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‘There’s more to life than money and health’: family caregivers’ views on the role of Power of Attorney in proxy decisions about research participation for people living with dementia

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Abstract

People living with dementia may experience difficulties when making decisions for themselves in the later stages of the condition. Whilst there are mechanisms in England and Wales for appointing an attorney to make decisions about welfare and finances on their behalf, there are no provisions for appointing an attorney to make future decisions about research participation. This is despite a growing focus on Advanced Care Planning and other processes that provide opportunities to discuss future preferences and ensure that decisions are made in line with those preferences. This qualitative study with 15 family caregivers who had acted as research proxies explored the role of Power of Attorney in their decisions about research, and their views about extending current legal arrangements to include research. Five themes were identified: the holistic nature of decision-making; the '*power*' of attorney; making decisions by putting yourself in their shoes; support for bringing research under the umbrella of attorney arrangements; and a unifying theme of trusting relationships. Legal provisions for prospectively appointing a research proxy may encourage discussion about future wishes and so enable decisions about research to be made that are in accordance with the person's preferences and wishes. However, further consultation with the public including people living with dementia and their families, and a range of stakeholders is needed. Providing guidance to families, people living with dementia, and the wider research community may provide greater clarity and improve decision-making in the meantime.

Introduction

Dementia is an increasingly significant global health issue, with a rising prevalence due to an ageing population (Cova et al., 2017). One of the main characteristics of dementia is the gradual loss of decision-making capacity (Kim, Karlawish, & Caine, 2002). This can require alternative processes to ensure the person living with dementia is enabled to continue to participate in decisions relating to their health and care, such as supported decision-making (Smebye, Kirkevold, & Engedal, 2012). Ultimately it may necessitate the need for other people to be involved in making decisions concerning the care of the person living with dementia (Fetherstonhaugh, Mcauliffe, Shanley, Bauer, & Beattie, 2017), often referred to as 'proxy' or 'surrogate' decision-makers (Lord, Livingston, & Cooper, 2015). Proxy decision-making is intended to respect the autonomy of the person concerned by using their past decisions or previously discussed preferences (Huxtable, 2015). However, this is based on the assumption that proxy decision-makers are sufficiently well informed to do so (Jones et al., 2016). Some family caregivers can feel overwhelmed by the responsibility of caring for someone living with dementia, and the feeling that 'everything falls on you' (Ploeg et al., 2019). Relatives of people living with dementia report that proxy decision-making can be particularly difficult and distressing (Lord et al., 2015), and proxies can experience stress and guilt as a result (Wendler & Rid, 2011).

Advance planning and appointing a Lasting Power of Attorney

There is a growing focus on ensuring future decisions reflect individuals' preferences through advance planning, including nominating who should act as a decision-maker in the event of a loss of capacity. Advance planning involves helping people to plan for their future care and support needs, including medical treatment, and therefore to continue to exercise their personal autonomy as far as possible (National Institute for Health and Care Excellence, 2018b). NICE guidelines on decision-making and mental capacity recommends that Advance Care Planning (ACP) should be offered to everyone who is

at risk of losing capacity or experiencing fluctuating capacity (National Institute for Health and Care Excellence, 2018b). Additionally, recent NICE dementia guidelines recommend offering opportunities for people living with dementia to discuss their preferences and plan ahead including making advance statements about their wishes, preferences, beliefs and values regarding their future care (National Institute for Health and Care Excellence, 2018a). Advance planning has been associated with reducing decisional conflict for proxies, suggesting that the benefits may extend beyond respecting people's wishes, to also reducing the burden on their loved ones who act as proxies (Chiarchiaro, Buddadhumaruk, Arnold, & White, 2015).

In the event that a person should lose the capacity to make their own decisions regarding their affairs, there are legal mechanisms to ensure that future decisions are made in accordance with their values and preferences and so continue to influence decisions made on their behalf (Porteri, 2018; J Samanta, 2012). Power of Attorney (POA) aims to enhance prospective autonomous decision-making in the event of future incapacity through enabling the appointment of a substitute decision-maker in the event of a loss of capacity (Jo Samanta, 2009). In England and Wales the Mental Capacity Act 2005 (MCA) provides a statutory framework for how to proceed when people are judged to lack capacity to make decisions for themselves (HMSO, London, n.d.). Under the MCA, individuals can appoint one or more people to hold a form of Power of Attorney (POA), termed a Lasting Power of Attorney (LPA), to make decisions regarding their health and welfare and/or their property and financial affairs should they lose capacity [s9](HMSO, London, n.d.). With an ageing population, and a growing awareness about the need to make plans about future care, the number of people registering an LPA in England and Wales is increasing (Office of the Public Guardian, 2016). Whilst the precise terms and legal arrangements vary, proxy decision-making is also permitted in many other jurisdictions (Jones et al., 2016).

In addition to issues around care and treatment for people living with dementia, there is also a growing focus on the importance of dementia research. In the UK, government funding for dementia research doubled between 2012 and 2015 to over £60m a year, with additional significant investment in dementia research infrastructure such as £290m funded UK Dementia Research Institute (Department of Health and Social Care, 2019). Low participation in clinical trials and other types of studies is considered to be one of the major challenges to advancing clinical dementia research (Alzheimer's Disease International, 2014). However, despite recommendations about the inclusion in research of people living with dementia at all stages of the condition (National Institute for Health and Care Excellence, 2018a), people with cognitive impairment are still frequently excluded from research (Taylor, DeMers, Vig, & Borson, 2012). This is due in part to the ethical concerns surrounding the inclusion of adults who lack capacity in research (West, Stuckelberger, Pautex, Staaks, & Gysels, 2017) who are considered to be 'vulnerable' groups, and a lack of knowledge and understanding about the legal provisions for proxy decision-making for research participation (Shepherd, Griffith, Sheehan, Wood, & Hood, 2018).

Provisions for involving people living with dementia in research

The MCA provisions cover decisions about research participation for adults lacking capacity to consent (HMSO, London, n.d.). The Act states that someone who is involved in caring for the person lacking capacity should be consulted for advice before they are included [s30](HMSO, London, n.d.). This 'personal consultee' is someone who has a relationship or personal knowledge of the person who lacks capacity [s32](HMSO, London, n.d.), usually a friend or relative. However, the role of Lasting

Power of Attorney for health and welfare in decisions about research participation lacks clarity (Jo Samanta, 2009). The MCA Code of Practice states that researchers *can consult* attorneys [s7.57] and that an attorney *is not prevented* from being consulted provided they are not acting in a professional or paid capacity (for example, the person's solicitor) [s11.25](Department of Constitutional Affairs, 2007). The Medicines for Human Use (Clinical Trials) Regulations (CTR), which governs clinical trials investigating medicines in the UK, including those involving adults who lack capacity to consent to the trial, does not contain any reference to the role of attorneys (The Medicines for Human Use (Clinical Trials) Regulations 2004 SI No.1031, n.d.). In all cases, the person acting as consultee or legal representative is either identified or nominated by the researcher or healthcare team. The legal mechanisms in England and Wales do not allow for prospectively appointing a proxy for decisions about research. However, the ability to specify willingness to be involved in research before capacity to consent is lost, or to identify ahead of time a research proxy to act on the person's behalf, may allay concerns surrounding the suitable choice of proxies and the harmonisation of proxy decisions with the wishes of those with dementia (West et al., 2017).

Welfare Attorneys and decisions about research participation

A survey conducted in the US found that most older people (96%) were willing to designate a proxy for research decision making (Karlavish et al., 2009). Previous studies have found that having prior discussions with the person selected to act as their proxy increased patients' confidence in their decision (Bolcic-jankovic et al., 2014), however few proxies (30%) have previously discussed research preferences with the person they represented (Coppolino & Ackerson, 2001). A report into the ethical issues surrounding dementia by the Nuffield Council on Bioethics identified a number of difficulties that arise when involving people who lack capacity in research under the current legal framework (Nuffield Council on Bioethics, 2009). Their report, produced through public and expert consultation, notes that advance decision-making and planning is generally available, but that this focus on future planning should also include research (Nuffield Council on Bioethics, 2009). It recommended that consideration be given to the role of the welfare attorney being explicitly extended to include decisions about research, both within the MCA and the CTR (Recommendation 19)(Nuffield Council on Bioethics, 2009). It proposed that in the interim the Mental Capacity Act Code of Practice should provide guidance about participation in research governed by the MCA when capacity is lost (Recommendation 20)(Nuffield Council on Bioethics, 2009). In the decade since these recommendations, there has been no research exploring the views of people living with dementia, their families, or the wider public regarding the role of POA and decisions about research participation.

We recently conducted a qualitative interview study to explore the experiences of family members in England and Wales who had acted as a research proxy (Shepherd, Hood, Sheehan, Griffith, & Wood, 2019). In addition to the topics covered as part of the original research, proxies described how they considered the decisions they had made about research also in the light of holding (or not) POA for the person they represented. The aim of this analysis of a subset of the interview data was to investigate how POA affected their decision-making in terms of their perceived authority as decision-maker. Participants' views about the current positioning of decisions about research outside the Lasting Power of Attorney legal framework, and any future changes to allow for prospectively appointing a research proxy, were also explored.

Methods

Design

Semi-structured interviews were conducted with family members who had acted as a research proxy for a relative who lacked capacity (Shepherd et al., 2019). The aim of the interviews was primarily to explore proxy decision-making about research, the findings of which have been reported elsewhere (Shepherd et al., 2019), however the participants in early interviews also had POA and spoke about how this interacted with their general decision-making and decisions about research. This paper reports on interviews with a subset of 15 participants in which the role of LPA was explored.

Recruitment

Participants were recruited from England and Wales, rather than throughout the UK, due to the difference in legislation governing research involving adults who lack capacity in other jurisdictions. Potential participants were identified through research networks, community interest groups, social media platforms, and research registries. Purposive sampling techniques were used to obtain a maximum variation sample. Participants included those who had made decisions within different family relationships (spouse or parent), research contexts (clinical trials and other forms of research study), and decision outcomes (agreed or declined participation on behalf of the person).

Ethical approval

Ethical approval for the study was provided by Cardiff University School of Medicine Research Ethics Committee (Ref 17/54). All participants received information about the study and had an opportunity to ask questions. All participants provided written informed consent prior to the interviews.

Data collection

A topic guide was developed, informed by relevant literature, findings from a recent systematic review (Shepherd, Hood, et al., 2018), and in conjunction with a lay advisory group. Interviews were conducted by one researcher (VS) with a nursing background and experience in conducting research with adults who lack capacity between January and July 2018. Following the initial interviews, during which the topic of POA arose, the topic guide was further refined for subsequent interviews to specifically probe for proxies' experiences and views about the role of POA in relation to decisions about research. This paper reports the analysis of the data relating to questions about POA from those 15 interviews. The types of questions asked included *'How do you see your role generally in relation to making decisions on behalf of [person living with dementia]? Is this different for decisions about research compared to others?'*, and *'Lasting Power of Attorney doesn't necessarily cover decisions about research, does that seem right to you, or not?'*

Adequacy of sample size can be determined through the number of events, incidents and experiences explored, rather than solely in terms of the number of participants (Sandelowski, 1995). Data collection continued until data saturation was considered to have been reached (Sim, Saunders, Waterfield, & Kingstone, 2018). The interviews were digitally audio-recorded with consent, transcribed verbatim by a professional transcription service provider, and anonymised.

Data analysis

Qualitative data analysis software (NVivo 11)(QSR International, 2015) was used to assist with data management. The interviews were first read by one of the researchers (VS) to check for completeness and gain an overview of participants' perspectives. The transcripts were initially coded by one researcher (VS) and then reviewed independently by members of the research team to establish the validity of the coding framework, prior to iteratively coding the remaining data. Data were analysed thematically (Braun & Clarke, 2006), and initial themes were explored and discussed between members of the research team until consensus was reached about the final themes.

Multiple strategies were used to ensure trustworthiness of the data analysis. This included purposive sampling of family caregivers, reflective discussions during regular data analysis meetings, and recording developments in the analytical process in field notes and data analysis memos held in NVivo.

Findings

Participant characteristics

Participants were predominantly female (11/15, 73%), and were either an adult son or daughter (11/15, 73%) or spouse (3/15, 20%) of the person they represented, and one person who was both a daughter and a spouse. Participants had been involved in making a decision about research on behalf of a family member either living with dementia (n=14) or who had an existing cognitive impairment and was considered to be at risk of developing dementia (n=1). Interviews were conducted either face-to-face at the participant's home or another location of choice (n= 10) or by telephone (n=5). The duration of the interviews was 19-90 mins (mean 50 mins). A summary of participant characteristics is provided in Table 1.

Table 1. Demographic characteristics of participants

| Characteristic | Sample <i>n</i> = 15 |
|--|-------------------------|
| Gender, <i>n</i> (%) | |
| Male | 4 (27) |
| Female | 11 (73) |
| Relationship to the person represented, <i>n</i> (%) | |
| Spouse | 3 (20) |
| Son/daughter | 11 (73) |
| Spouse and adult child | 1 (7) |
| Power of Attorney status, <i>n</i> (%) | |
| LPA Health & Welfare and Finance & Property | 12 (80) |
| LPA Finance & Property only | 1 (7) |
| Enduring Power of Attorney (Finance) | 1 (7) |
| No Power of Attorney | 1 (7) |
| Interview location, <i>n</i> (%) | |
| Own home | 8 (53) |
| Other location | 2 (13) |
| Telephone | 5 (34) |
| Interview duration, minutes (mean) | 19-90 (50) |

All but one of the participants held some form of POA. Most held a Lasting Power of Attorney (LPA) for both Health and Welfare matters and Finance and Property (12/15, 80%), one participant had LPA for Finance and Property only, and one had an Enduring Power of Attorney (an arrangement available prior to the introduction of LPA under the Mental Capacity Act which covers financial matters only).

Overview of the findings

Five key themes captured the way proxies viewed the role of Lasting Power of Attorney in relation to making decisions about research and how they saw their authority in terms of being both the person's welfare attorney and research proxy, and their views about incorporating decisions about research into attorney arrangements. One of these themes, the trusting relationship between the proxy and the person they represented, can be viewed as a central unifying theme. It is through this relationship that the family member is chosen to act as attorney, has the legal and moral authority to act as a consultee/legal representative, and they also use this relationality and familiarity as the basis for making decisions on the person's behalf.

Theme: Relationships and trust between the person and their proxy is key

The importance and relevance of holding Lasting Power of Attorney (LPA) on the decision-making process or actual decision itself varied between proxies. For some, it was regarded as something in the background of their daily lives, other proxies considered it to be merely 'rubber stamping' what was already there. Proxies often spoke in terms of their relationship, and that an LPA meant they were being trusted by the person to act on their behalf.

"I think it feels more than just a simple document, when I think about the responsibility that's attached to it, I think of it in relation to the trust that they put into me" [17, adult son, LPA for Health & Welfare and Finance & Property]

For many proxies, the relationship between them and the person they represented was key to knowing that person and being able to represent them and their wishes. This 'knowing' went further than just knowing their superficial likes and dislikes to knowing what values were important to them. One proxy who represented both her mother and her husband spoke about not just *what* you know, but *how* you know the person to reflect this deeper knowledge.

"It's not a question of doing it from having Power of Attorney that's got nothing to do with it. But..., it's just about how you know a person" [14, female spouse, LPA for Health & Welfare and Finance & Property]

Some proxies spoke about how it felt important to them that they had been chosen to act as attorney when a person creates their LPA, and what this authority to make decisions might mean. They considered that being the person's welfare attorney was an authority in itself that indicated that the person trusted them to make decisions on the person's behalf which could include decisions about research that might not necessarily have been foreseen by the person.

"I suppose I think lasting Power of Attorney for me is mum saying, "You make the decisions for me. No matter what," I suppose" [06, adult daughter, LPA for Health & Welfare and Finance & Property]

However, proxies did not feel that having decision-making authority under a Power of Attorney should be a legal requirement for acting as a proxy for decisions about research, as the basis for their relationship was trust (fiduciary), rather than contractual.

“Yeah, so I think I’d probably do it, I’d do it without even without that. And I think that’s what it is, forget the Power of Attorney and all that stuff” [06, adult daughter, LPA for Health & Welfare and Finance & Property]

Theme: Decisions about research are not isolated from health and wellbeing

All proxies reported that they hadn’t previously considered the role of LPA for health and welfare in decisions about research participation, even though all but one of them held some form of Power of Attorney. Proxies did not see decisions about research as being separate from those about the person’s health and welfare, but as intrinsically linked. Although proxies recognised that there were differences between decisions about research participation and those about care or treatment.

“I think it should probably be quite closely linked together... because research fits in with everything else that goes on in terms of sort of treatment and care and because I would be the person making those decisions, I’m best off making the decisions for everything. It’s a holistic thing so it would be research, treatment, medication, care, finances, whatever ...” [09, female spouse, no Power of Attorney]

Participation in research may be connected with issues about the person’s health or welfare. One proxy was concerned that this may leave the person making the decision about research in a problematic situation if they had insufficient decision-making authority in other areas.

“If you’re involved in any kind of research associated with an illness, then one of the consequences of that could be again involvement with social care or health so, without having that authorisation if you like, you could end up putting yourself in quite a difficult position” [05, adult son, LPA for Health & Welfare and Finance & Property]

Some proxies thought that the same person who made decisions about the person’s health and welfare should be the same person who would make decisions about research participation as this would be the person who cares for them and knows them and their wishes best.

“I just see research as my responsibility because I’m looking after [him] and hopefully I would make decisions that were appropriate knowing what his previous thoughts were and knowing that he actually said that he would do anything to help” [07, female spouse, LPA for Health & Welfare and Finance & Property]

Proxies suggested that decisions about research are closely linked to the moral character and values of the person, going beyond merely secular issues about the person’s finance and health, and so the decision-maker would need to know the values that were important to the person.

“Now when you get these Power of Attorney for Finance or for Health, there’s more to life than money and health. There’s ... the sort of thing that you’re talking about, and I’m putting it as a moral thing. That side of a person makes choices dependent on the type of person they are” [14, female spouse, LPA for Health & Welfare and Finance & Property]

Theme: Support for research coming under the ‘umbrella’ of an LPA for health and welfare

Proxies were generally supportive of a process to nominate an individual to make future decisions about research, with some proxies suggesting that there were benefits to including Power of Attorney for research participation under the existing arrangements for LPA for health and welfare. One proxy

spoke about the value of an opportunity for meaningful discussions about the person's wishes and preferences with their attorney that would occur through the process of creating an LPA for research participation, and how that might help them as the attorney who would have the responsibility to interpret their wishes.

"Well I, I think anything that can awaken conversations is important it just makes us stop and think" [15, adult daughter, Enduring Power of Attorney]

However, one proxy sounded a note of caution that decisions about research that are not necessarily intended to benefit the person directly need greater thought in comparison to those about health and welfare. They reported that having an LPA that included decisions about research may mean that there was less thought and discussion about the decision to participate or not.

"No, I think the research needed more thinking about. The lasting power of attorney gives you the right legally and therefore maybe you don't think about it quite so much, but yeah with the research I think I discussed it more because it wasn't under that umbrella" [04, adult daughter, LPA for Health & Welfare and Finance & Property]

Another proxy weighed up the potential benefits of having decisions about research under the umbrella of a LPA for health and welfare, recognising that there are differences, but that it might offer a practical compromise in comparison to the likelihood of creating an additional LPA and the legislative processes that would involve.

"I suppose I, I think there should be effectively a kind of LPA that relates to research....so amending the health one to put research into it might be the more practical thing to do and if that was the case, I can see why it is a bit different, but I still think you could do it" [17, adult son, LPA for Health & Welfare and Finance & Property]

Theme: Nobody questions a Lasting Power of Attorney

Proxies described the legal power that arises from having a Power of Attorney. Some proxies spoke about how an LPA helps others involved in the person's care, making it easier for third parties such as clinicians and financial institutions to speak to the person's relatives, which might be more important than just for the attorney themselves. One proxy talked about how knowing that there is an LPA in place brings a 'sigh of relief' for clinicians they came into contact with.

"If you've got a power of attorney it makes it easier for third parties to deal with issues which affect my mother, because they've got somebody to deal with, and that's where it seems to be even more important. Because when you're talking to clinicians and you've got power of attorney for health and social care, it's, they almost breathe a sigh of relief. They're thinking oh yes, it's okay, I can hold these conversations" [05, adult son, LPA for Health & Welfare and Finance & Property]

One proxy who was caring for someone who did not create a LPA spoke about how they thought their situation would be much easier if there was a LPA in place.

"Whereas if I had that Power of Attorney thing or lasting Power of Attorney, you'd just hand the document over and nobody would question a single thing then" [09, female spouse, no Power of Attorney]

Although another proxy who did have LPA spoke about how having an LPA isn't always helpful, and the problems associated with a lack of consistency in how it is viewed by different organisations.

"So, in some ways it feels like it's a waste of paper having it and because everybody treats it differently it's very difficult" [08, adult daughter, LPA for Health & Welfare and Finance & Property]

A proxy who had previously encountered problems with her mother's care spoke about her relief when they had a LPA in place which meant that there was better communication with clinicians involved in caring for her mother which enabled more appropriate care arrangements to be made based on more accurate information.

"We were in despair until we got that Power of Attorney, then we could start telling these people what the reality was. Then they started to get what they needed" [14, female spouse, LPA for Health & Welfare and Finance & Property]

Theme: Trying to put yourself in their shoes

Proxies' views about making research decisions are reported elsewhere (Shepherd et al., 2019), however when asked specifically about how they make decisions as the person's attorney about health and financial matters proxies, reported a range of views. Some reported that they try to make the decision that the person themselves would have made, if they were able to, perhaps through positioning themselves 'in the person's shoes'.

"you have to actually try and put yourself into their shoes and think what they'd like, so actually trying to remember discussions you've had before about different things and actually what they'd like to do" [08, adult daughter, LPA for Health & Welfare and Finance & Property]

Other proxies spoke about how it can be difficult to balance what the person would want, against what they would decide for themselves. One proxy spoke about the importance of respect – both respecting the person and their previous wishes.

"And you always get this dilemma, you know what you'd do but you have to respect, and I want her to do things, but you have to respect her decision really. So, it is a dilemma all the time" [03, adult daughter, LPA for Health & Welfare and Finance & Property]

This can leave them in a difficult position as attorney, where they feel that the person has clearly expressed their views previously about some issues and hence made their own decision, but at other times the attorney acts as the decision-maker on the person's behalf because their wishes are not known.

"That isn't something that I would have the decision, she's already said how she feels about that, but anything else obviously it is, it's very difficult, it's a difficult position to be in" [16, adult daughter, LPA for Health & Welfare and Finance & Property]

Decisions were not considered to be problematic by all proxies. One proxy talked about how, even for some of the decisions he had made about his family member's health, he hadn't deliberated for too long but had just 'got on with it'. Another proxy spoke about how their decision would be based on or informed by the person's previous wishes, but it would be their decision and one which they hoped would be a reasonable decision.

“Knowing what he would want and what he would think is best for him I mean he hasn’t told me what he wants me to do. I think it’s automatic, you just do it don’t you? If you’re put in a situation and a decision has got to be made well you’ve just got to do it really haven’t you.” [10, adult daughter, *LPA for Health & Welfare and Finance & Property*]

Discussion

Participants in this study recognised that there may be value in incorporating research into the LPA for Health and Welfare, if the donor wishes to do so. The benefits of this approach might include a mechanism for prospectively selecting the decision-maker, facilitating discussion about the person’s preferences and wishes about future research when drafting an LPA, and clarifying the role of the proxy where research overlaps with matters about the person’s health and welfare..

Concerns about the ‘accuracy’ of proxy decisions reported in previous studies (Shalowitz, Garrett-Mayer, & Wendler, 2006), are not reflected in the findings from this study. Proxies used what the person would have wanted as the basis for their decision but were more concerned about making decisions that were authentic to the person (Brudney, 2009) than decision accuracy. They viewed acting as a research proxy to be an intrinsic part of their caring role, both in terms of knowing the person and how participating would impact on them, as well as the practicalities involved. They considered themselves to have been chosen by the person by virtue of their relationship, which may reflect the view that the very nature of selecting the proxy is an expression of the values that are most important to the person, i.e. their relationships (Kim, 2011). The findings support other commentators’ views about the relational nature of Power of Attorney (Harding & Peel, 2018).

Participants’ views contrasted with those of health and social care professionals who, when surveyed, commonly assumed a LPA was needed in order to act as a research proxy (Shepherd, Griffith, et al., 2018). Participants described how the ‘power’ aspect of a Power of Attorney brought clarity. Having clearly designated decision-makers may make it easier for researchers to approach proxies in the knowledge that they have authority to make such decisions under the LPA. Current uncertainty about the locus of authority for these decisions (Shepherd, Griffith, et al., 2018) may be reduced, and the confidence of researchers and health and social care practitioners engaged in research involving adults who lack capacity may be enhanced, if greater legal clarity was provided about who is the legally designated decision-maker. However, the complexity of circumstances where multiple and joint attorneys are appointed, particularly where there may be disagreements (*Public Guardian v DA [2018] EW COP 26*, 2018), requires further consideration.

However, some commentators have sounded a note of caution about the legal designation of research proxies through LPA or other mechanisms as it may leave those who are either unable to, or merely fail to, designate a proxy being unable to participate in research because there would be nobody qualified to make a decision on their behalf (Yarborough, 2015). Secondly, designated research proxies would have to be given appropriate guidance on how they exercise their discretion in making decisions for those they represent (Yarborough, 2015). However, a legal requirement for a research proxy to hold a Power of Attorney for Research Participation (POA-R) is not supported by the participants in this study, nor those in a systematic review of previous empirical research (Shepherd, Hood, et al., 2018). In response to the concerns about a lack of guidance for those holding a LPA for research, there is currently no formal guidance available beyond brief references in the MCA Code of Practice

(Department of Constitutional Affairs, 2007). The Nuffield report recommended that the Code of Practice should be amended to include guidance on the role of welfare attorneys in decisions about research, regardless of any extension to their role to include research decisions (Recommendation 19) (Nuffield Council on Bioethics, 2009). The Code of Practice is currently undergoing revision (from January 2019) which may present an opportunity to include formal guidance regarding the role of welfare attorneys in decisions about research participation.

Potential alternatives to having a POA-R include Advance Research Decisions or Directives (ARDs) that allow the person to prospectively consent to future research in specified situations should they lose capacity (Pierce, 2010). The legal situation regarding the permissibility of ARDs varies widely across the world, (Andorno, Gennet, Elger, & Jongasma, 2016; Lötjönen, 2006; Ries, Thompson, & Lowe, 2017) despite antecedent consent being a highly contested area (Buller, 2015). It is unlikely that determinative ARDs could offer a stand-alone solution without the additional appointment of a proxy to implement the advance directives in the light of the complete information at the time the research is conducted (Andorno et al., 2016). A dual 'belt and braces' approach of a POA-R accompanied by an ARD has been supported in other jurisdictions, as it may increase the likelihood of gaining deeper understandings of potential participants' values and priorities and how they might apply to foreseeable research opportunities (Heesters et al., 2016). In England and Wales, statements regarding refusing or withdrawing specific types of treatment, such as life-sustaining treatment, can be made via Advance Decisions to Refuse Treatment (ADRT) under the Mental Capacity Act [s24-26](HMSO, London, n.d.), however the role of legally binding ADRTs, or non-binding formally stated Advance Statements, in decisions about research participation in England and Wales requires further clarity.

Strengths and limitations

This is the first study in the UK to explore the views of those who have acted as research proxy, many of whom were also attorneys, on the role of Power of Attorney in decisions about research. Participants included those who had agreed, as well as declined, to a family member's participation in a range of different types of research, and those with and without authority under POA arrangements.

Limitations include a relatively small sample of family members. Their views may not be representative of other family members who have acted as research proxy in different situations and may not be representative of the views of people living with dementia. The majority of participants had both health and welfare LPA and property and finance LPA in place, and all had a positive attitude towards research as illustrated by their willingness to take part in this study. People who do not have, or do not wish to draft, an LPA may have differing views about research decisions coming under the role of attorney or have less positive attitude towards research than those who participated.

Implications for practice

Early discussions should be encouraged between people living with dementia and their family caregivers about their research preferences in the event that they are unable to provide informed consent for themselves. Opportunities for these discussions may arise during advance planning about future care and treatment, or when establishing a Lasting Power of Attorney for health and welfare matters.

Guidance should be made available for family members acting as a personal consultee or legal representative, and for those acting as welfare attorney, about the respective roles and the intersection between them. Similar guidance should be provided for health and social care professionals and researchers who are involved in approaching family members to act as a consultee/legal representative.

If supported by additional research, amending the legislation regarding LPA arrangements to optionally extend the role of welfare attorney to include decisions about research participation could be considered in the future. Although amendments to the MCA are underway (UK Parliament, 2017), the current view is that the MCA is non-compliant with the UN Convention on the Rights of People with Disabilities (Martin, Michalowski, Jütten, & Burch, 2014), where one concern is that a substitute decision-maker can be appointed by someone other than the person concerned (Series, Arstein-Kerslake, Gooding, & Flynn, 2015). Therefore, examining areas where advance planning can be further extended to address the current legal lacuna between research provisions and attorney arrangements may be warranted.

Conclusion

Family members who have acted as a research proxy on behalf of a person who lacked capacity viewed decisions about research as an extension of their role in maintaining the person's health and wellbeing, and so expressed support for optionally extending the role of welfare attorney to include decisions about research. Given the complexity of decisions about research, which are highly contextualised and involve complex factors that are unlikely to be known in advance, nominating a POA-R to make decisions on a person's behalf based on their wishes and preferences may be both ethically and practically preferable to alternatives such as relying on legally binding Advance Research Decisions. Encouraging discussion between people living with dementia and their caregivers about their wishes and preferences regarding future participation research may help to make proxy decisions that are more in line with these preferences.

The findings from this study support the previous recommendations to consider extending the role of welfare attorney to include decisions about research in England and Wales as part of the growing emphasis on Advance Care Planning processes, and to provide further guidance on the role of welfare attorneys in decisions about research in the meantime.

Further research to explore the views of people living with dementia, the wider public, and other stakeholders about extending the role of welfare attorneys to potentially include research, the subsequent impact on the ability to conduct research involving adults who lack capacity, and the feasibility and value of developing a non-binding advance research statement, is needed.

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Declaration of conflicting interests

The Authors declare that there is no conflict of interest.

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References

- Alzheimer's Disease International. (2014). *Participation In Dementia Trials And Studies: Challenges And Recommendations*. Alzheimer's Disease International.
- Andorno, R., Gennet, E., Elger, B., & Jongsma, K. (2016). Integrating Advance Research Directives into the European Legal Framework. *European Journal of Health Law*, 23(2), 158–173.
<https://doi.org/10.1163/15718093-12341380>
- Bolcic-jankovic, D., Clarridge, B. R., Leblanc, J. L., Mahmood, R. S., Roman, A. M., & Freeman, B. D. (2014). Exploring Determinants of Surrogate Decision-Maker Confidence : An Example From the ICU. *Journal of Empirical Research on Human Research Ethics*, 9(4), 76–85.
<https://doi.org/10.1177/1556264614545036>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Brudney, D. (2009). Choosing for another: beyond autonomy and best interests. *The Hastings Center Report*. <https://doi.org/10.1353/hcr.0.0113>
- Buller, T. (2015). Advance consent, critical interests and dementia research. *Journal of Medical Ethics*. <https://doi.org/10.1136/medethics-2014-102024>
- Chiarchiaro, J., Buddadhumaruk, P., Arnold, R. M., & White, D. B. (2015). Prior Advance Care Planning Is Associated with Less Decisional Conflict among Surrogates for Critically Ill Patients. *Annals American Thoracic Society*, 12(10), 1528–1533.
<https://doi.org/10.1513/AnnalsATS.201504-253OC>
- Coppolino, M., & Ackerson, L. (2001). Do surrogate decision makers provide accurate consent for intensive care research? *Chest*, 119(2), 603–612. <http://dx.doi.org/10.1378/chest.119.2.603>
- Cova, I., Markova, A., Campini, I., Grande, G., Mariani, C., & Pomati, S. (2017). Worldwide trends in the prevalence of dementia. *Journal of the Neurological Sciences*, 379, 259–260.
[https://doi.org/10.1016/S0140-6736\(12\)60399-7](https://doi.org/10.1016/S0140-6736(12)60399-7)

- Department of Constitutional Affairs. (2007). Mental Capacity Act 2005: Code of Practice. *The Stationary Office*. <https://doi.org/10.1108/eb003163>
- Department of Health and Social Care. (2019). *Dementia 2020 Challenge: 2018 Review Phase 1*.
- Fetherstonhaugh, D., Mcauliffe, L., Shanley, C., Bauer, M., & Beattie, E. (2017). "Did I make the right decision?" The difficult and unpredictable journey of being a surrogate decision maker for a person living with dementia. *Dementia*, 1–14. <https://doi.org/10.1177/1471301217721862>
- Harding, R., & Peel, E. (2018). Polyphonic Legality: Power of Attorney Through Dialogic Interaction. *Social & Legal Studies*, 096466391880340. <https://doi.org/10.1177/0964663918803409>
- Heesters, A. M., Buchman, D. Z., Anstey, K. W., Bell, J. A. H., Russell, B. J., & Wright, L. (2016). Power of Attorney for Research: The Need for a Clear Legal Mechanism. *Public Health Ethics*, 10(1), phw035. <https://doi.org/10.1093/phe/phw035>
- HMSO, London. *Mental Capacity Act 2005*.
- Huxtable, R. (2015). Advance decisions: worth the paper they are (not) written on? *BMJ Heart*, 5(1), e000002. <https://doi.org/10.1136/EOLJNL-2015-000002>
- Jones, K., Birchley, G., Huxtable, R., Clare, L., Walter, T., & Dixon, J. (2016). End of life care: A scoping review of experiences of Advance Care Planning for people with dementia. *Dementia*. <https://doi.org/10.1177/1471301216676121>
- Karlawish, J., Rubright, J., Casarett, D., Cary, M., Ten Have, T., & Sankar, P. (2009). Older Adults' Attitudes Toward Enrollment of Non-competent Subjects Participating in Alzheimer's Research. *American Journal of Psychiatry*, 166(2), 182–188. <https://doi.org/10.1176/appi.ajp.2008.08050645>
- Kim, S. Y. H. (2011). The ethics of informed consent in Alzheimer disease research. *Nature Reviews. Neurology*, 7(7), 410–414. <https://doi.org/10.1038/nrneurol.2011.76>
- Kim, S. Y. H., Karlawish, J. H. T., & Caine, E. D. (2002). Current state of research on decision-making competence of cognitively impaired elderly persons. *The American Journal of Geriatric Psychiatry*, 10(2), 151–165.

- Lord, K., Livingston, G., & Cooper, C. (2015). A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *International Psychogeriatrics*, 27(8). <https://doi.org/10.1017/S1041610215000411>
- Lötjönen, S. (2006). Medical Research on Patients with Dementia – the Role of Advance Directives in European Legal Instruments. *European Journal of Health Law*, 13(3), 235–261. <https://doi.org/10.1163/157180906778852394>
- National Institute for Health and Care Excellence. (2018a). *NICE guideline NG97 Dementia: assessment, management and support for people living with dementia and their carers*.
- National Institute for Health and Care Excellence. (2018b). *NICE guideline NG108 Decision-making and mental capacity*. Retrieved from NICE website: <https://www.nice.org.uk/guidance/ng108>
- Nuffield Council on Bioethics. (2009). *Dementia: ethical issues*. Retrieved from <http://www.nuffieldbioethics.org>
- Office of the Public Guardian. (2016). *Office of the Public Guardian Annual Report & Accounts 2016/2017*. Retrieved from OPG website: www.gov.uk/government/publications
- Pierce, R. (2010). A changing landscape for advance directives in dementia research. *Social Science & Medicine*, 70(4), 623–630. <https://doi.org/10.1016/j.socscimed.2009.10.037>
- Ploeg, J., Northwood, M., Duggleby, W., Chambers, T., Peacock, S., & Fisher, K. (2019). Caregivers of older adults with dementia and multiple chronic conditions: Exploring their experiences with significant changes. *Dementia*. <https://doi.org/10.1177/1471301219834423>
- Porteri, C. (2018). Advance directives as a tool to respect patients' values and preferences: discussion on the case of Alzheimer's disease. *BMC Medical Ethics*, 19(1), 9. <https://doi.org/10.1186/s12910-018-0249-6>
- Public Guardian v DA [2018] EWCOP 26.*, (2018).
- QSR International. (2015). NVivo qualitative data analysis software Version 11.

- Ries, N. M., Thompson, K. A., & Lowe, M. (2017). Including People with Dementia in Research: An Analysis of Australian Ethical and Legal Rules and Recommendations for Reform. *Journal of Bioethical Inquiry*, 14(3), 359–374. <https://doi.org/10.1007/s11673-017-9794-9>
- Samanta, J. (2012). There's Nothing New in Dying Now: Will Welfare Attorney Decision Making at End of Life Make a Real Difference? *Journal of Law and Society*, 39(2), 241–268. <https://doi.org/10.1111/j.1467-6478.2012.00580.x>
- Samanta, Jo. (2009). Lasting powers of attorney for healthcare under the Mental Capacity Act 2005: Enhanced prospective self-determination for future incapacity or a simulacrum. *Medical Law Review*, 17(3), 377–409. <https://doi.org/10.1093/medlaw/fwp018>
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, 18(2), 179–183. <https://doi.org/10.1002/nur.4770180211>
- Shalowitz, D. I., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers: a systematic review. *Archives of Internal Medicine*, 166(5), 493–497.
- Shepherd, V., Griffith, R., Sheehan, M., Wood, F., & Hood, K. (2018). Healthcare professionals' understanding of the legislation governing research involving adults lacking mental capacity in England and Wales: a national survey. *Journal of Medical Ethics*. <https://doi.org/10.1136/medethics-2017-104722>
- Shepherd, V., Hood, K., Sheehan, M., Griffith, R., Jordan, A., & Wood, F. (2018). Ethical understandings of proxy decision making for research involving adults lacking capacity: A systematic review (framework synthesis) of empirical research. *AJOB Empirical Bioethics*, 1–20. <https://doi.org/10.1080/23294515.2018.1513097>
- Shepherd, V., Hood, K., Sheehan, M., Griffith, R., & Wood, F. (2019). 'It's a tough decision': A qualitative study of proxy decision-making for research involving adults who lack capacity to consent in UK. *Age and Ageing*, 1–7. <https://doi.org/10.1093/ageing/afz115>

Sim, J., Saunders, B., Waterfield, J., & Kingstone, T. (2018). Can sample size in qualitative research be determined a priori? *International Journal of Social Research Methodology*, 21(5), 619–634. <https://doi.org/10.1080/13645579.2018.1454643>

Smebye, K. L., Kirkevold, M., & Engedal, K. (2012). How do persons with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health Services Research*, 12(1), 241. <https://doi.org/10.1186/1472-6963-12-241>

Taylor, J. S., DeMers, S. M., Vig, E. K., & Borson, S. (2012). The Disappearing Subject: Exclusion of People with Cognitive Impairment and Dementia from Geriatrics Research. *Journal of the American Geriatrics Society*, 60(3), 413–419. <https://doi.org/10.1111/j.1532-5415.2011.03847.x>

The Medicines for Human Use (Clinical Trials) Regulations 2004 SI No.1031.

Wendler, D., & Rid, A. (2011). Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others. *Annals of Internal Medicine*, 154(5), 336. <https://doi.org/10.7326/0003-4819-154-5-201103010-00008>

West, E., Stuckelberger, A., Pautex, S., Staaks, J., & Gysels, M. (2017). Operationalising ethical challenges in dementia research—a systematic review of current evidence. *Age and Ageing*, 46(4), 678–687. <https://doi.org/10.1093/ageing/afw250>

Yarborough, M. (2015). Inconsistent Approaches to Research Involving Cognitively Impaired Adults: Why the Broad View of Substituted Judgment Is Our Best Guide. *The American Journal of Bioethics*, 15(10), 66–67. <https://doi.org/10.1080/15265161.2015.1075803>