded until consensus were reached. New codes were then fed back into the analysis to cross-check codes and themes and develop an overall interpretation of the data [34]. Trustworthiness of our data was achieved using several strategies, including immersion in data; reflexive analysis, and peer debriefing [35] [36]. These strategies ensured that the researchers remained open to the data and did not demonstrate bias during the data analysis as a result of preconceptions inherent in the researchers' clinical status and experience [35] [36]. Coders captured exemplar quotes supporting each theme.

**Table 1.** Interview guide.

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I would I would like to talk to you today about different approaches in health care. I want to understand whether you would be happy for these management approaches to be used depending on whether you are talking about yourself in the future, a family member in the present, and whether it matters if the person involved has a delirium which can improve in a short period of time, dementia which is unlikely to improve, or if they have no problems with how they are thinking but behaving in a way that is still putting themselves at risk of falling over and hurting them self e.g. not using walking stick when advised to.

This information will help us to provide more person orientated care.

Just to remind you: Dementia is a condition that interferes with how people think. It usually develops slowly and there is little prospect of improvement over time.

In contrast delirium occurs abruptly and can often be mistaken for dementia. Unlike dementia it can potentially resolve quickly once the cause is identified and treated. Delirium can often be caused by presence of an infection or an imbalance of the salts in your body.

I am going to show you a range of pictures of strategies often used to manage behaviours in acute care. Many have no evidence of effectiveness or are contrary to policy.

I will ask you how you feel about these items being used for:

- 1) Your parent (in best available cognitive condition)
  - 2) Your parent in presence of delirium (resolvable)
  - 3) Your parent in presence of dementia (permanent)
  - 4) Yourself (in future years in best available cognitive conditions)
  - 5) Yourself if you were to develop a delirium
  - 6) Yourself if you were to permanently have dementia
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### 3. Results

Participant demographics are outlined in **Table 2**. Participants in Group 1 were all male and their age ranged from 70 - 86 years. Reasons for hospital admission included hip replacement, blindness and frailty. There were 2 males and 2 females in Group 2 (health professionals), and age ranged from 27 to 47 years with representation from occupational therapy (OT), physiotherapy (PT) and General Practice. Half the participants in Group 3 (people < 55 years who have a parent who has received acute care within the past year) were male and age ranged from 42 - 59 years. Reasons for parent admission included: disease failure, gastroenterological problems, and Alzheimer's disease. The final group also had 2 males and 2 females (people < 55 years who have had no exposure to the acute care system personally or for their parent).

Four themes emerged regarding the experiences and perspectives of participants:

- 1) Enhancing dignity in institutional care
- 2) Trust and decision making about care needs
- 3) Rationalising care in the event of decline
- 4) The potential for choices to be over-ridden

**Table 2.** Participant demographics.

Participant Number	Group	Gender	Age (years)
1		Male	86
2	1) People > 65 years who have been admitted to the hospital within the past year	Male	79
3		Male	71
4		Male	70
5		Occupational Therapist, Female	32
6	2) Health professional	General Practitioner, Female	47
7		Physiotherapist, Female	42
8		Physiotherapist, Male	27
9		Female	59
10	3) Adults (<55 years) who have a parent who has received acute care within the past year	Female	42
11		Male	49
12		Male	49
13	4) Adults (<55 years) who have had no exposure to the acute care system (personally or for their parent) in the past year	Male	38
14		Female	56
15		Female	30
16		Male	46

### Enhancing dignity in institutional care

Participants in all groups expressed value in maintaining autonomy towards their preferred lifestyle and health care choices as they aged, whether in hospital and residential care. Specifically being able to maintain autonomy, whether alert or in the event of cognitive decline, was perceived to foster a sense of control and freedom. As a result, all participants expressed opposition to the use of restraint especially physical restraint and sedation, which were perceived to be the most invasive concerning limiting choice and self-expression.

*“I feel most strongly against physical restraint and sedation.” (Participant (P) 7, Group (G) 2, female, age 47).*

*“I would not like to be physically restrained or sedated. I just think it is very invasive and I would hope that there is some other measure that you could use before getting to that point.” (P9, G3, female, age 59).*

Another participant was adamant that less invasive practices, such as low-lying beds, equally violated a person’s dignity by creating a power imbalance that showed a disregard for the individual.

*“Everyone looking down on you [in a low lying bed] and you cannot see. I think people should be on equal level, you know, to talk to you.” (P10, G3, female, age 42).*

While all participants viewed all the restrictive nature of restraint practices as “disrespectful” (P9, G3, female, age 59), with the greatest ramification being the perceived impact pride and self-esteem. Instead, opportunities to maintain autonomy were valued as they promoted feelings of control over difficult circumstances.

*“It’s better to have some form of control than to have none at all .... When you have some control you have some sense of feeling of pride in your situation.” (P2, G1, male age 79)*

All participants, despite their age and experience with the health system, stated they were aware of the use of restraint practices and were reticent about their use. This was closely linked with fear of being made to feel helpless and inactive. In contrast, there was a preference for strategies that facilitated engagement in constructive activities, especially those that promoted function or provided a sense of distraction to any boredom or distress.

*“I feel like they could help me be doing something more useful. They [sitter] could help me doing physiotherapy activities, or just play cards.” (P11, G3, male, age 49)*

Health professionals expressed concern towards the use of restraint and cited policies that were in place to guide decision making to minimise use. In preference health professionals advocated for opportunities that prevented physical de-conditioning.

*“If you are restricting someone from mobilising on the basis of preventing falls, whilst you are potentially avoiding the harm of the fall, you are causing harm from deconditioning.” (P8, G2, male, age 27)*

In addition, health professionals discussed their experience with patient centred care practices, which they felt, should be used in the first instance when dealing with cognitive changes. These included creating a comfortable environment, reducing stimuli and making-surrounding familiar such as bringing in familiar items that the person might be comforted by recognise.

Some participants who had witnessed their loved one's journey of aging expressed concern about the use of a blanket approach towards restraint practices that restricted mobility. This was expressed in feelings of anger and disregard for the health system. For example one participant reported that their parent was immediately restricted after only one fall which was deemed premature and unreasonable since no further "chances" were given. Instead they witnessed an immediate negative impact on quality of life in their parent and feelings of dignity.

*"After the fall, they decided he [parent] was not allowed outside anymore [to walk to the local shop for a newspaper]—he was locked in after that. He went downhill after that." (P9, G3, female, age 59)*

Alternatively, other participants stated that the use of certain restraint measures could be a tool for ongoing education and communication. For example, the use of a sitter or alarm required a staff member to attend a patient, and this was seen as an opportunity for ongoing communication and reassurance.

*"I see an alarm as a warning system .... So if you are not meant to be getting up, chances are someone will come if the alarm goes off and then you could talk to someone about it." (P11, G3, male, age 49)*

Participants with experience with the health system reported that staff who took extra time to communicate, even when cognition was compromised, promoted dignity. The importance of communication and education towards implementing any intervention (therapy or a restraint practice) was most commonly reported by health professionals (Group 2), being a valued component of their own clinical practice. As a result, health professional participants expected that the system would engage them, or their family, in education and supported decision making even if restraint was considered necessary.

*"Communication about why we are recommending this and this and why." (P7, G2, female, age 42)*

#### **Trust and decision making about care needs**

While all participants expressed a desire to be able to place their trust in treating staff to provide the best level of care, many expressed feelings of mistrust. Participants who expressed the most concern about the use of restraint cited examples whereby they had witnessed the poor treatment of their loved ones and observed the experience of vulnerability and humiliation.

*"She [parent] was humiliated by it [alarm] ... she was scared to get up and go to the toilet because certainly her alarm would go off. She was so scared she would be told off—because someone had reprimanded her in the past." (P10, G3, female, age 42)*

Despite this, participants reported they would ultimately place their trust in

professional advice as this was deemed to be in their best interest and to maximise safety.

*“I would be relying on professional experience and their recommendations—even if they have not explained the reasons to me. I would still follow their instructions because I would not want to jeopardise my treatment in any way.” (P9, G3, female, age 59)*

Expressions of trust were commonly reported by health care professionals who indicated that their professional experience had given them understanding of factors underpinning clinical reasoning towards care, including restraint practices. This was not to say they supported the use of restraint, rather they trusted the decision making process that health professionals used when choosing to apply it.

*“I think because of my background ... so I know the reasoning behind it. Then you have just been able to accept that people are there to help you and they have advised me this for a reason.” (P7, G2, female, age 42)*

In contrast, participants across all groups stated they were unlikely to comply with professional advice and restraint that they felt they could get around, concerning toileting. This was primarily the case if participants felt they had to wait too long for toileting assistance especially after witnessing the distress in loved ones waiting for assistance in the hospital or aged cares setting. Specifically participants relayed “you hear things” (P14, G4, female, age 56) or had personally observed or experienced the lack of staff responsiveness to toileting.

*“There was not enough staff on at times and if the nurse was called away to something else, there was just no one around [to take you to the toilet].” (P4, G1, male, age 70)*

Indeed, those participants with recent health care experience indicated they felt confident they could gauge their own abilities to go to the toilet, so as not to soil themselves.

*“If I was, you know, sitting in bed and called for assistance to go to the bathroom or something like that and it had been five minutes and no staff had arrived, I would consider whether or not I wanted the risk versus benefit of me getting up and going to the toilet versus the risk of falling. So yeah I guess I would potentially go against the advice, yeah, but I would do that knowing that I had a risk of falling.” (P8, G2, male, age 27)*

*“I found that I was able to move quite confidently without any swaying into the toilet area itself. In actual fact, I probably should not have done it.” (P4, G1, male, age 70)*

### **Rationalising care in the event of decline**

All participants were reflective when considering scenarios where restraint might be considered necessary, such as if they were behaviour meant they be of harm to themselves and others.

*“I do not want to be tied down and yet my brain is saying on the other side there might be a good reason to tie you down.” (P4, male, age 70)*

*“You may have been restrained not only for your safety but for the safety of*

*others.” (P1, G2, male, age 86)*

In addition, participants were also more open to consider restraint practices in the short term when they were perceived as likely to recover, such as the experience of delirium.

*“I guess the short-term aspect of delirium means you can put up with some for a while—but if you have to face that for years on end, that is different.” (P14, G4, female, age 56)*

Other participants, with more familiarity with the health system, were open to consider the use of less invasive restraint measures that they had previously experienced or observed, such as bed rails.

*“I’ve seen that [bed rails] ... Particularly with short-term delirium that is going to get better. So I do not think it there use is completely unreasonable.” (P11, G3, male, age 49)*

A few participants who had observed the care of a parent identified scenarios where the use of sedation had been beneficial in reducing distress, especially in the event of delirium and pain, “to keep them calm.” (P14, G4, female, age 56).

Older participants and those with experience caring for an aging parent acknowledged, “There’s a balance we are trying to strike here,” (P11, G3, male, age 49) towards managing deterioration in health. In response, participants expressed a desire for opportunities for communication and participation in decision-making. When reflecting on future scenarios where they might experience their own progressive cognitive decline, all participants were open to processes that enabled them to have input into their future care. Participants identified a “staged planning” approach which involved a spectrum of lesser to greater use of restraint practices as their function deteriorated and their needs increased.

*“I think I would see it as a staged approach so I do not feel like I am completely losing control .... I think planning ahead is a nice way to kind of.” (P13, G4, male, age 38)*

However many participants felt planning for their future care would be a complex process. Even during the interview, participants found thinking about the future to be a difficult concept to comprehend and “even think about.” (P1, G1, male, age 86)

*“I think a lot of people have trouble writing up care plans for life or death stuff as it is .... I feel like most people’s automatic reaction is to defer that decision or to not do it.” (P8, G2, male, age 27)*

Health professionals in particular expressed that participation in future planning was a difficult concept and would require a significant amount of time and resources in order to provide adequate explanation and education to assist with decision-making. Participants reflected on the difficulties in describing the clinical reasoning towards complex care and even the use of restraint.

*“I think it is a good idea, but would need an awful lot of information about what the options are and exceptions.” (P5, G2, female age 32)*

One participant’s experience implementing advanced care planning identified that, “Some people are fine with that [talking about the future] and then others

*seem to not want to think about ... barely want to talk about it". (P6, G2, female, age 47)*

Other factors that were considered essential by participants when planning for their future care and the potential use of restraint included safety, futility and health system resources. All participants perceived that it was not acceptable for the health system to have to deal with violent patients who affected the safety of those around them.

*"If I am going to become a serious risk to myself or to people ... that's not acceptable either. It is how you strike the balance. (P2, G1, male age 79)*

Alternatively, some participants felt strategies were futile if "I could get around it [restraints]." (P10, G3, female, age 42) or if their opinions were not perceived to matter in due to course—due to poor memory or disorientation.

*"I won't be aware of what is going on ... your state of mind wouldn't comprehend what's going on." (P1, G1, male, age 86)*

### **The potential for choices to be over-ridden**

Participants from all groups perceived that their expressed wishes could readily be ignored or over-ridden if circumstances demanded, particularly if they were acting aggressively to others.

*"They could [over-ride it] if I became demented and aggressive .... that's when I think they would [over-ride it]. I couldn't blame them for overriding in that situation." (P4, male, G1, age 70)*

*"In terms of actual practicalities, I think it is nice to have them [patient preference] ... but I would want you to protect me. So I suppose you may need to ignore it." (P13, G4, male, age 38)*

Health professionals all identified scenarios whereby they had observed patient preferences had been "thrown out the door" (P6, G2, female, age 47) in order to preserve life and ensure patient safety. The ultimate decision was perceived to rest with treating doctors.

*"There is no way a health service is going to follow that, so it is not worth the paper that it is written. The medical practitioners will override and they can." (P9, G3, female, age 59).*

In fact, some participants viewed collaborative planning suspiciously as being an opportunity for the system to manipulate decisions to minimise resource use or hasten death, especially if patients were considered difficult to manage and resource intensive.

*"I think that people are being killed by doctors and nurses in the health system and that there are a whole lot of cost factors. With my mother, she had been on 15 years of dialysis, and she had nurses saying to her 'There are younger people who need these machines, we do not have enough machines.' .... I felt that they were really encouraging her to stop treatment .... she was be dead in a couple of weeks and I felt she had been coerced by health professionals." (P9, G3, female, age 59)*

When reflecting on their future care many participants raised feelings of concern toward the possibility of experiencing abuse and mistreatment. Specifically

participants' expressed fear towards the risk of abuse was when residing in residential facilities where they were dependent on other people for their basic care.

*"I think it is a very vulnerable state to be in [to be institutionalised]—how do you prevent [abuse] from happening?" (P13, G4, male, age 38)*

Participants noted wide variability in the quality of care settings and staff according to scenarios they that had seen, read or heard about.

*"They are not all 100 % good. It is just a job to them." (P15, G4, female, age 30)*

Further, participants felt that abuse, especially sedation, could be linked to staff convenience and cost cutting measures.

*"Were they more interested in just having a job and getting paid? Or was it a financial thing—to strap people in bed and keep them out of the way as much as possible to keep the staff [numbers] down? I do not know. But some of those things smack of ... let us do it easy. Let's sedate them. Let's keep them well-restrained so we don't have a problem." (P2, G1, male, age 79)*

Subsequently many participants perceived that having assets, superannuation or private health insurance meant they had greater choice and could pay for quality of care and "the assurance" (P15, G4, female, age 30). Paying for quality was closely linked with a personalised care approach that involved consultation concerning the best for the individual and restraint only when necessary.

*"Yes, with professional advice, knowing my impairment, I would like to be able to choose a pathway which gave me as much freedom as is reasonable according to my condition." (P2, G1, male, age 79)*

#### 4. Discussion

This study generates understanding towards how people would like to have aged care services delivered and provides insights into future care decision making. We identified that participants were aware of the use of restraints in hospital and aged care settings and were concerned about being on the receiving end of these. Participant comments indicated they were most averse to the use of physical restraint and sedation and preferred less invasive restraint measures, if required at all. Scenarios where restraint might be considered necessary included avoidance of harm to self or others due to change behaviours, such as aggression resulting from delirium or dementia, or if the use of restraint was likely to only be in the short term. Given the paucity of research exploring how people perceive their long term care options, this study sheds light on important factors for consideration.

Consistent with a growing evidence base towards the delivery of care in aged care settings, participants in this study desired autonomy [37], opportunities for engagement and to be treated with respect [38]. While all participants desired to trust health care professionals to make decisions for them, participants also expressed concerns about the quality of residential care based on stories of elder abuse and felt staff had ulterior motives towards the use of restraint (such as convenience for staff). This is in line with results from a recent systematic qua-

litative review of care home life which identified that residents who didn't feel their needs were being provided for felt unsafe, vulnerable and helpless [38]. Additional evidence highlights that non-patient factors such as staff skill, attitude and job characteristics influence the decision to use restraint [22] [39]. In contrast, implementation of PCC supports individual choice and autonomy in healthcare decisions to the extent that the individual desires. A recent systematic review and meta-analysis of the effectiveness of PCC in clinical practice for people with dementia identified that PCC interventions reduced agitation, neuropsychiatric symptoms, and depression and improved quality of life [40]. Further, evidence indicates that staff themselves benefit from using PCC approaches, with reduced stress, reduced burnout, and increased job satisfaction being reported [41].

All participants in this study were interested in processes that allowed them to participate in planning for their future care however, this was only perceived as being beneficial if their wishes were heard and adhered to. Participants perceived challenges to decision making and being able to make calculations about their future or fully comprehend the meaning of different options, especially as preferences had the potential to vary depending on changing health conditions. They also preferred a staged care approach, where decisions about care preferences could be revisited as their condition changes. Previous research indicates that people may shift preferences for care depending on the course of illness and recovery [42] or types of medical needs [43]. Indeed, learnings from ACP can be applied to dementia care, such that people can be supported to make decisions and express their values and preferences before they decline. This aligns with results from a recent study by Piers *et al.* [44] who undertook development of evidence based clinical recommendations toward the application of ACP in dementia care. These newly established guidelines advocate for the need to start ACP as early as possible and to integrate ACP into the daily care of people living with dementia, ideally before cognitive decline [44]. Key triggers for these discussions have been identified as changes in health status, place of residence or financial situation [45] in people with dementia. However, alongside ACP, we posit that similar discussions about how people with a diagnosis of dementia would like to be cared for (including use of restraint) in the future. Central to this process is commencing conversation about future care early and gaining an understanding of a patient's values and attitudes towards their care as their capacity diminishes. This process also allays patients and their carers having to make decisions at a time of crisis without any preparation.

There is much to learn about collaborative decision making in this context and currently only a minority of people with dementia get the opportunity to engage in ACP [46]. As a result, we suggest that more research is needed to explore patient perspectives. This is confirmed by results from a scoping review which identified only a small number of studies and methodological problems which made it difficult to draw conclusions about people with dementia pers-

pectives on and engagement with ACP [47].

#### 4.1. Strengths and Limitations

While this approach provided the opportunity to obtain diverse perspectives on what current and future aged care service recipients consider important when planning their ongoing care, the use of purposive sample may have resulted in an invested sample. Likewise, the sample was small and selected from a single urban location. It is difficult to contemplate future selves in vignettes that explore the future and participant reports may differ from actual long-term decisions. While participants highlighted both positive and negative views, the scope of the study did not allow for further exploration of these factors. This is the first time a study of this nature had been conducted.

#### 4.2. Conclusion

Older adults are one of the most vulnerable groups in our community. Our findings suggest a new way of perceiving the role of patients and their ability to engage in collaborative decision making. Actionable ways to promote collaborative decision making include educating providers and patients about their benefits. Our results indicate that people are willing to talk about the issue of restraint and how and in what circumstances it may be applied, but that these conversations will need to be supported with adequate education to ensure people understand the concepts being discussed.

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#### Conflicts of Interest

The authors declare that they have no competing interests.

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