

Peer Review File

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Reviewer A	Response
<p><u>Comment 1:</u> It lacked positioning within the evidence base/literature of patients' caregivers' and clinicians' understanding</p> <p><u>Comment 2:</u> It is well established that introducing a process for admission avoidance/ care based on patient's preferences is a complex intervention and such service improvements require reference to previous evaluations and findings and lessons to learn</p>	<p><u>Reply 1:</u> We appreciate that Reviewer 1 found the paper an interesting service evaluation, of huge local importance and adding to the body of knowledge. As the title indicates, the paper is positioned within the advance care planning literature rather than patients, caregivers and clinicians' understandings of complex interventions.</p> <p><u>Reply 2:</u> The study did not aim to investigate the background to the establishment of Ambulance Care Plans as a complex intervention to avoid unwanted admission to hospital. This process was undertaken by the Local Health District prior to the introduction of the ACPs. We aimed to examine the understanding and acceptance of the plans by the patients, caregivers and clinicians in our palliative care service.</p> <p><u>Changes in the text:</u> The discussion has been revised. Implications for practice based on this study and references to previous literature have been integrated into the discussion (refer pages 23-25).</p>

<p><u>Comment 3:</u> The number and duration of interviews is inadequate to achieve data saturation on this topic. The diversity of understandings of the plans does not go far enough in understanding the underpinnings for that diversity.</p>	<p><u>Reply 3:</u> The small sample size is indicative of a palliative care patient population who are unwell and often fatigued. They had been discharged from active treatment and referred to palliative care and an Ambulance Care Plan initiated. Rather than indicate diversity, the data shows a commonality of views in the patient/caregiver population interviewed. The data saturation that was achieved was evidenced by the commonality of the themes summarised in the Abstract (refer page 1) namely that patients and caregivers had little memory of signing the plans, were not actively involved in them, did not understand them and caregivers experienced anxiety as to what would happen if a Plan was activated. There was little diversity in responses.</p> <p><u>Changes in text:</u> The limitations section of the manuscript has been modified (refer page 26) “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.”</p>
<p><u>Comment 4:</u> A comment is made in the discussion about linkage to prognostic awareness but this is not presented in the data.</p>	<p><u>Reply 4:</u> We acknowledge this was not clear. Under the theme of Control Over Where to receive end of life care – lack of prognostic awareness was highlighted in the different understandings between patients and caregivers with uncertainty on how decisions would be made in a crisis – for example patients (quote 053) being clear on their current prognosis and the caregiver (quote 0114) saying “me personally, I would prefer they did their best to bring her back”.</p> <p><u>Changes in the text:</u> We have restructured this section and added a sub-heading <i>Lack of understanding of prognosis during a crisis</i> (refer page 14). “Lack of understanding of prognosis during a crisis....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.”</p>

<p><u>Comment 5:</u> It would be helpful to have clear research questions</p>	<p><u>Reply 5:</u> The study had two aims/research questions as stated: a) to understand the perspectives of patients, caregivers and their experiences of having an ACP and their understanding of the processes involved; b) to assess the acceptability of ACPs for clinicians.'</p>
<p><u>Comment 6:</u> It would be more valuable to have the findings presented in relation to the aims/ research questions.</p>	<p><u>Reply 6:</u> The aims of the study were to describe patient and carer perspectives on the plans and the acceptability of the plans to clinicians.</p> <p>The reviewer makes a good point as, on reflection, the data illustrates more unacceptable aspects of the Plans than acceptable. For example from the data it is clear that many patients simply did not understand the purpose of the plans. Clinicians in particular, had questions about the acceptability of many aspects of the plans. These are discussed under the theme of Barriers. Several of the clinicians found aspects of the ACP unacceptable under the theme of System Issues e.g. having to fill them out on the day of discharge when the patient and carer had only just been introduced to the service; the need for the carer to be present to sign, the delay in entering the ACP into the electronic medical record as well as entry into the NSW Ambulance Service database; also under the theme of Lack of Clarity as to whom needed to sign the ACP and which external clinician to involve; not knowing what medications the ambulance service would carry etc; there were particularly strong views about the acceptability of signing where to store the body after death.</p> <p>The main area of acceptance and agreement among clinicians was the role the ACP played in avoiding the patient being admitted to the emergency department.</p> <p><u>Changes in the text:</u> We have edited the Discussion to indicate more clearly that there were more unacceptable aspects of the Plans to clinicians than acceptable thus addressing this study aim more clearly (refer page 24)</p>

<p><u>Comment 7:</u> I am unclear about the sampling and thus the limitations beyond those of the inclusion/exclusion criteria.</p> <p>How were the inclusion/exclusion criteria operationalised when the trigger to invitation was lodging of an APCP on the ambulance website.</p>	<p><u>Reply 7:</u></p> <p><u>Changes in the text:</u> The data collection section of the manuscript has been modified for clarity (refer pages 7 and 8).</p> <p>‘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 caregiver were then sent a letter via mail inviting them to participate in the research project’.</p>
<p><u>Comment 8:</u> It is not clear how patients were identified from the 43 with APCP. 12 had apparently died before study start but the sentence starting line 201 then discusses 20 deaths and 10 living. Presumably this is the ‘subsequent’ events of the 31 eligible patients.</p>	<p><u>Reply 8:</u> . This study was a part of a larger health economics study and this comment prompted the authors to return to the screening data. Unfortunately, some of the screening data from the health economics paper was confused with the qualitative sub-study. The patient and caregiver subsection of the results section has been modified after noticing this error.</p> <p><u>Changes in the text:</u> A flow diagram has been included for clarity (refer figure 4). Of these 35 patients, 10 patients agreed to be interviewed. Twenty four patients were excluded for reasons including due to 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; page 9).</p>
<p><u>Comment 9:</u> There is no detail of response rate to letter of invitation and researcher phone call or sampling of those responses to interview the 10 patients of the study.</p>	<p><u>Reply 9:</u> Please see above comment</p>
<p><u>Comment 10:</u> The interviews seem very short in duration. ...may reduce the depth and breadth of the data.</p>	<p><u>Reply 10:</u> We agree, however the patients who were interviewed were unwell and fatigued so we indicated in our ethics application and at the beginning of the interview that interviews would only take 30 mins of their time (range was 10 – 35 mins) but as the data illustrates many lacked comprehension of the Plans, hence their responses to the interview questions were limited (refer page 8).</p>
<p><u>Comment 11:</u> How many days after discharge were they interviewed?</p>	<p><u>Reply 11:</u> The interviews were held at a time that was convenient to the patient/caregiver so the period of time after discharge varied but all were completed with a timeframe of 6 months</p>

<p><u>Comment 12</u>: Clinicians. How many were eligible? What grades. As this is a discharge document probably quite junior? Again quite short interviews</p>	<p><u>Reply 11</u>: All eligible clinicians, including those who worked in the specialist palliative care service and the acute hospital specialist palliative care referral service participated in a focus group on a day of their regular in-take meeting.</p> <p>Changes in the text: “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.” (refer page 11)</p>
<p>215 the switch from describing participants to the findings needs a break/subheading</p>	<p>The heading ‘Themes: Patients’ has been included after the description of patients and caregivers (refer page 11)</p>
<p>335 again a subheading would help the transition to clinician findings here.</p>	<p>The heading ‘Themes: Clinicians’ has been added to separate patient findings from clinician findings (refer page 16)</p>
<p>406: Typo ACP</p>	<p>This error has been amended.</p>