

Table 35: Addicott 2012¹³

Study (RefID)	Addicott 2012 ¹³	
Aim	To identify what particular barriers exist for non-cancer patients in accessing end of life care support.	
Population	n=141 NHS and other service providers:	
	Role District nurse	n= 10

	Healthcare assistant	2
	Hospice nurses	5
	General practitioner	3
	End of life care (or palliative) consultant	4
	Hospital specialist	4
	Practice nurse	6
	Delivering choice programme team member	11
	Service manager	39
	Specialists nurse	20
	Ward nurse	11
	Adult social care	7
	Care home staff	19
Setting	Three local health economies in England.	
Study design	Not described	
Methods and analysis	Not described	
Themes with findings	<p>Disease trajectory and patient identification- It is more difficult for clinicians to identify the stage at which non-cancer patients enter the end of life phase, or when they may benefit from more palliative support. This was in relation to the unpredictable nature of the disease trajectories for non-malignant diseases such as chronic heart or respiratory failure which affects prognosis. Participants reported concerns about the cost and resource implications of referring non-cancer patients to end of life services, particularly those who could be receiving such care for a long time period. Clinicians were wary of repercussions from the local funding body if inappropriate or costly referrals were seen to have been made. One Macmillan nurse reported:</p> <p><i>“If you’re talking about palliative care for somebody with MS [multiple sclerosis] you’re looking at a very long period of time and support and I don’t know if [dedicated end of life care providers] can sustain that, that that palliative patient on, because that could be 10, 20 years of their time”</i></p> <p>Some participants believed that it was possible to identify when people were entering the end of life phase. These views were predominantly from disease-specialists from non-cancer areas, and they acknowledged that these clinical triggers would not necessarily be so easily identifiable to a generalist health professional who may have had less of a history of interaction with a particular person.</p> <p>Care planning and prognostication- Participants reported that clinicians frequently fail to discuss the prognosis and subsequent preference and care planning with non-cancer patients for the following reasons:</p> <ul style="list-style-type: none"> • Non-cancer diagnosis acts as a barrier “... what’s going to have to change, what we’re going to have to get better at, is being honest and open and having those discussions with people. There’s more of an honesty in managing cancer patients about how things are, what the 	

	<p><i>prognosis is, what the future holds, that doesn't exist in other diseases yet"</i></p> <ul style="list-style-type: none"> ● "[clinicians] Shy away from those sorts of conversations because they are difficult conversations to have" ● Reticent to stopping treatment in non-cancer conditions as many people may be in the end of life phase for a prolonged period of time, and difficulty, particularly in hospital of 'admitting defeat': <i>"What we've seen is that doctors are able to diagnose dying very successfully... but what they don't do necessarily is then put the appropriate management systems in place to support that. So for example they recognise that the patients dying, but they find it very difficult to take down the drip, to stop the drug, to communicate to the patient and the relative that that's actually happening"</i> ● Many participants felt it should be the responsibility of the consulting doctor and specialists. One nurse reported: <i>"The family have got to be told that they are near to death. I would not go in and talk about discharge and fast track [funding] without that [conversation] being done first and I don't think it's a nursing job... because there are normally more questions coming back. And the last thing I want to say is 'actually I don't know'".</i> ● Some clinicians found it easier to have discussions with the family and carers rather than the person directly: <i>"It is very difficult. If I am honest, I don't tend to ask the patient-which is awful. I should do, I know. I tend to ask the family what their views are and then hopefully they discuss it with the patient"</i> ● Some staff expressed anxiety about having discussion with people regarding their preferences as they were unsure what support services were available to meet these preferences, or knew that in that area these services were not available.
Limitations	Very serious limitations. Very poorly described method and analysis section. No information on data saturation.
Applicability of evidence	Unclear what definition of end of life care was used. The quotes suggest that it encompasses both the last days of life and the last months.