

When palliative becomes curative? An ethical dilemma in end-stage heart failure treated with compassionate stem cell therapy: A case report

Medico-Legal Journal
1–4
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DOI: 10.1177/00258172251414075
journals.sagepub.com/home/mlj



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Abstract

Compassionate stem cell therapy (CST) is a potential treatment option for patients with end-stage heart failure who have exhausted all standard options. However, CST remains experimental. Its merits in treating heart failure are still being investigated with evidence so far suggesting limited or no sustained clinical benefit. We describe the case of a 65-year-old man receiving palliative care who underwent SCT, and whose end-of-life treatment decisions had to be reversed as a result of perceived clinical improvement. We consider the various ethical and medico-legal considerations that were weighed in the decision-making process. As access to non-standard therapies with uncertain efficacy increases, clinicians are likely to face similar challenging scenarios, but in the absence of clear guidelines. Hence, awareness of ethical and legal considerations, together with transparent, multi-disciplinary and shared decision-making, is vital to navigate these complex situations.

Keywords

Heart failure, stem cell therapy, end-of-life, resuscitation, ethical, medico-legal

Presenting complaint

A 65-year-old male (Mr A) with end-stage heart failure, managed within a palliative care framework, was admitted in April 2025 following an out-of-hospital cardiac arrest. He developed central chest pain and breathlessness 25 minutes prior to collapsing. Bystander cardiopulmonary resuscitation (CPR) was commenced and on arrival paramedics found him in pulseless ventricular tachycardia (VT). A single shock was delivered, re-establishing circulation after a downtime of 10 minutes. Upon recovery, he requested reactivation of his defibrillator and resuscitation in the event of further cardiac arrests.

Background

His past medical history included chronic lung disease and ischaemic heart disease with two prior cardiac arrests due to myocardial infarctions in his early 40s. Heart ultrasound scan (Echocardiogram) showed severe impairment of pump function.

Mr A remained under local heart failure services at a tertiary centre for medication optimisation. A cardiac resynchronisation therapy defibrillator (CRT-D) device

was inserted to synchronise pumping of both his ventricles and protect against potentially fatal arrhythmias that may otherwise result in sudden cardiac death. Despite guideline directed medical therapy (GDMT), dose uptitration was precluded by low blood pressure and the patient continued to be debilitated with symptoms (New York Heart Association class IV). As such, he was referred for heart transplant assessment in 2021 but deemed unsuitable due to pre-existing lung disease. He declined gradually over the subsequent period, eventually becoming wheelchair bound.

Upon clinic review in December 2024, it was evident that he was in end-stage heart failure with no further options for treatment. One-year mortality for patients with advanced heart failure is as high as 50%, with median time from advanced heart failure diagnosis to death being 12.2 months.¹ Additionally, median survival time has been shown to progressively decrease

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with each successive hospitalisation for heart failure.² Given the poor prognosis, a shared decision was made to undertake a palliative approach as per the Gold Standards Framework, prioritising quality of life and symptom control over prolongation of life expectancy.³ ICD (implantable cardioverterdefibrillator) was deactivated and arrangements were made for outpatient follow-up.

In the ensuing period, Mr A and his family encountered an institution offering compassionate stem cell therapy (SCT) as part of a donor-funded research initiative, solely available to patients with heart failure in whom no other treatment options are available. It entails harvesting the patient's own stem cells and delivering them to the diseased myocardium via intracoronary injections, on the premise that stem cells may repair damaged myocardium and restore cardiac function. Five weeks prior to his cardiac arrest, Mr A underwent compassionate SCT without any immediate sequelae and was discharged home following overnight stay.

Events during admission

Mr A made full neurological recovery after his cardiac arrest. Although ICD had been deactivated, he was resuscitated at home as community 'do-not-attempt-resuscitation' (DNAR) status had not been implemented.

Cardiac arrest was thought to be secondary to recurrent ventricular tachycardia (VT) due to known extensive ischaemic cardiomyopathy and ventricular scarring, with the recent stem cell infusion likely increasing the arrhythmic risk further. Arrhythmogenicity is a well recognised complication of SCT due to transplanted cells coupling poorly with the host myocardium, leading to electrical instability that may trigger abnormal rhythms.⁴ The trial team was notified as this was a serious adverse event.

However, Mr A reported significant improvement in exercise tolerance as well as being able to walk unaided and use the treadmill, a month after SCT. This appeared to correlate with increase in heart pump function on serial echocardiogram.

Mr A and his family requested reactivation of ICD and device therapies and resuscitation in the event of a cardiac arrest, instigating a series of conversations to ensure that this was justified and they understood the implications. Ultimately, an individualised plan was made which took into consideration the patient's wishes and that of his immediate family. Device therapies were reactivated whilst intubation, mechanical ventilation and CPR for any unshockable rhythms were deemed inappropriate.

The patient was subsequently discharged after treatment of a lower respiratory tract infection.

Discussion

This case presents an unusual and ethically challenging scenario in which an end-of-life decision had to be

reconsidered following the patient's reported improvement after an experimental intervention sought outside standard NHS care. Whilst the patient had previously been deemed to have end-stage heart failure with no viable treatment options, leading to management within a palliative framework, he subsequently sought SCT as part of a research trial.

The request to reverse life-sustaining treatment in this context raises complex questions for clinicians, particularly in the absence of established guidelines on integrating outcomes from experimental, non-NHS treatments into clinical decision-making. Such cases highlight the evolving landscape of modern medicine, where patients have increased autonomy and access to interventions beyond national healthcare systems which can result in the boundaries between research and standard care becoming blurred.

This case was ethically complex from the outset, beginning with the nature of treatment that was sought. Although the patient had the right to pursue potentially life-altering therapy outside the NHS, access to treatment via a trial reliant on donations, including donations from patients, raises concerns about equity and justice, as this may exclude those without the means but equal clinical need, and it adds (an unnecessary) financial pressure on patients to contribute. Moreover, directing such interventions to vulnerable, end-of-life patients with limited alternatives could be perceived as a commercialisation of hope, and as such, regarded as ethically problematic.

The patient, having capacity, had the right to participate fully in decisions about resuscitation and to request reactivation of his ICD therapies. From his perspective, the self-reported functional improvement post-SCT represented a meaningful change in his prognosis and justified revisiting earlier decisions. He had also 'defied the odds' by surviving a cardiac arrest. Respect for autonomy requires such requests to be considered seriously, even when the intervention is unproven or accessed outside standard care pathways. The GMC's 'Treatment and Care Towards the End of Life' guidance emphasises the need for regular review of decisions around resuscitation depending on clinical progress. However, it recognises that this may not be required when the condition is progressive and irreversible.⁵

Alongside respect for autonomy, healthcare professionals are bound by the principles of beneficence and non-maleficence, and have a duty to act in the patient's best interests by carefully weighing the benefits of treatment against risks.⁶ In this case, benefits of revoking palliative treatment had to be considered against risks of CPR which could subject the patient to an undignified death as well as the possibility of prolonged intensive care, long-term neurological damage and permanent disability in the unlikely event of successful resuscitation. Providing resuscitation when the likelihood of benefit is low may constitute harm, but refusing resuscitation in a patient whose condition has genuinely improved could deprive them of potentially beneficial treatment and so may be unethical. Guidance

explicitly states that patients with capacity have a right to refuse CPR and other treatments, but not to demand it.

From a clinician's perspective, Mr A had treatment with unproven efficacy and reported improvement may have been placebo-mediated or transient in nature. SCT for advanced heart failure remains experimental, with mixed results in clinical trials and no consensus on long-term efficacy.⁷⁻⁹ Notwithstanding, some objective evidence was available in the form of repeat echocardiogram which showed an improvement in pump function, and although still in the 'severe' range, it could not be dismissed. A separate dilemma relates to whether his recent cardiac arrest was iatrogenic, that is, caused by SCT directly rather than due to underlying cardiac disease. If yes, one could ask whether resuscitation was appropriate at all.

During further discussions, it became evident that the patient and his family struggled to accept the terminal nature of his condition, and that prolongation of life was valued more highly than its quality. The lack of a clear plan not to initiate resuscitation at the time of ICD deactivation probably contributed to this, highlighting the importance of effective communication. For the family, successful resuscitation was perceived as a potential lifeline, offering additional time together. Thus, potential harm that could arise from not providing CPR including the psychological detriment, distress, potential for conflict and loss of trust in the healthcare team, had to be considered.

From a medico-legal perspective, the patient and the family could assert that failure to reverse the decision in light of his clinical improvement breached Articles 2 and 8 of the Human Rights Act 1998 which outline that all individuals have a right to life (as deemed appropriate) and right to autonomy, bodily integrity and decision-making relating to their own care.¹⁰ That said, Article 3 which prohibits inhumane and degrading treatment could be invoked to justify withholding CPR when it is highly unlikely to be unsuccessful or cause significant injury, though withholding CPR when there is a realistic chance of benefit could paradoxically be interpreted as degrading.¹⁰ Hence, proportionality to achieve a balance between undertreatment and overtreatment is recommended.

In this case, the decision hinged on whether Mr A's improvement was sufficient to make CPR a meaningful intervention, with a reasonable likelihood of survival and acceptable quality of life. This was difficult to gauge in the absence of conclusive evidence, though existing data would suggest that the gains were short-term. Nonetheless, the patient's perspective which accorded equal significance had to be considered in the decision-making process.

Ultimately, a multidisciplinary approach was undertaken to develop an individualised plan that integrated the patient's values, clinical circumstances and previously outlined ethical and legal considerations, aiming to balance the patient's expectations with reasonable clinical judgement. The current consensus statement on DNAR

decisions emphasises the importance of respecting a patient's wishes, even when they request resuscitation despite understanding that potential harms may outweigh the benefits.¹¹ However, the same guidance also makes clear that patients and families cannot demand interventions deemed clinically inappropriate, and that healthcare professionals are under no obligation to provide such treatments, illustrating the inherent complexity of these decisions. Should a cardiac arrest occur at a later stage, clinicians are encouraged to make decisions that are responsive to the evolving clinical situation while remaining aligned with the patient's expressed preferences.

Conclusion

This case underscores the need for maintaining flexibility in care planning, ensuring that decisions remain responsive to genuine changes in a patient's condition whilst upholding ethical principles. It highlights an evidence gap that needs to be addressed to ensure consistency and transparency in future cases, though development of specific guidance may be challenging due to clinical heterogeneity. As access to non-standard therapies broadens, clinicians will increasingly face similar scenarios, often in the absence of established guidance. Transparent communication, active multi-disciplinary discussion and careful documentation are essential to navigating these challenges and delivering care that is patient-centred and legally defensible.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Ethical considerations

Ethical approval was not required.

Informed consent

Informed consent for publication was obtained from the patient.

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