Quality of life & palliative care needs of patients with advanced heart failure & their caregivers

Evidence into Practice Workshop: Action plan

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Background

A sequential confirmatory mixed methods study was undertaken to examine the palliative care needs of caregiver's of people living with advanced heart failure in Ireland and to explore any relationship between this and a range of other factors, including the patient's clinical profile and support available. There were 2 key phases to the research design; postal survey with advanced heart failure patient and their informal caregivers; face-to-face interviews with current and bereaved caregivers. Based on the research findings, five key recommendations were proposed:

Identification and Prognostication: There is a need for standardised documentation of clinical information in heart failure. Sensitive and specific prognostication tools need to be developed, implemented and evaluated as to whether they accurately identify patients with advanced HF needing palliative care.

Models of integration: Models to integrate palliative care and HF need to be developed that incorporate the needs of informal caregivers. Within these models, clear referral criteria and pathways need to be decided upon and evaluated in relation to patient and caregiver outcomes.

Improved communication: Communication training needs to be provided for healthcare professionals in order to address the lack of continuity and co-ordination between services reported here. We need to develop an awareness surrounding the importance for healthcare professionals to initiate conversations regarding poor prognosis, goals of care and ACP. We need to acknowledge the barriers to initiating these sensitive conversations and provide better opportunities for healthcare professionals to facilitate open conversations with patients and their caregivers.

Advance care planning: In order to successfully implement ACP for HF patients, we need an improved strategy to identify patients in need of ACP and processes need to be implemented using existing tools and operational guidance documentation.

Psychoeducational intervention development: Caregivers need accessible information related to the patient's diagnosis and HF symptoms to enable the caregiver to support the patient manage their condition. Caregivers need to recognise signs of deterioration and know who to contact in these situation. Improved knowledge could lead to improved self-care capabilities, better management of the patients' condition and a sense of empowerment for the patients and caregivers.

Evidence into Practice Workshop

An “Evidence into Practice” workshop was organised in November 2016 to launch the research findings and take the recommendations forward, to develop an action plan. Healthcare professionals from Northern Ireland and Republic of Ireland working in the community and hospital setting, in the area of heart failure and palliative care were invited to attend the workshop. The workshop included a presentation of the research findings and talks by guest speakers, Professor Sheila Payne, International Observatory on End of Life Care at Lancaster University and Dr James Beattie, Consultant Cardiologist and heart failure lead at the Heart of England NHS Foundation Trust in Birmingham. Following this delegates participated in group activities, with each group having an even representation from Northern Ireland, Republic of Ireland, palliative care and heart failure specialties.

Group work

The aim of the group work session was to collectively discuss the recommendations from our research and generate ideas from specialist healthcare professionals working in cardiology and palliative care, on how to take the research findings forward. There were 5 groups and each focused on a research recommendation; discussing the key stakeholders required, the main objectives and actions required for each of the recommendations (appendix 1).

Results

The information collected from each group for each of the five recommendations has been summarised and included in table 1.

Table 1 Summary of group work discussions surrounding each of the five recommendations

Recommendation:	**(Who)** **Stakeholders**	**(What)** **Objectives/goals**	**(How)** **Actions/tasks**	**(When)** **Timescale**
Identification & Prognostication	Hospital teams (HFNS). Community teams (AHP, social worker, Physio, PC teams). Charities.	Make timely management decisions. Avoid unnecessary hospital admissions. Effective management of care. Effective management of Pt.–CG expectations. Experiential Pt. holding their own records	BNP is not a useful marker of deterioration. Timely discussions needed surrounding device therapy. Need for weekly multidisciplinary team meetings.	5 years
Models of integration	Pt., CG, family. Heart failure teams (HFNS, cardiologist). Allied health professionals (social worker, OT, physio, dietician). Primary Care staff (GP, district nurse, practice nurse). Palliative care professionals (day hospice, Marie Curie night nurses). Out of hours (paramedics, on call staff).	Quality care for the Pt. (support at the right time/place). Better working (integration of services). Improve/Increase awareness of general & specialist PC to the public and healthcare professionals. PC education at undergraduate level & for all health professionals. Healthcare professionals need to have respect for each other's roles and contribution.	Education & training for AHP (free, online). Media/social networks. Research warranted exploring the barriers/challenges & effective dissemination to different groups of people. Reorganization of services (24-hour service). Improved communication. Interdisciplinary working Availability of recourses.	Tomorrow 3-5 years

Recommendation	(Who) Stakeholders	(What) Objectives/goals	(How) Actions/tasks	(When) Timescale
Improved communication	Pt. needs to be at the centre. Family, CG, HF teams, PC teams & community teams all need to be on board (in parallel)	Communication has a role in everything. Achieve clear understanding of realistic Pt. goals & outcomes. Acknowledge uncertainty. Achieve a smoother transition in services. Identify Pts. needs & reassess at key points. Recognize Pt. triggers/cues to initiate discussions surrounding the condition. Timely care Take cognitive capacity of the patient into consideration.	Identify appropriate needs assessment tools (combination of assessments). Australia have a PC needs assess that could be developed for Ireland. Training staff in advanced communication. key worker to act as champion (facilitate dissemination of info to HF & PC teams).	Target individuals in early education. NB There currently is no validated PC HF treatment model.
Advance care planning	Pt. needs to be at the centre. A multidisciplinary team is needed to include, family, HFNS, DN, GP.	Pt. & family centred goals individualized. Process of ACP (identify triggers to initiate ACP)	Education for GPs. Educate Pt. & family. Demonstrate outcomes on ACP. Joint working with services. Needs based assessment. Key care worker/coordinator.	Timely and early. Using triggers of failed discharges.

Recommendation	(Who) Stakeholders	(What) Objectives/goals	(How) Actions/tasks	(When) Timescale
Psychoeducational intervention development	HFNS (provide info on symptom management) Consultant Cardiologist (focus on ↑ Pt. CG self-care) GP, Practice Nurse, HFNS can be fragmented. Carers own needs to be prioritised. Multi-disciplinary team needed which also includes a Social Worker.	Pt. passport & mosaic of information is needed to promote self-care. Booklet that's empty and is filled out by different services over time. Help line, peer support group, on-line, family meeting facilitated by specialist team, community resources facilitated around GP practice.	Pt. & CG needs info on clinical course of HF (Treatment & symptom management). Healthcare professionals need to recognise the important role of CG & burden involved. Generic support available to CG needs to be flagged up to them. Support offered to CG (peer support during Pt.s' clinic appointments, drop in centre, info on screens at apts & leaflets in waiting area). Offer alternative therapies to the CG.	Diagnosis should trigger initiating CG support & info (symptoms & management). This should be re offered at periods of decline. Identifying CGs is the prime responsibility of the HF team.

Abbreviations: HFNs; heart failure nurse specialists, AHP; allied health professionals, PC; palliative care, Pt.; patient, CG; caregiver BNP; B-type Natriuretic Peptide, OT; occupational therapist, GP; general practitioner, HF; heart failure, DN; district nurse, ACP; advance care planning, apts; appointment

Appendix 1 Template worksheet for group work session

> **Recommendation:**
>
> **Advance care planning:** In order to successfully implement ACP for HF patients, we need an improved strategy to identify patients in need of ACP and processes need to be implemented using existing tools and operational guidance documentation.

In order to take forward the above recommendation to an action plan, consider the who, what, how and when.

(WHO?) STAKEHOLDERS	
(WHAT?) OBJECTIVES/GOALS	
(HOW?) ACTIONS/TASKS	
(WHEN) TIMESCALE	