

ACCEPTED VERSION

M. Brown, M.A. Brooksbank, T.A. Burgess, M. Young and G.B. Crawford

The experience of patients with advanced chronic obstructive pulmonary disease and advance care-planning: a South Australian perspective

Journal of Law and Medicine, 2012; 20:400-409

© 2013 Thomson Reuters (Professional) Australia Limited

This publication is copyright. Other than for the purposes of and subject to the conditions prescribed under the Copyright Act 1968 (Cth), no part of it may in any form or by any means (electronic, mechanical, microcopying, photocopying, recording or otherwise) be reproduced, stored in a retrieval system or transmitted without prior written permission. Enquiries should be addressed to Thomson Reuters (Professional) Australia Limited.

PO Box 3502, Rozelle NSW 2039. www.thomsonreuters.com.au

This article was first published by Thomson Reuters in the Journal of Law and Medicine and should be cited as M. Brown, M.A. Brooksbank, T.A. Burgess, M. Young and G.B. Crawford
The experience of patients with advanced chronic obstructive pulmonary disease and advance care-planning: a South Australian perspective, 2012; 20, Journal of Law and Medicine, 400

For all subscription inquiries please phone, from Australia: 1300 304 195, from Overseas: +61 2 8587 7980 or online at www.thomsonreuters.com.au/catalogue. The official PDF version of this article can also be purchased separately from Thomson Reuters at <http://sites.thomsonreuters.com.au/journals/subscribe-or-purchase>

PERMISSIONS

See email from publishers dated 6 July 2016

30 August 2016

THE EXPERIENCE OF PATIENTS WITH ADVANCED CHRONIC OBSTRUCTIVE PULMONARY DISEASE AND ADVANCE CARE PLANNING: A SOUTH AUSTRALIAN PERSPECTIVE

Brown Margaret, Brooksbank Mary A, Burgess Teresa A, Young Mary, Crawford Gregory B,

ABSTRACT

Advance care planning conversations with people who have Chronic Obstructive Pulmonary Disease (COPD) are important because of the severity of the disease and the unpredictable timing of death. Advance care planning is a process involving conversations about future wishes, including end-of-life care and appointing a substitute decision maker. This qualitative research explored issues relating to end-of-life decisions with 15 individuals and their carers living in the community who had severe COPD. Findings indicated that, although patients and carers would welcome the opportunity to discuss end-of-life decisions, almost no conversation about care planning had been initiated by health professionals with any of the participants. It also demonstrated that professional support is required to assist with advance care planning and completing the legal advance directive documents.

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is an incurable, progressive illness that is an increasing cause of mortality and morbidity.¹ It is now recognised as the fourth most common cause of death worldwide² and the care of people with COPD is becoming an increasing burden on both hospitals and the community. More importantly, many of these people are not receiving optimal care at the end of life and are rarely referred to palliative care services.³

One of the complexities associated with treating people with COPD is that there is no clear transition between advanced disease and when a person is approaching the end of their life or in the “terminal

¹ Sullivan S, Buist A and Weiss K, “Health Outcomes Assessment and Economic Evaluation in COPD: Challenges and Opportunities” (2003) 21(Supp) *European Respiratory J* 1s.

² Global Initiative for Chronic Obstructive Pulmonary Disease, *The Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease* (Medical Communications Resources, 2009).

³ Yohannes A, “Palliative Care Provision for Patients with Chronic Obstructive Pulmonary Disease” (2007) 5 *Health and Quality of Life Outcomes*, <http://www.hqlo.com/content/5/1/17> viewed 24 November 2011; Dean M, “End-of-Life Care for COPD Patients” (2008) 17(1) *Primary Care Respiratory J* 46; Au D, Udris E, Fihn S, McDonnell M and Curtis J, “Differences in Health Care Utilisation at the End of Life Among Patients with Chronic Obstructive Pulmonary Disease and Patients with Lung Cancer” (2006) 166 *Arch Intern Med* 326; Gardiner C, Gott M, Payne S, Small N, Barnes S, Halpin D, et al, “Exploring the Care Needs of Patients with Advanced COPD: An Overview of the Literature” (2010) 104(2) *Respir Med* 159.

phase”. This uncertain trajectory may be a reason for the lack of referral to palliative care services⁴ and a barrier to introducing conversations about future treatment decisions or advance care planning. It is rarely acknowledged by health professionals that patients with COPD are dying even though death may occur during a critical exacerbation at any time.⁵

Advance care planning is a process involving conversations about future wishes, including end-of-life care, and appointing a substitute decision maker. People can document these wishes either on legal advance directive documents (appropriate to the jurisdiction) or on an advance care plan. Advance care plans assist health professionals and family members to understand what types of treatment the person would or would not want if they become critically ill and unable to make those decisions. They are relevant for people with COPD who may suffer severe exacerbations resulting in hospital admissions including life-sustaining treatments in intensive care. Spathis and Booth emphasise the importance of advance care planning conversations with people with COPD because of the unpredictable timing of death and argue that difficulties in determining prognosis should not lead to “communication paralysis”.⁶

The legal advance directive documents in South Australia include the Medical Power of Attorney, which provides for the appointment of a substitute decision maker for medical decisions, and the Anticipatory Direction, a type of “living will”, which records the person’s wishes about care when either terminally ill or in a persistent vegetative state.⁷ (). In addition there is the Enduring Power of Guardianship which also provides for the appointment of a substitute decision maker for health and personal decisions.⁸ There are other advance care planning documents used, including the Respecting Patient Choices documents and personal letters, to inform family and health professionals about the person’s wishes.

Researchers in the United Kingdom explored the barriers to advance care planning for patients with COPD by conducting focus groups with health professionals.⁹ Participants reported that discussions

⁴ Department of Health, *End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life* (NHS, 2008); Murray S, Pinnock H and Sheikh A, “Palliative Care for People with COPD: We Need to Meet the Challenge” (2006) 15 *Primary Care Respiratory J* 362; O’Donnell D, Hernandez P, Kaplan A, Aaron S, Bourbeau J, Marciniuk D, et al, “Canadian Thoracic Society Recommendations for Management of Chronic Obstructive Pulmonary Disease – 2008 Update – Highlights for Primary Care” (2008) 15(Supp A) *Can Respir J* 1A.

⁵ Spathis A and Booth S, “End of Life Care in Chronic Obstructive Pulmonary Disease: In Search of a Good Death” (2008) 3(1) *Int J Chron Obstruct Pulmon Dis* 11.

⁶ Spathis and Booth, n 5 at 23.

⁷ *Consent to Medical Treatment and Palliative Care Act 1995* (SA)

⁸ *Guardianship and Administration Act 1993* (SA)

⁹ Gardiner C, Gott M, Small N, Payne S, Seamark D, Barnes S, et al, “Living with Advanced Chronic Obstructive Pulmonary Disease: Patients’ Concerns Regarding Death and Dying” (2009) 23(8) *Palliat Med* 691.

relating to advance care planning are rarely initiated, even though the English End of Life Care Strategy promotes advance care planning for all patients with advanced, life-limiting illnesses. Barriers identified included inadequate information about the course of COPD at diagnosis, lack of consensus about who should initiate advance care planning conversations and in which setting, and a lack of understanding of the meaning of “end of life” within the context of COPD.¹⁰ Reinke et al, in an American study of outpatients with COPD, found that a majority of clinicians (77.2%) did not involve patients in making decisions about what treatments they would want if they were too sick to speak for themselves.¹¹

This Australian research explored the issues relating to end-of-life decisions and advance care planning with individuals who had advanced COPD and were living in the community. It contributes to our understanding of the barriers to advance care planning and completing advance directive documents from the patients’ perspective.

METHODS

Study design

The study was undertaken as part of a larger research project by a multi-disciplinary team in South Australia which incorporated three separate but linked studies.. The aim of the overall project was to look at the unmet care needs of people with advanced COPD and to develop models of care for those living in the community. One of the studies involved qualitative in-depth interviews with participants and their carers to explore their need for services and support, and included discussions about advance care planning. Ethics approval was obtained through the Research Ethics Committees of the Royal Adelaide Hospital and University of Adelaide. Informed written consent was obtained from all participants. This paper reports the findings relating to advance care planning from that study.

Selection and recruitment

Fifteen participants with advanced COPD were recruited by two senior respiratory nurses through one large metropolitan public hospital and a regional public clinic in South Australia. Selection criteria included participants who were 18 years or older, able to speak English and not suffering from any significant cognitive impairment. Participants were living in the community, not in residential care.

¹⁰ Gardiner et al, n 7.

¹¹ Reinke L, Slatore C, Uman J, Udris E, Moss B, Engelberg R, et al, “Patient–Clinician Communication about End-of-Life Care Topics: Is Anyone Talking to Patients with Chronic Obstructive Pulmonary Disease?” (2011) 14(8) *J Palliative Med* 923.

As an index of the severity of their COPD, participants were required to have been hospitalised at least twice in the past 12 months and have lung function tests that met the requirements for GOLD Stage IV classification (a measure of very severe COPD)¹². They were not asked to repeat lung function tests if they had been completed within the previous year and if, on other clinical indications, they were at “end stage” COPD. Having a prescription for long-term oxygen therapy was not included as a criterion. Exclusion criteria included active treatment for lung cancer in the last five years, any other cancer in the last 12 months, or a lung transplant.

Interviews

The 15 participants, and their carers (where relevant), participated in two in-depth interviews in their home at six-monthly intervals with an experienced qualitative researcher (the first author), who was also skilled in advance care planning. One participant died before the second interview. The semi-structured interviews, with prompts, focused on the participants’ well-being, their understanding and knowledge of COPD, how they were coping at home and the care they were receiving.

The interviewer asked the participants whether they had completed any advance directive documents and sensitively explored issues relating to decisions about the end of life. In the first interview the interviewer asked: “Has the specialist, nurse or anyone at the hospital had a conversation with you (and your carer) about your future wishes and what types of treatment you may or may not want?” The two South Australian legal advance directive documents were left with the participants, and the conversation was raised again at the second interview.

Data analysis

All interviews were recorded, transcribed, and combined with the field notes. Thematic analysis was undertaken by two researchers (the first and second authors), who listened to all the interviews to ensure validity. They discussed any coding disagreements until they achieved consensus and identified a series of key themes. A thematic analysis approach was chosen to allow flexibility in examining the dense data produced from the interviews with participants and their carers.¹³

¹² Pauwels R, Buist A, Ma P, Jenkins C, Hurd S. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: National Heart, Lung, and Blood Institute and World Health Organization Global Initiative for Chronic Obstructive Lung Disease (GOLD): executive summary. *Respir Care*. 2001;46:798-825

¹³ Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77-101; Strauss A, and Corbin J (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* Sage. London

FINDINGS

The participants

Table 1: Participant demographic information

Participant	Location	Age	Gender	Lived alone	Lived with
1	M	74	M	Yes	
2	M	79	F		P/C
3	M	75	F	Yes	
4	M	64	F	Yes	
5	M	50	M	Yes	
6	SR	54	M		P/C
7	M	60	M	Yes	
8*	M	79	M		P
9	M	79	F	Yes	
10	R	67	M		P
11	R	72	F		P
12	R	65	M		P
13	R	67	M	Yes	
14	R	61	F		P
15	R	53	M		C

M metropolitan

SR semi-rural

R regional country

P Partner

C Adult child

* Died prior to second interview

Knowledge of advance directive documents and advance care planning

Eleven participants and five carers had not seen the advance directive documents before. Six thought they had heard of them and had given some thought to whom they might ask to make their decisions, but had not completed any documents. Only one couple had completed both documents prior to the first interview.

One carer (a participant's wife) stated,

“I think this one is about when they don’t want to be revived, if you got so bad ... it is for him to give permission for me to make his decisions on his behalf knowing what he wants?”.

The one participant and his wife who had completed the two documents were assisted by the local bereavement counsellor, who was also a Justice of the Peace and familiar with the legal documents. This couple, in a second relationship, both had children from previous marriages:

“[We] talked to children; son doesn’t want to go there. Not fair to put anyone through it, so we’ve decided [to appoint each other]”.

This couple was very active in the local COPD support group and was well informed on issues surrounding future decision making.

There was confusion amongst participants about the scope of the advance directive documents. Several referred to their will or to the Enduring Power of Attorney, which is for financial matters only not health care decisions, and one raised the topic of a funeral plan.

Discussions about resuscitation

Two participants could recall conversations with health care professionals about resuscitation, but not advance care planning more generally. One carer and one participant also reported traumatic and insensitive discussions in hospital about resuscitation in a crisis.

One participant who lived alone had witnessed her sister’s death after attempts at resuscitation and was clear she did not wish this for herself. When asked if she thought her children would feel comfortable in making that decision for her, she replied:

“I don’t think they would feel comfortable making that decision, I really don’t ... I can’t imagine them saying ‘let her go’.”

Because of the reluctance of her adult children to discuss her death, she had discussed the issue with her longstanding general practitioner who had provided a letter recording her wish not to undergo cardio-pulmonary resuscitation (CPR), which she kept in her handbag. Despite this, she had been resuscitated earlier in the year by two ambulance crews in her daughter’s home.

At the second interview she repeated her view that

“I don’t want to put it on somebody that they have to decide for me”. She added:

I’ve noticed now, when I leave the hospital, they give a letter like that to the ambulance man ... they just say to me “give this to the ambulance” and I opened it and looked at it and it just says “do not resuscitate”.

The other participant, who had been admitted to several different hospitals, thought her wishes were recorded “officially” at a public hospital but was not sure which one, and at the second interview she thought that the interviewer had “got that on record”. When the researcher asked more directly about resuscitation, the participant was initially unclear about the meaning of the term:

P: What actually is that now?

Interviewer: It's when they, if you stop breathing ...

P: Yes, I'm not to be brought back – if they think I'm brain dead, that's it, I just want to be left ... Let go peacefully. I don't want to linger on because of the family. If I'm brain dead – because what's the use of living if you can't recognise your family and that? It's only putting hardship on them ... I don't want that.

Interviewer: Is that written down somewhere?

P2: Yes, that's definitely another one that I had made, that I am not to be brought back if they think I'm brain dead. Isn't it, [son]?

Son: Yes.

P: You know my wishes on that.

Son: Yes, we already have that. Yeah, that was one of the things that they wanted to know about last time you went to hospital.

This woman was frequently admitted to the local public hospital, not the major metropolitan hospital, in an emergency. Her spouse-carer had been diagnosed with dementia by the time of the second interview, and their adult son had taken over all his responsibilities, including understanding his mother's wishes and the advance care planning documents, and he seemed quite well informed about these. The participant was also adamant that she did not want her daughter making any decisions for her. She told the interviewer:

"I think I've told you and you've made a note of it, that on no condition do I want any interference from my daughter about me."

Decisions in a crisis

The participants perceived that decisions about resuscitation made in a crisis are extremely traumatic and are often handled insensitively. The wife of one participant described how she was approached in the corridor of the hospital about resuscitation for her husband:

It wasn't just the corridor factor, it's right in your face. And when [husband] was admitted and in the emergency ... I think we were actually in there five minutes or something – and one of the doctors, right in your face – saying "do you want resus?" and all these sorts of things but more blunter.

But I'm thinking, hey, put it into three sentences at least, not just in front of this distraught relative of a sick person about I don't think we should resus him ... Come back in an hour or two or give me a few sentences.

When decisions have to be made in the absence of any advance care planning, or conversations about treatment in an emergency, this situation becomes fraught for the family and the treating medical team when decisions have to be made quickly.

The wife mentioned above described a further episode:

[husband] had been in hospital two–three days, so I was going to come in and see him and my daughter was on the train coming in to meet us. He had had a bad turn and it sounded like he was dying right there and then the way the doctor was going on ... What I did say to the doctor was my daughter's coming along separately, if you can you please stop her from going in until I get there ...

I eventually get in there as quick as I could and the daughter – they've given her the right royal on how ill he is and not for resus and everything and of course she's sitting there bawling her eyes out. Granted it's not their problem, not their business but I did ask them ... and straight away they'd blurted it all out to her. They knew I was coming, why couldn't they have waited?

So, yes, a lot of emotion, I'm angry, I'm upset, I'd really like to take some of them and shake them.

This woman was very distressed as she described both these occasions.

By the time of the second interview, this couple had visited a lawyer and completed the legal documents, very explicitly stating the man's wishes. His wife had discussed the wording and possible scenarios with palliative care staff and nurses, whom she found to be informed and willing to assist her with the decisions. The couple then guided the lawyer with the wording. This had taken time and persistent effort and was prompted by the distressing hospital experiences. The wife kept a large file with several photocopies of her husband's anticipatory directive (living will), which she produced on every admission and when the ambulance was called.

Wife: We all know it's there and I have told the carer who comes.

P: Every hospital gets a copy of it every time you walk in the door.

Wife: It goes with the ambulance people. It's one of the first things we hand them ...

Wife: There's a very good example in that brochure, but to the layperson, if you put a: Please do this. Please don't do this list, and then combine it ... That was a very good guide.

The brochure accompanying the Anticipatory Direction form provided a good guide for this couple given the participant's complex health problems. The participant had recorded his wishes on this legal form rather than in the Medical Power of Attorney document, which appointed his wife as his medical agent.

One male participant who lived alone had signed some papers during an emergency admission to hospital, which he thought might have been an advance directive, but he had no record of this.

‘If anything happens and we can’t get to you in time what do you want to do, instead of being stuck on a machine, you want us to turn you off?’ And I said you might as well turn it off.’ When the interviewer asked him at the first interview whether he would like to talk to someone again he answered vehemently, “No! No!”

Who to appoint as decision maker?

At the first interview 12 participants identified their spouse or partner (7), children (4) and a friend (1) as carers. For those who were married or partnered the choice of decision maker seemed relatively straightforward and each partner expressed a willingness to take on the role. But for those participants relying on the support of adult children the situation was not always as clear cut.

One woman (in a second relationship) whose children lived in other states reflected, on the possibility of her son making decisions for her:

P: He can’t make a decision if he’s way over there and I’m over here, and if life support, if that happened well I wouldn’t want to stay on it, I’d rather just go peacefully.

Interviewer: Would you like to talk to someone about it?

P: Yeah, it would be good. It’s going to happen sooner or later.

She called her partner in from the clothesline to ask him:

If they wanted to keep me on life support and you knew that I didn’t want that, I’d rather go peacefully than keep me alive on a life support machine. Something like that, it may never happen, but you know.

Partner: No worries, I could do that.

At the second interview, this participant indicated that she had spoken to her son about her wishes. It was unclear whether this was only related to financial matters or included her health care decisions.

Of the four participants who relied on adult children, two felt that the children knew and understood their wishes. One participant whose daughter was his live-in carer felt it would be difficult to ask her to make decisions for him:

Yeah, I don’t know. I suppose I could get off my whatever, and discuss it with her. Emotionally I don’t know – she’s quite an emotional girl. Sometimes when the chips are down or when I’m down, one of the two, I don’t know whether she could just say alright, turn the button off or whatever. I mean that’s a bit much to ask. She’s looked after me all this time, on and off when I’ve been sick. I don’t know, I’d just simply say to the doctor, if you don’t think I’m going to come out

of it, turn it off, be done with it. After all, I get the last say don't I? [The interviewer reminded him that he might not be able to or might be unconscious] Oh right, I never thought of it that way.

At the second interview, when his daughter was present, he was surprised to discover that his two daughters had already raised the issue with his brother, their uncle, who had agreed to take on a decision-making role if necessary.

P: I thought he was just doing the will part of it?

Daughter: No, and this stuff. It's just easier for us I suppose if anything bad was to happen. I don't think us girls would be capable of doing anything like that. So that's why we spoke to our uncle and he's quite happy to do it all.

For participants without family carers, the question was a difficult one. They all seemed to focus on appointing an agent as a decision maker, rather than making their own decisions in an advance directive, and this made the task almost impossible in their minds. Two male participants (living alone) who initially identified support from a friend reported that the relationship in both cases had failed by the time of the second interview. In each case there was increased contact with family; one with a cousin who had agreed to act as decision maker, and the other had tentative contact with a previously estranged daughter.

Another single male participant was still agonising over the possible role of an interstate, and not very reliable, "foster son": "I think with me, it's a matter of trust." This participant had been most enthusiastic about the documents at the first interview, "That's wonderful, that's the kind of thing that I would like to have." But he had not taken any action by the second interview.

Reactions to the advance care planning conversation

At the first interview most participants and their carers appeared comfortable in discussing advance care planning and future decision making, and some welcomed the opportunity to talk:

P1: Nobody has ever given us ... like I've thought about these, but never ever asked, but I think they are very important.

P2: Nobody has talked to me the way you do.

While most participants saw advance care planning as a way to avoid unwanted, invasive treatment at the end of life, one participant in the interviews suggested a possible impact on survival and hope: "I'd sort of thought about it, and you think, if I fill that out now, that could be the end of me."

However, despite the initial enthusiasm, by the second interview only one additional participant had completed the advance directive documents, with the help of a lawyer, in response to their difficult

experiences (described above). This participant was one of only two who were referred to palliative care services during the course of the study.

Although seven other participants had given it more thought, none had completed any of the documents or had follow-up conversations with health professionals about their future wishes. Several had misplaced the forms left six months earlier, including those who had previously been enthusiastic about the idea of advance care planning:

No, I don't know what I did with them.

It's something you keep shoving aside all the time. It's too hard. I don't feel like doing that.

Too much to think about.

I'm a real bugger for forms. I hate them. The worst thing you can do is give me a form to fill in because I'm likely to say, yeah, and have every intention to fill it in, then I'll take one look at the form, blow that.

The male participant described previously who had signed what appeared to be a “do not resuscitate” (DNR) paper in hospital was more comfortable discussing his decisions about end of life at the second interview. By now he was receiving support from a palliative care service and said: “I like to get prepared a little bit, just in case something does happen.”

Several participants expressed willingness to follow up with someone who could assist them with decisions and completing the forms such as the bereavement counsellor in the regional centre. No specific person could be identified for metropolitan people to be referred to. No-one reported that their general practitioner had raised advance care planning apart from the one participant who had a DNR letter from her general practitioner.

DISCUSSION

The participants in this study confirmed that, even in the face of advanced disease with poor prognosis and frequent hospital admissions, conversations about their future care were scant and inadequate. In the absence of advance care planning conversations, hospital admissions in a crisis led to unprepared and at times distressing discussions about resuscitation. Several participants were admitted to different acute hospitals at different times and this led to confusion about whether any decisions had been documented in the hospital records and whether these decisions were only about resuscitation. The one participant who had discussed the question of resuscitation with her general practitioner was unable to engage her hospital consultant in a serious end of life discussion. However, she

subsequently discovered that an order for no resuscitation had been given to ambulance officers at the time of her discharge

Despite the fact that advanced COPD is a terminal condition, there is generally not a clear transition to a recognised “terminal phase”, which might act as a trigger for advance care planning conversations or referral to a palliative care service. This study suggests that patients and carers would welcome an opportunity for such a conversation if it were sensitively introduced by a well-informed professional, as was demonstrated by their willingness to discuss these issues in the interviews.

The need for active support from well-informed and trained health professionals for the process of advance care planning was apparent. Ideally this would be a general practitioner who knows the person well or other health professional involved in their care, but specific knowledge of advance care planning legislation and processes as well as skill in end of life conversations are important. The participant who had completed the documents prior to the first interview sought assistance from a bereavement counsellor (and Justice of the Peace) even though she was not a member of their team of health professionals.

Completing advance directive documents presents a significant challenge for most people. Despite being provided with the documents, only one additional participant had completed advance directive documents by the time of the second interview, and this was with the assistance of a lawyer and advice from health professionals trained in palliative care. The process, however, was initiated and driven by the participant’s wife. These findings are consistent with previous Australian research by Brown et al which found that, while patients in a palliative care setting were willing to engage in advance care planning about their impending dying, they needed skilled, practical, face-to-face assistance to complete the required forms even though they were provided with comprehensive written materials about the documents and relevant legislation.¹⁴ Other Australian research found that the law and practice relating to completion of advance directives is complex, obtaining appropriate information when living in the community is difficult and the process of completing documents is hard without adequate support from a health or legal professional with specific training in this area.¹⁵

Advance care planning may include nominating a decision maker who can express the person’s wishes when they are too ill to do so. As this research indicated, appointing a substitute decision

¹⁴ Brown M, Fisher JW, Brumley DJ, Ashby MA and Milliken J, “Advance Directives in Action in a Regional Palliative Care Service: ‘Road Testing’ the Provisions of the *Medical Treatment Act 1998 (Vic)*” (2005) 13(2) *JLM* 186.

¹⁵ Brown M and S Jarrad S, “Putting ‘the Powers’ in Place: Barriers to Planning for the Future” (2008) 15(4) *JLM* 530.

maker is not always straightforward particularly for those who are not married or do not have long-term partners. The participants did not seem to realise that they could document their wishes in the absence of a suitable decision maker.

The findings about advance care planning from the larger research project were remarkably congruent. An expert panel and professional focus groups echoed the findings from the interviews with participants and their carers. There was uncertainty about whose role it was to raise advance care planning, when the conversation should be introduced and the scope of planning beyond the question of resuscitation. Rhee et al ¹⁶ also identified a significant difference between organisations and clinicians involved in aged care and end-of-life care in Australia regarding the purpose of advance care planning and how it is conceptualised.

Strengths and limitations

This research is one of the few studies in the current literature that includes the voice of people with COPD. The richness of the two in-depth qualitative interviews provides insight into experiences of people with COPD. The multidisciplinary nature of the research team was an additional strength to the design and research process. The limitations of this research include the small sample size, which limits the ability to generalise the findings, and the difficulties in determining the selection criteria. All participants were known to one respiratory service and none had any private health cover.

CONCLUSIONS

Advance care planning, which includes conversations about substitute decision makers, legal advance directives, the focus of care and end of life, should be introduced to all people with COPD. Advance care planning should be recognised as an ongoing conversation that is part of the treatment plan and recorded appropriately. This should be considered as soon as possible after diagnosis by a well-informed, trained health professional who understands the complexity of this disease and the current documents in the jurisdiction and can assist with the completion of the documents. A system must be developed so that the patients' wishes are available for clinical interactions at all sites and particularly emergency episodes. Electronic health records may assist with this. If the conversation is documented appropriately, it does not need to be revisited at every consultation but should be reviewed when clinically relevant.

¹⁶ Rhee J J, Zwar N A, Kemp L A, How is advance care planning conceptualised in Australia? Findings from key informant interviews. *Australain Health Review*, 2011, 35, 197-203

There is an increased awareness of the importance of advance care planning at the national level in Australia, including the release of the National Framework for Advance Care Directives, aimed at policy makers and administrators. Similarly in the UK the End of Life Care Strategy promotes advance care planning for all patients with advanced, life-limiting illnesses. The Inaugural International Advance Care Planning Conference in 2010 emphasised the importance of advance care planning for the entire population as people age, with a more detailed discussion about end-of-life plans when chronic or progressive illness occurs.¹⁷ Currently this is not common practice in Australia. The different advance directive laws across the Australian jurisdictions and the complexity of the legal documents are additional barriers. Health professionals must be well informed about the legal implications of advance care planning and the process of completing advance directives, as well as confident to initiate end of life conversations. As this research has demonstrated, people who are very ill with COPD are not being given the opportunity to discuss their wishes in advance about their care at the end of life.

ACKNOWLEDGMENTS

This research was funded by the National Health and Medical Research Council, Australia. We wish to acknowledge the other investigators, A/Prof Alan Crockett PSM, Dr Ral Antic and Prof Debbie Kralik, and the support given by Dr Kerry Hancock and Ms Janet Taylor. In particular we wish to thank the people with COPD and their carers who gave of their time and energy, and the many clinicians who also freely gave of their time to improve the care of people living with COPD. Editorial assistance was given by

ACKNOWLEDGEMENT OF GRANTS AND OTHER FUNDING

This research was funded by the National Health and Medical Research Council, Australia, Study No. 519359.

¹⁷ Detering KM, Hancock AD, Reade MC and Silvester W, “The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial” (2010) 340 *BMJ* c1345; Blackford J, Strickland E, Morris B, “Establishing a Sustainable Advance Care Planning Process in Residential Aged Care” (2007) 27(1) *Contemp Nurse* 141.