Home Based Critical Care and Quality of Life Outcomes: A Review of Literature

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Abstract: For a long time, home based care in India, was an unorganized and fragmented sector but with the advent of higher centers of healthcare providers and entry of skilled providers, this field is on its way towards an organized, technology-led industry with standards and protocols. Advances in medical monitoring enables many types of patients – including the critical patients - those needing specialized care but not necessarily dependent on life support, to be monitored remotely and provided care at home. With the ever increasing burden on available facilities, it is pertinent that home based care would soon become an extended arm of the healthcare centers to help reducelength of stay, reduce hospital acquired infections (HAI) and allow for a more judicious use of ICU admissions to the very deserving and needy. Home based critical care has been shown not only to support outcomes similar to that of a health center, but also to provide an improved quality of life for the patients. In this review, we look at the available literature across the globe to support the improved quality of life provided by home based care programs.

Keywords: Home Care, Critical Care at Home, Quality of life, ICU at home.

1. Background

Home based care is anorganization of out-of-hospital structured care, provided by skilled resources to patients, in their homes under the direction of a physician. Services provided in home based care generally include skilled nursing care; physical, occupational, and speech-language therapy; and psycho-behavioral counseling.¹Additionally, intensive care services at home are also possible – especially for patients no longer in the acute phase of their illness, but are not fully ready for an ICU discharge.²Home based care services aim to support families and an individual, to improve functioning and live with better independence; to encourage the patient's optimal levels of well-being; and to assist the patient to remain and recover at home, thus potentially evading hospitalization or admission to long-term care institutions.³

The World Health Organization (WHO-2001) has defined home based care as "the provision of health services by formal and informal care givers in the patient's home in order to promote, restore and maintain a person's maximum level of comfort, function and health, including care, towards a dignified death". An asset of this attitude is the dignity and privacy it provides to the patient and their families, to be cared for in the comfort of the patient's home.⁴

In India, estimates propose an approximate figure of around 70,000 ICU beds – encompassing across all types of hospitals and private nursing homes. These facilities cater to over five million patients requiring ICU admission every year – thus leading to a critical scenario of having a single ICU bed catering to approximate 70 eligible patients.⁵Home based services that offer structured and skilled intensive care at home can help reduce this burden and extend quality care at the home.

Rationale for Home based care

Studies carrying out bed audits at a large number of critical care hospitals across UK to identify patients who can be treated in alternative settings, find that up to 50% of bed days in these wards could theoretically take place in other settings. Of these 50% patients, around 80% of bed days are for patients who could, in principle, be treated more appropriately in other services such as intermediate care, rehabilitation and reablement, district nursing, social care or mental health (See fig 1).⁶



Figure 1: Appropriateness evaluation protocol study: alternative care locations for patients who could be treated out of hospital. (Adapted from Ref 6)

Increased stay at the critical care units has been shown to expose patients to potential avoidable harm. HAI (Hospital-acquired infections) continue to be a well-accepted risk, with a survey pointing out 6.4% patients contracting HAIs during the stay.⁷This figure can be higher in a country like ours where there could be scarcity of resource and high incidence of drug resistant nosocomial infections.

The risk of hospital-acquired infections is higher for pediatric and older patients.⁷ Immobility can also lead to

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particular problems for older patients and they may be able to maintain greater mobility in community-based settings.⁷ A study of healthy older adults found that 10 days of bed rest led to a 14% reduction in leg and hip muscle strength and a 12% reduction in aerobic capacity: the equivalent of 10 years of life.⁸

Impaired Quality of life post critical illness

Once the patient endures the phase of critical illness, they may experience numerous complications succeeding Intensive Care Unit (ICU) discharge. These residual problems can manifest as weakness, fatigue, breathlessness, anxiety,⁹ depression,¹⁰ posttraumatic reactions,¹¹ and reduced cognitive function which collectively limits activities of daily living and subsequently leads to physical deconditioning.¹²

There is growing evidence that ICU survivors experience long-term physical, neurocognitive, and mental health complications directly associated with their experience during ICU stay. This broad spectrum of complications can altogether affect the physical, mental, and social wellbeing of the patient thereby affecting their quality of life (QoL).¹²

Health-related quality of life (HRQoL) is made up of physical, psychological, and social domains which interact with each other and patient's perception. A majority of studies that evaluate the quality of life as an outcome parameter use the Short form 36 (SF-36) as most widely used scale to assess the QoL in critically ill patients.¹³ As the aftermath of critical illness, complications continues even at home, the quality of life may be compromised.¹²

Benefits of Home based care

There are multiple studies that show the evidence that a well delivered out of hospital care can benefit patients. Interventions for older people have been shown to reduce the falls at home and the number of hospital admissions.¹⁴ Early discharge for stroke patients supported by home based care, has been shown to increase likelihood of survival and reduce rates of illness.¹⁵

Other studies show a reduced rate of inpatient readmissions, such as patients with chronic obstructive pulmonary disease (COPD), receiving home care, had a substantial reduction in readmissions.¹⁶ Geriatric assessment and multidisciplinary intervention for older patients after discharge demonstrated lower rates of 30-day admission and 18-month emergency admissions, and patients who were functioning better both physically and mentally.¹⁷ Studies of early supported discharge and rehabilitation and reablement services have

demonstrated a reduction in the ongoing social care needs of those patients. $^{\rm 18-20}$

Assessing Quality of life with Home based care

Across studies evaluating the patient feedback on their level of care and overall quality of life, patients themselves rate a higher satisfaction when treated in community-based settings.^{19,21-24}

Community-based treatment can provide or support some of the key things that older people report as important to them: such as being in their own home; remaining socially engaged and contributing to their family or community, including being caregivers; having independence, dignity and choice; not being a burden; and continuing with activities that give their life meaning.²⁵Studies have also found improvement in quality of life measures and depression for patients treated at home.^{16,26}

Many studies found that patients treated at home had the same clinical outcomes as patients treated in inpatient hospital care. For example:

- In a review of five studies (n=844) that focused on services towards avoiding hospital admission through home care, the mortality rates at six months showed a significant improvement. Readmissions to hospital were not statistically significant and the overall functioning of the patients and quality of life were similar for comparative groups.²¹
- Data from 13 (n=1899)of early discharge due to availability of home care found insufficient evidence difference in mortality in patients recovering from strokes and older patients with multiple conditions. The evidence for readmissions was seen in these trials.¹⁹
- In a study on patients (n=100) with acute decompensation of chronic heart failure, no significant difference in mortality or subsequent hospital admissions was reported. The study showed that patients who received treatment at home, had a longer average time to first admission and a better quality of life.²⁶
- Another study in patients (n=104) with exacerbations of COPD,did not find any difference in mortality for patients treated at home. On the contrary itshowed an improvement in readmission rates, quality of life and their depressive state.¹⁶

Table 1 represents the key studies of schemes to provide healthcare in home based settings and their reported outcomes on clinical and Quality of life parameters.

No	Author	Publication	Description	included	Patient type	What improved
1	Shely AG et al ²⁷	2017	Randomized controlled trial of 35 patients,	Medical intervention plus individualized home-based exercises	Invasively mechanically ventilated for more than 48 h in medical ICU	Physical and mental QoL components
2	Laver et al ¹⁵		Overview of five systematic reviews and 21 randomized controlled trials. Outcome reported only for relevant services (international)	Early supported	Stroke patients	Satisfaction, Morbidity &Mortality
3	Han SJ	2013	Prospective descriptive study in 100	ADL services by	Home health care	Improved clinical

Table 1: Studies on home based care and their outcomes on clinical and Quality of life parameters

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	et al ²⁸		home health care patients	home care nurses	patients, who started receiving home health care services from a home health care agency in the US	outcomes and QOL after 60 days of home health care
4	Glendinning et al ¹⁸	2010	Study of 1,015 patients (UK)	Reablement	Older patients	Quality of life and social care-related quality of life
5	Shepperd et al ²¹	2009	Review of 26 trials (3,967 patients), of which 13 contributed to individual patient data meta-analysis (1,899 patients) (international)	Early supported discharge; hospital at home	Patients recovering from a stroke and older patients with a mix of conditions	Overall recovery: Move to residential care; Patient satisfaction
6	Shepperd et al ¹⁹	2009	Review of 10 trials (1,327 patients), of which five contributed to individual patient data meta-analysis (844 patients) (international)	acutely ill -avoiding	Patients > 18 years	Mortality at six months, Patient satisfaction
7	Tibaldi et al ²⁶	2009	Randomized controlled trial of 101 patients (Italy)	Hospital at home	Older patients with acute decompensation of chronic heart failure	Time to first readmission; Depression; Nutritional status; Quality-of-life scores
8	Ricauda et al ¹⁶	2008	Randomized, controlled, single- blind trial with 104 patients (Italy)	Hospital at home	Older patients with exacerbations of COPD	Hospital readmissions; Depression; Quality of life
9	Beswick et al ¹⁴	2008	Review of 89 trials including 97,984 people (international)	Home based care for preservation of physical function and independence	Older people	Readmissions risk, Falls, Physical function and QoL
10	Leff et al ²²	2005	Study of 455 community-dwelling older patients who required admission to an acute care hospital (USA)	Hospital at Home	Older critically ill	Fewer complications, QoL and satisfaction
11	Caplan et al ¹⁷	2004	Study of 739 patients (Australia)	Comprehensive geriatric assessment and multidisciplinary intervention after discharge	Older people	30-day admissions; 18-month emergency admissions; Time to first emergency admission; Physical and mental functions

Along with the success stories, there are some examples of failures of Home based care as well. In a published case study of operational failures in home based care, the author points out that the biggest areas of opportunity are failures that stem from 29 –

- a) Insufficient support from home health agencies and
- b) Inadequate coordination with patients and their families.

Organizations providing home care should therefore learn from employees' experiences with operational failures and take immediate protocol based steps to overcome the hurdles that include time management, right communication regarding visits, accurate handover to relievers etc.²⁹

Structured home care programs in India

Although home-based health care is in a nascent stage in India, the concept and service is quickly gaining traction. For a long time, home based care was an unorganized and fragmented sector but with the advent of higher centers of healthcare providers and entry of skilled providers, the field is on its way towards an organized, technology-led industry with standards and protocols. Advances in medical monitoring enables many types of patients – including the critical patients - those needing specialized care but not

necessarily dependent on life support, to be monitored remotely and provided care at home.

There are currently no studies on patients receiving home based critical care in India and therefore their role in current healthcare cannot be commented upon. On the other hand, an overview of a structured home based care program, provided by a private care provider, for 235 critically ill patients between 2015-2017 shows some promise. These patients had an ICU admission and the availability of home care allowed the care centers to offer early discharge under e-monitoring by the intensivist. On an average these patients received appropriate care that allowed for weaning from ventilators, removal of tracheostomy tube, improvement in GCS score and removal of central line - while receiving structured intensive care, at home. These improvements led to an improvement of the overall quality of life of the patients and caregiver satisfaction. Only a small percentage of patients required re-hospitalization while all deaths under care occurred at home -as wished by caregivers.

Fig 2 shows average improvements and death/hospitalization results noted across the selected populationreceiving critical care at home.

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Figure 2: Improvements and death/hospitalization results across 235 critical patients receiving critical care at home. (Data on file)

These data show promise and detailed well-structured studies are required to further elucidate their role in improving health and quality of life of critical patients that can be treated outside the hospital.

Current challenges

Although home based care is gaining traction in India, there are unique challenges for these services specific to our country. Some of these can be outlined as below –

- Lack of specific guidelines and protocols: There are no guidelines on the 3 W's i.e. What should be criteria for transferring a patient to home based care; When should a patient be provided home care option and Who is the right patient for it.
- Although the home based care market is more mature in the west, it is not possible to replicate their processes, as the nature of the Indian market is unique in terms of language barriers, behavioral practice and above all safety of the patient and the care staff.
- *Lack of skilled manpower:* The current Indian educational system does not provide any structured training program for home based health care. This necessitates vocational training for para-medical services by the providers.
- Lack of standardization of care: Home based care is based on the theme of making the patient at the center of care rather than the disease. This, necessitates that the provider structure services around tasks leading to a high dependence on the skill, competency or the general characteristic of the staff. Additionally, different patients may have specific necessities as regard to gender, language or maybe religion of the staff. This makes the task of linking the right staff to the right patient very challenging.
- *Lack of insurance coverage:* Not every patient can afford home based care making it restricted to the affluent class. Lack of insurance coverage for the home healthcare services is a stark cause. As home based care can potentially reduce costs for both the insurance providers and patients, it is pertinent that authorities, insurance players and the home healthcare providers adapt to make home based care affordable.

2. Conclusion

Although efficient hospital and intensive care unit (ICU) throughput depends upon the expeditious admission and discharge of ICU patients, health care systems are facing ethical challenges of caring for complex patients (having multiple morbidities). A large number of patients who are no longer in the acute phase of their illness, but are not fully ready for ICU discharge are candidates for intensive care services at home.

In our review focusing on the quality of life improvements through home based care, the literature summarized in this article suggests that there are generally good or equal outcomes for patients from delivering healthcare in home or community-based settings, yet more evidence is needed. Although there is established improvement in quality of life parameters across the groups of critical care, elderly and bedridden patients, most of the studies and reviews are from the western world and based on small patient cohorts. Publication bias may also have a role to play - as only successful services would have been reported and published; thereby limiting the scopeof available literature.

With home-based health care in its nascent stage in our country, we believe the concept and service will gain traction due to its role in reducing length of stay and subsequently HAI. They would also allow to free ICU beds for the larger population in need. It is thus imperative to consider structured home care programs for eligible patients and their role in reducing the burden on healthcare along with extensive original and systematic reviews on their benefits. With a sizable population in India that needs and is willing to pay for these services, Home health can support the hospital systems by reducing the average length of stay and enabling quicker turnover of patients. As these services expand, there is currently a need for structured training of resources and a clear, evidence-based treatment protocols that cover the range of protocols delivered by the care team.

3. Disclosures

Dr Gaurav Thukral works with Health Care At Home – a private home based health care provider.

Dr Samit Bisen works with McCann Health who are communication partners with Health Care at Home and supports with manuscript preparation

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