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Development of an instrument for measuring self-care after left ventricular assist device implantation

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Introduction: The number of heart failure (HF) patients living with left ventricular assist device (LVAD) is increasing. Successful long-term LVAD support includes a high degree of self-care by the patient and his/her caregiver.

Purpose: We aimed at developing an instrument to measure self-care in HF patients who are living at home with an LVAD.

Methods: A literature review on self-care in LVAD patients was conducted in order to generate items. The 'middle-range theory of self-care of chronic illness' with its three key concepts; self-care maintenance, self-care monitoring, and self-care management was used as a framework for the scale. Next, face validity of the newly constructed instrument was tested by the two rounds of Delphi survey involving 15 clinicians with LVAD and HF expertise from the Netherlands, Israel, USA, Canada, and Japan. In the first Delphi survey, the levels of importance, relevance, and clarity of items in the instrument were evaluated with 5-point scale (0 to 4) and open-ended questions. To gain a consensus of the results, a second Delphi survey was performed.

Results: A preliminary version of a 37-item self-care scale was developed to measure self-care behavior in patients supported by LVADs. The self-report scale consists of three subscales: self-care maintenance, self-care monitoring and self-care management. Through the Delphi surveys, 32 items were judged as being important and relevant, 6 items were excluded because of vague and duplication, and 2 items were added. In the final 33-item version, 18 items addressed LVAD self-care maintenance that measure activities related to maintenance of the device and percutaneous lead (e.g. record the LVAD speed, keep the driveline clean) and maintenance activities related to life style (e.g. adherence to medication, adjust physical activities). An additional 10 self-care monitoring items are included in the scale addressing monitoring of the LVAD lead and wound (infection), and monitoring HF symptoms and complications (e.g. monitor myself for signs of infection, worsening fatigue). Another 5 items measure self-care management and include handling alarms or coping with living with the device (e.g. contact the LVAD/HF team in case of alarms, talk with LVAD/HF team when I am feeling worried).

Conclusion: In addition to HF self-care behavior, patients supported by an LVAD need LVAD specific self-care. We developed a new device-specific self-care scale for HF patients supported with an LVAD. Reliability and validity of the new self-care scale have been tested in Japan, followed by testing in other countries. The new self-care scale might help to improve care and evaluations of HF patients supported with an LVAD.