“Professionals’ views and experiences in supporting decision-making involvement for people living with dementia”

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Abstract

Background: The provision of supported decision-making for people living with disabilities is an emerging area of practice and rights-based law reform, and is required under international law.

Objectives: This qualitative study aimed to understand how Australian health and legal professionals conceptualised their professional roles in the practice of providing decision-making support for people living with dementia.

Methods: The methods were informed by grounded theory principles. In-depth, semi-structured interviews were conducted with 29 health and legal professionals involved in providing care or services for people with dementia. Interviews explored how professionals described their practice of providing support for decision-making, and how they conceptualised their roles. The analysis was underpinned by the theoretical perspective of symbolic interactionism.

Results: Participants described providing support across a range of decision domains, some of which were specific to their professional role. Four key themes were identified: 'establishing a basis for decision-making', 'the supportive toolbox', 'managing professional boundaries' and 'individualist advocacy versus relational practice'. Participants identified a range of generic and specialised techniques they used to provide support for people with dementia. These techniques were applied subject to resource limitations and perceived professional obligations and boundaries. A continuum of professional practice, ranging from 'individualist advocacy' to 'relational practice' describes the approaches adopted by different professionals.

Discussion: Professionals conceptualised their role in providing support for decision-making through the lens of their own profession. Differences in positioning on the continuum of 'individualist advocacy' through to 'relational practice' had practical implications for capacity assessment, engaging with persons with impaired decision-making capacity, and the inclusion of supporters and family members in decision-making processes. Further progress in implementing supported decision-making (including through law and policy reform) will require an understanding of these inter-professional differences in perceived roles relating to the practice of providing decision-making support.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) asserts the equal enjoyment of fundamental human rights by people living with disabilities, including the right to legal capacity “on an equal basis with others in all aspects of life” (United Nations, 2006). Under international law, the CRPD requires signatory nations to replace ‘substitute decision-making regimes’ with legal frameworks ensuring access to support for people with disabilities in their exercise of legal capacity (Arstein-Kerslake & Flynn, 2015). While the CRPD definition of ‘disability’ clearly includes people living with dementia (Smith & Sullivan, 2012), rights-based approaches have been less prominent in dementia care than in the broader disability sector (Shakespeare, Zeilig, & Mittler, 2017).

Supported decision-making

Supported decision-making has been defined as “the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters” (United Nations Office of the High Commissioner on Human Rights, 2009, p15). This approach recognises that people with cognitive disabilities may require active assistance in order to make decisions and exercise their legal capacity. Supported decision-making encompasses both the formal frameworks (e.g. laws and policies) aimed at promoting persons’ rights to legal capacity, and the practical actions taken by others to provide ‘support for decision-making’ (Browning, Bigby, & Douglas, 2014). In Australia, the legal and policy frameworks underpinning formal supported decision-making arrangements have progressed variably across different jurisdictions (Then, Carney, Bigby, & Douglas, 2018), although none represent the full implementation of supported decision-making, which is thought to be a requisite for CRPD compliance (Bigby, Douglas, et al., 2017). For example, recent legislation in Victoria provides for formalised support arrangements for financial (supportive attorney) and healthcare (medical support person) decisions (Office of the Public Advocate (Victoria), 2018), however, the requirement for the appointor to have full, legal capacity effectively denies access to those with significant, pre-existing impairments (Bigby, Douglas, et al., 2017). Other Australian jurisdictions do not have access to such schemes, and rely on principles of ‘last resort’ in Guardianship legislation¹. Despite these differences in legal

¹ In Australia, guardianship refers to the legal process by which a Guardian may be appointed to make decisions for another person about healthcare, medical treatments and other lifestyle matters. Specific statutory provisions are in place in all Australian jurisdictions, supporting the protective jurisdiction of the Courts, and the quasi-legal authority of Administrative Tribunals. Guardianship appointments typically require a determination that the person is unable to make the relevant decisions for themselves, and that they are in need of a guardian.

frameworks, the provision of informal ‘support for decision-making’ is arguably already common practice (Fetherstonhaugh, Tarzia, Bauer, Nay, & Beattie, 2016; Tarzia, Fetherstonhaugh, Bauer, Beattie, & Nay, 2015). While there is some guidance for staff in the disability sector on providing support for decision-making (Bigby & Douglas, 2015), there is currently a lack of resources guiding this practice in the context of dementia care.

Recent research has investigated how care staff in residential aged care facilities support decision-making in people with dementia, through knowing the person well, simplifying options, negotiating compromises in decision-making, and interpreting non-verbal interactions (Cameron, Fetherstonhaugh, Bauer, & Tarzia, 2018; Fetherstonhaugh et al., 2016). However these studies also acknowledge both variability in staff competence, and the potential for these techniques to exclude the person from involvement in decision-making (e.g. through simplifying options in ways that limit meaningful choices, or basing assumptions about a person’s preferences on generalised interpretations of their prior wishes or non-verbal communication). Other research has demonstrated how care staff are forced to ‘work within an organisational system’, which is characterised by a hierarchical, risk-averse organisational climate, inflexible schedules, and a lack of time to provide support for decision-making (Sinclair, Field, Blake, & Radoslovich, (in press); Tarzia et al., 2015). Facilitating decision-making involvement among people living with dementia across the course of the illness trajectory can thus be seen as a complex area of practice, drawing on a range of advanced skill sets, as well as a nuanced understanding of the person.

The role of professionals

Professionals are holders of specialised knowledge, whose practice is socialised through their training and subsequent self-regulation (Noordegraaf & Schinkel, 2011). Compared with other ‘non-professional’ occupations, professionals are afforded additional responsibilities and role autonomy in applying their knowledge within health, social care and legal systems. Professionals provide information to enable decision-making (Groen-van de Ven et al., 2018;

Guardians can be ‘private’ (e.g. a family member or other person), or this role can be undertaken by a government agency (e.g. Public Guardian or Public Advocate), in situations of last resort (e.g. when a person has no appropriate relationships or where intractable family conflict makes a private guardian appointment infeasible). Similar mechanisms allow for appointments of financial administrators (e.g. a private financial administrator or ‘Public Trustee’). Notably, across all jurisdictions, people with full legal capacity are able to use enduring legal instruments to nominate substitute decision-makers for health and lifestyle matters (typically termed ‘Enduring Power of Guardianship’) or financial matters (typically termed ‘Enduring Power of Attorney’). For more information see (O’Neill & Peisah, 2017; Then, 2013).

Ries, 2016), are often 'gatekeepers' to higher level care services (Couture, Ducharme, & Lamontagne, 2012), and are also often involved in, or responsible for, assessments of decision-making capacity (Purser, Magner, & Madison, 2009).

People with dementia face decisions across a range of domains, including healthcare, lifestyle, financial, legal and everyday decisions (Samsi & Manthorpe, 2013; Sinclair et al., 2018). These diverse decisional contexts draw on a range of professional disciplines and skill sets. While a proactive, collaborative and inter-disciplinary approach has been identified as necessary to address key challenges in supporting the decision-making of older adults (Purser, Magner, & Madison, 2015; Ries, 2016; Waller, Sanson-Fisher, Ries, & Bryant, 2018), a range of barriers have also been identified. Limited awareness by professionals of the roles and specialist skill sets of other professional groups can contribute to delayed or missed referrals (Zuscak, Peisah, & Ferguson, 2016). Inter-professional differences in characterising the legal concept of 'competence' and the clinical concept of 'decision-making capacity' (Purser et al., 2009) can lead to misunderstanding and disagreement between professionals. Inter-professional collaboration may be further complicated by 'boundary work' aimed at defining and maintaining inter- and intra-professional boundaries (Powell & Davies, 2012). This is particularly relevant in the context of supported decision-making, which disrupts traditional expectations about decision-making in people with dementia and has implications for the re-negotiation of professional roles and boundaries (Smith & Sullivan, 2012). These differences and complications raise questions about how professionals involved in dementia care understand and implement their roles in providing support for decision-making.

This study aimed to understand how Australian health and legal professionals conceptualised their professional roles in the practice of providing support for decision-making among people living with dementia. Of particular interest were the views, perceived roles and accepted practices associated with specific professional groups, and the implications for future interventions aimed at embedding supported decision-making in dementia care.

Methods

Design

The project employed a qualitative research design with methods informed by grounded theory principles, including theoretical sampling and constant comparison (Corbin & Strauss, 1990). In-depth, semi-structured interviews aimed to generate insights into how health and legal professionals described their practice of providing support for decision-making in people with dementia, and their conceptualisation of their roles in this context. Symbolic interactionism was taken as a theoretical framework for understanding how professional roles were socialised and maintained, and how this influenced practice. Symbolic interactionism proposes that agents attend to the symbolic meanings associated with their actions, and that these meanings are learned through social interactions with others and self-reflection from the imagined perspectives of others (Aldiabat & Le Navenec, 2011). The 'I-Me' process of action and self-reflection with respect to symbolic meanings identified through interactions with the 'generalised other' (e.g. professional groups) and the related process of 'role-taking' are central to this approach. Applying this framework, the professional practice of supporting a person's decision-making can be seen as a negotiated process, which is sensitive to symbolic meanings ascribed to actions and perceived obligations to others, and which is refined through ongoing social interactions with clients and other professionals.

Sampling and recruitment

Participants were health and legal professionals who worked with people living with dementia as part of their role, and who had relevant experiences in facilitating decision-making involving people with dementia. Initial sampling aimed to ensure variation in professional roles, work settings, gender and experiences working with people with dementia (Coyne, 1997). Groups targeted included those from nursing, medical, allied health, and legal disciplines. Participants were recruited via email invitations, flyers posted at workplaces and verbally at conference presentations. Participants received written information about the study, had opportunities to ask questions of the interviewer and signed a consent form prior to participating. Following the interview, participants were reimbursed for their time with a generic shopping voucher worth \$50AUD. Recruitment continued until a point of saturation was reached across each of the professional groups, with further interviews identifying no new themes.

Data collection and management

Data collection was undertaken by a researcher with experience in clinical practice, aged care and qualitative interviewing (JBS). Interviews were preceded by a paper-based survey to collect information about each participant's background and professional qualifications. The semi-structured interviews were undertaken by telephone and followed a discussion guide covering professional experiences with decision-making, capacity assessment and providing support for decision-making (see Appendix 1). Further discussion prompts, relating to participant views on legislation for supported decision-making, are not reported here. Participants were encouraged to describe cases, and their experiences were contextualised within their professional roles and local work setting. Average interview duration was 39 minutes (SD = 7.1 mins). Interviews were audio recorded and transcribed verbatim by a third-party company whose staff were bound by confidentiality. Transcripts and research memos were managed using NVivo Version 11.

Analysis

Data analysis was undertaken concurrently with sampling and data collection. During initial stages of analysis, two randomly selected interviews were independently coded by two members of the research team (JBS, CS). Preliminary findings were also shared with three advisory groups associated with the project (consisting of people with dementia, family members of people with dementia, advocacy organisations, aged care service provider representatives, and other academic experts), with feedback informing the ongoing sampling methods and interview focus. Initial open coding was undertaken line-by-line, to identify individual units of meaning which formed the basis for a preliminary framework. Higher level themes were refined through ongoing coding and discussions with the research team (Corbin & Strauss, 1990).

The study procedures were approved by the University of Western Australia Human Research Ethics Committee (RA/4/1/8799), with relevant institutional governance approvals obtained as required.

Results

Twenty-eight health and legal professionals (22 female, 6 male) from six Australian jurisdictions accepted invitations to participate. Participants were employed across a range of settings including hospitals, aged care organisations, private practice, university and non-government organisations (see Table 1). Four key themes were identified; 'establishing a basis for decision-making', 'the supportive toolbox', 'managing professional boundaries' and 'individualist advocacy versus relational practice'. Each of these themes contained a number of sub-themes (see Table 2).

Participants described a diverse set of decision-making scenarios, both 'substantive' and 'everyday'. 'Substantive' decisions were encountered in a range of domains, including lifestyle (e.g. living arrangements, relationships, pets), healthcare (e.g. treatments, care planning and advance care planning), financial (e.g. investments, gifts) and post-death planning decisions (e.g. will-making and funeral planning). Different professional groups were typically engaged for certain types of these decisions (e.g. medical staff for treatment decisions, lawyers for will-making) consistent with their professional skill sets. 'Everyday' decisions occurred in the context of personal care or activities of daily living. While these decisions were typically navigated without the need (or opportunity) for significant professional involvement, participants who were involved in direct care provision (e.g. nursing, some allied health) identified these as being important aspects of care, and opportunities for meaningful therapeutic interactions.

Establishing a basis for decision-making

Professionals described a number of preliminary processes which helped them to clarify their obligations regarding their role and 'positioning' with respect to the person and the decision. This often led to a determination as to whether the person could make an independent decision, required support, or in some cases required decisions to be made on their behalf, by a substitute decision-maker. A number of professionals acknowledged the impact of their busy schedules on decision-making processes, and the potential for organisational priorities (e.g. availability of hospital beds) to frame decision-making, rather than the person's priorities. However, *understanding the person's priorities* was seen as a critical first step in ensuring that decision-making was centred around the person's wishes, as far as possible:

"I think part of people being a healthcare clinician is to focus on big milestone healthcare decisions, which are decisions 'that are important'... because they're the

most important things to us ... but actually the more important decisions are the decisions that are really important to [the person]. The first step to that process is finding out what is important to them and then fitting everything else that we do around that.” (Interview 16, Medical, Palliative medicine consultant)

Professionals drew on their own skill sets, and referred to other professionals, in *assessing decision-making capacity*. High quality assessments included consideration of any functional or cognitive impairments, as well as contextual factors that might influence the person’s decision-making processes (e.g. familiar environments, typical best times of day, and the presence of particular trusted people). Assessment also considered the person’s preferences for involvement in decision-making. For those with extensive skills and experience in assessing decision-making ability, such information was typically gleaned from informal discussions. These provided opportunities for professionals to establish, or build upon, their relationship with the person. In cases where the professional lacked the skills to undertake functional or clinical assessments, they referred to other professionals:

“... she had some confusion over that and that immediately rang alarm bells for me... The next step for me is that I cannot take any further instructions from this lady unless I get a capacity report to say that she’s capable of understanding the nature of what it is that she’s instructing me and will be able to undertake the advice, or options offered to her.” (Interview 21, Legal, Solicitor)

Some professionals acknowledged that referrals for formal cognitive or functional assessments could be perceived as threatening by the person with dementia. Professionals described approaching formal assessments carefully, aiming to reduce threat and protect existing professional relationships.

Knowing the person well was seen as a significant factor in establishing the basis for decision-making. Discovering information about the person’s history from prior to the professional relationship, or onset of dementia, assisted in establishing trust and understanding the person’s priorities and wishes. ‘Finding out about the person’ was seen as an ongoing process, which fostered understanding of effective strategies for supporting involvement in decision-making. Finding out about the person required professionals to be observant, and was facilitated by longer-term relationships and ability to see the person over time and in a range of settings (e.g. office or clinic and home or residential care settings). Knowing the person well also enabled professionals to assess the consistency of the person’s

preferences, and their ability to retain and use information over time in decision-making.

Knowing the person's support networks and key relationships (e.g. family members, friends, neighbours) was also regarded as influential in accurately interpreting the person's needs and wishes, their decision-making abilities, and identifying potential supporters:

“When I engage with a client and assessing them as I go about what I think their capacity is to make a decision, and then if there's a decision to be made I try really hard all the time to involve a family member, if I can, because they obviously know them better and what would be more appropriate for them...” (Interview 3, Nursing, Registered nurse)

Additionally, understanding the person's support networks and relationships assisted in identifying potential issues related to decision-making. Mistrust or unresolved grief among family members was sometimes identified as a source of conflict in decision-making. Professionals spoke of common scenarios in which family members or supporters made well-intentioned efforts to help or provide care, but unwittingly 'took over' or excluded the person from decision-making. Less commonly, professionals also described scenarios in which they suspected manipulation or undue influence from the person's support network. Health professionals identified the need to manage these situations carefully, in order that potential supporters were not alienated from the person, while endeavouring to privilege the person's wishes in the decision-making process. Legal professionals appeared to take a different approach, removing other family members from the decision-making process.

The 'supportive toolbox'

'The supportive toolbox' refers to the skills, strategies, techniques and resources engaged by professionals, aimed at assisting and enabling a person with dementia to be meaningfully involved in decision-making. Comparative analysis of the interviews indicated that a range of *generic techniques* were acknowledged by the majority of participants across all professional groups. These included allowing sufficient time, speaking clearly and directly, explaining the different options available, pausing to allow the person to process information, and repeating information if needed. Resources such as fact sheets and decision aides relevant to specific decisions were seen as valuable.

In addition, some professionals (typically allied health) referred to more *specialised techniques*, many of which were particularly relevant for people with communication

impairments. There were a range of 'Augmentative and Alternative Communication' (AAC) techniques described, including combining multiple sensory modalities (e.g. aural and visual), using structured approaches to communication and optimising the level of complexity in communication and decision-making:

"So we generally go through a scaffold in helping them answer ... obviously starting with open ended questions and working all the way down to a binary choice."

(Interview 7, Allied health, Speech pathologist)

"... I err on the approach of [using] as many communicative domains as possible. So I write it down, I have a picture, I say it, I gesture it, I reiterate it in every possible way." (Interview 7, Allied health, Speech pathologist)

Other individually-tailored approaches included incorporating meaningful photos or pictures of familiar objects or activities, to trigger memories and prompt communication. In some cases these were collated into individualised communication books, to assist the person in communicating with family members or other care workers. Assistive technologies (e.g. tablet devices and 'apps') were used particularly for people who experienced difficulties in expressive communication. For those who worked in team environments, the ability to coordinate these techniques and provide consistent and clear messages was important:

"I think using quite simplified language is probably very important for some of these clients and having the same message delivered from everybody involved in the team."

(Interview 22, Allied health, Speech pathologist)

Along with communication techniques, professionals identified the need to *simplify options*, while keeping choices meaningful to the person. This was particularly important for people likely to experience confusion or be overwhelmed by complex options. Some participants acknowledged how their own values or opinions might negatively influence this process, by limiting available choices, foreclosing options or influencing a person's choice:

"So it is part of your training that you should always remain objective and empower people to make decisions, but it's the art of being a health care professional and not allowing your personal views to come in or make a judgment based on someone's impairment. (Interview 12, Nursing, Registered nurse)

Some professionals described *being attentive to non-verbal cues*, including gestures, facial expressions, sounds and other observable manifestations of a person's preferences or wellbeing. While this information was used extensively by staff for everyday decisions

relating to activities or meals, occasionally these cues also informed more substantive decisions (particularly among nursing and allied health professionals). One community nurse described how a home visit alerted staff to the actions of a dominating care-partner, who had arranged a 'live-in' situation with the person with dementia:

"... I could tell by her facial expressions, her body language, the sounds that she made, the eye contact, the grimacing, all that sort of stuff, when he would come near her... I asked her if she wanted to be moved to care and she squeezed my hand and looked into my eyes and was giving me permission, more or less. So then we got Guardianship involved, because she no longer had family that were involved in her care. It was actually a really good outcome, and she was then really relaxed. All that body tension had gone and she was completely relaxed. She started to come back to herself a bit." (Interview 6, Nursing, Registered nurse)

Professionals who described using such non-verbal cues typically supported their interpretations through documentation, consultation with other colleagues and (for substantive decisions) through reference to independent sources of authority (e.g. Tribunals or Guardianship agencies).

While the 'supportive toolbox' was drawn on opportunistically and as required, its effectiveness was dependent on the cooperation of other professionals and family members, and was also subject to *resource constraints*:

"Time, that's the biggest thing. I was able to get in depth with that discussion with that particular patient. Had I had five other admissions on at the same time and someone who was particularly unwell, it would have been just a very quick "what would you prefer?" (Interview 11, Medical, Hospital medical practitioner)

Managing professional boundaries

Professionals described a range of expectations and obligations that they perceived as relevant to their role, and the impact of these on their ability to provide support for a person's decision-making. Professionals acknowledged obligations to their employer, regulatory bodies, and their specific profession, *acknowledging their scope of practice*, and referring to others when required. For example, determinations of decision-making capacity, advice on the risks and benefits of medical treatment options, or the preparation of legal documents often needed input from multiple professional disciplines. Professionals identified that

providing support for decision-making required them to understand the available services and scope of practice of other professionals, often with the aim of facilitating service navigation:

“...so with his permission I made an appointment at the Public Trustee. I went with him actually, but I wasn't involved in the process, I just took him to the appointment. So they were able to speak with him and understand his wishes and draw up the necessary document and I took him back then to have the document signed.”

(Interview 3, Nursing, Registered nurse)

For decisions requiring input from multiple professional disciplines, participants identified the importance of inter-professional collaboration, in order to provide optimal support for the person in their decision-making. For some this meant orchestrating teams of busy professionals to enable discussions. One nurse described a team approach to facilitating the decision-making of a person who was considering early exit from a rehabilitation program, to return home. The participant reflected on the importance of each team member recognising the person's ability to make an informed decision, despite their own reservations about the wisdom of the decision. By coordinating their approach to providing information, with each team member commenting in their own area of specialisation, the team facilitated the person's weighing of the issues, negotiating an arrangement in which she returned home, but visited the rehabilitation centre for daytime sessions:

“We all kept [to] our specialties and spoke about those and then opened up the discussion to her to have with the team.” (Interview 12, Nursing, Registered nurse)

Inter-professional teamwork was also identified in cases where professionals integrated the specific skill sets of legal and health professionals in providing services. At one community legal centre, a 'health-justice partnership' enabled the solicitor to involve a clinical team member when there were concerns about the person's decision-making capacity:

“We have an advocate who is a trained nurse. [If the client gives permission] she is permitted to enter every interview between client and lawyer. And it is for the nurse to actually red flag any possible issues with capacity.” (Interview 21, Legal, Solicitor)

In other cases, participants described how time limitations, the absence of relevant referral pathways or difficulties in coordinating team members made a team-based approach unwieldy or impossible.

In addition to navigating inter-professional boundaries in care and service provision, professionals perceived a need to *maintain professional distance* between themselves and the

person with dementia, as well as their family members and other support networks. In providing support for decision-making, professionals described the importance of providing information and assistance while ensuring that they were not influencing the decision:

“...it’s scary to think that you could accidentally influence someone’s decision or accidentally plant an idea in their head or do something that’s detrimental to their case.” (Interview 7, Allied health, Speech pathologist)

The practice of providing information and support, while maintaining distance from the actual decision-making was considered particularly important for ‘risky’ decisions. Perceived risk was dependent on the situation, and was perceived for a range of decisions, but was particularly prominent in decisions about hospital discharge (particularly to a ‘home alone’ situation), finances and will-making, and certain lifestyle activities (e.g. dietary choices in the context of swallowing difficulties). Professionals acknowledged the prospect of being held accountable for a decision that resulted in a negative outcome for a person, particularly if they were seen to have ‘crossed a boundary’, for example by going outside their own scope of practice, neglecting to maintain professional distance, or putting undue pressure on a person to decide in a certain way.

Individualist-Advocacy versus Relational Practice

Following from this description of how professionals provide support for decision-making in people living with dementia, we conceptualise a continuum of professional practice, to describe how different professionals understood their role and positioned themselves with respect to the person. At one end of the continuum, the term ‘individualist advocacy’ refers to an emphasis on advocating for the person with dementia as an independent decision-maker, with legal rights that hinged upon their decision-making capacity. The term ‘relational practice’ describes a more fluid approach, which actively engaged with the person with dementia and other members of their support network (typically family members) across the trajectory of the illness. Characteristics of this continuum are described below and illustrated in Table 3.

Individualist advocacy prioritised the person with dementia as the client, taking a strict approach aimed at ensuring that the person was the ‘decision-maker’. This hinged on the professional determining that the person was capable of understanding and making such decisions. This approach was more aligned with an ‘individualist’ view of autonomy, focusing on promoting the rights of the person to make an independent decision:

“...so as long as the person has capacity then the lawyer can really align themselves with that client and be their advocate.” (Interview 27, Legal, Solicitor)

Where decision-making capacity was uncertain, professionals emphasising this approach would typically refuse to involve the person in decision-making:

“... no matter how pragmatic I might like to be ... ethically I'm still bound by the fact that if I can't take instructions [from the person themselves] I can't do it.” (Interview 28, Legal, Solicitor)

'Relational practice' describes the approach which actively included the person with dementia along with others in their support networks. This approach viewed decision-making as a collaborative effort, with a more fluid approach emphasising 'involvement', even where the person was deemed to lack the ability to independently make complex decisions or provide formal consent. Professionals identified this approach as useful in accessing information about the person with dementia, educating family members, modelling desirable behaviours, building trust and using a 'gentle touch' in managing undue influence (e.g. through negotiation and providing advice). The majority of health professionals tended towards this 'relational practice' approach, identifying it as less adversarial and better suited to maintaining working relationships with the person and their family members. A 'relational practice' approach was able to adapt to changes in the person's decision-making ability, but encountered difficulties if relationships deteriorated or where the 'gentle touch' was unable to restrain the effect of 'pushy' family members or supporters:

“So where the family is sort of relatively functional and people are generally on the same page it's good, but when things are going wrong I think it can go quite wrong, and then it obviously could be really disempowering to people and they can actually be not able to properly assert what they want themselves at that point.” (Interview 28, Legal, Solicitor)

Thus, both ends of the 'individualist advocacy' and 'relational practice' continuum of practice can be seen to provide examples of practice that are not entirely consistent with accepted principles of supported decision-making. Individualist advocacy appears to fall short with respect to the person's right to access support in exercising legal capacity, while relational practice, at times, fails to promote the right to freedom from undue influence.

Inter-professional differences were apparent in the positions that professionals adopted along the continuum of 'individualist advocacy' and 'relational practice'. Health and legal

professionals described different approaches, particularly in situations where a person was judged to have impaired decision-making capacity, or where there was concern about interference from others in the person’s family or support networks. Legal professionals consistently adopted the ‘individualist advocacy’ approach. Health professionals tended to view this approach as adversarial, and used it only when there were significant concerns about a person’s family members acting contrary to the person’s interests.

Legal professionals identified that *involving supporters and family members* was problematic in terms of their professional role:

“I quite adamantly stick to the policy that the client is the client – the old person is the client and no other client should have input, although I may request or ask certain questions of the family members to verify what I’m searching for or what I’m looking for, but I generally don’t let a client have a support person in with me.”

(Interview 21, Legal, Solicitor)

The ‘individualist advocacy’ approach to practice either excluded family members and supporters from consultations, or ensured that the formal stages of decision-making (e.g. signing legal documents) were undertaken independently by the person with dementia. This was seen as a protection against coercion or undue influence by others, and a way of *privileging the person’s voice* in the decision-making process. On the other hand health professionals typically welcomed the involvement of supporters and family members in decision-making.

Health professionals occasionally reported using an ‘individualist advocacy’ approach, typically when a family member was clearly acting against the person’s best interest. This could lead to applications to Tribunals, seeking appointment of a guardian:

“they’re almost adversarial for health professionals ... where you’ve got to say ‘look, I don’t think this family member is acting in the best interests of the person’. And if that Tribunal decision isn’t upheld or that appointment isn’t made, then you’re pretty much kicked out of that family situation because you’re the sort of bringer of bad news.” (Interview 10, Nursing, Registered nurse)

This ‘individualist advocacy’ approach was seen to be a threat to the professional’s ongoing relationship with the person and their family members, and thus used only as a last resort.

Discussion

This study documents the practices of health and legal professionals in providing support for decision-making for people living with dementia. The themes extend previous work relating to care workers (Cameron et al., 2018; Fetherstonhaugh et al., 2016), demonstrating the roles of professionals in this process. The observed inter-professional differences illustrate how diverse professionals conceptualise their roles and professional boundaries. These findings have implications for the further implementation of supported decision-making, which are discussed below.

Support for decision-making within existing professional contexts

Encouragingly, most professionals could identify ways in which they already provided informal support for decision-making to people with dementia. In 'establishing the basis for decision-making', professionals considered a range of factors, which informed their judgement about how the decision might be undertaken. This went beyond a narrow focus on the person's cognitive capacity, particularly among health professionals who had an existing relationship with the person. This suggests that professionals viewed decision-making capacity as being embedded in a broader set of relational and contextual factors (O'Connor, 2010). However, among professionals who identified more strongly with the 'individualist advocacy' approach to practice, there was a tendency to take an 'all or nothing' or 'bright-line' approach to capacity assessment, which in some cases excluded the person from the decision-making process. It was also apparent that, in some situations, people were identified as 'lacking capacity' without adequate attempts to provide supports relevant to the person's situation. We argue that these practices are not consistent with the principles of supported decision-making.

The 'supportive toolbox' described both the generic and specialised skills, strategies and techniques employed to support people with dementia in decision-making. Different professional groups reported having access to different skills and resources (e.g. speech pathologists with specific skill sets in communication interventions), suggesting the need for professionals to be aware of the scope of services available and the specialised skill sets of colleagues from other professional groups (Zusack et al., 2016). The use of AAC techniques, while well-developed for other developmental disabilities, has been identified as an area of potential unmet need for people with acquired progressive conditions, such as dementia (Creer, Enderby, Judge, & John, 2016; Swan et al., 2018). Variation in competencies within

professional groups was also observed, suggesting a role for formal training in the skills and techniques underpinning the practice of support for decision-making. The importance of having adequate time available to employ these supportive strategies has been described in previous research (Tarzia et al., 2015).

In 'managing professional boundaries' participants acknowledged their own scope of practice. Participants described collaboration with other professionals, to ensure appropriate professional skill sets were included in the process. The acknowledgement of differentiated roles is consistent with the 'boundary work' concept (Powell & Davies, 2012), suggesting that these boundaries are relevant to the practice of providing support for decision-making. Professionals also described how they maintained distance from the ultimate exercise of choice. This is consistent with previous research, in which disability support workers reported providing support for decision-making, while noting the importance of maintaining objectivity and professional distance (Bigby, Whiteside, & Douglas, 2017). However, 'distance' can also be a form of professional risk aversion, as noted in recent research which suggests that regulatory frameworks can actually contribute to people receiving *less* support for the more substantive or 'risky' decisions (Harding & Tascioglu, 2018). This is of particular concern if it results in people being denied their right to the full exercise of their legal capacity in decision-making.

Individualist advocacy and relational practice: Differences in positioning

Professionals emphasised particular features of their roles in providing support for decision-making. We argue that the different approaches taken by distinct professional groups, particularly along the dimension of 'individualist-advocacy' versus 'relational practice', has implications for the broader implementation of supported decision-making. This may be a product of professionals adhering to their own professional guidelines (Castles, 2018), viewing supported decision-making principles through the lens of their own profession, and identifying ways in which they might best incorporate these within existing roles and boundaries. This is consistent with the symbolic-interactionist concept of 'role-taking', in which agents actively reflect on the symbolic meanings of their own actions, from the imagined perspective of their own professional group (Aldiabat & Le Navenec, 2011).

These differences in 'positioning' with respect to the person or client have implications for how different professional groups will provide support for decision-making. Our research

suggests that legal professionals currently tend towards an 'individualist' approach, focusing on advocating for the rights of the individual person, as long as they are satisfied that the person has decision-making capacity (Castles, 2018). This approach risks inappropriately excluding people with impaired decision-making capacity from the decision-making process entirely. Health professionals, on the other hand, typically tend towards a more fluid, relational approach, which includes people with dementia and their support networks in the process, while navigating transitions into greater reliance on others or formal substitute decision-making. While this may enable the inclusion of people with impaired decision-making capacity, it also potentially marginalises their views within a broader network of agents in the decision-making process (Harbottle & Schonfelder, 2008). This issue has been identified within the related literature on 'shared decision-making' (Miller, Whitlatch, & Lyons, 2016; Smebye, Kirkevold, & Engedal, 2012), which promotes inclusion and collaboration of different parties, but arguably lacks the explicit frameworks for ensuring that the person's will and preferences are respected (Simmons & Gooding, 2017).

The question arises as to whether an 'individualist-advocacy' or 'relational practice' approach is superior, or better suited to a particular scenario. We argue that both of these approaches have strengths and weaknesses, and in different cases either approach may be inconsistent with accepted principles of supported decision-making. In the absence of legal frameworks prescribing supported decision-making practice, professionals must find ways to work together effectively, even when other professionals position themselves at different points on the continuum (Castles, 2018). Purser et al. (2015) proposed that the adversarial nature of the legal system has both strengths and weaknesses, which can expose inter-professional differences in practice. While legal professionals value the way this system privileges formality and due process, health professionals often note that this is at the expense of collaboration, communication and compromise.

Practitioners also need to be mindful of the diversity in clients' needs or desires for support in decision-making. These differences include characteristics of the person's condition, life situation, key relationships, previous experiences, access to support, and preferred decision-making styles (Sinclair et al., 2018). Previous research with people with mental illness has identified that different personal understandings of the illness experience can influence preferred decision-making styles (e.g. independence versus dependence) and preferences for professional support for decision-making (Knight et al., 2018). Our previous research

demonstrated that people with dementia had varying preferences for the provision of support in decision-making, with the majority wanting close involvement of trusted and familiar supporters (usually family members) (Sinclair et al., under review). This research identified a key professional role in educating family members and supporters, thus facilitating their involvement in providing support (Sinclair et al., under review; Zusack et al., 2016).

At a broader level, these different approaches highlight some of the challenges in training professionals, and informing the community, about the key principles of supported decision-making. The language of the CRPD places a strong emphasis on respect for the individual's will and preference (United Nations, 2006), while simultaneously promoting 'relational autonomy' as the mechanism for enabling the right to legal capacity among those with impaired decision-making capacity (Sinclair et al., under review). Relational autonomy conceptualises agency in a broad sense, whereby individuals may enact their will and preference *through* others. Our research suggests that different professional groups will adopt positions that privilege certain conceptualisations of agency (i.e. individualist versus relational), in ways that are consistent with their current professional roles. Where these differences are inconsistent with supported decision-making principles, or result in inter-professional conflicts, this may be counter-productive with respect to the person's care and the broader aims of supported decision-making.

Future directions

The interview format explored professionals' descriptions, rather than direct observation of practice (Reinardy, 1999). It is likely that the professionals who volunteered to participate were those with specific interest in dementia care and/or rights-based approaches, hence the findings may reflect the practice of those with a special interest in this area, as opposed to being representative of broader practice. Future research would benefit from direct observation of actual practices in dementia care. Whilst some professional groups were not extensively represented, the data from each professional group reached a point of saturation across the key themes presented. However, broader in-depth sampling, particularly of those with less experience or interest in supported decision-making, would be advantageous in future studies. The sampling from several Australian jurisdictions was helpful in describing similarities and differences in practice, but the specific legislation, policy environments, funding frameworks and services in each participant's local jurisdiction should factor in to any observations drawn.

Implications

These findings suggest a number of implications for policy and practice in implementing supported decision-making. Access to training and resources specific to the context of dementia will be important, and may include specific training modules in certificate or graduate-level training programs, as well as practice guidelines or frameworks, similar to those already employed in the disability sector (Bigby & Douglas, 2015). Aged care organisations will also need to assess their policies with respect to supported decision-making, in order to provide clear guidance for employed or visiting professionals providing services (Sinclair et al., (in press)). Developing rights-based practice that is also sensitive to the relational contexts of people with dementia will likely challenge inter-professional boundaries. Health-justice partnerships (Ries, 2016), and inter-disciplinary approaches to training and professional development (Purser et al., 2015) may assist in enabling professional groups to collaborate more effectively. Inter-professional boundaries are neither arbitrary nor static, but are continuously contested and re-defined in response to external influences (Powell & Davies, 2012). Professional colleges may play a role in this process, by developing high-level position statements (e.g. American Bar Association, 2016; Australian Medical Association, 2018). Ideally, this would be a coordinated process, to ensure interoperability and consistent terminology (Purser et al., 2015). Finally, the ongoing process of legislative reform in Australian jurisdictions (e.g. New South Wales Law Reform Commission, 2018) will have implications for professional practice.

Conclusion

This study has illustrated existing professional practice in providing support for decision-making for people living with dementia. Professionals described ways in which they provided support for decision-making, however their diverse approaches were informed by their own professional group. The key differences emerged in their emphasis on an ‘individualist advocacy’ as opposed to a ‘relational practice’ approach. In some cases, the descriptions of practices in support for decision-making were inconsistent with the optimal implementation of supported decision-making. These findings have implications for the ongoing implementation of supported decision-making in the context of dementia care.

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Declaration of Competing Interests

The authors declare that there are no competing interests.

As Accepted

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Characteristic		Number (%)
Gender	Male	6 (24.1%)
	Female	22 (75.8%)
Age (Median, IQR)		46 (20)
Professional group	Medical	6 (21.4%)
	Nursing	8 (28.6%)
	Allied Health	10 (35.7%)
	Legal	4 (14.3%)
Work setting	Hospital	6 (21.4%)
	Aged care (residential)	8 (28.6%)
	Aged care (community)	4 (14.3%)
	Aged care (transitional)	1 (3.6%)
	Outpatient	2 (7.1%)
	General practice	3 (10.7%)
	Community legal practice	2 (7.1%)
	Private legal practice	2 (7.1%)
Years experience with people with dementia	1-3 years	4 (14.3%)
	4-9 years	11 (39.3%)
	10-20 years	9 (32.1%)
	20+ years	4 (14.3%)

Table 1: Participant characteristics (N=28)

Themes	Sub-themes
Establishing the basis for decision-making	Understanding the person's priorities Assessing decision-making capacity Knowing the person well Knowing person's support networks
The 'supportive toolbox'	Generic techniques Specialised techniques Simplifying options Being attentive to non-verbal cues Resource constraints
Managing professional boundaries	Acknowledging scope of practice Maintaining professional distance
'Individualist advocacy' versus 'relational practice'	Inter-professional differences Involving supporters and family members Privileging the person's 'voice'

Table 2: Themes and sub-themes from analysis of interviews

Aspect of practice	Individualist advocacy	Relational practice
Conceptualising decision-making capacity	Individualist, the person is the decision-maker	Sensitive to the person's supportive relationships
Assessing decision-making capacity	Formalised assessment, referral to professionals 'Bright line' approach, capacity is present or not	Informal discussion within existing clinical relationship. Fluid approach, transition to increasing involvement of family members in decision-making over time
View on involving family members and supporters in decision-making	Excluded entirely, or from final stage of decision Viewed with suspicion	Encouraged and actively included across different stages of illness Opportunity to build relationships
Managing undue influence	Excluding others Advocating for person's rights	Educating, negotiating, advising, avoiding adversarial approach

Table 3: Characteristics of 'individualist advocacy' and 'relational practice', and implications for professional practice in providing support for decision-making