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LVAD-DT: The final destination

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Background: LVADs can extend and improve quality of life for individuals with advanced heart failure. Fifty percent of LVAD implantations are destination therapy (DT), which is long-term support for non-heart transplant candidates.

Purpose: To investigate whether conversations about LVAD deactivation occurred with LVAD-DT recipients and their family caregivers (FCG) and whether device deactivation occurred prior to the recipient’s death.

Methods: LVAD-DT recipients and their FCGs, from 2 longitudinal prospective studies, were individually interviewed and asked if discussions about device deactivation at end of life (EOL) occurred. Following the death of LVAD recipient, FCGs were interviewed about their loved one’s death and about LVAD deactivation. Interviews were analyzed using a qualitative content analysis. Electronic medical records (EMR) were reviewed to determine device deactivation.

Results: Thirty-five LVAD-DT recipients and their FCGs were interviewed. There majority of the LVAD recipients were male (80%); while FCGs were female (86%). The mean time with an LVAD was 1.5 years (3 months to 5 years). During enrollment LVAD recipients had on average 6 readmissions. Six patients (17%) died during the study, no LVADs were deactivated. Seventeen percent (6/35) had advance decisions in the EMR: all completed prior to LVAD implantation; none included wishes regarding device deactivation. LVAD recipients did not recall conversations about device deactivation at the time of implantation or after implantation and only 1 FCG remembered having those discussions.

During the post-death interviews, caregivers said:

One doctor came and talked to me about it and I really didn’t want to hear about it. I didn’t even think you had to turn it off…and we have to turn the pacemaker off and to me that was like murder. I didn’t want to hear about it. I said come back tomorrow.

The first I heard about it was when I was reading some of the literature….I never give it any thought up till then…you mentioned it as part of the research study…the doctors never did.

At some point it should be shared a little bit more… what happens at EOL and this is a possibility [device deactivation] and what you may have to do. Because it’s something that we never really talked about with anybody.
Conclusions: The pre-implantation period is a very busy time, if discussions about device deactivation at EOL occurred, they were not remembered. Despite an average of 6 hospitalizations post-implantation, discussions about device deactivation did not occur. Discussions about EOL decisions are important, particularly with a person with a life-limiting disease. These discussions and the advance decisions should be updated as a person’s condition changes and advanced therapies are added to prolong life. The ultimate goal is for the terminal trajectory to be one that is peaceful and acceptable to the person who is dying and their family.