

Long Term Care: An Egyptian Perspective

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The term "Long term care" refers to a variety of services that includes medical and non-medical care to people who have a chronic illness or disability. It can be provided both at home or within the community as well as in a variety of facilities adjusted to meet the different needs of the elderly. It may be carried out both informally by family, friends and volunteers, and formally by health care professionals. It may also be in the form of services provided to the elderly such as meals and transportation services.

Background

Traditionally speaking, it has been the responsibility of the family to care for their elderly including those who need special care or assistance in activities of daily living. Only the poor who lacked family were forced to confine to what was then called "almshouses". But with the demographic shift and increased urbanization, more and more elderly were left uncared for in the absence of the traditional extended families. Some of the first nursing homes were established by women's groups for the disabled elderly who belonged to their own social classes and religious groups yet the poor were still left to almshouses in which their percentage started to increase with the rising attention to other groups such as children and the mentally ill and younger infirm patients. Today's long term care facilities come as a result of continuous recognition of the needs of the elderly who can't live on their own and who may lack social support, and the ongoing development of these institutions and the regulations that ensure their provision of standard care to this needy age group. The first homes of the aged in Egypt were established in the last decade of the nineteenth century by expatriate communities and were intended mainly to serve older members of these communities who had no relatives to provide care.

The first homes for Egyptians were initiated by local Christian and Jewish communities during the 1930s. The first Muslim home

was established in the following decade. The establishment of the first ministry of Social Affairs in 1939 represented a milestone in social work. Due to the traditional system of family support which is still the case, the number of new foundations remained limited. According to a report from Cairo Demographic center, most of the elderly people (66.8%) live with sons and daughters and (13%) live with spouse and 9.1% live with relatives other than fore mentioned and the same percentage live alone due to different reasons. However, social changes e.g. rural-urban migration with older people behind left Egyptian women increasingly being employed outside home, changing in housing stock (nuclear instead of extended family) and decreasing family size with fewer people in the young generation available to take care of larger numbers of people in the older generation. All these factors caused changes in living arrangements resulting in increasing number of older people living alone especially females. This has created some demands for extra familial services raising the needs for institutions for the aged.

At the end of the 1970s, 28 homes for the aged were registered with Ministry of Social Affairs. The number has quadrupled since 1978. Yet the registry at the Ministry fails to include nursing homes that are run by mosques and churches and other charity organizations. The precise number of care facilities for older persons remains unknown [1]. The official policy has encouraged and supported social work through numerous

associations. One of those is the General Association for the Care of the Aged established in 1981 to offer social, cultural and religious services to the aged with branches in different governorates. The association has given the priority to two services: setting up homes and clubs for the aged and training staff for this purpose.

Mission of Long term Care Services

The philosophy behind long term care is care oriented rather than management oriented. Long-term care is primarily concerned with maintaining or improving the ability of elderly people with disabilities to function as independently as possible for as long as possible. Long-term care also encompasses social and environmental needs and is therefore broader than the medical model that dominates acute care. It is primarily low-tech, although it has become more complicated as elderly persons with complex medical needs are discharged to, or remain in, traditional long-term care settings, including their own homes.

Types of Provided Care

Elderly needs differ greatly according to their medical, social and care needs. Thus long term care has developed substantially to meet those different needs putting costs as well into consideration. The most popular long term care institutions are group homes, assisted living facilities and skilled nursing facilities, better known as nursing homes, all of which meet different needs of an increasingly diverse population. Group homes are facilities that offer personalized service to small groups of adults. These residential homes provide lodging, meal services and assistance with daily living activities. They offer a smaller, more home-like family setting for seniors. They do not typically have a medical professional on-site. Limited, part-time medical care is offered, but it's not a primary focus of this

type of senior living community. They are designed to meet social needs rather than medical or care needs. A typical assisted living facility resident would usually be an elderly person who does not need the level of care offered by a nursing home but prefers more companionship and needs some assistance in day-to-day living. Skilled nursing facilities (also known as nursing homes) are designed for those need medical supervision and nursing care as well as extensive help with activities of daily living. All three facilities are available in Egypt; however there is usually a lack of differentiation, and sometimes a lack of specialization by the existing institutions.

Institutional long term care is far from the only form of long term care that can be provided to the elderly. Home care is a rising trend in long term care which is based on the idea that elderly belong at home and should be cared for at home. Home Care, is health care provided in the patient's home by healthcare professionals. It of course provides a much preferred option according to most patients than institutionalization. It offers the advantage of a familiar environment, social support, preserved functionality and avoids many complications of institutionalization. Nowadays, it is possible for patients to receive high-tech including monitoring and mechanical ventilation by specialized medical staff.

Less known forms of care are delivered within the community but are still deficient in Egypt such as adult day care facilities that help families who only need care during working hours and hospice care that specializes in palliative care for the terminally ill.

Nursing Homes

Common risk factors for nursing home placement are lack of social or informal support, immobility, impaired mental status (eg, dementia), incontinence, older age, living alone, inability to care for self, poverty and female sex. The length of stay

depends on the condition and needs of patients. There are the short-term residents who stay for 3 months or less and are usually patients in for rehabilitation and terminal care. Other residents stay for at least one year and the long-term residents stay for around 5 years and are usually dementia patients. Indications for admission include: a need for patient observation, evaluation of treatment plans, and updating of medical orders by the responsible physician; a need for constantly available skilled nursing services such as for patients with a tracheostomy, indwelling catheter, surgical wounds or pressure ulcers....etc. and patients who have a physical or mental functional limitation [2].

Services Provided at Nursing Homes:

Services provided at nursing homes vary, but the basic services include room and board, personal care, monitoring of medication, social and recreational activities and 24 hour emergency care. Additional services include rehabilitation, short term post-acute care, terminal care and respite care.

Recommended Design for Nursing Home

The ideal nursing home starts with its architecture. It should give spaces a homelike, rather than institutional, size and scale with natural light and views of the outdoors and create a warm reassuring environment by using a variety of familiar, non-reflective finishes and cheerful, varied colors and textures, keeping in mind that some colors are inappropriate and can disorient or agitate impaired residents. It should also provide each resident a variety of spatial experiences, including access to a garden and the outdoors in general and promote traditional residential qualities of privacy, choice, control, and personalization of one's immediate surroundings. Disorientation is a major problem in elderly patients so design should have clocks, calendars, and other "reminders" at hand. It

should also encourage resident autonomy by making their spaces easy to find, identify, and use.

Higher lighting levels are vital for residential occupancies to avoid falls. The nursing home design should promote staff efficiency by minimizing distance of necessary travel between frequently used spaces and allow easy visual supervision of patients by minimal staff as well as make efficient use of space by locating support spaces so they may be shared by adjacent functional areas, and by making prudent use of multi- purpose spaces. A consistent and well thought out system of way-finding, helps to maintain the residents' dignity and avoid their disorientation. It should use multiple cues from building elements, colors, texture, pattern, and artwork, as well as signage, to help residents understand where they are, what their destination is, and how to get there and back. There should be architectural features and landmarks which can be seen from a distance, as well as symbols, signage, art, and elements such as fish tanks, birdcages, or greenery to help elderly find their way and to avoid prominent locations and high visibility of doors to spaces which patients should not enter.

Many residents may be ambulatory to varying degrees, but will require the assistance of canes, crutches, walkers, or wheelchairs. To accommodate these residents, all spaces used by them, both inside and out, should be designed so that all spaces, furnishings, and equipment, including storage units and operable windows, are easily usable by residents in wheelchairs. It must be equipped with grab bars in all appropriate locations and must be free of tripping hazards. Ideally, it should be located on one floor if feasible, preferably at grade. If residents' bedrooms must be located on more than one floor, then dining space must be apportioned among those floors, not centralized [3].

Required staffing for Nursing Homes:

Ideally a nursing home should have a staff composed of a licensed charge nurse on site 24 h/day, certified nurse assistants, a full-time social worker if the facility has more than 120 beds, a medical director (clinical, education, quality of care), a qualified recreational therapist to provide recreational programs, a rehabilitative therapist and a dietitian. Physicians, pharmacists, dentists, and pastoral services to be available as needed, but not required on site. The positive relationship between nurse staffing levels and the quality of nursing home care has been demonstrated widely and different research groups have used different methodologies but few spell out specifically different quantitative conclusions [4]. Regulations differ, however, in the U.S, according to the federal Nursing Home Reform Act (NHRA), as part of the Omnibus Budget Reconciliation Act (OBRA) it is required that there be registered nurses (RNs) and licensed practical nurses (LPNs), and a minimum educational training for nurse's aides (NAs). The NHRA requires Medicare and Medicaid certified nursing homes to have: an RN director of nursing (DON); an RN on duty at least 8 hours a day, 7 days a week; a licensed nurse (RN or LPN) on duty the rest of the time; and a minimum of 75 hours of training for nurse's aides. The law allows the DONs to also serve in the capacity as the RN on duty in facilities with less than 60 residents [5]. According to UK guidelines in 2009 by the Regulation and Quality Improvement Authority, The following framework is a guide to determining reasonable and practical ratios of staff to patients in nursing homes in the first instance:

8.00 am - 2.00 pm ratio of 1:5

2.00 pm – 8.00pm ratio of 1:6

8.00 pm - 8.00 am ratio of 1:10

Within this ratio framework there is a minimum requirement for a skill mix of

35% registered nurses to 65% care assistants over the 24 hour period [6].

The typical nursing home physician is a primary care internist or family physician who devotes 2 hours per week to nursing home care. Physician role in the nursing is admission and follow up. Admission procedures should include a comprehensive geriatric assessment, labs as needed, review of medications and correlation with diagnosis, review of old records, assessment for presence of pain and establishing advance directives. Formulation of a problem list should be done based upon individual goals in addition to medical condition. For example a patient in for rehabilitation following a fracture or a short term post-acute care patient will have different goals than a patient with advanced dementia or a patient with terminal illness. Whereas the former need a more management oriented care, the latter may need palliative care focused on comfort. Establishment of good relationships with residents and their families as well as staff is vital to the success of the care oriented philosophy of long term care. Follow up should include checking vital signs, weight, labs and consultant reports since last visit and a review of medications in light of problem list and care plan and review of medications. Nursing and caregivers are a vital source of information to the physician and addressing their concerns is vital. As opposed to acute care, where the patient-doctor encounter may be short, long term care is a long and challenging road that requires utmost social skills and compassion on the part of the physician.

One of the major problems we face in Egypt is the lack of geriatric training for staff members and lack of awareness of nursing home “culture”. In addition most nursing homes are understaffed and maybe defective in some of the necessary skilled staff members such as a dietician and a rehabilitation therapist. There are few regulations to ensure meeting of standards and payment is usually out of pocket which poses a financial burden for families or paid

for by charity both from religious institutions or social non-governmental organizations. There is also much room for improvement of medical care through proper documentation, screening and preventive measures and using guidelines.

Important Problems

Long term care, however are not without their problems. Patient stay may be complicated by a host of different problems some of which are social as isolation, sense of being trapped in a facility with often infrequent visitors. The sense of lost credibility and competency which all may be not lost on the patients even those with dementia and which may all lead to depression. Medical complications include falls, pressure ulcers, infections, polypharmacy and neglect by in an understaffed or unsupervised facility.

Ethical Considerations

Ethical considerations pose a considerable challenge for long term care staff. The most important ethical principles of long term care include: beneficence, non-maleficence, futility of treatment, confidentiality, autonomy and informed consent, physician-patient relationship, truth telling, justice and non-abandonment and recognizing limited resources [7].

Beneficence is doing right by the patient, which implies that the physician's main concern should be the welfare of the patient doing the interventions and treatments that are medically helpful. Maleficence is avoiding harm, which implies that the physician should avoid situations or interventions that are not likely to benefit the patient, but may even harm them. A good example for this is avoiding unnecessary hospitalizations that may lead to complications or a diagnostic work-up if it is unlikely to result in a meaningful survival of the patient. Futility of treatment means that treatment should be consistent with patient's (clinically realistic) goals and

that the physician must assess each case individually so as to determine whether treatment would be beneficial, and avoid interventions that would not benefit the patient and/or prolong suffering. The physician must assume the role as an educator to help clarify issues. Complete and absolute confidentiality is the underlying tenet and physician must comply with local laws regarding disclosure to public health authorities and third parties.

Autonomy and informed consent mean that a patient has the inherent right of self-determination and that a patient has the right to consent and a right to refuse diagnostic work-up or treatment. This includes protection from unwanted touching. A patient has the right to be educated on the pros and cons of a medical decision. Although patient/proxy may request care in excess of what is considered good medicine, individual autonomy should not violate the principle of beneficence and force physicians to go beyond appropriate medical intervention. Autonomy ceases when a patient's request breaks the law or jeopardizes public health or safety (eg, smoking in one's room in a LTC facility). To ensure autonomy a patient has the right and is encouraged to execute an advance directive. The physician's role as an educator is important in this process. To make autonomous decisions, patients must have capacity pertaining to the complexity of the situation. However, the level of capacity may vary as to the complexity of the decision (refusing to be turned in bed may require less mental capacity than deciding on the pros and cons of a complex operation). Surrogate decision making may be used when a patient's wishes are unknown or unclear or the patient lacks capacity. The amount of value placed on the principle of autonomy varies with different cultures. Some cultures may regularly use a surrogate as the decision-maker even if the patient has capacity to decide.

A therapeutic alliance should exist between physician and patient. There should be fidelity, trust, confidentiality, and protection

from intended harm. Physicians have an important role in educating their patients. Physicians also have a duty to tell the truth and be honest versus incomplete statements of encouragement. This should be integrated into good “bedside” manner and patient support. Simple language must be used to avoid obscuring the facts and an honest communication of the estimate of prognosis should be made. Physicians have a duty to uphold the principle of fidelity—not to abandon the patient after establishing a therapeutic relationship. A physician may voluntarily terminate care of a patient after the patient/proxy has been informed and provided with a reasonable amount of time to make other arrangements. The physician may be asked to help with such alternative arrangements when there is conflict between a patient/proxy and physician concerning a course of treatment, guidance may be obtained through an ethics committee, ombudsman, and/or Department of Health.

Justice includes distribution of resources and treatment in an equitable manner and the use of objective decision-making processes, not emotional or subjective ones. Physicians must realize that there are limited health care resources.

The previous ethical consideration have been developed and legalized in Western societies, but many of them may need review in the context of our own culture and laws. Among the more complicated issues is truth telling, should we deny the patient telling him/her about the reality of their medical condition? This issue is more complicated in our eastern paternal culture. Who is the decision maker? In absence of a clear proxy or surrogate which are absent in the Egyptian legal system, sometimes the physician can get caught up in conflicts between patient’s preferences and those of the families or worst yet between different family member’s demands. An easy solution would be to have clearly written advance directives, but is it? How ethical is it in the context of our own culture to state end of life options such as discontinuation of treatment? All the previous questions still

need answers which should be ideally addressed by a multi-disciplinary committee of geriatricians, religious leaders and lawyers.

Conclusion

Various services and facilities have developed over the years to meet the needs of the elderly who are a growing and diverse population. Provision of adequate and competent long term care is not only a moral obligation by society but is dictated by a reality of the aging of the Egyptian population and current demographic changes leaving more and more elderly without the social and financial support, they need to live what is left of their lives in dignity.

References:

- [1] Boggatz, T. (2011) Growing Old in Egypt. American University Press, Cairo.