The intricacy of interactions: qualitative exploration of prefernces and perceptions of advance care planning among healthcare professionals, patients and those close to them

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The intricacy of interactions: qualitative exploration of preferences and perceptions of advance care planning among healthcare professionals, patients and those close to them

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Abstract

Objectives: Advance care planning (ACP) is a way of documenting preferences in case of a change or decline in health *via* verbal discussion and may include a written document. ACP relates not only to treatment preferences but to all aspects of future care such as place of death, plans for dependents and spiritual beliefs. Research has shown that ACP can have a positive impact but needs further understanding to enhance communication and increase uptake. This article focusses on the importance and intricacy of interactions and why a preference-based approach may be beneficial for the future.

Methods: This article reports two separate, but related, pieces of qualitative research. First, focus groups to evaluate perspectives of healthcare professionals (HCPs) following their attendance at a North Wales ACP training workshop. The second study comprised interviews exploring the views of patients, those close to them and HCPs regarding ACP.

Results: ACP interactions are complex and intricate. There is an association with end of life rather than changes in health among patients and HCPs often view discussions as akin to 'breaking bad news'. Good communication between patients, loved ones and HCPs is essential to reduce distress and ensure preferences are understood. Trust between patients and HCPs is of high importance and often a patient will have a preferred HCP who they feel comfortable discussing ACP with.

Conclusion: A preference-based approach to ACP has potential to widen participation in ACP, relieve anxiety and ease burden for patients and carers. Further research is needed to identify ways to increase inclusivity.

Keywords: advance care planning, health interactions, health personnel, palliative care

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Key Messages
- ACP can be beneficial for patients, families and health professionals
- ACP interactions are complex
- ACP can ease anxiety and feelings of burden
- Relationships with trusted HCPs are vital
- HCPs facilitate ACP uptake *via* interaction with patients
- Perspectives from HCPs, patients and carers foster a holistic understanding of ACP

Introduction
Advance care planning (ACP) is a way in which an individual can document their wishes for future care should they experience a change or

decline in health. While ACP is available *via* the National Health Service (NHS), previous work has shown that there are areas of uncertainty and a need for further research into the use of ACP.[1,2] NHS Wales offers several ways to plan for future care and provides documentation to be filled in by healthcare professionals (HCPs), patients and relatives or carers.[3] Formal recording of ACP can take several forms including Advance Decision to Refuse Treatment form, which is legally binding, (2020) the All-Wales Hospital Treatment Escalation Plan (2020) and the Future Care Plan form (2021) for those who lack mental capacity which are not legally binding.[3]

Alongside these plans there are also options for less formal ACPs to be made, which document not only treatment-related preferences, but also wishes for other aspects of care including place of death, who cares for whom, plans for any dependents and spiritual or religious beliefs.[3] The Statement for Wishes and Preferences is one option for this kind of ACP document although individual health boards and organisations may have their own versions.[3] These ACPs are flexible and can be changed as and when the individual wishes.

ACP documents should ideally be used in conjunction with open discussion between individuals and HCPs and may also include family members or carers.[1,3] ACP can be useful for patients and their families and care networks; it has been recommended that ACPs focus on what matters most to people and follow a 'socially inclusive approach'.[2]

Evidence from previous research has shown that ACP can have some positive impact for patients and carers, but further research is needed, and the evidence base for use of ACP needs expanding.[1,2] While ACP can be helpful in many ways, there are several issues that need further understanding. ACP is often framed in terms of circumstances of death and end-of-life treatments or treatments to prolong life; however, it has been suggested that ACP may be better utilised if it is approached in a more holistic manner.[2] A more holistic approach would define the things that matter most to the individual, which would then lend itself towards facilitating end-of-life discussion.[2] In providing this more holistic approach, it is important to identify what factors are

important to patients when it comes to 'living well' and that patient values need to be considered and not just how life can be prolonged.[4] Previous work has shown that individuals rate dignity, avoiding pain and suffering and remaining independent more highly than longevity of life.[4]

A recent review aiming to understand uptake of ACP and the approaches towards it found that enhanced communication between HCPs and patients can facilitate uptake.[5] Patients in previous studies have expressed that they would like increased communication with HCPs with whom they already had an established relationship.[1] It has also been found that some patients prefer to have ACP discussions with their HCP without their family involved to reduce perceived burden on family members.[1] This may also be beneficial for those who wish to make their own wishes clear without the influence of family members who may have differing opinions.

However, despite there being some evidence that ACP discussions with HCPs can be beneficial and are desired by patients, HCPs do not often engage patients and families in these discussions.[6,7] Interactions surrounding ACP are complex and consultations and conversations can be challenging for both HCPs and their patients.[8] Some HCPs have expressed a need for support and training in dealing with these complex interactions.[8,9] HCPs may have difficulty in starting these conversations and there is likely to be a concern that ACP conversations may distress or startle patients who see them as a sign that they are nearing the end of life.[1,10,11] HCPs have reported a lack of time and lack of confidence in having ACP discussions and patients may not be aware of ACP at all or feel unsure what it is or how to ask for it.[1] For patients there may also be confusion between ACP documents and other documents such as do not resuscitate (DNR) orders and treatment escalation plans.[2]

Betsi Cadwaladr University Health Board (BCUHB) and the research team from Bangor University conducted an evaluation of a regional training programme for HCPs regarding ACP discussions. The evaluation included focus groups with HCPs, which highlighted the areas that required further research into the use of ACP with patients and families.

As patient and carer voices were not included in the service evaluation and were also found to be underrepresented in ACP literature, a further qualitative interview study was designed to explore the views of patients, those close to them and HCPs. This article reports findings from the programme evaluation and the subsequent qualitative work and focusses on the importance, and the intricacy, of interactions that occur in ACP discussion and why a preference-based approach may be the future of ACP.

Methods

This article reports on two pieces of research into ACP. The second study was designed in response to the lack of patient and carer voices in the first and in recognition of the need to include everyone involved in ACP discussion. To give a full account and to be inclusive of all participants views, the findings of these two studies are reported together here. Qualitative methods were utilised in both studies and data were brought together for interpretation.

Study 1: evaluation of a North Wales ACP training programme for HCPs and social-care professionals: focus groups with HCPs

Aim. The aim of the focus group study was to explore, in-depth, the views of HCPs on the impact of the half-day ACP training workshop on their practice, and to identify barriers and facilitators to implementation of ACP in North Wales. As in-depth views and perspectives were desired, a qualitative approach was the most suitable. To capture interactions and shared experiences, a focus group methodology was utilised.

Participants. HCPs who attended a regional training course were asked to also complete an electronic questionnaire. A total 22 out of 57 HCPs (19%) who completed the electronic questionnaire indicated they would be willing to participate in ACP focus groups. All 22 were invited and were given options for timing of and venues for the focus groups.

Of the 22 HCPs invited, 12 responded to the invitation and participated in the study across three focus groups. The 12 participants came from a range of professional roles and areas of clinical

work (Table 1). As all of those who responded were then recruited, the population was not big enough to allow for purposive sampling. All HCPs had had a period of at least 6 months between attending the ACP training workshop and participating in the focus group. This was to allow time to practice and use the learning from the ACP training workshop.

Focus groups. Focus groups were conducted by a member of the research team (J.P.) who is an HCP and moderated by a senior member of the team (J.H.) who is an experienced qualitative researcher. Participants were informed that JP was not acting in her capacity as an HCP, but as the study researcher. The focus groups lasted between 60 and 90 min, were held in the University research office meeting room and followed a predefined topic guide. All focus groups were audio-recorded with permission and transcribed verbatim.

Analysis. The study findings were analysed using Framework, a systematic, five-stage matrix-based system, which facilitates analysis both by theme and by case.[12–14] The Framework approach was chosen over other methods of qualitative analysis as it is valued for its transparency and clarity and recognised for its suitability for applied studies such as this. Framework was also chosen due to its ease of use in team research.[13] The five stages of the Framework approach were conducted in both studies. The first stage is re-familiarisation with the data, which involves researchers reading all transcripts in detail and noting potential themes. Second, there is an inductive development of a thematic coding index. Coding (or 'indexing') the data is the third stage. The data are then synthesised into thematic charts, which are then used for the final interpretation stage.[13] The interpretation aims to seek patterns, associations, and linkages, moving the analysis 'beyond the descriptive'.[13]

Study 2 – exploring the views of patients, those close to them, and HCPs on ACP using qualitative case study methodology

Aim. The aim of the study was to address the gap in the knowledge identified in the first study by exploring the views of patients; those close to them; and HCPs caring for them on their views, experiences and preferences regarding ACP. A

Table 1. Study sample.

Study 1 sample					
Geographical area	Area 1	Area 2	Area 3		
	5	6	1		
Years in post or practice	<5	5–10	>10		
	4	5	3		
Professional role	Healthcare assistant	Chaplain	Management or training or education	Nurse	Psychologist
	1	1	3	5	2
Study 2 sample					
	Male	Female	Renal unit	Cardiac unit	SPC
Patients	2	1	1	1	1
Carers		2		1	1

SPC, specialist palliative care.

qualitative approach was used to obtain depth and richness of data to understand the complexity of the topic. Case study methodology was used because it is recognised that there were likely to be differing perspectives on ACP between participant groups.

Participants. Patients were recruited *via* their HCPs through specialist palliative care (hospice) day care centre, renal and cardiac units, and specialist palliative care teams in Wales (Table 1). Patients were eligible if they had a primary diagnosis of cancer or organ failure, were residents and receiving healthcare in Wales; had an expected prognosis of less than 3 months; and were able to nominate at least one person close to them and one HCP who were involved in their ACP. Patients were excluded if they were unable to understand study information or give informed consent or if they had a complaints procedure in process. Purposive sampling was not possible as the population groups were too small to allow for it. Patients were recruited *via* HCPs according to their use of ACP rather than other characteristics and persons close to them and HCPs were recruited according to patient nominations.

Interviews. In-depth qualitative interviews using a predefined topic guide were conducted in participant's homes by a member of the research team (J.P.). All interviews were audio-recorded and fully transcribed.

Analysis. The interview data were analysed using the Framework method as previously detailed above.[13] Two members of the research team (J.P. and A.H.) conducted the analysis, and several interpretation workshops were held with the wider research team.

Data synthesis
The data from both studies were synthesised to enable the dual reporting of the study findings. The Framework charts from both studies were brought together and data were interpreted in the context of both study aims and populations. Interpretive workshops were conducted with the research team to identify patterns and establish connections between datasets.

Impact of COVID-19 pandemic
Due to the impact of the COVID-19 pandemic, we were forced to halt data collection for the second study much earlier than anticipated. As study participants were vulnerable and time demands on carers and HCPs were considerably increased, the research team and the funder accepted the need to cease data collection early and proceed to

analysis. Therefore, the sample is smaller than originally planned and this article includes data from five interviews, three with patients and two with family members (as well as the focus group data).

Findings

The findings from both studies revealed the ways in which interactions involving ACP are intricate, complex and potentially difficult to navigate for HCPs, patients and those close to them. The findings also show that a preference-based approach and individualisation of ACP discussions may facilitate and improve interactions.

The association with the end of life

Findings from the focus groups indicated that HCPs viewed ACP as being focussed on end-of-life decisions and associated it with other documents such as DNR orders and issues such as funeral arrangements. In the interview study, patients and carers also saw ACP as strongly associated with end-of-life care; when asked why they thought ACP discussions has been initiated, they explained it was because they knew they were approaching the end of life. Carers also believed that ACP discussions were initiated by HCPs when someone was dying. While both patients and carers in the interview study agreed that ACP interactions might be easier if they were introduced earlier in a wider healthcare context, this was with the benefit of hindsight, and they also explained that they thought it was unlikely that anyone who was still fit and healthy would see the point in having ACP discussions or using the document.

Breaking bad news and fears about distress

HCPs in the focus group study also expressed concern that the introduction of ACP discussions would be interpreted by patients as a sign of treatment failure, which may cause upset and loss of hope. There was a view among the HCPs that ACP interactions were akin to 'breaking bad news' and therefore distress in patients and families was anticipated. This fear of causing distress meant that HCPs were cautious and therefore selective about who they chose to introduce ACP to, choosing to select those that they thought were less likely to become distressed, rather than offering those interactions with all their patients or

taking a preference-based approach and establishing individual needs. HCPs also had concerns that ACP interactions could cause distress for both patients and HCPs themselves, either in terms of worry that they did not have the time to have adequate discussions or because they felt guilty at potentially distressing patients. Patients and carers in the interview study showed that they too had concern about lack of HCP time and resources for adequate engagement with ACP. One patient participant was distressed as she had taken the time to carefully complete her ACP booklet and, on being admitted to hospital, found that none of the HCPs had time to look through it with her.

> But they do make you feel like that because they don't want to read it. What I hate even more is when they take it off you and go, 'I'll read it on my break', and I could turn around and see exactly where it is, and it didn't move at all. (Interview participant, Patient)

Approaching ACP discussions

Focus group participants were committed to the use of ACP; however, they reported differing, sometimes conflicting, views on how ACP discussions should be initially approached. The HCPs who saw ACP as a tool to empower patients to take control were more likely to introduce the concept of ACP to all their patients. Potential timings for the introduction of ACP included when a person was moving to residential care or an option at diagnosis for those with degenerative conditions such as motor neurone disease. Other HCPs were more likely to select who they introduced ACP to by waiting for indications from patients that they would be interested in having more control over decision-making.

There were views expressed in both studies regarding the most suitable setting for ACP interactions to be initiated with some HCPs believing that the hospital wards were too busy and too crowded to facilitate discussion and advising that private consulting rooms or similar would be more suitable. Some interview participants had discussed ACP within their home and reported that they felt that to have been the right setting for them.

> You couldn't have this talk on a ward as it's too busy. (Focus group participant, nurse)

Family dynamics and ACP discussion

Patient interactions with family regarding ACP differed depending on the ways in which patients viewed ACP and who they chose to discuss it with. Two participants with large families took very different approaches to ACP interactions with their children. One patient participant took a very family-based approach and included all her five daughters in the discussions and in completing an ACP booklet. She said this was so that everyone would be aware of what she wanted. However, another participant who also had five children had chosen not to include any of them in his ACP interactions as he wanted to be able to make decisions without influence and he felt that this would reduce any potential burden on his family. The use of the ACP booklet was also reported by both patients and those close to them to be useful as it meant that, as everything was in writing, there could be no confusion as to the wishes of the patient.

> With all of us, we can't argue with what mum wants because it's in her writing. (Carer)

Regarding the potential for carer burden, more than one patient in this study expressed a wish not to burden their families with difficult decision-making following bereavement and explained that the ACP booklet was a way in which they could make sure there was no potential for burdensome tasks or emotional upset regarding their wishes.

> A relief really, because things were getting sorted out for the end. And to me it's like a relief. So the kids don't have to be burdened with all of this. (Patient)

The trusted HCP and ACP interactions

ACP interactions are not always straightforward and there can be barriers to communication between family members. One patient participant in the interview study explained that his daughter was involved with all his decision-making and that as long as she was aware of what he wanted, then that was all that was necessary. However, when his daughter was interviewed, she explained that she had found it very difficult to discuss her father's wishes with him and that his thoughts were often contradictory and confusing for her. This was overcome by having a more structured ACP interaction which included a trusted HCP.

And I sat down with Dad to go through it and I found it difficult to ask him those questions. He didn't . . . you've met my Dad, we kept going off on tangents. He didn't answer the questions in a helpful way. (Carer)

When HCPs are involved in ACP interactions, the relationship between HCP and patient seems to be of utmost importance. HCPs in the focus groups explained that they believed rapport and trust needed to be established before any kind of ACP interactions were introduced.

> I know all my clients well, so I found it easy to discuss what their wishes were. (FG participant, nurse)

Participants in the interviews also placed great value on their relationships with HCPs and each one named a particular HCP, often a nurse, who they had felt comfortable enough with to discuss ACP. Interview participant and his daughter had relied on their trusted HCP to facilitate their ACP interaction and found that their communication difficulties were resolved by having the input of the HCP. This participant also reported that he only agreed to engage with ACP as it was his trusted HCP who had initiated the interaction.

> If it was the GP who would've said it, I wouldn't have taken any notice, it's just I was here with (nurse) and she knew about the pain I was going through. (Patient)

Discussion

Interactions surrounding ACP are intricate and complex and can be challenging for both patients, their families and HCPs.[8] The findings of the two studies presented here, and those of previous work, indicate that ACP is strongly associated with end-of-life care and decision-making by patients, their families and HCPs.[2] It has been suggested that for ACP to be more accessible and useful to individuals, there should be a more holistic and inclusive approach to ACP discussions and the focus should be moved away from end of life.[2] It may be that utilising a more preference-based approach to ACP could facilitate uptake and increase the usefulness of ACP for patients and families.

Our study affirms the findings of Abel *et al.*[1] in that there appears to be confusion among patients

and families between ACP documents and other, specifically end-of-life documents such as treatment escalation plans and DNR orders. Our findings show that ACP has the potential to be used earlier as part of wider health interactions, but HCPs may require further education and training to support them in those interactions.[8,9] Our findings suggest that currently, those who are young and in good health are unlikely to engage with something they believe to be for those at the end of life and therefore public health initiatives which focus on increasing health and death literacy may be useful in facilitating uptake of ACP.[2]

While HCPs may understand the potential benefits of ACP, they can have difficulty engaging in these interactions and often do not discuss ACP with patients and families.[2,6,10,11] Some HCPs in the focus groups reported being selective about which individuals they discuss ACP with meaning that other patients may not know that it is available. Patients may be unaware of ACP or unsure how to raise the topic themselves even if they would like to.[1,7] One of the key reasons cited by HCPs in previous work for not engaging in ACP interaction was a desire to avoid any potential distress in their patients who they believed would see the introduction of ACP and a sign of treatment failure and the end of life.[2] It has been further shown in this article that HCPs viewed ACP in the same way as they viewed 'breaking bad news' and therefore anticipated distress in patients. There are also concerns about having a lack of time or appropriate setting for adequate interactions about ACP, which may distress patients and induce guilt in HCPs.[1] The findings of the interview study confirm that patients may be distressed if HCPs are not able to devote enough time to ACP interactions. This further highlights the need to understand patient preferences when ACP is introduced.

ACP matters to both patients and their care networks and our interview study confirmed this.[2] Decisions around family involvement in ACP interactions may differ between individuals depending on their views and preferences. Some people may choose to involve several family members in the discussion while others may prefer to complete their ACP plan alone to avoid influence from others and reduce any perceived burden on loved ones.[1] This finding was confirmed in the data from the interviews with patients and carers. Some individuals may find communication regarding ACP with their loved ones to be complicated

and experience difficulty in establishing the wishes of the patient. In all of these ACP interactions, there is a need for the involvement of an HCP to facilitate communication and bring an objective perspective to the ACP process.

Patients have expressed a preference for the involvement of a trusted HCP with whom they have already established a good relationship.[1] There is evidence in the literature that HCPs have also shown that they believe relationships with patients to be important and that trust and rapport should be built before engaging in ACP interactions.[5] These positions of trust are often held by nursing staff as they are regarded as having especially good relationships with patients and families, being empathetic and non-judgemental and as taking the time to carefully explain and discuss ACP.[1] These findings are echoed by the findings of our study, which showed how valuable patient and HCP relationships can be and how important patient preferences are.

Conclusion

Interactions regarding ACP are complex and intricate and careful thought needs to be given to their approach. The desire to avoid confusion and distress for patients and carers is of utmost importance and HCPs are focussed on the wellbeing of their patients; however, this can lead to selectivity in offering ACP and the potential for some patients to be unable to take advantage of a service which may benefit them. The relationships between HCPs and their patients are key to facilitation of ACP discussion and many patients will have a particular, trusted ACP who will be in the ideal position to approach ACP with them. By recognising and nurturing these positions of trust, HCPs will be able to minimise distress and facilitate uptake in those who would like to consider ACP. While ACP is optional and may not be desirable for everyone, it is empowering for patients to be able to make their own choices regarding its use. A more inclusive and preference-based approach to ACP has the potential to widen the use of ACP and to relieve anxiety and ease burden for patients and carers. While it is recognised that transferability of the findings from these studies may be impacted by the small sample size and single geographic area, it gives insight into patient, relative and HCPs perceptions regarding ACP. Further research is needed

to identify ways in which the approach to ACP can become more preference based and to find the best ways to provide ACP for those who would benefit.

Declarations

Ethics approval and consent to participate
In accordance with Health Research Authority guidelines, study 1 did not require ethical review due to being a service evaluation with healthcare personnel in their professional roles.

Study 2 was granted ethical approval by Bangor University School of Health Sciences ethics committee (2019-51655). Study 2 was also granted full ethical approval by Wales REC 5 on 23 May 2019 (19/WA/0143). All participants were given written study information prior to consent. Participants in study 1 gave consent to be contacted *via* the electronic questionnaire and verbal consent to taking part in the focus groups. All participants in study 2 gave written informed consent at the time of interview.

Consent for publication
All participants consented to the use of anonymised quotes appearing in subsequent publications. Participants in study 1 gave verbal consent and those in study 2 gave written consent.

Author contributions
Annie Hendry: Data curation; Formal analysis; Investigation; Project administration; Writing – original draft; Writing – review & editing.

Jacqueline Pottle: Data curation; Formal analysis; Investigation; Writing – review & editing.

Rosalynde Johnstone: Conceptualization; Funding acquisition; Writing – review & editing.

Marlise Poolman: Conceptualization; Funding acquisition; Investigation; Methodology; Writing – review & editing.

Julia Hiscock: Conceptualization; Formal analysis; Funding acquisition; Investigation; Methodology; Writing – review & editing.

Availability of data and materials
Study data and materials are available upon request from the corresponding author.

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