Marie Curie’s evidence to the APPG on Heart Disease’s Inquiry into Living with Heart Failure

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About Marie Curie

- Marie Curie is the UK’s leading provider of care and support for people affected by terminal illness.
- We provide free care to people with any terminal illness, either in their own home through the Marie Curie Nursing Service or in one of the charity’s nine hospices. We have previously worked in partnership with the British Heart Foundation on the ‘Better Together’ project to deliver better patient care to advanced heart failure patients.
- We fund and manage the largest programme of research into the best ways of caring for people with a terminal illness in the UK.
- Our report ‘Triggers for Palliative Care: Improving access to care for people with diseases other than cancer’ explicitly looked at the barriers to access faced by people with heart failure.
- In April 2015 we launched the Marie Curie information and support service, which provides confidential information about any aspect of terminal illness. Our services include a telephone support line, an online community, information pages on our website and a series of online and printed booklets.

Response to inquiry questions

This response focuses on the inquiry’s questions relating to palliative care for people with heart failure.

What is the experience of patients with heart failure, and their families and carers, of palliative care? What impact does this have on them? What evidence exists around this?

Comparatively few people with heart failure receive palliative care in relation to need. Marie Curie’s ‘Triggers for Palliative Care’ report reviewed the research and policy evidence about palliative care for people with heart failure and found that:

- Patients with heart failure and their families may feel uninformed, excluded from decision making, and feel control is taken away from them;
- End of life care has often not been discussed, with conversations focused typically on disease management even though some patients would welcome conversations about end of life;
- Patients do not always realise the seriousness of their condition – although some may not want to discuss end of life care with their clinicians, many are not given the opportunity;
- The length of time from referral to palliative care to death is short –
one study found an average of just 21 days (Bakitas et al., 2013);

- Palliative care services are typically less available to people with non-cancer conditions – for example, despite studies showing a higher level of incidence of symptoms of pain, fatigue, breathless and insomnia for people with chronic heart failure compared to people with lung cancer (Murray et al., 2002).

Generally speaking, the evidence shows that many people with heart failure miss out on palliative care even though they would benefit from it. Those who do receive palliative care often do not get it until they are very close to the end of their life.

However, earlier introduction of high-quality palliative care – which is based on need rather than diagnosis, and may therefore be episodic - has been shown to be beneficial to both patients and carers:

Best Practice Evidence: The Better Together Partnership
Marie Curie and the British Heart Foundation's Better Together Project provided a service that combined the expertise of two sets of nurses – the British Heart Foundation Heart Failure Specialist Nurses and Marie Curie Nurses and Healthcare Assistants – in locations across England and Scotland.

The nurses worked closely together, providing hands-on care to meet the health and social care needs of heart failure patients who were identified as approaching the end of their lives and were being cared for at home. Although this service was developed and delivered in a markedly different commissioning environment (it concluded in 2009), its findings still have relevance for future service planning:

- The University of York’s independent evaluation found that the Better Together intervention was associated with an overall reduction in the costs of care and increased likelihood of death at home.
- Patients reported greater confidence in the service, and greater reassurance and a better quality of life by having Marie Curie Nurses' hands-on care to help with their physical symptoms and anxiety in addition to support from Heart Failure Specialist Nurses.
- Nurse reports showed that at least 47% of patients were kept at home by the service, and averting hospital admissions was found to be cost-saving.
- 74% of patients died in their preferred place of care (for more info, see here).

Case Study Evidence
Flexible palliative care interventions have been shown to offer improvements to patients' physical and psychological wellbeing to the extent that they are discharged from specialist palliative care and therefore do not need to begin end of life care. Case study evidence also shows it provides a welcome support to carers:

- “..when initially introduced to palliative care.. and it is explained to you, the first emotion is one of utter relief that someone is offering a safety net in a time of crisis..”

- “..in (my husband’s) case, it boosted his self-confidence and self-esteem, giving him a better quality of life…he was able to manage his disability without the constant need for hospitalisation, thus cutting out stress of some magnitude”

- “It is difficult to separate his relief from mine, because by making his life more bearable, it made my task easier (even though it was still an ongoing 24 hour job), and because my life was made easier, he began to be more relaxed too.” – quotes from a carer of a person with heart failure (source)
What are the barriers to patients with heart failure being identified as approaching the end of life and accessing palliative care?

Marie Curie’s review of the evidence in *Triggers for Palliative Care* found a number of barriers:

- The unpredictable course of heart failure means many are not identified as approaching the end of life, and can make clinicians reluctant to discuss this issue with them;
- The ‘surprise question’ – “Would I be surprised if the person in front of me died within the next six months or one year?” – is inappropriate to use as referral to palliative care trigger;
- A lack of recognition of condition-specific triggers which can help to signal that a palliative care approach would be appropriate, or that the person with heart failure is reaching the end of life stage (this may be very different to the symptoms expected of someone with terminal cancer, which palliative and hospice care services were traditionally geared towards), resulting in substantial delays;
- A lack of awareness that heart failure may be a terminal condition;
- Under-developed links between cardiologists and palliative care teams.

How can these barriers be overcome?

Palliative care is clearly beneficial to people with heart failure and their carers, particularly when it is introduced in a timely and integrated way. The evaluation of the Better Together Project evidences that an unpredictable prognosis need not be seen as a barrier to the provision of end of life care for patients with heart failure. It is possible to provide care at an appropriate time within the last year of life, accepting that some patients will suffer unexpected and sudden death.

In *Triggers for Palliative Care* we suggest a ‘triggers’ based approach to palliative care referral which is more closely aligned to people’s needs, rather than their diagnosis. A more dynamic or episodic involvement of palliative care is also likely to be appropriate in these cases. These include:

- Complex or persistent problems with symptoms such as:
  - intractable pain
  - difficult breathlessness
  - nausea
  - vomiting
  - mouth problems
  - difficulty sleeping and fatigue
  - psychological issues, such as depression and anxiety.
- High levels of hospital use, especially unplanned admissions;
- Having more than one condition (multimorbidity);
- The introduction of new interventions (e.g. ICD implant)
- In some cases, at the point of diagnosis;
- When a screening tool indicates that it would be appropriate (e.g the Sheffield Profile for Assessment and Referral to Care (SPARC) or the Supportive and Palliative Care Indicators Tool (SPICT)).

Overcoming barriers also requires a joined-up approach from commissioners, service managers planners, and health and social care professionals. We believe the following actions would go some way to ensuring fewer people with heart failure who need palliative care miss out in future:

- Ensuring that Heart Failure Nurse Specialists have a clear understanding of the role of palliative care, and know when and why to refer people (as per the outcomes of the Better Together Partnership);
- Involving palliative care in integrated MDTs early on, to help prevent a linear ‘are we there yet?’ approach to referral;
- Improved training in palliative and communication skills for all clinicians, including training in how to recognise the ‘triggers’ which indicate that palliative care may be appropriate – ‘Most palliative care problems suffered by (chronic heart failure) patients should be within the abilities of the usual medical team’ (Johnson MJ, 2010). Making palliative care a compulsory element of continuing professional development and ensuring undergraduates have a clinical attachment to palliative care teams would help to move this agenda forward.

Note on sources

Source materials are cited in text. Information predominantly gathered from the Better Together partnership evaluation, presentations from the ‘Caring Together’ conference on this topic in 2012 and Marie Curie’s Triggers for Palliative Care report.

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