

Chapter 16

Home-Based Care for Survivors of Critical Illness



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Home-Based Care

Home-based care is defined as any type of health service provided to patients directly at home with support from trained health care professionals [1]. Home-based care aims to provide guidance, assistance, and social support for individuals with important health care needs to empower them to live as independently as possible in their own home environment [2]. One important goal of home-based care interventions is to address the needs, values, and preferences of patients affected by multiple comorbidities, frailty, and disabilities, who usually require intensive medical management and rehabilitation or have difficulty accessing traditional facility-based care services. This model of care is feasible as a health policy, because it ensures cost-effectiveness while respecting the preferences of an increasing number of people to remain in their own homes rather than move to residential care facilities [3]. Nevertheless, home-based care interventions are not limited to the care of bedridden patients. Both patients and family caregivers are provided with guidance and psychological and social support aimed at improving treatment adherence, engagement in rehabilitation, prevention of complications, and quality of life.

Home-based care requires highly qualified professionals, since specific competencies, especially those related to interpersonal relationships, are necessary in order to effectively coordinate with patients, family members and caregivers, and multiprofessional teams [4]. It also demands autonomy, responsibility, and

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technical and scientific knowledge. Home-based care involves specific complex tasks that demand professional experience and home practice qualification.

A recent systematic review and meta-analysis of 20 randomized clinical trials assessing the effectiveness of hospital-initiated postdischarge interventions showed that home-based interventions, such as home visits and follow-up phone calls, were associated with lower rehospitalization rates [5]. Among postdischarge patients, two or more home visits were associated with a lower risk of hospital readmission compared with none (24% vs. 36%; odds ratio [OR], 0.6; 95% confidence interval [95% CI], 0.4–0.7). Similarly, two or more follow-up phone calls were associated with a lower risk of hospital readmission compared with none (OR, 0.7; 95% CI, 0.6–0.8). After controlling for follow-up duration, patient diagnosis, and exposure to discharge education, patients with the lowest risk of readmission were those exposed to multiple home visits and multiple follow-up phone calls (OR, 0.5; 95% CI, 0.4–0.7). Studies have also demonstrated the benefits of home-based interventions in specific contexts [6–8]. A randomized clinical trial of a home-based behavioral intervention involving patients with dementia and family caregivers showed less functional dependence, less dependence in instrumental activities of daily living, greater patient engagement, and greater caregiver well-being and confidence compared with controls at 4 months [6]. The home-based intervention included up to 12 home visits or phone contacts over 4 months by health professionals who assessed patient capabilities and deficits and trained families in home safety, task simplification, and stress reduction. Caregivers in the control group received phone calls and educational materials. Likewise, in a randomized clinical trial, a 10-session, home-based, multidisciplinary program in which occupational therapists, registered nurses, and home modifiers addressed self-identified functional goals by enhancing individual capacity and the home environment during home visits resulted in a substantial decrease in disability scores at 5 months among low-income community-dwelling older adults [7]. A systematic review and meta-analysis of 17 randomized clinical trials comparing the efficacy of home-based nonpharmacological interventions with usual care of patients with depression found that a combined, home-based, psychological, and exercise intervention was associated with improved depression scores and higher disease remission rates [8]. These results emphasize the effectiveness of home-based care for preventing unwanted outcomes in complex populations. Although evidence of effectiveness for home-based interventions in survivors of critical illness is scarce, it is plausible that this benefit may extend to patients recovering from critical illness as well.

Why May Survivors of Critical Illness Require Home-Based Care?

The long-term morbidity and mortality of patients who survive acute critical illness is a reason for concern for critical care clinicians and policy makers [9, 10]. The traditional focus of critical care on reducing short-term mortality has been

challenged by the poor long-term outcomes of post-ICU patients. Current evidence shows reduced long-term survival in ICU survivors compared with the general population [11, 12]. Moreover, post-ICU patients often experience physical, cognitive, and psychological disabilities that may impair their quality of life and contribute to frequent hospital readmissions and increased use of health care resources [13–15].

About 15–20% of hospitalized Medicare patients are readmitted to the hospital within 30 days of discharge [16, 17], and these rates can reach up to 25–30% among patients recovering from sepsis [18]. Some authors have referred to this group as hospital-dependent [19]. Many contributing factors have been proposed, including the high burden of physical, cognitive, and psychological disabilities and comorbidities in this population, poor transition from hospital to outpatient care, lack of adequate medication reconciliation, and poor access to health services after discharge, such as timely postdischarge appointments with primary care physicians and specialists and specific rehabilitation programs for ICU survivors [20–24]. These factors may contribute to an increased risk of serious complications requiring in-hospital management, such as infections, exacerbation of chronic diseases, new organ dysfunctions, drug toxicities, and cardiovascular events [21]. Moreover, the pressure for shorter hospital stays and cost reductions has condensed the time and resources available for ICU clinicians and other hospital personnel to properly prepare patients and their caregivers for the transition from hospital to home. In this context, many survivors of critical illness encounter difficulties in self-management, resulting from either the impairment of their functional status or the lack of awareness of what to do and how to get help if their health worsens after discharge [23]. Caregivers are likewise infrequently prepared to manage the patient's prescribed treatments, lifestyle modifications and rehabilitation, or to recognize subtle changes in the patient's health status before the onset of overt symptomatology.

Post-ICU follow-up has been implemented in some settings to improve the long-term outcomes of critical illness survivors. Evidence suggests that post-ICU follow-up is a promising strategy to this end, but its proven benefits are still small and thus far mainly related to mental health outcomes (the most commonly studied outcomes to date) [25]. Interestingly, although the severity of patients' disabilities after critical illness is a plausible impediment to attending appointments, most studied post-ICU care models are mainly focused on facility-based follow-up, in which patients have to attend health facilities to benefit from rehabilitation programs. In one recent systematic review and meta-analysis of studies assessing the effects of post-ICU follow-up, only 11% of included studies implemented home-based care interventions [25]. Moreover, a study conducted in a middle-income setting showed that the burden of disability after critical illness was associated with the inability to attend clinic-based follow-up visits [26]. This finding suggests that the facility-based model may deprive the most disabled patients of appropriate care, thereby contributing to health inequalities in the post-ICU care setting. Alternative models, including home-based care, may be of great value to address the needs of this population. Close contact between clinicians and patients and their families and/or caregivers plays an important role in optimizing patient rehabilitation after critical illness and avoiding preventable complications by

providing: (a) patient and caregiver education and guidance; (b) screening for post-ICU disabilities; (c) medication reconciliation; (d) development of personalized treatment and rehabilitation plans; (e) specialized care and social support; and (f) prevention of complications. Contact with the patient's home environment (via telehealth or face-to-face) will provide the clinician with opportunities to assess and address barriers to postdischarge rehabilitation that would otherwise remain undetected. Furthermore, for many patients, home visits help them develop a stronger connection with the clinician, which may promote a greater sense of trust between patients and providers and increase the likelihood of continued communication after discharge. A list of suitable home-care interventions for survivors of critical illness can be found in Table 16.1.

Table 16.1 Suggested home-based care interventions for survivors of critical illness

Intervention	Components
Goals of care discussion	Defining and establishing goals of care with patients and/or their surrogate decision makers to match home-based interventions with patient values and preferences.
Screening for disabilities	Physical disabilities: reduced physical functional status and/or ability to perform activities of daily living, muscle weakness, joint contracture, dysphagia, malnutrition, and compromised lung function. Cognitive disabilities: deficits in memory, attention, mental processing speed, and problem solving. Mental health disabilities (for both patient and family member): symptoms of anxiety, depression, and post-traumatic stress disorder.
Review and adjustment of long-term medications	Assessment of long-term medications to (1) discontinue treatments without ongoing indication or (2) adjust doses as needed based on body mass, renal, hepatic or cardiac function changes after critical illness.
Specialty referrals	Early referral to subspecialist follow-up based on screened disabilities (i.e., referral of a patient with dysphagia for speech therapy evaluation).
Individualized rehabilitation plan	Creation, maintenance or modification of a rehabilitation plan based on screened disabilities and patient and family needs.
Environment assessment and modification	Adapt or modify the home environment to facilitate physical rehabilitation and prevent falls.
Anticipatory guidance: "red flags"	Educate patients and family members regarding signs and symptoms that may indicate worsening condition and need for additional evaluation.
Education and engagement	Educate and engage patients and family members regarding post-ICU recovery, addressing concerns and values.
Preventative care	Prevention of infections (i.e., vaccination, family and patient education on risk factors), prevention of decompensation of chronic diseases (i.e., heart failure, renal failure or chronic obstructive pulmonary disease).
Palliative care	Introduce and offer palliative care (alone or combined with curative and/or rehabilitation interventions) to improve symptoms and quality of life.

The Brazilian Model of Home-Based Care

From a global perspective, home health care programs around the world share some similarities [27]. Except in the United States, these programs are typically publicly funded, comprehensive (offering postacute, supportive, and end-of-life home care in one program), and use need-based rather than income-based or risk-based eligibility criteria.

In Brazil, the “Better at Home Program” is a public home-based care program provided through the Brazilian Unified Health Care System that aims to: (1) promote the dehospitalization of stable patients, who may have their health care continued at home and whose level of care complexity is greater than that primary care is able to offer; (2) avoid hospitalization of patients referred from primary or emergency care settings; and (3) avoid hospital readmissions [28]. The program serves patients classified as levels AD2 and AD3 of care, according to the Home Care Ordinance of the Brazilian Ministry of Health (Table 16.2).

The “Better at Home Program” is suitable for people who have temporary or permanent difficulty leaving home in order to reach a health care facility, and for people who are in situations where home care is the most appropriate form of care for their needs. Home care aims to provide patients with care while keeping them close to their families, thus avoiding unnecessary hospitalizations and reducing the risk of infections while maintaining patients in contact with their loved ones in the comfort of their homes. Patients who need weekly or more frequent visits may be followed up by specific home care teams. Services are provided by multidisciplinary

Table 16.2 Eligibility criteria for the Better at Home Program based on the Brazilian home care classification criteria

AD2 criteria	AD3 criteria
Demand for more complex procedures that can be performed at home, such as: Complex dressing and abscess drainage, among others; Dependence on frequent monitoring of vital signs / unstable conditions; Frequent and systematic need for less complex laboratory tests; Patient and/or caregiver adaptation to the use of the tracheostomy device; Patient adaptation to the use of orthoses/prostheses; Patient adaptation to the use of probes and ostomy bags; Postoperative home follow-up, as indicated by the surgical team; Rehabilitation of people with permanent or transient disabilities who need frequent care until they are able to attend rehabilitation services; Use of airway aspirator for bronchial hygiene; Need for permanent or transient nutritional attention; Frequent care in terminally ill patients/pain relief measures; Need for intravenous or subcutaneous medication.	Existence of at least one of the situations accepted as inclusion criteria for care in AD2 modality and the need to use at least one of the following devices / procedures: Invasive or noninvasive ventilatory support (continuous positive airway pressure [CPAP] or bilevel positive airway pressure [BIPAP]); Peritoneal dialysis; Paracentesis; Use of total parenteral nutrition.

teams consisting primarily of physicians, nurses, nurse technicians, physical therapists, and social workers. Other support personnel may also be included in the teams as necessary, such as speech therapists, dietitians, dentists, psychologists, occupational therapists, and pharmacists. Each team can follow, on average, 60 patients simultaneously. Home care teams are hired by state or city governments. The Unified Health Care System organizes the services for care delivery from Monday through Friday, with teams working 12 (twelve) hours per day, and ensures health care delivery on weekends and holidays by on-call teams.

Conclusion

Survivors of critical illness may benefit from home-based care interventions, since the post-ICU period is often marked by disabilities that are long-lasting and associated with poor quality of life. Home-based interventions may improve the outcomes of critical illness survivors by improving their access to support and rehabilitation services. Additionally, home-based care interventions may improve patient and family caregiver outcomes by improving engagement, social and psychological support, and education.

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