

Table 47: Seymour 2010⁴⁰⁸

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Aim	To examine how community palliative care nurses in England understand ACP and their roles within ACP. To identify factors that may facilitate or constrain community nurses' implementation of ACP and nurses' educational needs.
Population	Healthcare professionals: Twenty three community nurses from 2 Cancer Networks in England.
Setting	UK.
Study design	Focus groups conducted under an action research framework (places emphasis on collaborative working between multiple partners in gaining

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Methods and analysis	<p>practical knowledge to effect change).</p> <p>Twenty three community nurses from 2 Cancer Networks in England were recruited to 6 focus group discussions and 3 follow-up workshops. A meeting was held for those interested in hearing more about the study, which provided an opportunity for nurses to shape the objectives of the study. Roles of nurses who took part included: clinical nurse specialist in palliative care (Macmillan nurses), heart failure or respiratory care (9), hospice nurses (4), community matrons (4), district nurses (3), community staff nurse (1), community psychiatric nurse (1), end-of-life care programme facilitator (1). Each of the nurses had received some level of training about ACP although this varied in terms of its depth and content. For most, it had taken the form of attendance at local study days about the Mental Capacity Act or local practice development meetings. The nurses took part in 6 focus group discussions about their experiences of providing end-of-life care and views about ACP. Three follow-up workshops with nurses who had participated in the discussion focused on collaborative interpretation of the focus group data and identification of key themes and developing ideas about educational resources for ACP. Focus groups were transcribed with nurses' permission and analysed with the qualitative data analysis package NVIVO. Authors used Strauss and Corbin's constant comparative method to generate categories, patterns and themes from the transcribed textual data relating to experiences and perceptions. Emerging categories and themes were subsequently verified by the research team at dedicated project meeting and then discussed with the nurses at the follow-up workshops. This acted as a form of respondent validation and also generated new insights.</p>
Themes with findings	<p>Nurses saw their role in ACP as engaging with patient to elicit care preferences, facilitate family communication and enable a shift of care focus towards palliative care.</p> <p>Challenges perceived to ACP included: timing, how to affect team working within ACP, the policy focus on instructional directives which related poorly to patients' concerns, managing different patients' and family's views.</p> <p>Perceived barriers included: lack of resources, lack of public awareness about ACP, difficulties in talking about death.</p> <p>First encounters and understanding of ACP:</p> <p>Nurses reported not feeling confident they properly understood the various possible components of ACP.</p> <p>'I think, maybe for me, it was when I worked in (locality) which was over 2 years ago, we started to go to GSF meetings ... over the last 2 or 3 years it's becoming in but now a little bit more formally and a little bit more structured I suppose.' (Community staff nurse).</p> <p>Some recalled being confused about the differences between day-to-day 'care planning', which they regarded as a key aspect of their role, and the more unfamiliar ACP.</p> <p>'I think one of the problems-sort of being on the outside looking in – is that a lot of DNs think, oh not another project, not more paperwork, and it's been in a way perhaps not greeted with huge enthusiasm, although as some people have said here before, it's something that a lot of district nurses and healthcare professionals say; we've been doing this for, we've done this but haven't actually formalised it, and that's very much how I see the ACP.' (Hospice nurse).</p> <p>Challenges:</p> <p>Identifying the best time and most appropriate person to introduce ACP issues to patients.</p>

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	<p>'I found it interesting, on a GSF form in one practice we've got preferred place of death, and often GPs will say "oh no, it's too early to talk about that yet"'. (District nurse).</p> <p>'But when do they need it? Is it a form of diagnosis? And I think that's the difficult thing because obviously consultants don't have time to do it, and obviously it comes down to [Macmillan] nurses doesn't it, [or] support nurses within the hospital, because that's usually where the diagnosis is made'. (Macmillan nurse).</p> <p>Managing differences in staff understanding of ACP in the wider healthcare team.</p> <p>GPs are often reluctant to consider and discuss specific decisions relating to ACP with patients or their representatives. It was felt that this reluctance arose from discomfort raising ACP issues with patients for fear of raising issues about the end of life 'too soon'.</p> <p>Nurses were especially aware of difficulties of prognostication in people with non-cancer long term conditions and the risk of raising issues about the end-of-life care at an inappropriate time that would harm the person and not be congruent with their coping strategies.</p> <p>'Patients with heart failure and COPD may be living for 10-15 longer years. So I suppose it's pitching just when it's appropriate to have those dialogues, and I think it's very different for every person, and I think the same as has been said earlier that there are some people who are going to be very happy, for want of a better work, to discuss that, and there are other patients who don't want to go there.' (Community nurse).</p> <p>Managing the emphasis on instructional directives and the drive to bureaucratize ACP practice.</p> <p>Concerns were raised about the bureaucratisation of ACP leading to a potentially blunt, harmful 'one size fits all' approach.</p> <p>'... what I have seen unfortunately is sometimes it's used as more of a checklist, you know, with tick boxes...'. (End-of-life care programme facilitator).</p> <p>One Macmillan nurse perceived that if nurses and other practitioners were encouraged to regard ACP as a set of procedures or a 'check list of questions' this could effectively subvert the goals of good end-of-life care practice. In particular they perceived that some people, on admission to hospital were being asked about resuscitation decisions inappropriately and in the absence of any wider discussions about care.</p> <p>'It's interesting though when a patient's take into hospital now there is a resus status put on them straightaway'. (Heart failure nurse specialist).</p> <p>'But straightaway they were talking to her daughters about her resus status, you know, that was the first thing that when she got out of the admissions hall that happened...'. (District nurse).</p> <p>Documentation and communication of ACP discussions across healthcare systems.</p> <p>Nurses also observed that GPs were often reluctant to engage in discussions about resuscitation or any other end-of-life issues. Nurses perceived a general reluctance to disengage from the 'active' curative mode of care resulted in GPs not acting on the perceptions of nurses or relatives about patients' wishes, even when these had been recorded in an advance care plan.</p> <p>'... a duty doctor was called out in the middle of the night, and they took him to hospital, and unfortunately he died in hospital, which is not what</p>

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	<p>he wanted, [it] caused a lot of issues for his family as well ... And I think the care home staff at the time were pretty adamant his wishes are that he doesn't but the duty doctor was: "no he is going", and sort of overruled it all...'. (Community psychiatric nurse).</p> <p>Lack of readily available or clear documentary evidence of a person's advance statements and uncertainty about the status of the wishes of close family members in relation to the person's best interests were seen as reasons why medical staff and senior nursing staff might take the least 'risky' course of action when presented with an unfamiliar person who was acutely ill towards the end of life.</p> <p>'(My colleague) was actually put into a bit of dilemma because [patient] was really ill, and he subsequently died ... she wanted to send him to hospital because he needed hospital treatment. But the daughter had said expressly ... she preferred him to stay in the residential home and got very angry when he was admitted to hospital, but it wasn't recorded anywhere.' (District nurse).</p> <p>Documentation, storage and retrieval of ACP records were perceived as a significant issue across systems of care, especially when people had many sets of notes and multiple hospital admissions.</p> <p>A lack of resources to support family carers was perceived as 1 reason why there may be a disjuncture between patients' and carers' views.</p> <p>'... the family were so concerned, worried, although we assured them they'd have a great care package, in reality ... it doesn't always come to fruition and there isn't always the care there to support those families ... We can't guarantee 24-hour cover but we will try our utmost.' (District nurse).</p> <p>Barriers:</p> <p>Lack of resources (including time and end-of-life services) with which to meet patients' preferences and support family carers.</p> <p>Nurses perceived that ACP could only be implemented authentically if there were adequate services and resources in place.</p> <p>'...you can try and get the services together and coordinate them, but often they're not there. And I think people can manage very well at home if that's where they want to die as long as we've got the services to keep them at home and to support them.' (Macmillan nurse).</p> <p>'Certainly, around heart failure at the minute we do struggle for palliative care support. There isn't a specific unit that patients can go into. When they talk about the hospice, there's actually only day care hospice, X hospice is only for cancer patients.' (Heart failure nurse specialist).</p> <p>Lack of public and patients' awareness about ACP and other end-of-life issues.</p> <p>Nurses perceived lack of knowledge among the general public, patients and their family members about the availability of help and support during illness and end-of-life care and a contemporary tendency to not think about one's reaction to serious illness until it actually occurs.</p> <p>'People don't know ... what they want until they're in that situation. Because often people will say to me I didn't know there were all the services out there.' (Macmillan nurse).</p> <p>Nurses also perceived that patients and the public lacked knowledge about the course and outcomes of common life-limiting conditions. This created a further barrier to ACP conversations as many people perceived they were irrelevant to their situation.</p> <p>Taboos and fears about death and dying among public and patients.</p>

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	<p>Nurses perceived that people had many fears about death and illness, which combined to create a taboo surrounding the subject. Fears identified included being frightened of death, fears about going into hospital, about being alone and dying alone. Nurses described how fears could be alleviated once people were encouraged to put into words what they were most worried about.</p> <p>‘And it’s also sort of about unpicking why people are ... maybe to facilitate the talk [there is a need] to actually unpick that, what is the fear around, for those people who don’t want to talk about it yet.’ (Macmillan nurse).</p> <p>Perceptions to training and education:</p> <p>Among the greatest challenges that nurses perceived to be associated with ACP were their own and colleagues’ knowledge and skills about communication practice, recording and follow-up.</p> <p>‘... we’ve still got – when you look at teams – a lot of nurses that aren’t confident to have those conversations. They say: “well you like palliative care, you’re good at it”, and they back off ... That’s my worry – the confidence of the staff, teaching them to do it and then following it through.’ (Macmillan nurse).</p> <p>‘I’ve been in post three years, so for me it’s the uncertainty or where you do document all this information and actually how you can get it through to other people so the patient’s wishes are respected – the documentation is a big thing for me’. (Community matron).</p> <p>Alongside formal training and education, whether by face-to-face teaching or distance learning, some saw the use of mentorship and apprenticeship styles of training as crucial.</p> <p>‘I think there is so much to learn about communication skills and dealing with patients which you can emulate from a role model. And I feel very passionately that junior nurses need to work with senior nurses much more at the bedside, not in the classroom because I think there’s a theory and practice divide.’ (Macmillan nurse).</p>
Limitations	<p>Serious limitations. the authors do not claim to have achieved data saturation and recommend further research takes place to check the transferability of results.</p>
Applicability of evidence	<p>Indirect population. nurses who participated were self-selecting and therefore likely had a particular interest in the topic in hand.</p> <p>The authors note that their focus group design may have obscured possible differences between specialist palliative care nurses (who mainly looked after people with cancer) and non-specialist community nurses (who looked after people with cancer and many others).</p>