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Patient perspectives of prognosis communication

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Background: Several studies describe that patients with heart failure (HF) find it important to discuss prognosis and that they want to be informed about the expectations about the illness progression. However, little is known about their actual preferences for professional communication about prognosis.

Purpose: to explore patient’s perspectives regarding communication with health care professionals about the HF prognosis.

Methods: 15 patients participated in focus group interviews and a further 9 patients completed individual semi-structured interviews. The patients (75% men, 52-87 years of age) were in NYHA I-III, and were not diagnosed with any other major life threatening disease. Data was analysed using thematic analysis to identify and interpret patterns in the data.

Results: One overarching theme was identified: “The tension between hoping for the best and preparing for the worst” with three sub-themes.

Ignorance is bliss. Describes how patients preferred to avoid thinking about the HF prognosis because they did not want to lose hope for the future. They lived one day at the time, focusing on here and now, wanting to forget about the illness altogether. Patients also preferred to decide themselves whether they wanted to talk about the prognosis with professionals or not.

Nothing but the truth. Describes how patients wanted to know the objective and absolute truth about their illness and its’ prognosis and were afraid to live under false expectations. The truth about their prognosis was that they might die because of their illness. Even though the truth may hurts, they believed that knowing the truth was necessary to live as good as possible.

Good news only. Patients described that they knew that HF was a chronic illness but they were ambivalent in their approach towards discussing prognosis. They wanted to know the truth about their prognosis, but at the same time they did not want to know anything since they fear they might hear something they do not want to, as this may hurt. They only wanted to receive “good” and positive information from the professionals, since they perceived such information to be something that they can benefit from.

Conclusions: This study shows that patients have different preferences for communication about prognosis and uses different approaches in order to cope living with a serious condition such as heart failure. Professionals need to respect the strategies a patient uses, and be ready to support the patient according to their needs, preferences and life situation.