Spiritual support in advanced heart failure: rationale and elaboration of the SPIRIT-AHF trial protocol

J Miles [1], L Ross [2], J M Beattie [3], S Noble [4], K Hood [4], Z Yousef [5] , J Segrott [4], R Playle [4], R Lowe [4], J Round [6]

[1]Aneurin Bevan University Health Board, [2]University of South Wales, [3]Cicely Saunders Institute London, [4]Centre for Trials Research, Cardiff University, [5]Cardiff and Vale University Health Board, [6]Institute of Health Economics, Canada

Background:

Spirituality is fundamental to the human condition.
Not necessarily linked to religious belief, this refers to a person's deep-seated sense of self, meaning, purpose and connection which may be challenged by illness.

Patients with advanced heart failure [EF ≤ 35%; NYHA III/IV] (AHF), declining on the unpredictable heart failure disease trajectory and those close to them who provide much informal care, are subject to spiritual distress.

Patient and carer dyads have demonstrable unmet needs for spiritual support (SS).

Purpose:

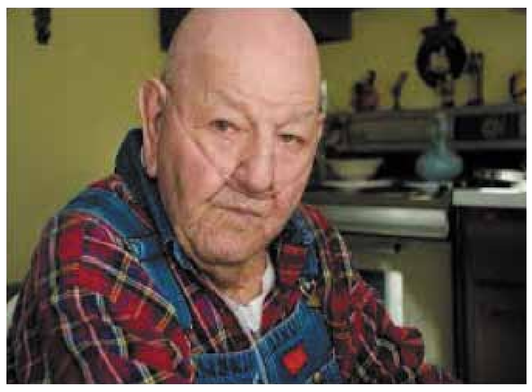
- To design an holistic care model which includes SS for patients with AHF and their carers.
- Assess the model's feasibility, acceptability, and effectiveness for this patient group in the United Kingdom (UK).
- Evolve the treatment paradigm for chronic heart failure in the UK which tends to be dominated by a relatively rigid guideline-driven biomedical model.

Methods:

An extensive literature search elucidated examples of SS which were not well defined and were generally confined to cancer care. Proof of concept work highlighted challenges with patient recruitment and retention.

AHF patient / carer dyads, embedded within the project team, provided insight into their lived experience, defining important elements of health-related quality of life (HRQoL) and attitudes to SS.

Informed decisions were made on the mode of care delivery and selection of patient reported outcome measures (PROMs) to assess the fidelity of the intervention.



'I want a life. I haven't got one at all, so what can you do about that? Can you give me a new life?'

Results:

A logic model of the intervention was produced and, consistent with our previous proof of concept work, the 2-Question Spiritual Assessment Model (2Q-SAM) and Spiritual Enquiry Tool were chosen to assess spiritual concerns as the basis of SS. SS to be sequentially delivered by purposely trained heart failure nurse specialists (HFNS).

- The Kansas City Cardiomyopathy Questionnaire (KCCQ) will assess HRQoL.
- Spiritual wellbeing and satisfaction with SS will be assessed using FACIT-Sp and the Lothian PROM respectively.
- The Hospital Anxiety Depression Scale (HAD) and EuroQol 5D will assess psychological and economic burden.
- Carer assessment will include the Modified Caregiver Strain Index (MCSI).

Conclusions:

A comprehensive feasibility cluster randomised controlled trial (SPIRIT-AHF) is proposed. This will examine the efficacy of bespoke SS as determined by specific spiritual needs assessment within an holistic care model when delivered to AHF patients and their carers by HFNS, compared with usual care.

Clinical Research and Innovation Centre, Aneurin Bevan University Health Board, St Woolos Hospital, Newport, Wales, UK
University of South Wales, Faculty of Life Sciences & Education, Pontypridd, UK

No interests to declare

jackie.miles2@wales.nhs.uk

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Aneurin Bevan University Health Board

University of South Wales Prifysgol De Cymru