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VIEWPOINT

The consequences of the COVID-19 pandemic for self-care in patients supported with a left ventricular assist device

Tuvia Ben Gal[1]*, Binyamin Ben Avraham[1], Miriam Abu-Hazira[1], Maria Frigerio[2], Maria G. Crespo-Leiro[3], Anne Marie Oppelaar[4], Naoko P. Kato[5], Anna Stromberg[5,6], and Tiny Jaarsma[5,7]

[1]Heart Failure Unit, Cardiology Department, Rabin Medical Center, Petah Tikva and Sackler Faculty of Medicine, Tel Aviv University, Tel Aviv, Israel; [2]Cardiologia 2 - Insufficienza Cardiaca e Trapianto, Dipartimento Cardiotoracovascolare, De Gasperis Cardio Center, ASST Grande Ospedale Metropolitano Niguarda, Milan, Italy; [3]Unidad de Insuficiencia Cardiaca y Trasplante Cardiaco, Complexo Hospitalario, Universitario A Coruna (CHUAC), INIBIC, UDC, CIBERCV, La Coruna, Spain; [4]Department of Cardiothoracic Surgery, University Medical Centre Utrecht, University of Utrecht, Utrecht, The Netherlands; [5]Department of Health, Medicine and Caring Sciences, Linköping University, Linköping, Sweden; [6]Department of Cardiology, Linköping University, Linköping, Sweden; and [7]Julius Center, University Medical Center Utrecht, Utrecht University, Utrecht, The Netherlands

Self-care is essential for patients supported with a left ventricular assist device (LVAD) to prolong survival and maintain a good quality of life.[1] Adequate self-care can decrease the risk of infection, bleeding, pump thrombosis, cerebral events, and other complications related to the device or to the various comorbidities that are common in this group of patients.[2] Patients and their caregivers receive intense education and support on how to perform appropriate self-care and to cope with factors that may hinder optimal self-care. However, with the recent pandemic COVID-19, LVAD supported patients, their close caregivers and the healthcare professionals face some completely unprecedented and unexpected challenges that may affect their ability to maintain optimal self-care. Patients with cardiovascular risk factors and established cardiovascular disease represent a vulnerable population when suffering from COVID-19 and patients with cardiac injury in the context of COVID-19 have an increased risk of morbidity and mortality.[3]

In this short communication, we summarize some of the consequences of the COVID-19 pandemic for self-care of LVAD patients, with the aim to support the patients, their caregivers, and healthcare providers and to offer some input on self-care related challenges that are probably similar worldwide. This paper might also guide future education programmes and organizational strategies to prepare for similar crises. This viewpoint paper presents guidance to centres that – until now – might not have organized ambulatory care and education protocols for their LVAD supported patients. Other centres might already have such care on a distance in place and can serve as a model of 'best practices' to those who need to reorganize care for those patients. This viewpoint is based on experiences from centres that have experience with LVAD patients during the COVID-19 pandemic in different professional roles in different European countries.

Self-care for LVAD supported patients includes care for the system and the driveline, maintaining a healthy lifestyle, and adhering to the prescribed medical regimen.[1] Additionally, LVAD supported patients and caregivers should monitor signs and their symptoms including regularly monitoring device and vital parameters, which changes may require prompt recognition and actions. Threats for appropriate self-care imposed by COVID-19 are related not only to the occurrence of the disease itself, but also to social constraints, transportation restrictions, social distancing, difficulties in accessing drugs and supplies as needed, and psychosocial stress.[4]

Essential self-care behaviour and threats/challenges during the COVID-19 pandemic

System maintenance and driveline care

Patients and caregivers must take care of the external components of the device (controller, power module and batteries) and the dressings on the driveline exit site wound must be changed by the patient, a family caregiver or by a care provider. Help by a non-cohabitant family caregiver might be impossible due to quarantine regulations, illness of the caregivers, or patient's fears

*Corresponding author. Heart Failure Unit, Heart Transplantation Service, Cardiology Department, "Rabin" Medical Center, 39 Jabotinski Street, Petah Tikva 49100, Israel. Email: bengaltu@gmail.com

to get infected. Some patients do not want to come to the hospital to collect the materials they need since they are afraid of being infected when visiting the hospital.[5]

With the inter and intra-national travelling restrictions, some healthcare settings face challenges in obtaining and delivering equipment during this time, both to individual patients and to hospitals. Patients even may be tempted to ration their bandages or re-use materials because their fear from running out of dressing materials, thus significantly increasing the risk of driveline infection.

Lifestyle

Patients need to keep a healthy lifestyle to maintain or improve their physical and mental fitness.[6] These self-care behaviours can become complicated in the COVID-19 pandemic by lack of healthy food, inability to be physically active, decreased adherence to medication and decrease in social support. Due to the need to stay in prolonged isolation, patients might have limited access to fresh and healthy food, resulting in increased consuming of canned foods with high sodium content. Patients cannot come to the rehabilitation centres since they are closed and cannot walk in their neighbourhood or gather with friends because of social distancing.[4] This can lead to substantial weight gain either from increased caloric intake, decreased activity level, or from fluid retention (peripheral or pulmonary oedema). In cases of fluid retention, pulmonary congestion with worsening shortness of breath or elevated central venous pressure resulting in peripheral oedema and liver congestion may reduce the functional capacity of the LVAD supported patient. Increased sodium intake may facilitate hypertension, with inherent risks for cerebrovascular events. Furthermore, changes in the food composition might influence the international normalized ratio levels, with increased risk of stroke and/or bleeding.[7] Adherence to the prescribed medications may be jeopardized by actual or feared difficulties in drug supply, unproven news about possible interactions between cardiovascular drugs and coronavirus infections that are popular on the web or other media, and by depression and anxiety.[8]

Psychosocial wellbeing

Optimal self-care includes behaviour to maintain and increase psychological wellbeing to optimally cope with the LVAD. As a consequence of the COVID-19 pandemic, patients have an increased level of distress at the same level as the general population, but most often much higher as being in a high-risk group.[8] Patients worry about being infected and they worry about the wellbeing of their caregiver (who will take care of me if my caregiver gets ill?). Patients also worry about changes in their relationship with their close homebound caregiver on whom they become even more dependent. Psychological distress can be accelerated by the lack of physical activity, social deprivation, isolation and loneliness, feeling less motivated to accept limitations and responsibilities imposed by living with the device. Not only patients are distressed but also their caregivers, which might lead to extra stress in the relationship. Due to the quarantine or the social distancing, caregivers are deprived from their regular social support. This increases their feelings of anxiety, loneliness and of responsibility.

Some patients feel extremely vulnerable and lonely unable to take decisions, some of which are unfortunately common in the COVID-19 times like to attend or not a funeral of a loved one who died from COVID-19.

Self-care and relationships with specialized healthcare providers

Left ventricular assist device supported patients get expert support from the referral centre or from specialized, home-based healthcare services. Due to deviation of many resources to contrast the COVID-19 pandemic, less time may be available for all outpatient activities, including surveillance of LVAD recipients by LVAD specialists. Moreover, accesses to the hospital should be discouraged to reduce the risk of hospital-acquired infection. Thus, monitoring of regular function of the device, laboratory tests, and clinical evaluation may be postponed or made less frequent. Patients may find it more difficult to contact their referral centre/ventricular assist device coordinator, or may perceive reduced attention, making them afraid about the possibility to get the same levels of quality of care they were used to receive, thus contributing to anxiety and reduced quality of life.

Symptoms of anxiety and depression and worry might overlap/mask symptoms of shortness of breath or cerebral events. Some symptoms like tingling in the lips or fingertips or shortness of breath with atypical chest pain commonly seen in anxiety states, might mistakenly be taken as signs of stroke or pulmonary congestion but can also represent those medical emergencies and be regarded as signs of anxiety common during these days. LVAD supported patients, instead of seeking medical help timely, might delay in contacting their LVAD coordinators or take blood tests from the fear of being sent to the emergency department. LVAD supported patients with the indication of bridge to transplantation might recline an offer to undergo heart transportation because of the fear of being infected from the donor or because they fear they will not get the optimal care from the overstressed healthcare system.

Solutions and practical tips

Due to the COVID-19 pandemic many LVAD centres are organizing remote patient's care and are carefully weighing the advantages and disadvantages of 'real life' contact vs. video or phone calls. Although video conferencing, phone and/or video-consultation were already proposed by expert's consensus or guidelines for the follow-up of LVAD supported patients[9–12] almost a decade before the COVID-19 pandemic, most LVAD implanting centres did not implement those follow-up protocols. The current situation might stimulate practitioners to implement such guidelines.

Several applications exist and centres are advised to explore which applications are available in their local healthcare systems.

Some of our experiences in delivering optimal support to LVAD implanted patients during the COVID-19 pandemic include

Table 1 Practical tips to improve left ventricular assist device (LVAD) self-care during the COVID-19 pandemic

- Create local support networks to deliver educational materials
- Replace usual follow-up visits, management and monitoring of patients in an emergency or in the context of known complications (driveline infection, stroke, bleeding, etc.) by video consultation. Medical history can be taken, and patients can use the camera to assess their fluid status and rule out or assess the severity of existing driveline infection. The simple video may also assist in managing and monitoring new or known LVAD-related complications like cerebrovascular events or bleeding: overt like epistaxis or unnoticed gastrointestinal bleeding presenting with paleness or shortness of breath
- Consider an online/virtual group for the LVAD supported patients and their LVAD coordinators
- Regular structured telephone or preferably an audio-visual contact from the VAD coordinator to the LVAD supported patients
- Transmission of structured report on self-monitored parameters, including a photo of the cutaneous wound of the driveline to the health care provider.
- Provide telerehabilitation and send video instructions, preferably given by the local physiotherapist known to the whole group of LVAD supported patients
- Encourage the use of exergames if they are available to the patient
- Emphasize the importance of contacting the LVAD coordinators in any event of change in their wellbeing
- Pre-prepared packs of the materials that are needed for dressing of the driveline exit site could be delivered directly to patients' home or may be consigned to patients or their delegates minimizing the time spent within the hospital facilities
- Enable 'clean' pathways throughout the hospital facilities securing safe assistance to heart transplant and LVAD recipients[13]
- Enable 'clean' pathways in the local laboratories or organize home-based blood sampling for high-risk patients including those supported with a LVAD
- Create modes of direct delivery of medical materials needed for dressing of the driveline exit site to the LVAD supported patients' home

creating local support networks to deliver educational materials, extra pro-active phone calls from the LVAD team, video conference to perform minimal physical examination by checking the CVP, the presence of pedal oedema, and assess the appearance of the driveline exit site (*Table 1*).[13] Others created video instructions for wound dressing. Telephone follow-up and video conferencing are shown to be beneficial and also might be used to contact the LVAD supported patients with family members who are hospitalized with COVID-19 and in a critical state.[9,10]

Video and teleconsultation may raise several problems for example concerning the transmission of patient's data which are supposed to be encrypted, they may raise regulatory issues and possible problems of medical liability, since the follow-up is only partial in particular. Some centres also might face financial challenges since these exchange and follow-up justify remuneration supported by healthcare systems, which for the most part is not yet ready.

A solution to promote physical activity for LVAD supported patients can be by telerehabilitation sessions, exergaming, or by sending video instructions given by the local physiotherapist known to the group of LVAD supported patients.[14,15] This can be preferred above 'standard online video instructions' since the patients see a familiar face, are familiar with his/her instructions and by that, not only improve their adherence to physical activity but also decrease their feeling of isolation. Basic monitoring should be ensured with locally elaborated solutions, according to local- and patient-specific risks of being infected and the estimated risk–benefit profile of skipping the follow-up appointments vs. accessing the hospital. Follow-up calls should be structured to check all relevant points, including the availability of drugs and dressing supplies for the near future. Additionally, time should be spent for psychological support and reassurance.

Where highly prevalent, COVID-19 may become very absorbing and stressful for hospitals and healthcare organizations. Most energies and human resources are devoted to identification and care of critical respiratory patients, and other activities may appear as superfluous or not relevant. However, complex patients, whose survival and quality of life depend largely on continuing specialized healthcare support, among whom are the LVAD supported patients, always need to be highly prioritized.

In conclusion, self-care behaviour of LVAD supported patients during the COVID-19 pandemic is very challenging, thus jeopardizing their quality of life and survival. Healthcare providers need to be flexible and creative to support patients optimally, and future educational programmes should address these challenges that might become relevant more often.[5]

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