

We need to talk about Palliative Care

Professor Scott A Murray

1. What has been your experience in terms of access to palliative and end of life care?

- I work clinically as a GP, and find that access to specialist palliative care advice and support for my patients with diseases other than cancer is difficult to obtain as currently palliative medicine specialists do not seem to deal much with such patients. Such advice could really help me give general palliative care in the community as a GP.

2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

- We know that patients with cancer have much better access than people with other life threatening illnesses, both with respect to specialist palliative care in hospices and generalist palliative care approach in the community or in hospitals. In 2012-13, 72% of patients who died of cancer were listed on the GP palliative care register before death while 27% of patients who died as a result of non-malignant conditions were listed on the PCR. In 2013-14, cancer identification remained the same but identification of other long-term conditions had improved to 32.5%. (Report of recent Scottish national evaluation funded by Macmillan Cancer Relief, 2015)
- To further address this we must actively seek to identify all types of patients who can benefit from palliative care and try to help them according to their needs rather than their diagnosis. There is a “diagnostic” lottery rather than a postcode lottery going on. So Edinburgh University colleagues and I are conducting various studies, for instance, with stroke patients, liver patients, patients with COPD and patients with heart failure. Separate studies into how patients with these different diagnoses can be identified and receive appropriate palliative care are ongoing based at the Royal Infirmary of Edinburgh and in the Lothian community with promising results.
- The best ways to help people with these various conditions are now being tested through research where patients are identified either in the hospital or in the community and supported in the community by various staff, including specialist nurses e.g. Heart, Respiratory, Liver specialist nurses. Hospices are to be congratulated for starting to try to work more with all types of patients. They could, for instance, start outpatient clinics in either hospices or in hospitals to start integrating palliative care together with the treatment of the specific illness.

- Similarly work specifically identifying and targeting people with 2 or more illnesses, now called “multimorbidity” who would benefit from palliative care is needed, as they are particularly needy and underserved.(1)
3. **Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?**
- The key issue to promote access is that patients and carers have to be first identified as potentially benefitting from palliative care, or they have to ask for palliative care before they can be helped (which they rarely do). There is a key sequence of **identification, then assessment and then care planning** which must always take place. Clinicians in the community and hospitals must identify patients earlier so they can benefit from palliative care, not just in the last days or weeks of life when it is too late. Early palliative care can save money, and a number of studies from the USA now show this can help people with cancer live longer.(2) Two research studies to promote early identification have recently been completed by Edinburgh University:
 - **How can general practitioners better identify patients for palliative care in the community in general practice?** Initial work using computer searching of patient records has shown that this can help GPs identify people for palliative care and anticipatory care. This is currently being further tested in more practices throughout Lothian, before we plan a widespread release to all practices. Once they are identified they are immediately eligible for a Key Information Summary (KIS) (see later).(3)
 - **Identification of family carers.** Lack of identification of family carers is the main reason why family carers fail to get support at the end of life. A review of the literature in this area in primary care was published and informed the recent parliamentary review of informal carers.(4). A study of operationalising this in primary care in some Lothian practices has been completed and is under review. Primary care is ideally placed to identify and support such people but this will need prioritised in practices to allow time for a “carer liaison” role to be developed by PHCT members.
 - Scotland is internationally leading in developing how best to identify people who might benefit from palliative care using the SPICT Tool (www.spict.org.uk . This can be used as a screening tool by GPs and nurses in everyday practice to identify more people, and is currently advocated by Scottish Government.

4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

- The WHO recommend that ***at diagnosis of a life threatening illness*** is the right time to consider using a palliative care approach. This means supporting people physically, psychologically, socially and existentially and planning for the future as soon as a life-threatening disease is mentioned, usually long before dying. This does not immediately mean talking about dying, but there should be some acknowledgement that this is a possibility. In Scotland there has been a national initiative to start “anticipatory care” for all patients with cancer and non-malignant illnesses, such as heart failure and chronic bronchitis earlier in the course of the illness. Such anticipatory care does consider all patients dimensions of need and make a plan and covers most aspects of palliative care. A recent (2014) study in some Lothian practices has shown that **around 75% of people have anticipatory or palliative care before they die, 66% of people with dementia or frailty have access to anticipatory care before they die and 41% of people with organ failure.** This is considerably higher than the percentages that are officially receiving palliative care at the end of life. This is a success story due to the work of primary care teams and the presence of the Key Information Summary which allows them to do this and communicate these anticipatory plans to the emergency services and hospitals. This intervention is allowing many more patients to receive physical, psychological, social and existential support and planning.
- Clinically this again is operationalised through instruments such as the SPICT if there is a decline in the functional status of a patient or any specific indicators they can then be identified.

5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?

- Questions such as “you seem pretty cheerful today but are there ever days when you don’t feel so good?” can allow patients to open up. Most people have “competing stories” in their mind with a public account that they are well but given time and a conducive atmosphere they often like to have an opportunity to explain their worries, their “private account”. This however needs time and training of staff to allow patients to speak quite openly.

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

- These are an excellent way of introducing the concept that the person needs holistic care. I have recently conducted an evaluation (see above) of the use of the KIS and found its popularity with patients and primary care and out of hours care is good, but that hospital staff need further training to start to access it. Having a KIS in itself is very highly associated with dying outside hospital. The national KIS development group should be reconvened to improve the software so it is easier to use in practice and to be accessed routinely when a patient is admitted.

7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?

- Public awareness such as Good Life, Good Death, Good Grief are an excellent way to promote a greater public discourse about death and dying. This website and campaign also encourages individuals and communities to use their own assets to support people with terminal illnesses and this should also be encouraged. <http://www.goodlifedeathgrief.org.uk/>

8. What training and support is provided Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?

- Some training of primary care teams is happening, but this needs strengthened especially about how clinicians can identify patients and carers, and how they can deal with the uncertainties of such patients.

9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

- A study in 2008 showed that routinely starting advance care planning to all residents in care homes can reduce hospital admission by 50% (5) Thus all people should have such a discussion routinely at admission to a care home, and this is now greatly facilitated in some Health Boards by increased payments to General Practices to care for the many very ill patients in care homes.
- The National Palliative Care Directly Enhanced Service is now requiring practices to state the total number of patients on the palliative care register which is useful as it encourages them to identify more. A recent study undertaken at Edinburgh University shows that anticipatory care planning is starting much earlier than palliative care has traditionally started. For instance, with cancer it is starting around 14 weeks before death rather than 9 weeks, and with frailty and dementia now 20 weeks rather than 9 weeks. So further studies to identify this would show when such discussions are starting.

10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?

- The challenge here is that to document palliative care means that general practitioners have to discuss what palliative care is with patients which will of course bring up the subject that they have terminal illness. This can be difficult and if patients suggest they do not want to talk about this, then the palliative care cannot be recorded in the record. Starting anticipatory care and recording this however is more straightforward as it generally involves a

conversation to explain that we want to anticipate future needs and let out-of-hours know the details of the illness: very nearly 100% of patients and their carers approve of this. In due course a special “tab” can be alerted to change this into formal palliative care but anticipatory care covers most aspects of palliative care including, for instance, Do Not Attempt Resuscitation and preferred place of final care.

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