



# Patients', caregivers' and clinicians' understandings of an advance care planning process: the example of ambulance palliative care plans

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**Background:** With the introduction of New South Wales Ambulance Authorised Palliative Care Plans within a metropolitan palliative care service, the perspectives of patients, caregivers and clinicians and their understandings of the processes involved in completing the Plans were investigated.

**Methods:** This qualitative sub-study used semi-structured interviews. Nineteen patients and caregivers who had received an Ambulance Palliative Care Plan and 10 clinicians who completed the Plans were interviewed (n=4) or participated in a focus group (n=6). Grounded theory provided theoretical and procedural direction. Thematic content analysis utilized the constant comparative method.

**Results:** Thematic analysis of patient/caregiver interviews revealed four major themes (I) a lack of involvement in signing the Plan; (II) a need for clear communication about the Plan; (III) trust in the handing over of difficult decisions to family; and (IV) control over where to receive end of life care. Patients indicated that they had little understanding or memory of what the document was or of its purpose, and there were some significant caregiver anxieties about the Plans. Those who were clear on the rationale for the Ambulance Palliative Care Plan demonstrated more prognostic awareness about their condition and the benefits or burdens of resuscitation and treatment. Clinicians identified the main benefit as avoidance of Emergency Department (ED) admission and for patients to be able to choose their preferred place of death. Barriers were mainly systemic and included a lack of clarity around the signature processes and the early implementation of the Plan where the palliative care service was new to patients and families.

**Conclusions:** The Ambulance Palliative Care Plans are a complex intervention that are sometimes misunderstood by patients, particularly those who are very unwell or who have little prognostic awareness. Clinicians perceive the major benefit to be avoidance of admission to the emergency department.

**Keywords:** Palliative care; patients; caregivers; nurse practitioners; physicians

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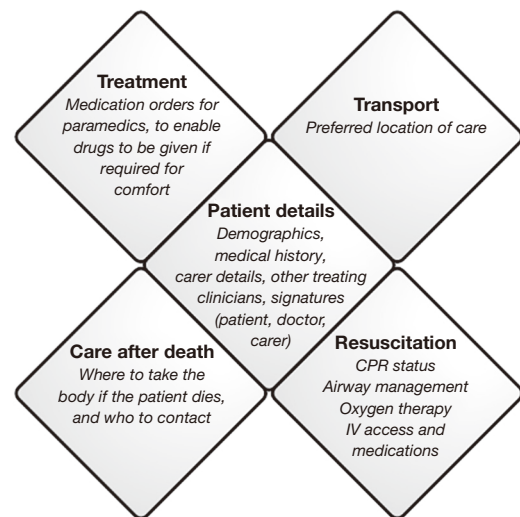
## Introduction

While there are approximately 33,000 predictable deaths per year in Australia where patients could have benefited from an advanced care plan, almost 50% of deaths occur in the acute setting (1). Further, approximately 20% of family members of advanced cancer patients report that end of life care wishes were not adhered to with just over half of these patients dying in their location of choice (2). Advance care planning is increasingly seen as essential to minimise dying people's exposure to non-beneficial treatments, for instance cardiopulmonary resuscitation or other burdensome care that prolongs dying without any gain in quality of life (3). When a palliative care patient is being cared for in the community, a cascade of inappropriate treatment can often be triggered by a call for an ambulance during a crisis. The resulting emergency transfer may lead to treatment which is provided without full awareness of the dying person's disease status and prognosis (3). The challenge for clinicians in this situation may be intensified by the sense of urgency that can overwhelm patients or families when a dying person's clinical situation deteriorates rapidly.

Advance care planning processes hold the promise of preventing such crises by giving patients and families a chance to prepare themselves, to think ahead, to understand what to expect, and to put plans in place about how and where they want to be cared for when they are dying. This frequently involves decisions about ceasing aggressive and burdensome treatments (4), a preference to avoid admissions to acute health care settings and emergency departments wherever possible (5), in some cases indicating a preferred place of death which may be at home (2) or in a palliative care unit, and a preference to receive care that prioritises comfort, with distressing symptoms controlled. Advance care planning which involves ambulance services is thus a potentially valuable strategy to help minimise the risk of unnecessary or unwanted admissions to acute hospital settings.

### *Authorised palliative care plans (APCP)*

In response to these challenges, NSW Ambulance developed a process to document Authorised Care Plans for patients who are receiving palliative care (6). These plans allow the documentation of a person's diagnosis and current treatment, their wishes concerning resuscitation and the emergency management of their condition, whether they wish to die at home, where they should be transported to if



**Figure 1** Domains included within NSW Ambulance Palliative Care Plans (APCP).

they require admission, and what to do if they die during the transfer. Orders for medications can be included in the plan, so that paramedics are able to treat distressing symptoms either using the standard protocols and medications endorsed by NSW Ambulance, or using the patients' own emergency medications if necessary (Figure 1). At the time of this study the document required signatures from the patient, caregiver, and a medical doctor, and information on whom to contact for additional clinical information was included. The APCP has been subsequently revised and signatures from patients and caregivers are no longer required. Current practice requires a medical doctor or nurse practitioner (within their scope of practice) to have discussed the plan with the patient and/or their family, carer or enduring guardian. A medical doctor remains responsible for completing the resuscitation status section of document (6). The resulting document is endorsed and uploaded to the NSW Ambulance electronic records site, where it is flagged to the address that is given in the plan. A copy of the completed endorsed plan and a covering letter is sent via post or e-mail as preferred to the patient with a covering letter. Thereafter, in the event of a callout to that address, the electronic flag will indicate to responding paramedics that there is an Authorised Care Plan in place relating to a person living at that address. On arrival the paramedics need to sight a hard copy of the plan, as the completed document is not held in their electronic system.

One Sydney metropolitan specialist palliative care

service has a policy to ensure that all patients on their Service being discharged from hospital had a completed Authorised Palliative Care Plan in place. This study is part of a mixed methods project exploring the uptake of these plans, and their impact on the patients and the Service. Here we report the perspectives of patients and caregivers and their understandings of the processes involved and the acceptability of NSW Ambulance Authorised Palliative Care Plans for clinicians. We present the following article in accordance with the COREQ reporting checklist (available at <http://dx.doi.org/10.21037/apm-21-288>) (7).

### **AIM**

The study had two aims: (I) to understand the perspectives of patients, caregivers and their experiences of having an APCP and their understanding of the processes involved; (II) to assess the acceptability of APCPs for clinicians.

### **Methods**

#### **Study design**

Semi-structured individual interviews were used to elicit the perspectives of patients and caregivers and their understandings of the processes involved in the APCPs and semi-structured telephone interviews in caregiver dyads and a focus group assessed the acceptability of Ambulance Palliative Care Plans for clinicians.

#### **Setting**

Participants were recruited from a metropolitan specialist palliative care service and/or public hospital in a NSW metropolitan local health district. The service receives its referrals from primary care providers, as well as from all public and private hospitals in this area, and has a stand-alone 32 bed specialist inpatient unit to which patients can be admitted for symptom management, end of life care, or respite. It has a well-developed model for provision of community palliative care which includes care of patients at home and in residential aged care facilities, in consultation with other primary palliative care providers. Consult-liaison services are provided to other hospitals in the area.

#### **Participants**

This study included purposive sampling (8) of patient and

caregiver dyads, and clinicians. Participants included (I) palliative care patients who were recently discharged from an acute palliative care service and/or public hospital and referred to a community palliative care team; (II) their caregivers, defined as the person nominated to co-sign the patient's APCP; and (III) their treating specialist palliative care doctors.

#### **Inclusion criteria**

##### **Patients/caregivers**

- (I) Aged 18 years or over;
- (II) Able to provide informed consent and communicate in English to a level that allows an interview and completion of other assessments;
- (III) Cognitively able to participate in the study;
- (IV) Discharged to the community (i.e., their own home or the home of a relative or carer); and
- (V) Completed an APCP prior to hospital discharge.

##### **Clinicians**

Treating doctors in the palliative care service and/or public hospitals completing an APCP for community based palliative care patients who provided informed consent to participate in the study.

#### **Exclusion criteria**

- (I) Patients who it was thought likely to die in the next 48 hours were excluded;
- (II) Patients discharged to a nursing home

#### **Data collection**

##### **Patients and caregivers**

When an APCP was completed by a treating clinician, it was sent to NSW Ambulance. The researcher (CS) then checked the new referral patient database to see which patients had an activated APCP. Eligible patients and their caregivers were then sent a letter via mail inviting them to participate in the research project. The letter offered a phone number on which a message could be left if the person did not wish to be contacted further. The letter was followed by a phone call from the researcher (CS), and participant information and consent forms (PICF) were mailed with a reply paid envelope. The PICF contained information about the purpose of the research, possible risks and benefits of participation, and listed the researcher CS as an investigator

1. What do you understand is the purpose of the Ambulance Palliative Care Plan?
2. How was it explained to you?
3. What was the process of completing the plan like for you?
4. Would you like to make any comments or suggestions about the process of completing it?
5. Do you have any concerns or worries about the plan and the information in it?

**Figure 2** Patient/caregiver interview guide.

1. Were there any difficulties in explaining the reason for the APCP to patients?
2. Were there any difficulties in completing the details of the plan with them?
3. Were there any difficulties in gaining the involvement of the patient's caregiver/family member?
4. Do you have any comments about the timing of the APCP for patients?
5. What are the likely benefits for patient of the APCP?
6. Do you have any concerns or suggestions about the APCP process?

**Figure 3** Clinician interview guide. APCP, authorised palliative care plans.

and point of contact for the study. After receipt of the signed consent forms a brief, semi-structured interview was held between 28<sup>th</sup> September 2016 and 29<sup>th</sup> March 2017 addressing their understanding and expectations of the APCP, the process of completion of the APCP, and any concerns that they had about it (refer *Figure 2*). Patients were able to elect for consenting caregivers to be interviewed and/or complete on their behalf if they preferred. Interviews were conducted face to face by the researcher (CS) in the participant's home or by phone according to participant preference. The interviews were to be of 30 minutes duration as patients were likely to be clinically unwell and fatigued. Interviews were audio-recorded with consent and transcribed verbatim.

### Clinicians

After completion of any APCP, as identified by their details as included in plans lodged with NSW Ambulance, the signing clinician was contacted by email and invited to participate in a brief semi-structured interview or a focus group to address acceptability and usability of the APCP, difficulties with its completion, and clinicians' perceptions regarding the timing of the APCP. Clinicians were given the option of participating in a telephone interview or attending a focus group. Written consent forms were signed and returned via e-mail or collected in person prior to the focus group session. The interviews and focus groups were the audio-recorded with consent and transcribed verbatim. The clinician focus group and interviews were undertaken by CS in May 2017 in the doctors' meeting room at a Metropolitan hospital. A topic guide for the clinician focus

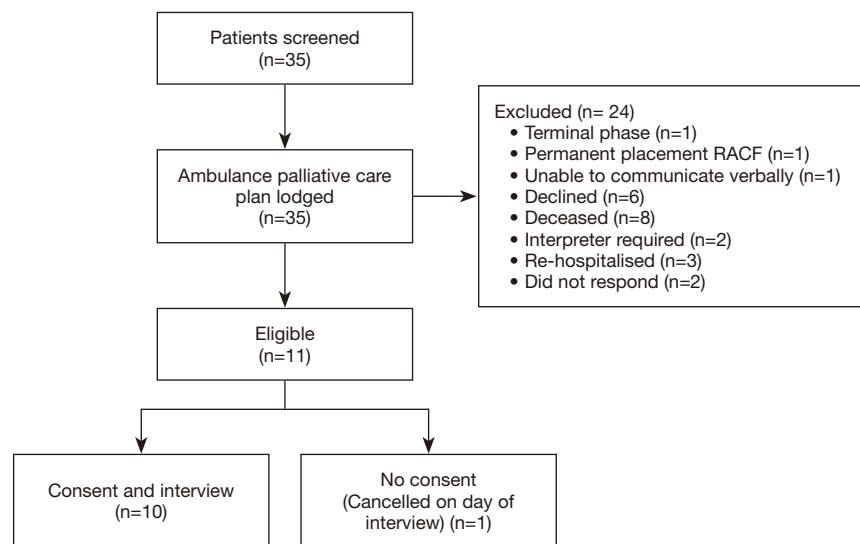
group and interviews is presented in *Figure 3*. Patient and clinician interview guides were reviewed by the study advisory group prior to study commencement.

### Reflexivity

The interdisciplinary research team comprised of an experienced female palliative care doctor and researcher (CS) and a female professor of palliative care with over 20 years' experience in qualitative and palliative care research (EAL). There were no pre-existing relationships between the research team and patient/caregiver participants prior to study commencement. However, the clinicians were known to the researcher (CS). To counter bias, a second member of the research team (EAL) attended the focus group as a scribe.

### Data analysis

The transcribed interviews and focus group data were entered into HyperResearch software (v 3.7.5) and were read by EAL and CS to identify and confirm major themes. Procedural direction from grounded theory informed data analysis. Key elements of thematic analysis (9,10) guided the development of themes using the coded datasets. Blinded coding of 10% of transcripts was undertaken by the two researchers (CS, EAL) to classify initial codes. Open and selective coding was used to analyse the data (11). The researchers discussed these codes and reached consensus. The main researcher (CS) coded the other transcripts based on the initial codes. The constant comparative method (12)



**Figure 4** Flow diagram.

guided the development of themes derived from the data. These themes were discussed and agreed to by CS and EAL. Data saturation was attained with conclusive categories identified for the coded data (9). Quotes to exemplify themes are de-identified.

### **Ethical considerations**

Ethics approval was obtained from the Prince of Wales Human Research and Ethics committee HREC ref no: 16/106 (HREC/16/POWH/220). This study was conducted in accordance with the Declaration of Helsinki (as revised in 2013).

## **Results**

### **Patients and caregiver dyads**

One hundred patients were referred and screened on discharge to a community palliative care team and 43 had an ambulance palliative care plan in place and were eligible for inclusion. Of these 35 patients, 10 patients agreed to be interviewed. A flow diagram has been included for clarity (refer *Figure 4*). Twenty four patients were excluded for reasons including death (n=8), re-hospitalisation (n=3); entering the terminal phase (n=1), permanent placement in a residential aged care facility (n=1); inability to verbally communicate (n=1); and requiring an interpreter (n=2). Six participants declined participation and two patients did not

respond (refer *Figure 4*). Interviews were conducted with 10 patients and 9 caregivers named on the APCP (refer *Table 1*). Patients were predominately women (80%) who were born in Australia (50%). The mean age of participants was 73 years (SD  $\pm 10.5$ ). Caregivers were predominately male (60%). All interviews were undertaken in the patient's home. In eight interviews, the patient and their caregiver were interviewed together at the patient's request, for reasons including fatigue, difficulty remembering or concentrating, and to provide physical assistance. In one interview the caregiver was interviewed separately and in another interview the caregiver was unable to attend. Interviews ranged from 10 mins to 35 mins in duration.

### **Clinician interviews**

Ten palliative care clinicians consented to participate, of which six opted to attend a focus group of one hours' duration held at the referring acute hospital. These six clinicians included two palliative care consultants, two career medical officers, and two registrars. Four clinicians opted for a telephone interview of approximately 15–23 minutes' duration. These clinicians included two registrars, one consultant and one career medical officer.

### **Themes: patients**

Three key themes among patients and caregivers were identified, including: (I) lack of understanding of the plans;



**Table 1** Patient and caregiver dyads

Gender patient	Age	Country of birth	Gender caregiver	Caregiver relationship to patient
Female	79	Australia	Male	Husband
Female	64	Australia	Male	Husband
Female	65	Yugoslavia	Male	Husband
Female	89	UK	Male	Husband
Female	68	UK	Male	Husband
Male	57	Turkish	Female	Wife
Female	71	Australia	Female	Daughter (not interviewed)
Female	88	Australia	Female	Daughter
Male	77	UK	Female	Daughter
Female	79	Australia	Male	Husband

(II) trust in handing over difficult decisions to caregivers; (III) control over where to receive end of life care; and (IV) clear communication about the plan.

### Understanding of the plans

Participants were asked about their understanding of the plans, and the reason for completing the document. Some responses indicated that a benefit of the plan was recognition that such a plan would help them to get appropriate care at the time they were dying.

*What I remember, she said to me there is ambulance care plan, she did say that, she did say it, and then she says – I said, “What am I going to do?” She said, “When you see him sick or something, instead of calling normal these people will come up and then we don’t go to normal hospital, we’ll just take him to [facility] and then they’ve got all the information about him.” (0155 caregiver)*

But there were also major misunderstandings of the rationale for the plan. Some patients perceived the role of the care plan was to ensure the patient was transported swiftly to hospital while one patient perceived that the Plan was associated with active euthanasia, which increased the patient’s psychological distress:

*Well I thought it was the fact that if I’m in the process of dying, I was under the impression that [caregiver name] would give me the injection or whatever medication or the ambulance people would or I would have to, and it scared the life out of me ... Well the morphine injection, you know that’s going to put me to sleep. So it just worried me. He was either going to have to kill me or they will have to kill me... (0284 patient)*

When asked if they were involved in actually completing

the document, few of the patients themselves were, and indeed most signed it without reading it. Many had little recall of the process. While this would not be a barrier to the endorsement of the plan by Ambulance Services NSW it could be perceived as a barrier to understanding the purpose of the plan by patients and carers.

*I really don’t know because it wasn’t my idea in the first place. So whoever thought it up must have... No but the papers were just shoved at my daughter and that’s about all I know. (0301 patient)*

*We both signed a lot things but I don’t know what they are. (0312 patient)*

*No, the doctor filled in the form and she... Yeah she asked a few questions and she filled it in. (0278 patient)*

These interviews suggest that a barrier to the plan is that it did not reflect patient or carer wishes in that patients frequently did not participate in the decision-making process in a substantive way, and nor were they fully aware of what had been discussed and decided.

### Trust in handing over decisions to caregivers

Nonetheless, these patients did not express concern about the role of their family or caregivers in largely completing the document on their behalf. The same trusting relationship within which caregiving takes place seems to permit patients to comfortably hand over responsibility for decisions and conversations to their family members.

*So I don’t have to worry about that of course because I know everybody is watching out for me and they all know what I want. So that’s good. That makes me feel good, yeah. (310 patient)*

*We’ve been married 60 years so I think that he knows me. (299*

patient)

Some respondents also recognised that the issue is of significant concern to their caregiver/s, who might have to deal with a crisis that the patient themselves has only minimal awareness of at the time they are dying. The mutuality involved in the caregiving relationship was evident as these patients and family members expressed their concern about each other's potential distress.

*And I don't want to die at home. Because I don't want my daughter and my sisters having to deal with that (0297 patient)*

*For me, I just want to make sure that he doesn't feel any pain, and that for me was the main thing with mum as well. I mean they're there and you just hope that they don't know what's going on and they're completely out of it. (310 caregiver)*

### Control over where to receive end of life care

The control offered by the plan was the chance to choose where to receive end of life care, in this instance, in the specialist palliative care service/hospice rather than be transferred by ambulance to an acute hospital for potentially ineffective/unwanted interventions.

*...because of mum's request before of some services to be withheld, she didn't want to be kept alive on life support, and it was suggested that she go – if she had the ambulance plan she could go straight to (palliative care facility) which is where she wants to be. (0114 carer)*

Others were very clear about procedures that would not be of benefit to them, and expressed relief at the possibility of avoiding these interventions.

*Well because they (palliative care facility) understand what – you've been a patient there and they understand you, you know, and they sort of know what kind of a person you are and that you don't want to hang around for 10 years gasping your last breath away, you know. (0299 patient)*

### Lack of understanding of prognosis

However the Plan itself did not completely alleviate uncertainty about what is likely to happen, what should be done, and how decisions should be made in a crisis, indicating a lack of clarity on the patient's prognosis and whether any clinical intervention would be undertaken in a crisis.

*The way I'd be treated seeing that it's the fi – oh because it may – when I do go into hospital and need an ambulance, it may not be the end. (053 Patient)*

*They're going to – I mean it's written down what they're going to do, they either respiratory and whatever what they're going to do, but not resuscitating or anything like that – am I correct*

*there?... I've got my own thoughts on that – me personally, I would prefer they did their best to bring her back but then I don't know, maybe not. (0114 caregiver)*

Understandings differed between patients and caregivers at times, such as whether the patient should be transferred to the acute hospital for active treatment or to the specialist palliative care service for end of life care and potentially death. In discussing the purpose of the plans with one patient and her husband, the patient clearly expressed recognition of her current prognosis, opting for end of life care and that the main role for any acute intervention would be to relieve symptoms, whilst her husband expressed a different understanding of his wife's treatment options such as transfer to the acute hospital for treatment/intervention and the role of the ambulance plan in a crisis.

*Well it was a good conversation. I mean I know I'm not going to get better and stuff like that... Because if you haven't got back-up you ring the ambo and they know what to do, you know. When you ring them and tell them what's happened and they come straight in and make you, easier. Make it easier breathing, you know. Make you relaxing? (0278 patient)*

*Depends on the sickness. I mean ... they could go to [acute hospital]...Like if she can't breathe, you know. If she needs the, like, life support or something like that. That's what they said, you know, because in (palliative care facility) they don't have a life support...That's what the doctor explained to us. But they said if she got like a – if she got like 'flu or something and got an infection, can take her to (acute facility) and the doctor can treat her there. (0278 caregiver)*

### Communication about the plan

For those patients and caregivers who could recall the process of completing the plan, a common perception was of receiving a clear explanation which they understood and agreed with.

*Oh yeah, and she said, “– if the ambulance comes you've got give them that.” ...The doctor explained it very, very well, very clearly, and what I understood about, she said, “If you call the ambulance, you give them this form, they'll know exactly how to treat her, what to do and you'll tell them which hospital you want to go to,” and I said, “Well it would be [facility]” ... (0299 caregiver)*

However for those patients or caregivers who did not fully accept or understand the rationale for the plans, and who may have had uncertainties about the patient's prognosis, they were confused by the plans, unsure how they had been decided on, and some felt under pressure to sign them.

... it seemed to me like it was just something that everybody was given. It was this ambulance plan, to come along and fill that in and then if you are in any bother... Just to ring 000 and it'd go to them and they'd have a number and they'd know that it was... I said to [Name], I thought I don't know why we really had to fill that out because if you were at home and under any circumstances and you're in trouble, you ring an ambulance, you ring 000 and get an ambulance to you. (0284 caregiver)

It was all filled out when it was given to me... Doesn't matter I suppose, it's not important I suppose. But, um, uh, and they visited me and asked me questions each day, and, um, so, um, I, um, uh, I suppose it all had been said and questions had been asked, you know. (053 patient)

### Themes: clinicians

Clinicians identified a number of key issues surrounding the implementation of APAPs including: (I) avoiding admissions to the emergency department; (II) barriers to signing the ambulance care plan; (III) stigma of not for resuscitation orders; (IV) systems issues; and (V) lack of clarity around signatures required to implement an APCP.

#### Benefits of the ambulance care plan—avoiding admission to the emergency department

Clinicians expressed the view that the main benefits of the Ambulance Care Plans was that they avoided admissions to the Emergency Department. They were seen as a practical “common sense” document and a provided a checklist that needed to be done in a timely and sensitive manner. APCPs were also perceived by clinicians to provide a sense of relief for their patients.

*“I find it much easier to discuss with the patients than the doctors sometimes. Yeah, most patients are receptive to the idea. Obviously – yeah most patients are receptive to the idea of kind of a security blanket.” (MD 2)*

*“I find that they actually feel very relieved that they won't need to go through the hospital system again and be stuck in ED with people that don't know them and things that they don't want done, and I think for them it's actually a fairly big comfort to know that there is a plan and they don't necessarily have to do that difficult I guess discussion again....” (MD 6)*

#### Barriers to signing the ambulance care plan

A number of barriers to signing the Ambulance Care Plan were identified by clinicians. These included: lack of awareness among the doctors of these newly introduced plans; the need for the plan to be signed on the day of

discharge; the time needed to complete the document; the preparation of the plan when families had only just met the palliative care team and whether to activate the plan.

At the time of this study it was necessary to obtain the signature of both the patient and the caregiver on the Plan. As the Plans had just been introduced there was a lack of awareness among doctors that the Plans were not just for use in palliative care and that oncologists were not familiar with the document and completing it was not a priority for them.

*“I think within oncology the doctors are aware of that and then happy to fill them out, although it doesn't always appear to be a priority but outside of cancer a lot of doctors don't know about the ambulance plans and we're doing a lot of education about what they are and how to use them and why it would be appropriate”. (MD 3)*

It was noted that when the Plans are completed on day of discharge it presented a problem as the carer needed to be there to sign

*“And I think some of that comes from the carers needing to sign it and so knowing that on the day of discharge the carers is going to be there because they're the ones taking them home, and I think that some of the issue”. (MD 4)*

Clinicians indicated that it took more time as it was not just filling in a form but a conversation that needed to be held with the patient and their carer so that all expectations could be met.

*“Sometimes it's quite tricky, especially here at (acute facility), to meet everyone's expectations to know what plan it is, to fit in with what everybody wants. I like it to be pretty clear that they're palliative, I like that to be – I like it to be further straightforward”. (MD 1)*

One of the barriers identified by clinicians was the need to complete the Plan when they first met the family and family was also meeting the palliative care team for the first time.

*“They take a whole lot more ownership of those decisions when actually the NFR decision still is a decision between us and the patient and I think it puts a whole lot of burden on the families”. (MD 5)*

The importance of having a copy of the Plan on hand when the ambulance arrived and the lack of certainty as to whether the patient and/or caregiver could or would use the Plan when needed was discussed.

*“I mean because there's two issues here, there's completing the plan and actually having the plan and produce the plan, like you can complete as many plans as you like but if they're not produced when you need them to be, I mean that is an issue as I work in the*



community". (MD 1)

"All you can do is what the patient wants and do your best, and do your best to explain to the family, and if at the end of the day they don't produce it well so be it". (MD 3)

### **Stigma of not for resuscitation orders**

There was a perception that signing a "Not for Resuscitation" form which is essential for a Plan to be completed was a big stigma to families and put the burden to families and if the carer was not on board or disagreed (even if it is the patient's wish) the carer would not sign.

"Patient's families have this big stigma that I signed the form that allowed that – you know, that stigma of I signed the form that allowed them to turn off the machine or do I need to sign the NFR, do I need to say that..." (MD 3).

"Because I've actually had a man who clearly said he didn't want to be resuscitated and his wife said in front of him she wants him to be resuscitated, and in that setting you send out an ambulance plan. Like there's no way she's going to produce that plan. (MD 1)

Patients and families considered it a finality once the APCP was documented in writing and that as soon as it was in writing, it had a 'different status'.

### **Systems issues**

The APCPs are part of discharge process and therefore need to be done on day of discharge. As well as the issues of asking for the Plan to be completed when the clinicians and the family have just met, if the Plan is not in the system immediately if presents a problem if 'the wheels fall off quickly'.

"I think we're finding they're filled out on the day of discharge and part of the discharge plan, and I think that that's a problem because obviously they don't get put on the system for some days. So if you're sending somebody home and there's the potential for it to fall apart, the plan won't be on the system." (MD 3)

The Plans were seen as both a benefit and a disincentive in residential aged care facilities.

"I think there's a really low threshold for calling ambulances in aged care facilities. So I probably think that person could potentially benefit from an ambulance care plan". (MD 3)

– it's just it's not on my radar to do an Ambulance Plan, and if they're complicated I'd want Palliative Care visiting them anyway and they can help make the call". (MD 2)

"but equally, you know, is there any point in me putting in place this thing if actually it's going to be overruled anyway or

that it's against the institution's normal practice". (MD 4)

A major theme among the clinicians was a lack of clarity over who signs the document.

I think the signatures are really complicated... Some of us didn't realise you could do the whole process without having it signed (MD 4)

Yeah but we don't know they're not necessary. (MD 2)

There was also uncertainty about whether patients need to sign the care plan given that it was the carer who was responsible for making decisions if the patient was unable to respond.

I would – as long as I've actually met people and explained everything, I would discuss on the phone or discuss in person but not have the form there on the day and just sign the form myself after a discussion with the family and let them know they've got to produce it and that it's just my signature on it" (MD 3).

"I don't think I've hardly ever seen the patient sign it, usually it's the carer" (MD 2).

There was also a lack of clarity around whether they needed to consult the patient's GP first. for example, if the patient wanted to die at home.

"I think though if we're sending – not all of the time but if you're sending someone out on an ambo plan with the goal of staying at home, you kind of check the GP does home visits, so you'd kind of.....so that they should be aware of the plan" (MD 2).

There was also lack of clarity around what medications ambulance personnel carry. Whilst the Plans can be useful to prescribe crisis medications the carer (in a moment of crisis) needed to know to go to the cupboard and get the medication as well as find the Plan.

"This is what took me a while, (a) to know what the ambulance would carry, so me writing Hydromorphone on there was useless because they didn't own it, they didn't carry it". (MD 4)

"I must admit, even if they're on oral meds, if we're sending out an ambulance plan and send out 5 amps of the meds we're putting on the list so that they're there. I didn't kind of really realise what they had in the ambos so I just was kind of sending them anyway". (MD 2)

There was also uncertainty about the role of external consultants, for example oncologists or cardiologists, and whether they would be routinely notified by the palliative care consultant that there was an Ambulance Care Plan in place.

"It depends on what the primary issue is. Why are they palliative? If they're palliative because of the oncology at XXX and they're expected back there, I suppose you would do some sort of courtesy update between treating teams in theory. But if it's palliative intent, no it wouldn't be on my radar. The only time I

*ever think of ringing anybody else is when you're turning off a defibrillator but that's the only time I ever do it" (MD 2).*

There were also situations when clinicians would not sign an Ambulance Care Plan such as the section on how to dispose of the body if the patient were to die en-route to hospital or if there was no NFR in place.

*"I often don't even fill out the disposal of the body because we haven't discussed it and I actually don't know where the body is, I suppose, to go to anyway". (MD 3)*

*"I would never – yeah, never put it on someone who doesn't have an NFR order, I would never – I wouldn't do it". (MD 2)*

Additionally if a palliative care patient was on chemotherapy there was a belief that they needed to go to the Emergency Department.

*"I must say if people are still having chemotherapy, even if it's palliative intent, I don't bother; [Yeah] because I think if they are unwell and need to call an ambulance they need to come through their GP". (MD 4)*

## Discussion

This study, undertaken at the early introduction of Ambulance Palliative Care Plans has identified a number of concerns from both the patient, carer and clinician perspective.

The most striking finding was that a number of patients had little direct involvement in the decision-making, little memory of signing the plans, and some of these patients and their caregivers were quite confused about what the Plan was, and how and when it should be used. For them, their Plans provided little reassurance and it can be presumed they would have little effect on patients' ability to have their preferred treatment, in their preferred place of care. However for those patients who were clear about their disease status and their wish for palliative care either at home or in a palliative care unit the value of the plans was much clearer. These findings are consistent with previous research where paramedics are often confronted with families who are unprepared for their loved one to be transferred to hospital or who have unclear expectations of the scope of an emergency visit (13).

These results highlight the importance of being respectful of patients' choice regarding where they would like to die and to appropriately cease active treatment which is likely to enable healthy grieving and reduce emotional trauma (14). This is particularly important in the context of COVID19, where recent changes in phone and telehealth consultations, social distancing and frequently changing

restrictions on the number of visitors allowed in hospital and palliative facilities may also affect patients' perspectives on their preferences for care as they near end of life.

Support for caregivers, who have been identified as burdened by the responsibility of initiating a care plan is also essential moving forward. Caregiver burden with the APCP process and its implementation is likely exacerbated by inadequate conversations with a lack of openness or clarity about the nature of the disease and prognosis, inadequate time to discuss complex prognosis (15) and/or lower levels of caregiver health literacy. While caregivers are no longer needed to sign an APCP our results indicate that strategies to reduce fear associated with finality caregivers associate with initiating a care plan, and reassurance of the continuity of care for symptom management after a care plan is initiated is essential. Proactive appointment of a proxy early in the palliative care trajectory and at the initial discussion of an APCP is also likely to ensure consistency between the preferences for care of the patient and caregiver knowledge of these preferences as well as weaken burdensome feelings in the caregiver when end of life care decisions are required (14). Ongoing, continuous education of patients and their caregivers is required to better support their understanding of the dynamic nature of the patients' prognosis (13).

Our findings also indicate that there were more unacceptable aspects of the Plans to clinicians than acceptable. Systems issues included completion of the plan on the day of discharge when the patient and carer had been introduced to the service; the need for the caregiver to be present to sign the APCP (no longer required); delays in entering the APCP into the electronic medical record as well as entry into the NSW Ambulance Service database; lack of clarity as to who needed to sign the APCP and which external clinician to involve and where to store the body after death. Gaps in understanding of the role of external clinicians and paramedics with respect to the implementation of APCPs, and uncertainty of responsibilities within differing scopes of practice have also been identified. To address these uncertainties, palliative care clinicians need to facilitate collaborative timely discussions with paramedicine staff and medical professionals involved in patient care prior to or at the time of implementing an APCP to ensure that patient safety is maintained and that their preferences for care as they enter the palliative phase are identified and carried out in a manner that is respectful of their needs, and to prevent instances of 'communication paralysis' due to uncertainties around determining prognosis and timing of death (16).

Multidisciplinary education around what palliative care services are available, and how these services are integrated within other areas of the health care system are also required (13). Such integration is necessary to achieve Palliative Care National Standard 5, i.e., ‘that care is integrated across the person’s experience to ensure seamless transitions within and between services (17). Reassurance and support for paramedics to counter fear of reprimand for breaching practice standards (13) or litigation for not making the right decision to transfer a patient to an ED, and to trust their intuition and experience in clinical decision making within the scope of an APCP rather than choosing an ‘easier’ or pragmatic option of transfer is also needed (18). Australian state health services have also recognised the changing needs of health professionals completing and implementing APCPs with the increasing integration of specialist palliative care services in the community (19). Amendments to APCPs that seek to enable paramedics to better support patients with their decision making as to whether to stay home according to their preferences or be transferred to hospital as required, and to complete the verification of death procedure are in progress (19). Providing opportunities for better interdisciplinary collaboration and consultation, for example between community palliative care nurses, palliative physicians and paramedics may be one way to assist in real time to align paramedics’ moral dilemmas with providing beneficent care (13). Interdisciplinary collaboration might include a system that alerts the palliative care team in the instance of an emergency call to provide an opportunity for the treating team or community nurses to facilitate ongoing outpatient care in accordance with patients’ and caregivers needs (20). Delphi groups or collaborative forums involving paramedicine, acute care staff specialists, and palliative care clinicians will also assist in creating consistency in service provision within and between specialities and instill confidence between all members of the multidisciplinary team in initiating and implementing APCPs for their patients (15,16).

### Limitations

Purposive and convenience sampling from patients discharged from one local health district may introduce a self-selection bias, thereby reducing generalisability to the national palliative care patient, caregiver and clinician populations. The small sample size is indicative of a palliative care patient population who are unwell and often fatigued. However, the authors are confident that the

commonality of views expressed in the patient/caregiver population demonstrate that data saturation was achieved.

### Conclusions

The Authorised Palliative Care Plans are a complex intervention that are sometimes misunderstood by patients, particularly those who are very unwell or who have little prognostic awareness, and their caregivers. Clinicians perceive the major benefit to be avoidance of admission to the ED.

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### Footnote

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consent was taken from all individual participants. This study was conducted in accordance with the Declaration of Helsinki (as revised in 2013).

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