

Title: Advance care planning – a “hard” skill for cardiology clinicians?

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The rising prevalence of heart failure in response to changing demographics and the modified natural history of disease in response to effective treatments is well described. For the individual and family, heart failure has a wide-reaching personal impact, with reduced quality of life and function within society, and a prolonged dependence on healthcare services. This high cost to the individual and to healthcare services is projected to increase further, yet there is little emphasis in practice on solutions to prevent or manage its implications. A recently published systematic review of studies from ten countries across Europe and North America investigating cost-of-illness in heart failure presented important concerns.¹ During the course of heart failure, the costs of medical care are largely driven by hospital admission and are highest in the year after diagnosis and in the last 6 months of life. The most common predictors for higher care costs are comorbidity (the cause of around three-quarters of readmissions in people with heart failure) and advanced stage of disease. Management of people with New York Heart Association Class IV heart failure accounts for 70% of total annual heart failure costs.¹

While the first peak in costs following diagnosis is intuitively appropriate, the second peak at the end of life raises important concerns about inappropriate admissions and the use of invasive, burdensome and futile interventions. People with advanced disease are in double jeopardy: if inappropriate care **is** being received, they may **not** receive the care which **would** be helpful to them and their families. Evidence-based practice consists of three pillars: the best quality relevant research evidence, clinician expertise and patient values. Prioritisation of clinical service time for life-prolonging interventions to the exclusion of an assessment of patient and family unmet needs leads to the omission of the third pillar. The second pillar is needed – for clinicians to interpret the relevance of trial results to the older patient with multi-morbid advanced disease sitting in front of them in clinic. These patients are those at most risk of admission in the last 6 months and the population most often excluded from clinical trials.

This problem is not peculiar to people with heart failure. Over the past decade advance care planning has been introduced across a range of diseases to “help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.”² Advance care planning is defined as “... a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.”² Preliminary evidence from a systematic review of 113 papers suggests benefits with regard to increased concordance with patients’ end of life wishes and reduced health service costs.³ Despite the escalating clinical problem and enough published research to furnish a review of 80 systematic reviews representing 1,660 individual articles, implementation in clinical practice remains partial or non-existent in heart failure care.⁴

Very little is published in heart failure. A systematic review of the effectiveness of ACP in heart failure with regard to hospital admissions found eight papers of which only four were randomised controlled trials (RCTs).⁵ Only three of the RCTs were evaluation phase trials and in all of these ACP was delivered as a component, and in the context, of multi-disciplinary specialist palliative care. The effectiveness of ACP *per se* was therefore not the primary objective of the trials. Findings indicated a reduction in hospital admissions but the direct contribution of ACP alone cannot be assessed. One feasibility trial was a cardiology-led ACP intervention.⁶ Since this review, a further feasibility non-randomised study from a cardiology-led palliative care service which included an ACP with medical ceilings of intervention reported findings.⁷ Both cardiology-led studies^{6,7} showed preliminary evidence of benefit with reduction in hospital admission. Cardiology-led, rather than specialist palliative care-led, ACP must signal the way forward: i) ACP may be pertinent to discussion of treatment plans at any stage of health irrespective of stage of heart failure, ii) cardiology and primary care teams can be trained effectively in ACP and thus referral of all patients to specialist palliative care for ACP is unnecessary, iii) the sheer numbers of patients involved are too great for

the limited resource of specialist palliative care and would be unsustainable, iv) ACP is often a useful doorway through which a referral to specialist palliative care is made for those with persistent and severe symptoms, or where care/death in hospice is preferred – a reluctance to engage with ACP often goes hand-in-hand with poor access to specialist palliative care.

So, why is systematic implementation of ACP in heart failure services such a rarity? In this issue Schichtel and colleagues present a literature review and meta-analyses examining the effectiveness of interventions to increase completion of ACP in heart failure practice.[Schichtel et al reference] From the 13 included RCTs, they demonstrate that interventions targeting patients (support and education about ACP and training in how to raise the subject and discuss with their clinicians), clinicians (education) and systems (using IT systems to trigger reminders to clinicians) improve completion of ACP. Interventions which included a number of targets had a larger effect size. These findings are consistent with the broader chronic illness literature presented by Jimenez *et al.*⁴ They discussed how barriers exist at all levels from the patient and family, service providers, and institutional through to organisational and policy. All of these need to be addressed if ACP is to be implemented routinely (see Table 1). Of note, the cardiology-led palliative care service⁷ involved serious multi-level commitment: additional training and support for the lead clinicians including for job planning to allow time; reconfiguring of clinics to form an advanced disease clinic which functions across hospital and community; and the joint commitment of the regional health board and two major national charities (Greater Glasgow and Clyde Health Board, British Heart Foundation and Marie Curie).

Table 1. Elements needed for successful implementation of ACP. (Adapted from Jimenez *et al.*)

| Main Factor | Specific Elements |
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| Whole-system strategic approach | <ul style="list-style-type: none"> • Interventions target patients, family carers and clinicians concurrently • Cultural and social issues at all levels (individual, institution and society) and targets (patients and families, clinicians, commissioners and policy makers) must be addressed to ensure that honest and difficult, but supported, conversations are legitimatised as a core component of service • Address structural constraints to support delivery (e.g. consider reconfiguration of service delivery, and ensure clear understanding of legal issues) • Ensure funding and sufficient skilled staff including medical personnel |
| Components of effective ACP programmes | <ul style="list-style-type: none"> • Interactive information sharing with knowledgeable and skilled person to allow discussion of concerns • Facility for repeated conversations for ongoing patient education and allow completion of advance directives or ACP records • Implement and evaluate across sites and ensure communication between healthcare settings • Ensure processes for conflict resolution (ethics committees, mediation, guidelines, advanced communication skills training) |
| Further innovations | <ul style="list-style-type: none"> • Use of IT solutions to facilitate scale (training, reminders, communication between healthcare settings) |

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| | <ul style="list-style-type: none"> • Work to facilitate storage and retrieval of documentation across IT systems supporting electronic health care records • Use an agreed, common ACP record across disciplines and health care settings with flexibility for disease specific issues such as device therapy (e.g. especially important for the patient with multi-morbidity) • Moving from a hospital-led to a community-led programme will further facilitate communication between specialties, particularly where the patient’s overall care is co-ordinated through primary care |
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In a healthcare system which, in many places, feels overwhelmed, and in a specialty where exciting new interventions to prolong life continue to arrive at a dizzying rate, this message is timely given the impending socio-economic and personal disasters if not addressed. It is also deeply uncomfortable for many. The “between-the-lines” messages conveyed by Schichtel *et al* are disturbing. It is disturbing that it is necessary to train, educate and support patients to discuss such vital issues with their doctors. This necessity is consistent with a still pervading attitude in clinical practice – particularly medical - that communication skills are “soft”, despite the implication of poor skills in complaints representing both enormous personal cost to the patient and costs to services. Why is advanced communication skills training not a mandatory part of specialist cardiology training and regularly updated no matter how senior the practitioner to ensure they model good practice to their teams? How can clinicians, invested in the patient’s survival and personally distressed by challenging but honest conversations, be supported not to perpetuate a conspiracy of unqualified optimism? Failure to reframe hopes from unrealistic to realistic potentially denies patient and families much needed support, and risks subjecting them to futile treatments. The third pillar of evidence-based practice can only support decision making when the patient and family are fully appraised, and their views actively and sensitively sought. This “hard” skill must be given its place as a core component of person-centred care that is every clinician’s responsibility to provide.

The literature published thus far gives us clear pointers as to how to implement ACP but heart failure care has been slow to come to the table. For too long, the unpredictable nature of heart failure has been used as a reason to avoid an exploration of a patient’s values to provide a frame within which to individually tailor heart failure management, taking both best and worst case scenarios into account. Surely, if there is any uncertainty, then, by definition, there must be a risk of future deterioration which should be addressed. As Braun *et al* state so succinctly in their American Heart Association/American Stroke Association Policy Statement, “Instead of serving as a reason to avoid conversation, uncertainty should be a trigger for exploration.”⁸

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