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Healthcare-providers experiences with Advance Care Planning and Goals of Patient Care medical treatment orders in Residential Aged Care Facilities; an explanatory descriptive study.

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Introduction

Advances in healthcare have led to significant increases in the life expectancy of older adults (1). However, living longer leads to increasing frailty with accumulation of illness as the population ages and more people require permanent care in residential aged care facilities (RACF)(2). Advance Care Planning (ACP) is a process by which people discuss and, maybe, document their instructions, preferences and values for healthcare in an Advance Care Directive or some other written format; planning for a time when they may not be able to speak for themselves. It is based on autonomy and the idea that this autonomy should extend to situations where a person's capacity becomes impaired (3), which is the reality for over 50% of RACF residents. There has been increased penetration of ACP in RACF in recent years. However it has not shown the efficacy that was expected(4). Positive effects have been reported in terms of quality-of-life and decreasing family distress (5) but less so in terms of hospitalisation rates (4). Persisting issues exist with both the clarity of completed Advance Care Plans (6) and the activation of these plans when residents become unwell.

In RACF in the USA, medical treatment orders such as the Physician Orders for Life-Sustaining Treatment (POLST) were introduced to address limitations of ACP documents. These included difficulty with their interpretation (7-11) and instructions not being in a form that paramedics could follow (12). Studies in the USA show more appropriate treatment decisions for residents with the introduction of POLST, and others adapted from it (13), compared with ACP documents alone.

The Goals of Patient Care (GOPC) process was developed in Australia building on the POLST concept (14). It addresses identified shortcomings in previously used 'Not for Resuscitation' orders. GOPC are medical treatment orders completed by a Medical Practitioner, following clinical review of the resident's current medical status and discussion with the resident or their substitute medical decision maker plus other interested parties. The GOPC document takes account of what is medically possible and the resident's preferences within those limits. It helps guide healthcare decisions at time of clinical deterioration, particularly in emergency situations. It was developed to improve pro-active healthcare decision-making.

There are limited studies on ACP from a healthcare professional's perspective. Those available reported that ACP is mainly judged positively (15-19). However its implementation presented significant challenges including whether current service provision for end-of-life care could meet resident wishes (18). Further barriers included the many and varied ACP documents in use (20) and family-related issues (21).

Healthcare providers are instrumental in the completion and the activation of both ACP documents and medical treatment orders. This study was part of a larger study comparing (i) GOPC plus usual ACP, with (ii) usual ACP alone. The aim of this study was to better understand how healthcare providers understood ACP and GOPC in terms of resident autonomy, their legal authority, and differences between ACP and GOPC. The study also sought to understand their experiences of using both these documents when making decisions about treatment, transfer to hospital, and end of life care.

Methods

The qualitative study used an explanatory descriptive approach (22). It took place in three RACF in northern metropolitan Melbourne in 2016. In these facilities a RACF version of the GOPC medical treatment orders was introduced twelve months prior, alongside the facilities' usual ACP. Usual ACP in these facilities is frequently undertaken by family members due to the high incidence of cognitive impairment among residents.

All the RACF in this study have access to local hospital specialist Residential In-reach (RIR) geriatric services, namely 'Outreach' and 'Residential Care Intervention Program in the Elderly (RECIPE). Each is staffed by geriatricians, aged care trainees and clinical nurse consultants, and support the primary care team by providing acute and sub acute review of aged care residents within the facility as an alternative to hospital transfer(23).

Advance Care Plans were completed within the RACF with the resident and/or their family. This led to differing quality of ACP completion due to varied understanding of the documents. The GOPC medical treatment orders were completed following a process of the medical physician ascertaining the health status and trajectory of residents by reviewing their records and their health, cognitive and functional status with the RACF staff. A meeting then occurred with all interested parties to complete the document which had already been provided both to residents and next of kin for review.

Within the three RACFs where the GOPC medical treatment orders were trialled, focus groups were conducted by RM and BH with facility staff, and semi-structured interviews conducted by RM with visiting GPs. All were audio-recorded. The same question guide (Appendix1) was used with each focus group and semi-structured interview (Appendix 2) and unanticipated themes were explored in subsequent focus groups and interviews.

Twenty-one participants were recruited and, at the time that the final interviews and focus groups were being completed, no new themes were emerging. The analysis process can be seen in figure 1. The transcripts were read independently by a second researcher (BH) and no further themes identified.

The audio-recordings were transcribed verbatim and Nvivo used for the data analysis. Drawing on aspects of Grounded Theory (24), initial themes were identified within the transcripts and coded. A list of these themes was generated. Relationships between the initial themes were identified and the themes organised and grouped. Finally, the themes were organised into overarching themes.

It should be noted that at the time of the study, all facilities were using non-legislated ACP documents, often developed by the facility, for recording medical treatment preferences and values.

Figure 1 Data Analysis in Qualitative Research, PI Principal Investigator, BH Barbara Hayes

Results

Participant characteristics

The facility staff participating in the focus groups included endorsed nurses, registered nurses, clinical care co-ordinators and facility managers, all of whom had a role in helping with completion of ACP documents and/or activating ACP/GOPC documents at a time of resident deterioration, . Experience ranged between two and twenty years. Each of the three focus groups had between 3-8 participants (total of 18 participants). Three semi-structured interviews were conducted with three GPs, each a visiting GP at one of the RACF.

Themes

Healthcare providers reported ACP and GOPC as beneficial but also went on to discuss many issues, which will be described under four main themes:

1. Use of advance documentation (ACP and GOPC)
2. Resident autonomy
3. Enablers
4. Barriers

Use of advance documentation (ACP and GOPC)

Participant's responses highlighted that nurses had incorporated the completion of ACP documentation into their admission processes. The differences between ACP and GOPC were not well understood by participants but they saw both as helping guide healthcare decision-making.

In all facilities it was the nursing staff primarily who assisted the resident or family with completing ACP documents. Nursing participants commented on this being appropriate, saying,

'As nurses we are more empathetic, we spend time with them, we know how the family is.'

The level of involvement of the GPs in completion of ACP documents varied between sites but the optimal situation was described as,

'…always the GP, the family and the nurse.'

There were special situations in which the GP had increased involvement. This was often in situations where the family circumstances was perceived as complex with respect to the healthcare planning, as illustrated by a nursing participant,

'Sometimes the family is very anxious and we have to have a meeting to discuss everything and then it's all signed by the relative and the doctor.'

It was clear from the discussions that participants saw ACP as a guide to healthcare decisions rather than defining treatment decisions, as illustrated in the following quote,

'I think we like them because it gives us the direction, direction which way we're going.'

It appeared that participants did not perceive either the ACP or GOPC document as legally binding and neither document replaced the need to confer with family when a situation of clinical deterioration arose as a participant illustrated,

'A phone call in accordance plays still a big part on the day when they are unwell.'

Confusion about the different purposes and authorities of an ACP document and a GOPC form was a recurrent theme. One nursing participant illustrated it saying,

'I find it a little bit confusing because we have a [facility name] one and then this one [GOPC] and I wasn't sure whether we copy that information onto [facility name] or vice versa.'

Some participants saw no difference between their facility ACP document and the GOPC medical treatment orders, one nursing participant illustrated this saying,

'*It's pretty much similar to what we have on our assessments on admissions with the ACP.'*

Another participant mentioned the fact that regardless of the presence of a completed GOPC they still are required to fill out the facility's ACP document. An example being,

'They said oh no we did one with the doctor but we needed them to complete our form also.'

The inference being that there is a strong facility imperative to have an ACP document completed, even though the resident's preferences and values may already be captured within the GOPC document.

Some participants did however recognise that the GOPC provided a mechanism to document residents' values and preferences, and that these could be used as a guide to future decision making. One participant described the GOPC form as providing a mechanism for improving communication of healthcare wishes of residents and focusing on key information,

'Our form, there is a lot of information, and a lot of detail whereas with this one you've got the key things in there.'

Another participant felt that it helped with healthcare decision-making for residents by being more suitable for people with poor health literacy,

'It gives you tick boxes to give you a choice of what would be acceptable and that's what I liked.'

It was unclear from this statement whether the staff member also identified the significance of the medical professional input into the GOPC form.

Resident autonomy

The importance of residents' autonomy and the need to capture their values, goals and preferences on ACP documentation, while they still had decision-making capacity was clear to participants and a recurring theme in the analysis. By doing so it made the decisions about treatment and hospital transfer more in keeping with the resident's own values and preferences rather than that of a proxy. The benefits were described by a number of participants, with one illustration being,

'I think my big take would be that we should try and involve the resident as much as possible because they have the right and I think that should be their say whether I want this or not. So, try to do it when they're in good health.'

Many residents, however, lack capacity to complete an ACP document and it is often family members who are engaged in the ACP process. There was a common view among participants that ACP documents completed with family members often reflected what the family wanted for the resident, rather than reflecting the known preferences of residents themselves as illustrated here,

'I know a lot of family members say, "This is what mum wanted" but when mum has deteriorated, or dad has deteriorated, [and] they can no longer advocate for themselves its more so what they [the family] want.'

While it is possible for an ACP document, completed by family, to faithfully convey the resident's own autonomous wishes for future care, it was clear from participant descriptions like this one that participants thought this not to be usually the case.

Enablers

Study participants described experiences which promoted the completion of ACP and GOPC, including motivated nursing home staff, supportive specialist resources, and the effect they recognised the completed ACP documents had when patients deteriorated including improving end of life care and patient dignity.

Overall, ACP documents were described by healthcare providers as a valuable resource when making patient-centred treatment decisions. Changes to the format of ACP documents with better capture of residents' preferences was highlighted by a nursing participant,

'It [ACP] has progressed to be more comprehensive and more a formal process, [it has] become more person-centred.'

This finding highlighting that although participants had some reservations about whether ACP documents truly reflected residents' (versus family members) values and preferences, that having these plans available did support their efforts to provide treatment and care that was in-line with the residents' preferences.

Recognition of ACP as an important resource that supported their clinical decision-making in a time of crisis, motivated staff to undertake ACP and to document patients' preferences. It was particularly important to participants to know whether a resident should be transferred to acute care, as described by one nursing participant:

'It is very helpful especially in time of crisis, [when we are deciding] whether we have to send them to the hospital.'

The clinical relevance and importance staff placed on having completed ACP documentation available, was reflected by staff reports of increased uptake of ACP and how they had changed their routine processes to ensure ACP documents were completed early following admission to the RACF. Many participants described increasing uptake of ACP over time, all commenting on an increased prevalence of completed documents as described by a GP,

'The penetration rate, we've increased dramatically. Whereas you used to be trying to make decisions at crisis time.'

Residents currently entering RACF were described as being much frailer compared to previous times. This resulted in greater urgency to address ACP earlier in the admission process, anticipating deterioration in the very near future. One nursing participant commented,

'They come in and we bypass the initial assessment period and start with ACP first, just to make sure and usually it's the right decision.'

Participants reported that completion of ACP documentation had also translated into provision of improved palliative and end of life care within their facility. The process of conducting ACP and GOPC discussion raised GPs awareness of the importance of planning the provision of palliative care within the RACF. One participant commented,

'I find most GPs now, since we've been on our band wagon of ACP, they're very prepared. So they already have a lot of palliative care medication and plans, treatment plans prepared, once we've had family conversations and they are discussed.'

In addition, participants reported that ACP improved resident's care at end-of-life as described in the following quote,

'It's allowing people to die with privacy and dignity now, where a lot of people before weren't allowed to die with dignity.'

An important enabler to conducting effective goals of patient care and advance care planning discussions was the availability of expert clinicians who could lead family meetings and provide advice to both GPs and RACF staff. The access the RACF have to local specialist Residential In-reach (RIR) geriatric services, namely 'Outreach' and 'RECIPE', who visit residents within the facility to provide medical assessment and advice about prognosis and treatment, also enabled future planning for their residents. The support these

teams provided for goals of patient care and palliative care decision making was also highlighted by participants,

'Outreach and the RECIPE teams are fabulous….I use them a lot to bring the family around that this is palliative. They'll often sit the family down and the person will be palliative from that point on [they provide] the extra layer of authority.'

This support was particularly useful when families disagreed with treatment plans recommended by facility staff and their visiting GP. A GP described the situation of a RIR registrar visiting saying,

'So when the doctor, and sometimes it's only a junior registrar- they come in and say there's nothing we can do and there's nothing we can do in hospital they believe them …….[as they are] not just the GP.'

Barriers

The above descriptions suggest a greater willingness of RACF staff to engage with ACP, however they also described their experiences with barriers to implementing ACP within routine care and the effects these barriers had on decisions about treatment, hospital transfer and end of life care. Participants consistently reported that cultural and religious traditions and beliefs affected residents and their families' willingness to engage with ACP, with some families expressing concerns about ending life prematurely. A GP participant illustrated this saying,

'The resistant groups are the Catholics, the southern Mediterranean Catholics.'

In addition, misconceptions by families about palliative medications including morphine, also impacted on staff members' ability to provide appropriate end of life care were also described. Regarding the use of morphine one participant recounted an experience saying,

'Then she [the daughter] told me and the doctor and the [Residential In-Reach] team, "I'm not killing my mother, you can do it if you want". [She believes] that morphine will kill mum and we're trying to kill her mum and so that up to the last day she dies without morphine.'

Low levels of health literacy and a lack of understanding by residents and their families regarding the purpose of goals of care discussions was also identified as a barrier to completion of ACP documentation. Nurse participants felt there was a considerable lack of understanding and awareness about ACP due to poor health literacy of families and residents stating:

'I think it's an unawareness, it's a knowledge, and they're not educated.'

Poor health literacy was also attributed to families having a mistrust of ACP. One participant illustrated families' mistrust of written ACP documents saying,

'I think relatives are just a bit nervous. "If I fill that in, then does that mean they're not going to look after mum anymore".'

A GP illustrated how families' can misunderstanding of ACP can be a barrier to its use with the following example,

'They'll say, "No I don't want her to go no, don't send her to hospital". And then they'll add at the end, "Unless she gets any worse". And that's the thing that gets me all the time. I have to say, "Hang on hang on. Let's go back to the drawing board here".'

Family members' willingness to adhere to the outlined plan of care when a crisis did occur was also identified as a barrier to consistent implementation of the GOCP. This is illustrated well by the following quote from a nursing participant, who describes a personal experience,

'I did send a man to hospital recently but his advance care directive said no more hospital transfers but at the time the family said, "No send him to hospital" '.

One reason given for deviating from the instructions on an Advance Care plan was that the decision was easy to make in advance but difficult to follow through on at a time of deterioration as described,

'Like now to hand a form and say can you fill this in is easier to when you get to the actual point of time, it can change quite dramatically.'

Concerns about providing their family member with the best possible care and internal conflict within the family were identified as the reason some family members preferred to transfer their loved one to acute care rather than following the ACP. Many participants

reported that they believed feelings of guilt to be a reason ACPs are not always adhered to by families. This is described in regards to a resident's wife:

'For her to decide whether I'm [resident's wife] doing the right thing or not, it's very hard on them and they feel so guilty about it.'

Internal conflict for family members was also reported to play a role in not following ACPs as one participant described,

'She is still not in acceptance with what is happening to her husband so she still in her mind feels that she hasn't done enough'.

Another important barrier to effective use of ACPs and provision of palliative care within the facility was the out of office hours availability of GPs who knew the residents. Facility staff found that locum GPs were reluctant to commence people on palliative care plans thus impacting on their ability to follow resident's preferences as illustrated by a nursing participant,

'He wanted to die here and the locum kept sending him to the hospital. He kept saying, "I don't want to go to hospital" but the locum wouldn't write him up for anything and this poor man actually died in pain before we could even get him a morphine order, so it was quite horrific.'

Nursing participants went on further to describe healthcare providers unfamiliar with the resident, as a strong reason for unwillingness to follow the instructions on an ACP document, as is illustrated by the following comment,

'I often have them [Locum GPs] still say, "Send then to hospital"….with an ACP to the contrary.'

Mistrust of the ACP documents was identified as a barrier to following their instruction as a GP described,

'If it's a nurse that's filled it out, the doctors won't follow what nurses have done. Not just necessarily locums. They won't take that as gospel.'

Discussion

The study confirmed previous findings that ACP is regarded positively, as a helpful tool in the RACF setting (15-19). It identified the participating healthcare providers believed ACP, when performed in a timely manner, promoted resident autonomy. However, when delayed and completed by a proxy the documents were felt to reflect less clearly the resident's values and preferences and more that of those completing the plans. In terms of the legal authority of the future planning documents it was clear that both ACP and GOPC were seen as a guide for healthcare choices and didn't replace the necessary communication with family at times of deterioration. Healthcare providers described both ACP and GOPC as helpful tools with decisions for treatment, hospital transfers, and at end of life but these decisions could be amended by family when this deterioration occurred.

ACP has been described as a difficult topic to broach (25), but the nursing participants in this study appeared willing to discuss ACP and saw themselves as being best suited to doing this because of their closer relationships with residents and families. This barrier to ACP have also been reported from other studies (26). In more complex or difficult situations where families had what the nursing participants considered unrealistic expectations of medical treatment, they wanted involvement of the GP or Residential Inreach services. They described the doctor as having greater authority to put necessary treatment limitations in place. Cultural beliefs and health literacy of residents and families were identified as two barriers to ACP document completion consistent with previous findings (27).

As noted in prior research, participants posited that when the ACP document was completed by family members, it could reflect more their wishes than the resident's(16). This means that the ACP aim of promoting autonomy may not be achieved when people other than the resident completes an ACP document and highlights the value of ACP being undertaken directly by the person while they retain capacity.

As previously reported (23), families were often unwilling to adhere to decisions recorded in ACP documents. Health literacy causing misunderstanding about the purpose of ACP is described in this study as one contributory factor. This misunderstanding about the purpose of ACP affecting adherence has not been described previously. Lack of adherence to the plans by families has led to healthcare providers not expecting that the ACP document would always be followed. Interestingly in a prior study on ACP it was found that although 78% of relatives felt ACP would always be followed, only 44% of the medical staff believed this (28).

Despite the reported increasing use of ACP in RACF, trust of the ACP document by both familiar and unfamiliar clinicians was a new theme identified to affect adherence to ACP. This was particularly significant when the Advance Care Plan needed to be activated by clinicians unfamiliar with the resident, such as locum GPs and agency nurses; arguably the time when a written ACP document would be expected most useful. This finding of mistrust has not been previously described. However, it could be hypothesised that if ACP documents may reflect the family's wishes, rather than the resident's, then perhaps this mistrust is valid.

Even when ACP documents are in place, and the health professionals were willing to trust and follow the document, there could still be barriers to providing the requested end of life care of the resident in the RACF. Nursing participants frequently reported that locum GPs were not happy to commence residents on a palliative care plan when they deteriorated outside normal hours. This negatively affected end of life care and could force unwanted transfers to hospital in order to obtain the necessary palliative care.

It has been reported that the many and varied future planning documents lead to confusion which was confirmed in this study (20). Despite this confusion among RACF staff about the relative authority and roles of ACP and GOPC, findings from this study suggest that the GOPC forms were helpful to nursing and medical participants when a resident's condition

deteriorated. Other published findings from this study reported that when the GOPC was added to usual ACP, there was a statistically significant 40 percent reduction in hospital transfers at 12 months without increase in mortality (29). This further supports the additional benefit of GOPC over ACP alone, despite the confusion by participants about the theoretical difference with ACP. The GOPC form was seen to have potential to improve the communication of residents' wishes as compared with the standard ACP documents.

A limitation of this study is that not all key stakeholders were included in the focus groups and interviews. Residents, their substitute medical decision makers and locum GPs were not included, so their insights completing and following ACP documents and GOPC forms were not examined.

Conclusion

Findings from this study have identified both ACP and GOPC as helpful when making treatment decisions for residents but participants appeared uncertain about the relative roles of both. Participants described support for ACP, willingness to initiate ACP discussions and increasing prevalence of ACP. Health literacy and culture were identified to be barriers to ACP.

The purpose of ACP to represent the resident's autonomy, and the resident's own healthcare preferences and values, appears not always well understood. This results in confusion both when completing and activating the ACP document. This led to mistrust of ACP documents and reluctance to adhere to them by family, and also by unfamiliar clinicians. This new finding of mistrust is important given that this is the time when ACP might be expected to be most relevant. If ACP is to be useful it needs to be a trustworthy record of the resident's own instructions, preferences and values regarding medical treatment.

The GOPC form was regarded by participants as another type of ACP document without recognition of the different purpose and authorship. A positive aspect identified was its clear documentation to guide the resident's medical care at a time of deterioration, which is consistent with previously reported findings from this study (29).

A recommendation can be made from this study that further education of clinicians and non-clinicians is required to improve understanding of ACP and the GOPC. This is essential for increasing trust in the completed documents so that they can be followed in the manner in which they were intended and help improve resident centred care. Standardisation of future ACP and GOPC documents would help all key stakeholders in their completion and activation.

Registration took place with the Australia and New Zealand Clinical Trial Registry, Trial ID: ACTRN12615000298516) prior to study commencement.

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Figure headings

Figure 1 Data Analysis in Qualitative Research, PI Principal Investigator, BH Barbara Hayes

Appendices

Appendix 1 Question guide for focus groups

Appendix 2 Question guide for medical practitioners

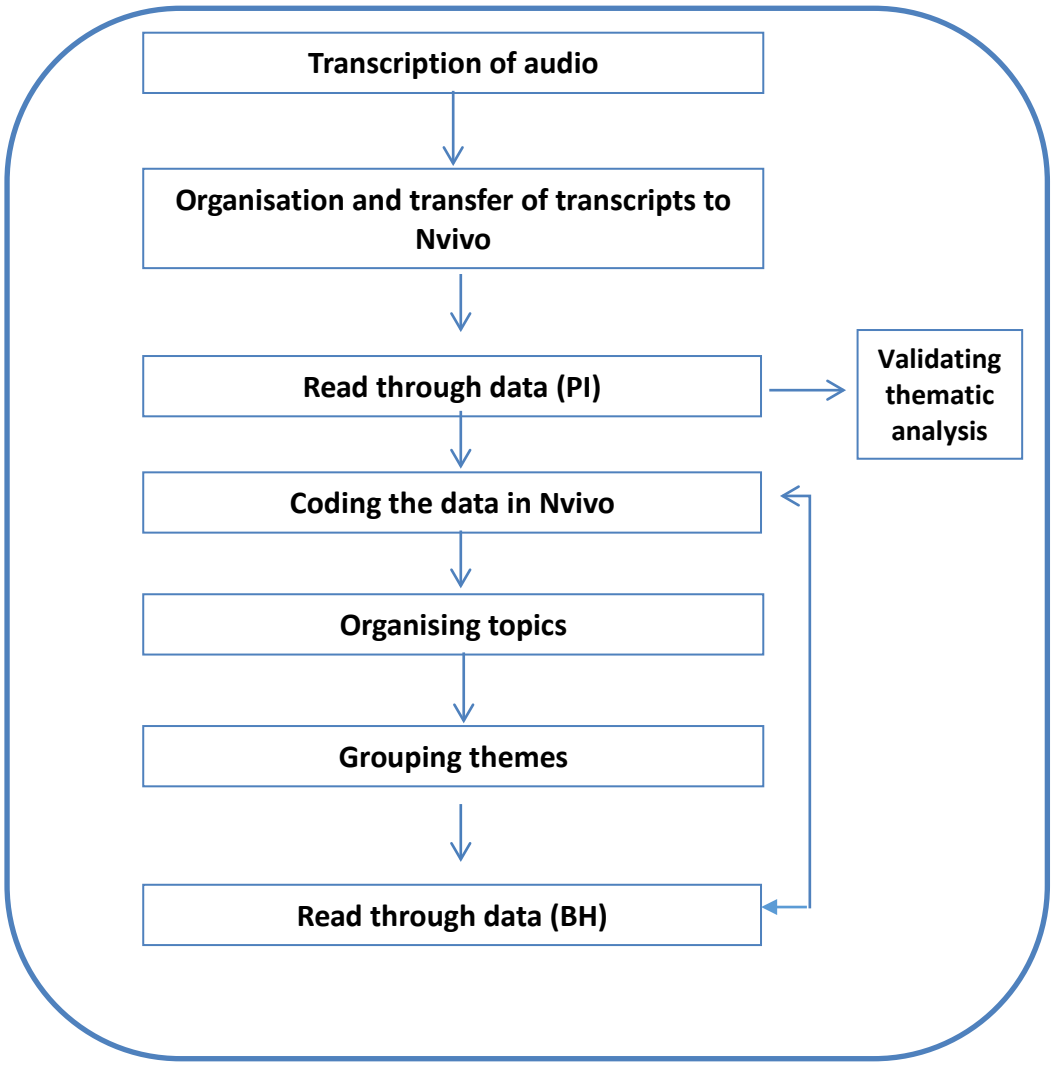


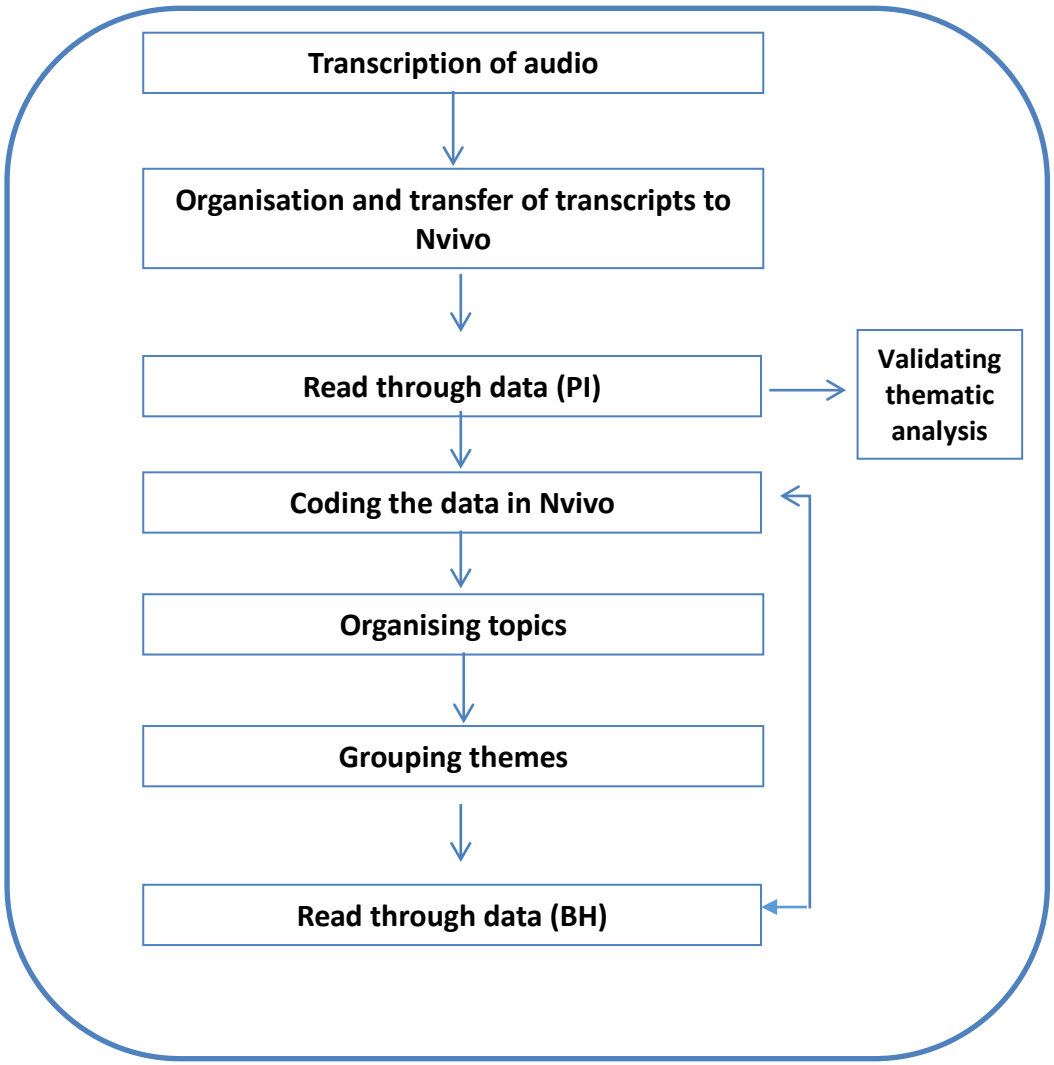
Figure 1 Data Analysis in Qualitative Research , PI Principal Investigator, BH Barbara Hayes

Objectives: Advance Care Planning (ACP) is a process by which people communicate their healthcare preferences and values, planning for a time when they are unable to voice them. Within Residential Aged Care Facilities (RACF) both the completion and the clarity of ACP documents is variable and, internationally, medical treatment orders have been used to address these issues. In this study, Goals of Patient Care (GOPC) medical treatment orders were introduced alongside usual ACP in three RACF to improve healthcare decision-making for residents. This study explored the experiences of RACF healthcare-providers with ACP and GOPC medical treatment orders.

Methods: The study was of Explanatory Descriptive design. Within three RACF where the GOPC medical treatment orders had been introduced, focus groups and interviews with healthcare-providers were performed. The transcribed interviews were analysed thematically.

Results: Healthcare-providers reported support for ACP and GOPC but also discussed many problematic issues. Analysis of the data identified four main themes: Enablers, Barriers, Resident autonomy and Advance documentation (ACP and GOPC).

Conclusion: Healthcare-providers identified ACP and GOPC as positive tools for assisting with medical decision-making for residents. Although barriers exist in completion and activation of plans, healthcare-providers described them as progressing resident-centred care. Willingness to follow ACP instructions was reported to be reduced by lack of trust by clinicians. Families were also reported to change their views from those documented in family-completed ACP, attributed to poor understanding of their purpose. Participants reported that GOPC led to clearer documentation of residents' medical treatment-plans than relying on ACP documents alone.



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