

1. REVIEW OF LITERATURE

Coulter A and Cleary PD. (2001) carried out patient surveys in Germany, Sweden, Switzerland, the United Kingdom, and the United States in 1998–2000 revealed high rates of problems during inpatient hospital stays. Problems with information and education, coordination of care, respect for patients' preferences, emotional support, physical comfort, involvement of family and friends, and continuity and transition were prevalent in all five countries. These dimensions of patients' experience appear to be salient and relevant in each of the five countries.

Thi PL et al (2002), has viewed that longer the length of stay of the patient, the lower the satisfaction on specific domains such as comfort, visiting, and cleanliness, which seemed logical, as in other studies. In addition, we found that patients who already had had a previous hospital admission tended to be more demanding or critical and have lower satisfaction level on relevant areas such as information or human care, comfort, or cleanliness.

A voluntary initiative sponsored by the California Healthcare Foundation, called the PEP-C project (for Patients' Evaluation of Performance), the 2003 Technical Report has results from surveys nationwide, where hospitals are doing best on physical comfort, involving family and friends, and coordination of care. They are doing worst on emotional support, transition to home, and providing information and education. The score on respecting patient preferences is 74 per cent. Clearly, there is considerable room for improvement on all these patient-centred dimensions of quality (Stichler JF, Weiss ME. 2000).

W. Qureshi, et al. (2009) conducted a study in a hospital in Kashmir and they found that there is lack of communication between the doctor and the patients. Patients' satisfaction of the admission and registration procedures, poor services in the wards, poor sanitation and hospital cleanliness, no quality nursing care, poor quality of laboratory work and giving patient hearing to complaints and suggestions for implementation in the hospital are all factors that affect patient satisfaction.

The need for customized services is there in India. Affluent and educated Patients who are admitted in the hospitals expect doctors to fully explain the disease, cost and treatment plan, before hospitalization. Attitude & behaviour of nurses and paramedical staff towards patients and attendants needs to be improved. For a healthcare organization to maintain and improve its

standards, constant monitoring of perceptions and expectations of the patients and their attendants is essential (Arpita Bhattacharya, PremaMenon, VipinKoushal, K.L.N. Rao. 2003).

Biggest Concerns for Patients with Serious Illness

%Biggest/ One of Biggest Concerns

Doctors might not provide all of the treatment options or choices available	58%
Doctors might not talk and share information with each other	55%
Doctors might not choose the best treatment option for a seriously ill patient's medical condition	54%
Patients with serious illness and their families leave a doctor's office or hospital feeling unsure about what they are supposed to do when they get Home	51%
Patients with serious illness and their families do not have enough control over their treatment options	51%
Doctors do not spend enough time talking with and listening to patients and their families	50%

Shepperd S, Iliffe S. (2002), states that Service quality deficiencies are common among medical inpatients, and are strongly associated with patients' dissatisfaction with the hospitalization. Compared to hospital care, HCS increase patient satisfaction but the data do not indicate which aspects of home care services particularly affect satisfaction.

Ratner, E. (1999) opines that all patients, regardless of age, prefer to be cared for in their own home. Every article about quality of care problems in hospitals, nursing homes and assisted living facilities strengthens the evidence for this preference. Following the dimensions of care outlined in the Picker/Commonwealth Program for Patient-Centered Care, home care calls:

1. respect customers' values, preferences and expressed needs;
2. support coordination and integration of care;
3. facilitate information, communication and education;
4. support physical comfort;
5. provide emotional support and alleviation of fear and anxiety;
6. support involvement of family and friends; and
7. Facilitate transition and continuity is usually followed.

Therefore, Home Care Service increases satisfaction as compared to hospital care.

Richards DA, et al. (2005) and Montalto M., (2002) viewed that there is growing evidence to show the effectiveness of a model of hospital in the home in which Australia and New Zealand are leading the world by providing services of sufficient scale to offer a real alternative to inpatient care. Providing acute hospital-level care in a patient's 'home is an alternative to hospital care

Kokotis K. (2005) also points out that the presence of HCS programmes facilitates early discharge and improves the quality of care received by patients receiving care at home, particularly where technical interventions such as home infusions are involved.

Antoniskis A. (1978) and Larkins R. (1995) said, the adverse events which have commonly occurred in a hospital are reduced through HCS. Older patients in particular had more to gain from HCS because hospital-related adverse events are more common in older patients. In addition, it seemed logical that replacing care in hospital with care at home must also be cheaper

and more effective as the HCS model enabled the re-allocation of beds to deal with wait times, and the provision of appropriate care, while reducing iatrogenic complications.

Shepperd S, Iliffe S. (2002) pointed out that, in comparison to hospital care, caregivers for terminally ill patients reported greater satisfaction with home care services; however, lower morale was experienced if the patient survived more than 30 days.

Rebecca Askew et al. (2003) viewed that there are ten most common client satisfaction issues for home health agencies such as: handling requests to change caregivers, informing family about treatment, involving family in care planning, nurse's concern for patient, aide's concern for patient, contacting patient when caregiver will be absent or late, teaching patients self-care, technical skills of nurse, effectiveness of initial plan of care in meeting needs, helpfulness of person making initial arrangements for service.

Maxwell RJ. (1995) argued that the critics of HCS programmes have said that HCS offered inferior care at greater cost. However, the growing evidence base has provided data suggesting that HCS may be a true advance on in-hospital treatment, offering reduced complications, better health outcomes and greater patient satisfaction.

Perez-Lopez J. (2008) and Ingram P. (2008) in their study have pointed out that the HCS safety literature focuses predominantly on the physical safety of patients in the HCS setting. They opined that HCS schemes across studies deliver care as effectively as hospital, rarely with clinically important differences in health outcomes achieved.

Liu A. (2002) said adverse event rates are similar between patients who receive HCS care versus inpatient care. An adverse event rate of 1.7 events per 100 HCS admissions has been observed in one study, where the adverse events were directly attributable to HCS management. However Mahomed N. (2008) has also pointed that equivalent complication rates (e.g. hip dislocation, deep vein thrombosis and infection) for HCS care compared with inpatient care have generally been observed across studies (Liu A. 2002; Perez-Lopez J. 2008; Ingram P. 2008).

Loeb M. (2006) has stated that the treatment of medical conditions commonly managed in HCS can be improved by the use of clinical protocols, and can result in comparable clinical outcomes to inpatient care, reduce hospitalizations, bring in safety and decrease healthcare costs.

Monalto M.(2000) opined that medical cover in HCS should be co-ordinated, hospital-linked, supported by a regular visiting schedule and be readily available, and home-based acute nursing staff should give timely and accessible medical support if care provided is to meet minimum standards of safety and quality.

Nanako T et al (2002) opined that family caregiver factor is very important in diverse cultures. Understanding the home care services needs across diverse populations with different cultures in India is a challenge. Canadian policy makers have undertaken cross-cultural analyses and found out that caregiver factors are not considered under the new Japanese insurance system, the new system may not meet the needs of patients, such as elderly people who have low care needs, but whose caregivers require additional support.

Brennan T. (2004) has opined that countries all over the world are facing an increasing demand for home care services. The acute care of patients at home is one of the fastest-growing healthcare sectors internationally and is gaining acceptance in many countries.

S.K. Inouye et al. (1999) and E.H. Bradley et al. (2006) in their studies have pointed out that a related program, the Hospital Elder Life Program (HELP), which provides a nursing-centred interdisciplinary team approach applying standard protocols to prevent delirium and functional decline, has been adopted in more than sixty U.S. hospitals and in ten hospitals in Britain, Canada, and Australia.

M. Mezey et al. (2004) viewed that the Hospital-based nursing programmes such as Nurses Improving Care for Health system Elders (NICHE) is a comprehensive programme used by hospitals to foster system wide improvements in the care of older people, have been adopted in more than 100 U.S. hospitals.

Palmer,R.M et al. (1994) observed that ACE is designed to foster the independent function of patients. It is a multifaceted intervention that integrates geriatric assessment into the optimal medical and nursing care of patients in an interdisciplinary environment. It includes a patient friendly environment, multidisciplinary assessment, medical care review, pharmacological review and early discharge planning. Under ACE, the journey for patients is improved by focusing on four key principles: admission under dual specialty, comprehensive holistic geriatric

assessment beyond the presenting illness, optimises care by focusing on promoting independence and function, early discharge planning.

I.J. Higginson et al. (2003) and R.S. Morrison et al. (2008) viewed that Palliative care programmes have been developed that employ an interdisciplinary approach to symptom management and focus on establishing goals of care, supporting patients and caregivers, and improving continuity; these programmes are reported to improve symptoms and reduce inpatient costs.

Anthony F. Jerant, Rahman S. Azari, Thomas S. Nesbitt, Frederick J. Meyers. (2004), advocated a new model called as TLC model of palliative care for older patients. In this model, palliative care is defined as care aimed at improving the quality of life of persons nearing (but not necessarily at) the end of life and facilitating the transitions before death. This increasingly endorsed definition, which contrasts with common usage of the term palliative care as a synonym for terminal care, does not simply arbitrarily extend the period before anticipated death. Rather, it acknowledges the prolonged process of nearing death faced by many older patients who have chronic illnesses and accounts for the wide variation in the point in time at which patients, families, and physicians perceive that death is approaching.

Below is a survey conducted on how important people think palliative care is:

	<u>Democrats</u>	<u>Independents</u>	<u>Republicans</u>	<u>Tea Party Supporters</u>
Very important	78%	63%	55%	64%
Somewhat important	18%	23%	34%	27%
Not too/ Not at all important	1%	10%	9%	8%

What do patients believe to be true about palliative care?

Statements Tested	Strongly Agree	Total Agree
It is important that patients with serious illness and their families be educated about palliative care options available to them together with curative treatment.	78%	95%
Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.	73%	94%
Discussions about palliative care treatment options with a doctor should be fully covered by health insurance.	71%	86%
Discussions about palliative care treatment options with a doctor should be fully covered by Medicare.	60%	80%

Coleman EA, Min S, Chomiak A, Kramer AM. (2004), views that from that time patient is scheduled to be discharged from the hospital, the Care Transitions Model helps older patients at high risk for complications or rehospitalisation. The Transition Coach, a specially trained nurse, visits with the patient and their caregivers over four weeks both in the hospital and at home and helps patients learn to manage multiple prescriptions, follow post-hospital recommendations, and present their other healthcare providers with the information they need to be effective. Over 100 hospitals and healthcare systems had adopted the model by 2007.

Fretwell MD. (1990) opined that the ageing of the population results in an increasing number of frail elderly being admitted to acute hospitals for medical and surgical treatment, but shorter length of stay means that they more frequently require post-acute care for rehabilitation or restoration of function. It is recognised that many of these frail older patients do not do well in hospital, which has led to many studies comparing at home with in-hospital post-acute care.

Cheng J. (2009) is of the opinion that improvements in technology and their greater acceptability have narrowed the gap between care in the hospital and care in the home. More patients with more diagnoses are receiving a greater diversity of hospital-type treatments at home than ever.

There is a growing body of evidence assessing the effectiveness and cost-effectiveness of HCS programmes.

Chiu L., Tang KY., et al. (2000) said, to be cost-effective, home care services should target patients with medium physical disability, and nursing home care services should focus on patients with high levels of dependence.

Shakti Gupta et. al. (2004) opined that India being a Middle Income country as categorized by WHO there was no long term care administered to its citizens. The emphasis of care is shifting from inpatient to day care. The healthcare facilities must plan for: Day-care Facilities, Home care Facilities and Trans mural care i.e. patient tailored care provided on basis of close collaboration and joint responsibilities between hospital and home care services personnel.

FrenyManecksha (2010) points out that Kerala's community led initiative aiming to provide home-based palliative care has grown into a genuine people's movement and is hailed as a model that can be replicated in other states. Neighbourhood Network of Palliative Care (NNPC) was formed in 2001. Trained volunteers help, not just in caring for some 2500 patients each week, but also in providing the hugely-needed emotional support. Sometimes they raise funds within the community to assist the patient like buying a water bed which can help prevent bed sores. The massive involvement of the local community that has made this Palliative care programme such a success and has enabled it to be cited by the WHO as a model for developing nations. Kerala is the only state where the National Rural Health Mission has taken up palliative care and appointed the Institute as the nodal agency where doctors, nurses, community nurses and volunteers are trained.

A report, jointly prepared by the World Health Organization and the World Economic Forum (2008), says India will incur an accumulated loss of \$236.6 billion by 2015 on account of unhealthy lifestyles and non-accessibility to adequate and proper medical screening and care. The resultant chronic diseases - heart disease, stroke, cancer, diabetes and respiratory infections - which are ailments of long duration and slow progression, will severely affect people's earnings. The income loss to Indians because of these diseases, which was \$8.7 billion in 2005, is projected to rise to \$54 billion in 2015. The burden of population ageing also is posing a challenge which cannot be ignored.

Patients Awareness About Palliative Care

How knowledgeable, if at all, are you about palliative care?



*Data from a Public Opinion Strategies national survey of 800 adults age 18+ conducted June 5-8, 2011.