

Table 44: Minto 2011³²⁴

Study	Minto 2011 ³²⁴
Aim	To determine the factors associated that assist or hinder the primary care health professionals having discussions about the end of life.
Population	<p>Healthcare professionals: One GP and 1 district nurse from each of 3 GP practices.</p> <p>SAMPLE: A purposive sample of GPs and DNs who care for people with life-limiting conditions in the primary care settings was selected. The rationale for the sampling was to locate participants who could provide appropriate data for the area being studied; therefore the process of sampling involved the researcher making a judgement regarding which potential participants would provide the most informative data. Those with experience of ACP for their patients approaching the end of life and who had been in their post for at least 6 months were considered.</p>
Setting	The study was conducted in a primary care setting in an urban area of Scotland and involved GP practices that are signed up to using the Gold Standards Framework (GSF). The community palliative care clinical nurse specialists (CNS) based in a local hospice work closely with the GP practices in the area, with each CNS having several allocated GP practices. The study concentrated on 8 local GP practices. The CNS team regularly attend the GSF meetings of their allocated GP practices, meeting with the GPs and DNs. ACP is routinely discussed for patients at this time.
Study design	Qualitative study using Semi-structured interviews.
Methods and analysis	The qualitative and interpretive methodology of phenomenology was used, as the study focused on an exploration of experiences and perceptions. Individual face-to-face semi-structured interviews were the method of data collection. All participants chose to be interviewed in their own workplace. The interviews were conducted by the lead researcher. The interviews were digitally recorded and transcribed verbatim by the lead researcher. The transcripts were then returned to the participants to verify their authenticity. The participants at this stage had the opportunity to withdraw any or all of their data, but none did. The data were analysed by the lead researcher using Colaizzi's (1978) thematic approach. Notes were made on the transcripts to reflect the researcher's initial thoughts in regard to emerging themes. Validation of the findings is enhanced if they are returned to the participants to ensure that there has been no loss of meaning, but unfortunately this was not possible owing to time constraints. However, the analysis of 1 of the transcripts was externally verified by a researcher not involved in the study.
Themes with findings	<p>The findings clearly depict two of the challenges faced by GPs and DNs in the community: emotional labour and balancing patients' and families' expectations about care provision in the community where limited resources are available.</p> <p>Four key themes emerged that appeared to illustrate the participants' experiences of ACP in end-of-life care. These were the evolution of palliative care, managing transitions of care, the emotional labour of ACP and balancing expectations. The first 2 themes address communication and the need for education and were not presented in depth. The second 2 themes were presented in depth.</p> <p>Emotional labour of ACP: The potential for health professionals to become distressed themselves owing to the sensitive nature of ACP discussions.</p>

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	<p>Some of the participants highlighted experience as a factor in being able to deal with the emotional impact of ACP. 'Personally I'm ok with it now ... it definitely gets easier when you've don't it ... read the leaflets and learned from other people's experiences as well.' (DN1).</p> <p>Learning from others how to approach end-of-life care issues can help to reduce professionals' anxieties. 'I think it will get easier and easier and easier ... But certainly if you asked me three years ago, I'd be like "Oh dear god, no: I'm not prepared at all." And see how [a consultant] spoke so openly about death and dying and how much the patient really appreciated that rather than skirting round it.' (DN3).</p> <p>Balancing expectations: Most of the interviews highlighted a disparity between the resources available and the patients' and family's expectations. District nurses faced challenges when trying to prioritise their time to enable them to manage the person dying at home in conjunction with their regular workload. '...what their expectations are that can be provided for them as well ... Sometimes that can be a big stumbling block in advance care planning because, particularly if place of death is to be at home, and obviously coming from the district nurse's perspective, that is a big difficulty ... As well as doing palliative care we also have our normal caseload so that does make things very difficult for us' (DN3). 'Families are expecting to have a Marie Curie nurse and then have the equipment there to actually ... If that's not there, does it stop them dying at home, if that's their preferred place?' (DN2). '...because you can just see their faces-you know, "I want this hospital bed for you and it would help your legs, it would ease the pain, it would do that but unfortunately, we just have to wait until one's available so ...". (DN1).</p> <p>The DNs were unanimous in their views regarding respecting a person's choice to die at home, but they reported experiencing frustration when having to wait for the equipment required to achieve this. This aspect of patient care was not identified by the GPs.</p> <p>There was a strong sense that health professionals are committed to providing the care required for people at home at the end of life if that is the person's wish. However, some of the factors identified that hinder this include a lack of resources, balancing palliative care patients with the normal workload and supporting the family caregivers. The emotional toll it takes, along with feelings of guilt if the person does not achieve their wish to die at home is reflected in the following statement: 'Is the family going to be able to handle this? Because it is a huge emotional, physical, spiritual journey ... and often in terms of you know, being able to escort somebody from this world into the next in putting in spiritual terms ... there are very few families that actually have the resources to do the whole package.' (GP2)</p> <p>Palliative care has evolved to focus on care being delivered in the community setting. The primary healthcare team therefore is the main service provider and this may raise resource implications and feelings of failing both for the patient and the family. '... the main burden is with the family if they are going to do a whole anticipatory care ... they sometimes struggle and struggle, it's the main factor.' (GP1).</p> <p>'I think everything we can try to put into place in advance care planning, if you don't have the family on side with you ... it can become extremely difficult.' (DN1).</p>

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Limitations	Very serious limitations. Small sample size due to time restrictions. The lead researcher had limited experience in qualitative reviews. The lead researcher works as a clinical nurse specialist in palliative care and was known as such to the study participants.
Applicability of evidence	Direct evidence from UK setting.