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"MIND THE GAP": PATIENT KNOWLEDGE AND UNDERSTANDING OF THEIR CONDITION, TREATMENTS AND PROGNOSIS REMAINS AN ISSUE FOR THOSE WITH END STAGE HEART FAILURE (ESHF)

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10.1136/bmjspcare-2012-000264.14

Introduction It has been suggested that end of life care is rarely discussed with ESHF patients and that many do not appreciate the seriousness of their condition. Consequently, a range of guidelines have been published that aim to improve communication and practice in this sphere.

Aims and Methods To examine how ESHF patients and carers make sense of their condition and plan for the future, and explore what part health professionals play? Semi-structured interviews with ESHF patients (29) and their carers (19). Interviews explored participants' knowledge and understanding of the condition including prognosis. Qualitative data analysed using thematic analysis but informed by normalisation process theory (NPT). Inclusion criteria: Grade 3 or 4 NYHA classification heart failure; who have ongoing symptoms despite optimal therapy; and have a history of admissions for this condition.

Results The gap between recommended "best practice" and patient experience remains wide. While some participants clearly know their condition is "severe" or "serious" there remains a much uncertainty around prognosis. Levels of knowledge, understanding and communication remain sub-optimal. Advances in treatments and technologies mean pose new challenges for this patient population. For example, problems relating to understanding and communication surrounding the role of Implantable defibrillators (ICDs) is an emerging issue.

Conclusion Knowledge and understanding of diagnosis and prognosis remains problematic. Issues relating to ICDs, particularly deactivation, seem to be an emerging problem. More counselling/support services are needed to help support ESHF patients who have a range of unmet needs and help bridge the gap between published guidelines and patients' real experiences.