BJPsych Open (2019)
5, e50, 1–8. doi: 10.1192/bjo.2019.42

Advance decisions to refuse treatment and suicidal behaviour in emergency care: 'it's very much a step into the unknown'

Leah Quinlivan, Rebecca Nowland, Sarah Steeg, Jayne Cooper, Declan Meehan, Joseph Godfrey, Duncan Robertson, Damien Longson, John Potokar, Rosie Davies, Neil Allen, Richard Huxtable, Kevin Mackway-Jones, Keith Hawton, David Gunnell and Nav Kapur

Background

Complex challenges may arise when patients present to emergency services with an advance decision to refuse life-saving treatment following suicidal behaviour.

Aims

To investigate the use of advance decisions to refuse treatment in the context of suicidal behaviour from the perspective of clinicians and people with lived experience of self-harm and/or psychiatric services.

Method

Forty-one participants aged 18 or over from hospital services (emergency departments, liaison psychiatry and ambulance services) and groups of individuals with experience of psychiatric services and/or self-harm were recruited to six focus groups in a multisite study in England. Data were collected in 2016 using a structured topic guide and included a fictional vignette. They were analysed using thematic framework analysis.

Results

Advance decisions to refuse treatment for suicidal behaviour were contentious across groups. Three main themes emerged from the data: (a) they may enhance patient autonomy and aid clarity in acute emergencies, but also create legal and ethical uncertainty over treatment following self-harm; (b) they are anxiety provoking for clinicians; and (c) in practice, there are challenges in validation (for example, validating the patient's mental capacity at the time of writing), time constraints and significant legal/ethical complexities.

Conclusions

The potential for patients to refuse life-saving treatment following suicidal behaviour in a legal document was challenging and anxiety provoking for participants. Clinicians should act with caution given the potential for recovery and fluctuations in suicidal ideation. Currently, advance decisions to refuse treatment have questionable use in the context of suicidal behaviour given the challenges in validation. Discussion and further patient research are needed in this area.

Declaration of interest

D.G., K.H. and N.K. are members of the Department of Health's (England) National Suicide Prevention Advisory Group. N.K. chaired the National Institute for Health and Care Excellence (NICE) guideline development group for the longer-term management of self-harm and the NICE Topic Expert Group (which developed the quality standards for self-harm services). He is currently chair of the updated NICE guideline for Depression. K.H. and D.G. are NIHR Senior Investigators. K.H. is also supported by the Oxford Health NHS Foundation Trust and N.K. by the Greater Manchester Mental Health NHS Foundation Trust.

Keywords

Self-harm; suicidal behaviour; emergency services; mental capacity; Mental Capacity Act.

Introduction

Advance decisions to refuse treatment enable people to express their treatment preferences when they may lack mental capacity in the future.[1,2] In England and Wales, the Mental Capacity Act specifically sets out provisions governing advance decisions to refuse treatment for people aged 18 or over.[1] These decisions are legally binding, if they were made at a time when the patient had mental capacity and they are valid and applicable to the current circumstances.[2] In addition, if an advance decision is to apply to life-sustaining treatment, it must be written, signed, witnessed, acknowledge that life is at risk and not have been subsequently withdrawn.[2,3] In the absence of a valid advance decision, judgments are made on the basis of the patient's best interests.[3] Where a patient has mental capacity, and is able to communicate their treatment preferences, they can refuse treatment verbally.[2] Mental capacity is determined by the ability to understand, use and weigh relevant information, retain that information long enough to make a decision and communicate a decision with others.[2]

Related terms that have been used in the international literature include advance directives, advance statements and Ulysses contracts. Advance directives refer to treatment choices in the future more generally and advance statements are requests for healthcare treatment wishes or preferences.[3,4] Ulysses contracts are used to mandate treatment procedures if the person loses capacity (for example, treatment choices/preferences when capacity may be lost during psychiatric illnesses such as bipolar affective disorder).[5] However, the Mental Capacity Act only legally applies to advance decisions to refuse treatment.[1] In this paper, we focus on advance decisions to refuse life-saving medical treatment specifically in the context of suicidal behaviour.[1–3]

A recent scrutiny of the Mental Capacity Act in England found low levels of implementation and a lack of awareness and understanding of the Act that may result in clinicians acting in a risk averse way, inhibiting patient autonomy.[1,6,7] Previous research indicates a lack of understanding of roles and responsibilities within the Act among clinicians.[8–11] Clinical and public awareness over the

advance decisions component is low.[3] In the decade since the implementation of the Act, only around 3% of the general population have made an advance decision about medical care choices.[3,6] Despite the low implementation of the Act, there is an increasing trend in the use of advance decisions and directives in mental healthcare.[12] In a recent survey of 554 patients with bipolar disorders, 199 (36.6%) participants were familiar with the Mental Capacity Act, 54 (10%) had an advance decision to refuse treatment and 62 (11%) had an advance statement for treatment wishes.[13]

Advance decisions to refuse life-saving treatment and suicidal behaviour

Despite the legal basis in the Mental Capacity Act, there are likely to be challenges in the use of advance decisions to refuse treatment in the context of suicidal behaviour, and evidence suggests little consistency in patient management.[1,14–16] Legal, ethical and clinical experts have questioned the validity of advance decisions for patients who attempt suicide, particularly in the context of complex psychiatric histories.[15,16] In England and Wales, treatments that are prohibited in an advance decision may be provided under the Mental Health Act 2003 in certain circumstances if the individual is assessed as meeting the criteria for detention.[1,17] However, patients with a psychiatric diagnosis should not be assumed to lack capacity to make such decisions.[2]

Given that there are approximately 220 000 self-harm presentations to emergency departments annually in England,[18] a greater understanding of advance decisions to refuse treatment following suicidal behaviour is important. There is a scarcity of research examining frequency of advance decisions and suicidal behaviour but one study showed that 2.5% of patients who presented to hospital with self-poisoning and then died had an advance decision in place.[15] The existing research is predominantly case studies and relates to advance directives in the context of terminal or chronic physical illnesses and/or disabilities.[16,19]

Advance decisions to refuse treatment present particular challenges in the context of suicidal behaviour in hospital services but there is limited research in this area. Little is known about how emergency services evaluate advance decisions to refuse treatment and there is evidence from documented cases that ethical, practical and legal difficulties may arise.[14,15]

Objectives

The aim of this study was to evaluate the use of advanced decisions to refuse treatment in the context of suicidal behaviour from an emergency service perspective. Our objective was to explore the views of front-line clinicians and people with lived experience on the use of advance decisions in the context of suicidal behaviour. The findings will be useful to inform policy and practice in relation to the feasibility and acceptability of advance decisions to refuse treatment and suicidal behaviour in emergency services.

Method

Design and participants

The study was conducted as part of a large mixed methods and guideline development study on advance decisions, mental capacity and suicidal behaviour. For the focus group component, we used a qualitative pragmatic design, consisting of discussions with paramedic, emergency department and liaison psychiatry clinicians and people with personal experience of self-harm, suicidal behaviour and mental health services. Focus groups were used because group interaction encourages participants to ask questions, share experiences and present points of view on areas of importance to them.[20] We were particularly interested in the experience and suggestions of participants.

Recruitment

We used purposive sampling to ensure adequate staff and lived experience group representation. Individuals were eligible to take part in the study if they: (a) were working in clinical services, or (b) had lived experience of psychiatric and/or self-harm services, or (c) were a member of a community support group with experience of mental illness, self-harm and/or advance decisions.

Participants for the clinician focus groups were identified through local collaborators in five participating National Health Service Trusts in North West and South West England. The Trusts were chosen purposively to include a wide geographic and professional range of front-line clinicians and experiences for the focus groups. People with experience of self-harm, mental illness and/or advance decisions were recruited through relevant community groups in two centres. A £20 shopping voucher as compensation for participant's time was made available.

Two experienced researchers L.Q. (chartered psychologist/research associate) and J.C. (nurse/senior research fellow) conducted the focus groups. Participants were informed that all identifiable information would be removed from the transcripts, but that job titles would be included when reporting the findings. Participants were made aware of their right to withdraw from the study before, during and after data collection. Because of the sensitive nature of the discussion the availability of emotional support for participants from line managers and group facilitators, if required, was explained.

Ethics statement

The study was reviewed and approved by the North West- Greater Manchester Research Ethics Committee (REC No: 16/NW/0173) prior to commencement.

Focus group procedure

All participants provided written informed consent for participation and audio recording of the group discussion. We used a structured topic guide with probes to ascertain people's views on advance decisions to refuse treatment and the Mental Capacity Act in the context of suicidal behaviour. The topic guide was developed in line with our research objectives and included the following open-ended questions: (a) 'What experience have you had of the Mental Capacity Act and advance decisions?'; (b) 'How do you think the presence of an advance decision which refuses life-saving medical treatment should influence the medical management of patients presenting to hospital with self-harm?'; and (c) 'Do you think patients who present with serious self-harm and are conscious should be able to refuse life-saving medical treatment?'

Participants were also asked for their opinion on a fictional clinical vignette in order to aid discussions and focus the topic on suicidal behaviour (see Supplementary Appendix 1 available at https://doi.org/10.1192/bjo.2019.42). Fictional vignettes are widely used in qualitative research as a way of discussing sensitive research topics.[21] Vignettes are useful in focus groups with sensitive topics as potential fears or stigma can be situated on to the vignette rather than on to the participants themselves.[22]

Analysis

Focus group discussions were recorded, transcribed verbatim and analysed in accordance with the thematic framework method,[23,24] (see Supplementary Appendix 2 for further details). In brief, L.Q. summarised transcripts and wrote notes on non-verbal behaviour

and context. Preliminary categories and codes in the coding framework were discussed within the team (R.N., L.Q., S.S. and N.K.) and revised accordingly. The transcripts were then re-read and the framework tested by S.S. and R.N. for two focus groups independently to ensure the codes adequately represented the data. The data were summarised and charted by category and by occupation and lived experience group membership. Emerging themes were refined and revised through discussion between R.N., L.Q. and S.S. Saturation was indicated when no further themes emerged from the charts and/or discussions. QSR International's NVivo 10 Software[25] was used for data management and Microsoft Excel for summarising and charting.

Results

A total of 41 participants (28 clinical staff and 13 lived experience group members) took part in one of the six focus groups conducted between June 2016 and January 2017. The focus groups took place either on-site or at the university hosting the research (see Table 1). Each lasted approximately 90 min. No participants declined to take part in the study. Characteristics of focus group participants are displayed in Table 1.

Themes

Three main themes and ten subthemes emerged from the data and are shown in Appendix 1. A brief description of the main themes is provided in Appendix 2.

Participants reported a lack of awareness and anxiety over the management of patients presenting to emergency services with an advance decision to refuse treatment in the context of suicidal behaviour. Several participants had some experience of advance decisions in the context of physical health and end-of-life care. One paramedic had experience of managing two elderly patients with advance decisions in the context of physical illness. The potential for patients to refuse life-saving treatment following suicidal behaviour in a legal document was challenging and the feasibility of the policy was questioned by clinician and lived experience groups.

Theme 1: advance decisions and suicidal behaviour – aid clarity but create uncertainty

Aid clarity and support patient autonomy

The usefulness of advance decisions in the context of suicidal behaviour was viewed as contentious across groups. Some emergency department clinicians and ambulance paramedics saw advance decisions as potentially useful for aiding clarity when understanding a person's wishes and treatment preferences.

> 'I think it would provide clarity to the situation because what we often find with incidents involving mental health patients is that they're very complicated and very rarely would we get any clear documentation giving you a clear treatment plan or what to withhold from that patient.' (Paramedic 4)

Lived experience group members felt that advance decisions could help them have their treatment choices respected when they lacked capacity and could be particularly useful when health advocates or family members were not available to put forward their wishes.

> '…but say, like I've just said, if you've got no family appointee for you, I've always felt there should be some sort of legal propriety there, for somebody to have an appointee no matter what, to have their wishes down, legally.' (Lived experience group 6)

Legally binding documents

Table 1 Characteristics of focus groups participants

	Ambulance paramedics ($n = 5$)	Emergency department clinicians[a] (group 1) ($n = 11$)		Emergency department clinicians[b] (group 2) ($n = 6$)	Mental health liaison clinicians[c] ($n = 6$)	Lived experience group (self-harm) ($n = 4$)	Lived experience group (mental health patient/carer group)[d] ($n = 9$)	Total ($n = 41$)
Location of focus group	University	Hospital		Hospital	University	Community group premises	Community group premises	
Age, median (range)	36 (24–42)	40 (28–44)		37 (32–61)	42 (31–48)	48 (47–61)	47 (34–68)	41 (24–68)
Gender, *n* (%)								
Men	3 (60)	10 (90.9)		2 (33.3)	1 (16.7)	3 (75)	4 (44.4)	23 (56.1)
Women	2 (40)	1 (9.1)		4 (66.7)	5 (83.3)	1 (25)	5 (55.6)	18 (43.9)
Formal religion, *n* (%)								
Yes	2 (40)	8 (80)[e]		3 (50)	4 (66.7)	1 (25)	3 (33.3)	21 (52.2)[e]
Ethnicity, *n* (%)								
White British	5 (100)	3 (27.3)		5 (83.3)	5 (83.3)	4 (100)	9 (100)	31 (75.6)
Black and minority ethnic group	0	8 (72.7)		1 (16.7)	1 (16.7)	0	0	10 (24.4)
Years of clinical experience, median (range)	11 (0.6–17)	12 (3–28)		12 (7–25)	14 (5–37)	NA	NA	12 (0.6–37)

a. Emergency department doctors and consultants.
b. Emergency department doctors and nurses.
c. Liaison psychiatry nurses.
d. People with lived experience of self-harm, attempted suicide, death by suicide and/or carers.
e. Formal religion missing for one individual in the emergency department clinicians group.

Some healthcare workers viewed advance decisions as legally binding documents that should be adhered to following checks of authenticity and evidence of capacity at the time of writing.

> '…if it was crystal clear and as it was with the advanced decision … I think it would just be followed and respect the patient's wishes, their advanced decision.' (Paramedic 3)

Emergency department clinicians and ambulance paramedics noted that life-saving treatment may have already commenced before clinicians become aware of an advance decision, for example in self-poisoning incidents that can be reversed with specific medications.

Questioning the appropriateness of advance decisions for suicidal behaviour

In contrast to those clinicians that felt that advance decisions are legally binding documents that should be adhered to, some clinicians were uncertain if advance decisions should be used in the context of suicidal behaviour. Several liaison psychiatry clinicians suggested that advance decisions are more appropriate for end-of-life treatment preferences. Some suggested that suicidal behaviour, suicide ideation and self-harm were symptoms of a psychiatric illness that people could recover from which is different from a terminal physical illness where recovery may not be possible.

> '…if they are terminally ill they're not getting better. If they're depressed, there is treatment and there is the hope that they can get better and that view may be different. Whereas you're terminally ill, there's no going back from this. Depression, there is a way back.' (Liaison psychiatry clinician 1)

There was a strong view expressed by the liaison psychiatry clinicians that people can change their mind about suicide.

> 'To treat or not to treat. This is always difficult as many patients we see who have attempted suicide are relieved that their actions were not fatal. This is backed up by research of survivors. There is no doubt that in many cases the intent "in the moment" is to end their life. Considering this then treatment should be provided. Intent behind the actions would need to be explored, which unfortunately is not always possible.' (Liaison psychiatry clinician 1)

Lived experience group members echoed this and recalled personal experiences of changing their mind about suicide. One lived experience group member reflected:

> 'I did change my mind after I got better, and I was obviously lucky, looking back at it now, I must admit. But at the time, I was very serious.' (Lived experience group 2).

Participants also queried the desire to die if the person had phoned an ambulance or presented themselves to hospital as this may indicate that they had changed their mind.

> '…it could have been current when she took the overdose but if she then sought help and requested somebody to bring her to hospital, is it then still current? Does that indicate she has changed her mind about her belief, her wishes for this advanced directive, as it would with physical health issues if someone could one minute they said they wouldn't have the treatment they may be kept in hospital and monitored, but they may change their mind the next day.' (Liaison psychiatry clinician 4)

Mental state and distress fluctuate

Several participants argued that because of the fluctuating nature of mental state/distress advance decisions should not be adhered to without considering the context, including the severity of psychiatric illness, the person's previous medical and mental health history, age and mental state at the time of writing the advance decision and the length of time passed since writing the advance decision.

Participants described the mental state of people in a suicidal crisis as severely distressed, in disarray and focused on attempting suicide. Clinicians indicated that when people attempt suicide, they are not 'thinking that straightforwardly' (Emergency department clinician 1), and lived experience group members suggested that when you are in that state you are 'not in your right mind' (Lived experience group 2), reflecting on their own personal experiences. The responses from the focus groups indicated that treatment refusal in this context is further complicated by the notion that acute mental distress fluctuates. Mental health was seen as 'cyclical' (Emergency department clinician 1) and at different times a person's mental state can be very different; like 'chalk and cheese' (Lived experience group 3).

> 'I actually know what it's like to hit rock bottom, and I really wouldn't wish that on anybody. And, like, maybe a week later, I might be really low, but I mightn't be as low as I was the week before. But I wouldn't be that far away from it. And so, my thinking would be that little bit different because I'm not at rock bottom, but I'm just a bit up from it. So, therefore, my opinions will be slightly different.' (Lived experience group 4)

Theme 2: advance decisions with suicidal behaviour – anxiety provoking for clinicians

Professionally and personally challenging

There was anxiety around deciding whether or not to comply with the advance decision in the context of suicidal behaviour. All groups noted a strong feeling of 'assisting suicide' if adhering with the advance decision. Community group members acknowledged that it was a 'horrible' (Lived experience group 5) and 'difficult' (Lived experience group 6) decision for doctors to make. Mental health clinicians echoed this suggesting it was an 'uncomfortable decision to make' (Liaison psychiatry clinician 2). There was discussion in all of the clinician groups that anxiety stemmed from feeling that the situation was going against their training and professional role.

> 'Yeah, it's very much a step into the unknown isn't it? I think with a decision like this, because the essential ethos of a paramedic is to preserve life and to act with an advanced directive like this, culturally it's very difficult I think for paramedics to take on board, we're better at it than we ever have been don't get me wrong but I still think it's quite a leap of faith.' (Paramedic 2)

Clinicians also expressed a sense of going against their own personal ethics:

> 'from my point of view it's right to do it in the sense that it's legal, but whether it's right to do it from a moral point of view is a bit different.' (Liaison psychiatry clinician 3)

Anxiety about litigation

Anxiety also stemmed from fears of litigation in this particular context. Some clinicians feared that non-adherence could be seen as 'assaulting' the patient (Emergency department clinician 2) and that there was a need to be accountable for your actions.

> '…these would be unusual incidents, these aren't going to be everyday run of the mill decisions, they're not going to happen frequently and there's going to be a degree of scrutiny afterwards and I think that's kind of what we're alluding to and there's the self-scrutiny as in you reflect back on did I make the

> right decision, have I done the right thing there? Which weighs heavy on some people compared to others.' (Paramedic 2)

Some emergency department clinicians felt that the decision for medical management ultimately rested with them, that if you are 'unsure you should treat' (Emergency department clinician 4) because 'you're going to get in trouble by standing back and letting people die' (Emergency department clinician 5). Emergency department clinicians felt that although the guidance is clear, they would 'struggle with that decision' (Emergency department clinician 1).

Some clinicians argued that the age of the patient with an advance decision would not affect their care plan, but it would be 'a really emotive decision' (Paramedic 5). If a patient was young, concerns were expressed about the duration of mental health difficulties, the transient nature of mental distress over the years and the level of experience necessary in order to make life-ending treatment decisions.

Dissipate anxiety: share the burden of decision-making

Reaching a treatment decision was viewed as a significant responsibility that should be shared with others in order to ease the burden and reduce anxiety. Ambulance paramedics suggested that they would consult with senior colleagues about the decision. Emergency department clinicians indicated that they would consult with senior colleagues, mental health teams and take legal advice. Ambulance paramedics highlighted the need for supervision and emotional support following the decision. However, the logistics of shared decisions were at times not straightforward. For example, mental health clinicians felt they were not always contacted for assessments when patients presented to the hospital with self-harm.

Theme 3: the challenge of validation

Cautious of accepting advance decisions with suicidal behaviour

Clinicians generally refused to accept an advance decision in the context of suicidal behaviour without extensive validation checks. The inability to check mental capacity at the time of writing the advance decision was expressed as a particular concern.

> 'And what would make you satisfied that it is if you've never met this person before? You've got the document, were they harassed? I don't know. Well, did they have capacity at the time, a few months ago? I don't know. It says here, who signed it? I don't know. Who was it? Was it a relative? How could you ever be satisfied? (Emergency department clinician 6)

At least in circumstances where the patient was conscious or drifting in and out of consciousness but had an advance decision, there would be an opportunity to assess the current mental capacity of the patient to corroborate the advance decision.

> 'I was going to say, if they'd had an advanced directive three or six months ago, and then they're sitting there telling you the same thing, then that increases your belief in them wanting that decision, that being the decision they truly want…' (Emergency department clinician 4)

Validating advanced decisions in emergency service: practical issues

The groups expressed several practical difficulties when validating an advance decision in an emergency situation. The emergency department clinicians and ambulance paramedics expressed difficulties making verification checks given that mental health crises typically occur outside normal working hours when 'getting access to someone is incredibly difficult' (Emergency department clinician 1).

The ambulance paramedics noted difficulty with making a decision at the scene of the incident in the absence of the patient's full details.

> '…we don't have access to the same records, the patient summary care records and I think that can be what throws us into the unknown because we don't know what the patient is that's led up to that point where we're…they've presented to us and we're seeing them. So we're trying to understand very quickly a lot of information about that patient in a very short space of time and very rarely can we get hold of all information to help us make a balanced decision.' (Paramedic 4)

Participants in the lived experience groups, ambulance paramedics and emergency department clinicians suggested that advance decisions should be registered centrally with the general practitioner or hospital and be available electronically to enable 24 h access for verification. The clinicians preferred the advance decision to be signed by a general practitioner. The lived experience groups felt more confident about clinicians adhering to the advance decision if the patient also had a health advocate or someone with a power of attorney. The lived experience groups, ambulance paramedics and emergency department clinicians all highlighted the need for advance decisions to be clear and detailed, outlining the specific treatments to be given and withheld, to avoid confusion and uncertainty. There was a strong consensus from participants across all groups that advance decisions, including assessment of capacity, should be reviewed regularly to reflect the current views of the patient.

Corroboration from families but with caution

While there was a desire to speak to families for corroboration, both emergency department and liaison psychiatry clinicians were tentative, seeing a need to 'make sure that they weren't harassed or bullied into signing it' (Emergency department clinician 6). This was echoed in the community groups, where members gave specific examples of instances where families had ulterior motives; they may 'want this person out of their lives or may get some money for her passing' (Lived experience group 6). Lived experience group members felt it was possible that a person in a distressed mental state could sign a document without any consideration of its content.

Discussion

Main findings

Advance decisions to refuse treatment following suicidal behaviour were perceived as having serious ethical, personal, professional and legal implications that limit their acceptability in emergency services. Suicidal intent and mental state were perceived as dynamic and in an emergency setting it was deemed practically impossible to verify the patient's mental capacity at the time of writing the advance decision. Clinicians felt that treatment decisions for patients presenting with advance decisions and suicidal behaviour had increased emotional gravity and professional consequences because a patient with psychiatric difficulties might recover, in contrast to a patient with terminal physical illness. Some participants queried whether advance decisions to refuse treatment were appropriate for use in the context of suicidal behaviour and/or mental health in general.

There were differences between the clinical groups in terms of complying with an advance decision. Emergency department

clinicians and ambulance paramedics stressed the legally binding nature of an advance decision and that non-adherence may result in litigation. In contrast, liaison psychiatry clinicians tended to view advance decisions as more appropriate for physical health conditions. All of the clinician groups highlighted difficulties accessing the level of patient information needed to make a treatment decision and would not accept advance decisions without any credibility checks or verification from other professionals. Paramedics did not always have access to full patient records and had to make rapid decisions, so they relied predominately on consulting with senior colleagues. In contrast, emergency department and liaison psychiatry clinicians had stronger relationships with more shared and accessible data about patients.

Issues discussed by clinicians and lived experience group members were largely similar; both highlighted the fluctuating and changing nature of suicidal ideation and raised concerns about the appropriateness of advance decisions in this context. The lived experience groups also expressed the view that advance decisions may offer psychiatric patients the opportunity to have control over their treatment choices and stressed the usefulness of an advance decision when a person does not have a healthcare advocate or power of attorney. A similar expression of patient autonomy came from the paramedics and emergency department clinicians, but focused on the potential for advance decisions to detail patients' treatment choices or existing treatment plans, which could be included in the decision-making process.

Participants in the lived experience groups highlighted the importance of considering the context of the suicide attempt and understanding the person's psychiatric history when making any treatment decisions. In addition to differences between the groups, there were also differences of opinion within both the clinician and community groups; some argued that advance decisions may not be appropriate in the context of suicidal behaviour, whereas others argued that they are legal documents that must be followed.

Comparison with previous research

Previous empirical studies that examined experiences and views of healthcare workers about the Mental Capacity Act demonstrated a lack of knowledge and training among clinicians.[8–11] In the current study, clinicians were aware of the Mental Capacity Act[1] in general but, consistent with the House of Lords report[6] and Huxtable,[3] there was a lack of familiarity with advance decisions and their validity in the context of suicidal behaviour. Similar to research with people who survived serious suicide attempts,[26,27] participants highlighted the potential for recovery from severe psychiatric distress and the ambivalence inherent in suicidal behaviour, which raises ethical dilemmas for the use of advance decisions to refuse treatment in this context.

In contrast to previous research, we focused on the advance decisions component of the Mental Capacity Act because of the particular issues that may arise in the context of suicidal behaviour.[15] Differences between our study and previous research may be because the clinical setting in previous studies have typically examined geriatric and/or end-of-life healthcare, whereas we focused on emergency care.[8–11]

The discussion by clinicians and lived experience group members about suicidal behaviour involving distress and fluctuating thought processes is congruent with research indicating that a person who is suicidal may be in a cognitive state with restricted and limited decision-making capacity.[28] People in this state of suicidal crisis may view their only options as to live or die at that moment.[29] There is also evidence that a person's suicidal intent varies within and between episodes of self-harm.[30,31] Advance decisions in the context of long-term and sustained suicidal ideation might raise different issues, which would be important to explore in future research.

Strengths and limitations

There is a scarcity of research on the medical management of patients presenting to emergency services with advance decisions to refuse treatment and suicidal behaviour. To our knowledge this is the first study to evaluate the use of advance decisions in this context from the perspective of clinicians and people with lived experience of mental illness and/or self-harm. Our results highlight the challenging and complex nature of clinical care when treating patients who have engaged in suicidal behaviour and refuse treatment with an advance decision. Our findings will be important to inform further research, clinical training, policy and practice in this area. We investigated the feasibility and acceptability of advance decisions following suicidal behaviour in emergency services. It was beyond the scope of our study to explore the significant ethical and moral issue of allowing a person to die from the consequences of a suicidal act but this should be explored in future research.

We recruited front-line clinicians because our research was focused on the evaluation of advance decisions to refuse treatment following suicidal behaviour in emergency settings. Clinical decisions about advance decisions following self-harm for psychiatric in-patients may be different to those for patients who are admitted to emergency services.[32] The management of advance decisions may also raise separate and further important issues in other settings such as general practice, which necessitates further research.

Our cross-disciplinary approach enabled us to examine experiences, knowledge and views from different clinical perspectives. We also included a broad range of patients and carers with experience of mental health services, mental illness, attempted suicide, self-harm or had lost a significant other to suicide. Future research could more narrowly focus on patients with experiences of attempted suicide to more fully develop themes from this important perspective. There were larger numbers of clinicians than lived experience group members so there is a risk that the clinical stance may have dominated the patient perspectives in the analysis. Future research in this area could use co-design methods to gain a comprehensive evaluation of advance decisions for suicidal behaviour from a patient perspective and recruit a larger sample.[33]

We did not recruit any consultant psychiatrists for our liaison psychiatry focus groups, which is a recruitment limitation. Consultant psychiatrists are important to include in research in advance decisions and suicidal behaviour. The expert opinion of consultant psychiatrists is a key determinant in evaluation of capacity and best interests for patients presenting with suicidal behaviour and refusing treatment. Our multidisciplinary team included three senior consultant psychiatrists (J.P., D.L. and N.K.) who were instrumental in the design of the study, interview questions, case study and analyses, which increases the trustworthiness of the findings. However, the views of liaison nurses on advance decisions to refuse treatment were useful to include as they provide the immediate front-line capacity assessments when a person presents to the emergency department with self-harm.[34]

Although we ensured that context was considered in the analysis by using contextual notes and examining whole transcripts, a weakness of thematic analysis is that a de-contextualisation of speakers' words may occur that may misrepresent the intended meaning. As with all studies involving the use of focus groups, the findings are the result of interaction within the focus groups. Experienced researchers facilitated the focus groups, which minimised the potential for some participants to dominate the discussions. Future

research in this area, could use alternative methods such as individual interviews or open-ended anonymous online surveys that may provide richer and more personal data especially from the patient perspective.

Impact on policy and practice

Advance decisions, if developed appropriately and robust hospital policies were in place, could potentially help to clarify complex situations, remove some of the subjectivity involved in the decision-making process and promote patient autonomy. However, the application of advance decisions in the context of suicidal behaviour is fraught with challenges and great care is needed when considering how these decisions should be managed in emergency services.[15] The Mental Capacity Act in England and Wales acknowledges people should be treated if there is any doubt over the validity of the advance decision. The Mental Health Act can also be used to provide treatment in some cases if there is evidence of a psychiatric disorder warranting hospital detention.[34] Clinicians may need additional support when managing patients with an advance decision with suicidal behaviour because of the rarity and gravity of such events. Clinicians may also feel that their professional training to provide life-saving treatment may be challenged.

There is an urgent need for wider discussion around the acceptability and feasibility of advance decisions in the context of suicidal behaviour in hospital services, particularly from the patient perspective. Training to help clinicians recognise a legally valid advance decision and recommendations for the management of advance decisions with suicidal behaviour could help to support clinicians. As these cases are likely to be individual and complex, it may be useful to have evidence-based, legal and ethically informed guidance and training is this area. Given the level of anxiety that clinicians may experience over the use of advance decisions to refuse treatment following self-harm, it is important to ensure adequate support and supervision following such incidents in emergency services.

In conclusion, clinicians questioned the feasibility and acceptability of advance decisions to refuse treatment with suicidal behaviour. In this context, advance decisions were perceived as anxiety provoking and placed additional demands on both professional and personal ethics. Some clinicians stressed the legal implications of non-adherence with patients' advance decisions, but others were uncertain about their appropriateness in the context of suicidal behaviour or mental health generally. Conversely, advance decisions were viewed as having the potential to help people who self-harm gain more self-determination over their treatment in emergency settings.

The application of advance decisions in the context of suicidal behaviour is ethically contentious as patients who might otherwise recover may die from the consequences of a suicidal act.[15,34] Clinicians should proceed cautiously given the fluctuation of psychiatric distress and suicidal ideation.[15] Developing guidelines or clinical recommendations for the management of patients presenting with advance decisions with suicidal behaviour could be helpful in terms of policy and practice and may help to overcome some of the clinical uncertainty and anxiety associated with these situations.

Leah Quinlivan, Research Associate, Centre for Suicide Prevention, Manchester Academic Health Science Centre, University of Manchester; and NIHR Greater Manchester Patient Safety Translational Research Centre, UK; **Rebecca Nowland**, Research Associate, Centre for Suicide Prevention, Manchester Academic Health Science Centre, University of Manchester, UK; **Sarah Steeg**, Research Associate, Centre for Suicide Prevention, Manchester Academic Health Science Centre, University of Manchester, UK; **Jayne Cooper**, Senior Research Fellow, Centre for Suicide Prevention, Manchester Academic Health Science Centre, University of Manchester, UK; **Declan Meehan**, Senior Mental Health Practitioner and Operational Manager, Greater Manchester Mental Health NHS Foundation Trust, UK; **Joseph Godfrey**, Emergency Medicine Consultant, Emergency Department, Manchester Royal Infirmary, Manchester University NHS Foundation Trust, UK; **Duncan Robertson**, Senior Paramedic, North West Ambulance Service, UK; **Damien Longson**, Consultant Psychiatrist, Greater Manchester Mental Health NHS Foundation Trust, UK; **John Potokar**, Consultant Psychiatrist, Avon and Wiltshire Mental Health Partnership NHS Trust; University Hospitals Bristol NHS Foundation Trust; and Department of Population Health Sciences, University of Bristol, UK; **Rosie Davies**, Research Fellow, The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care West (NIHR CLAHRC West) at University Hospitals Bristol NHS Foundation Trust; and Faculty of Health and Applied Sciences, University of the West of England, UK; **Neil Allen**, Barrister and Senior Lecturer, School of Law, University of Manchester, UK; **Richard Huxtable**, Professor of Medical Ethics and Law, Department of Population Health Sciences, University of Bristol, UK; **Kevin Mackway-Jones**, Emergency Medicine Consultant, Emergency Department, Manchester Royal Infirmary, Manchester University NHS Foundation Trust, UK; **Keith Hawton**, Professor of Psychiatry, Centre for Suicide Research, University Department of Psychiatry, Warneford Hospital, UK; **David Gunnell**, Professor of Epidemiology, Department of Population Health Sciences, University of Bristol; and National Institute for Health Research Bristol Biomedical Research Centre, University Hospitals Bristol NHS Foundation Trust and University of Bristol, UK; **Nav Kapur**, Professor of Psychiatry and Population Health and Honorary Consultant Psychiatrist, Centre for Suicide Prevention, Manchester Academic Health Science Centre, University of Manchester; NIHR Greater Manchester Patient Safety Translational Research Centre; and Greater Manchester Mental Health NHS Foundation Trust, UK

Correspondence: Leah Quinlivan, Jean McFarlane Building, University of Manchester, Oxford Road, Manchester M13 9PL, UK.
Email: leah.quinlivan@manchester.ac.uk

First received 6 Nov 2018, final revision 19 Mar 2019, accepted 13 May 2019

Acknowledgements

We would like to thank the NIHR Fast-R service and our other patient, carer and clinician advisors for their input into the study. We would also like to thank the Research and Development departments for hosting the research. We are grateful to Steve Lankshear from the NIHR Clinical Research Network staff, Salena Williams and Jennifer Jones in University Hospital Bristol NHS Foundation Trust, for helping to set-up the study and assisting with local recruitment. We are grateful to staff from the hospitals at each site for participating in the research.

Funding

This paper presents independent research funded by the National Institute of Health Research (NIHR) under its Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-0610-10026). The views expressed are those of the authors and not necessarily those of the NHS, the National Institute of Health Research or the Department of Health.

Supplementary material

Supplementary material is available online at https://doi.org/10.1192/bjo.2019.42.

Appendix 1 Themes and subthemes

Topic	Advance decisions and suicidal behaviour		
Main themes	Aid clarity but create uncertainty	Anxiety provoking for clinicians	The challenge of validation
Subthemes	Aid clarity and support patient autonomy	Professionally and legally challenging	Caution about accepting advance decisions
	Legally binding document that should be adhered to	Anxiety about litigation	Validating advance decisions in emergency services: practical issues
	Questioning the appropriateness for suicidal behaviour	Dissipate anxiety: share the burden of decision-making	Corroboration from families but with caution
	Mental state and distress fluctuate		

Appendix 2 Advance decisions and suicidal behaviour: theme descriptions from the focus groups

Theme	Theme description
Aid clarity but create uncertainty	Advance decisions were viewed as having the potential to promote patient autonomy and aid clarity in treatment decisions. This clarity was offset by uncertainty about whether the documents could be used given the complexity of suicidal behaviour. Some argued that they should be followed and stressed the legality of the document, whereas, others were unsure if they should apply in the same way as advance decisions in 'end-of-life' contexts. This uncertainty about whether advance decisions should apply in the context of suicide centred on two issues: (a) whether they were inappropriate in the context of suicidal behaviour and that (b) mental state and distress fluctuate
Anxiety-provoking for clinicians	Participants frequently expressed feeling 'anxiety' about the management of patients with advance decisions and suicidal behaviour. There was anxiety related to advance decisions being professionally and personally challenging and also concern about ligation. Participants suggested that the burden of decision-making in this context should be shared by making a multidisciplinary decision
The challenge of validation	Clinicians required intensive formal checks before accepting an advance decision but the process of validation was deemed challenging because of the time constraints in emergency services. Corroborative evidence was seen as important, but caution was suggested about consulting with family members because of potential for conflicting motives

References

1 Department of Health. *Mental Capacity Act*. TSO, 2005.

2 Department of Constitutional Affairs. *Mental Capacity Act 2005 Code of practice*. TSO, 2007.

3 Huxtable R. Advance decisions: worth the paper they are (not) written on? *End Life J* 2015; **5**: e000002.

4 Seymour J, Gott M, Bellamy G, Ahmedzai SH, Clark D. Planning for the end of life: the views of older people about advance care statements. *Soc Sci Med* 2004; **59**: 57–68.

5 Gergel T, Owen GS. Fluctuating capacity and advance decision-making in bipolar affective disorder—self-binding directives and self-determination. *Int J L Psychiatry* 2015; **40**: 92–101.

6 House of Lords. *Select Committee on the Mental Capacity Act 2005*. TSO, 2014.

7 Marshall H, Sprung S. The Mental Capacity Act: a review of the current literature. *Br J Commun Nurs* 2016; **21**: 406–10.

8 Dunlop C, Sorinmade O. Embedding the Mental Capacity Act 2005 in clinical practice: an audit review. *Psychol Bull* 2014; **38**: 291–93.

9 Evans K, Warner J, Jackson E. How much do emergency healthcare workers know about capacity and consent? *J Accid Emerg Med* 2007; **24**: 391–93.

10 Samsi K, Manthorpe J, Nagendran T, Health H. Challenges and expectations of the Mental Capacity Act 2005: an interview-based study of community-based specialist nurses working in dementia care. *J Clin Nurs* 2012; **21**: 1697–705.

11 Sorinmade O, Strathdee G, Wilson C, et al. Audit of fidelity of clinicians to the Mental Capacity Act in the process of capacity assessment and arriving at best interests decisions. *Qua Ageing Older Adults* 2011; **12**: 174–79.

12 Campbell LA, Kisely SR. *Advance Treatment Directives for People with Severe Mental Illness*. *Cochrane*, 2009.

13 Morriss R, Mudigonda M, Bartlett P, Chopra A, Jones S. National survey and analysis of barriers to the utilisation of the 2005 mental capacity act by people with bipolar disorder in England and Wales. *J Ment Health* 2017: 1–8.

14 David AS, Hotopf M, Moran P, Owen G, Szmukler G, Richardson G. Mentally disordered or lacking capacity? Lessons for management of serious deliberate self-harm. *Br Med J* 2010; **341**: c4489.

15 Kapur N, Clements C, Bateman N, Foëx B, Mackway-Jones K, Huxtable R, et al. Advance directives and suicidal behaviour. *Br Med J* 2010; **34**: c4557.

16 Nowland R, Steeg S, Quinlivan L, Cooper J, Huxtable R, Hawton K, et al. The management of patients with an advance decision and suicidal behaviour: a systematic review. *BMJ Open* 2019; **9**: e023978.

17 Humphreys RA, Lepper R, Nicholson T. When and how to treat patients who refuse treatment. *Br Med J* 2014; **348**: g2043.

18 Hawton K, Bergen H, Casey D, Simkin S, Palmer B, Cooper J, et al. Self-harm in England: a tale of three cities. *Soc Psychiatry Psychiatr Epidemiol* 2007; **42**: 513–21.

19 Houben CH, Spruit MA, Groenen MT, Wouters EFM, Janssen DLA. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc* 2014; **15**: 477–89.

20 Kitzinger J. The methodology of focus groups: the importance of interaction between research participants. *Sociol Health Illn* 1994; **16**: 103–21.

21 Barter C, Renold E. The use of vignettes in qualitative research. *Soc Res Update* 1999; **25**: 1–6.

22 Schoenberg NE, Ravdal H. Using vignettes in awareness and attitudinal research. *Int J Soc Res Methodol* 2000; **3**: 63–74.

23 Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013; **13**: 117.

24 Ritchie J, Spencer L. Qualitative data analysis for applied policy research. *Qual Res Companion* 2002; **573**: 305–29.

25 QSR. *NVivo Qualitative Data Analysis Software (Version 10)*. QSR International Pty, 2012.

26 Rosen DH. Suicide survivors: a follow-up study of persons who survived jumping from the Golden Gate and San Francisco-Oakland Bay Bridges. *West J Med* 1975; **122**: 289.

27 Pajonk F-G, Ruchholtz S, Waydhas C, Schneider-Axmann T. Long-term follow-up after severe suicide attempt by multiple blunt trauma. *Eur Psychiatry* 2005; **20**: 115–20.

28 Szanto K, de Bruin WB, Parker AM, Hallquist MN, Vanyukov PM, Dombrovski AY. Decision-making competence and attempted suicide. *J Clin Psychiatry* 2015; **76**: e1590.

29 Ellis TE, Rutherford B. Cognition and suicide: two decades of progress. *Int J Cogn Ther* 2008; **1**: 47–68.

30 Kapur N, Cooper J, O'Connor RC, Hawton K. Non-suicidal self-injury v. attempted suicide: new diagnosis or false dichotomy? *Br J Psychiatry* 2013; **202**: 326–8.

31 Kleiman EM, Turner BJ, Fedor S, Beale EE, Huffman JC, Nock MK. Examination of real-time fluctuations in suicidal ideation and its risk factors: results from two ecological momentary assessment studies. *J Abnorm Psychol* 2017; **26**: 726.

32 Cook R, Pan P, Silverman R, Soltys SM. Do-not-resuscitate orders in suicidal patients: clinical, ethical, and legal dilemmas. *Psychosomatics* 2010; **51**: 277–82.

33 Goodyear-Smith F, Jackson C, Greenhalgh T. Co-design and implementation research: challenges and solutions for ethics committees. *BMC Med Ethics* 2015; **16**: 78.

34 National Collaborating Centre for Mental Health. *Self-Harm. The Short-Term Physical and Psychological Management and Secondary Prevention of Self-harm in Primary and Secondary Care*. *National Clinical Guideline Number 16*. National Collaborating Centre for Mental Health, The British Psychological Society and The Royal College of Psychiatrists, 2004.