Editorial Reviews

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A description of new architectural directions in health care program facilities and assisted living residences, identifying the core changes in health care delivery expected in the future and the design needs which those changes will require. The 16 essays written by architects, doctors, and facilities managers target the impacts of healthcare reform, technology, community care in the UK, and the more particular issue of creating buildings which humanely and efficiently accommodate requirements for long term care, senior day care, assisted living, nursing homes, dementia care, and hospice care. The design descriptions and outlines are patient focused, and sometimes involve reusing existing buildings. Includes illustrations and some photographs. Annotation c. by Book News, Inc., Portland, Oregon.

Synopsis
As we approach the 21st century, health care delivery will continue to undergo radical changes. The growth of HMOs and managed care organizations is just one example of how health care planners have shifted strategies. This book, edited by two architects specializing in health care facility design, is intended to help the health care providers of today plan facilities that will be useful and relevant in the future.

Chapter 13

The In-patient Hospice-- Theory and Case Study

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The concept of the 'in-patient hospice' programme is relatively new. The following narrative and description, based upon programming (briefing) discussions held between the Hospice of Lancaster County in the United States and the author in 1993 as part of the design process for the Essa Flory Hospice, outlines a philosophical approach for the design of residential hospice.

Definition

The hospice is a model of care designed to support the physical, psycho-social and spiritual needs of people at the end of life. Its goal is to allow the dying process to unfold with a minimum of discomfort, maintaining dignity and quality of life. Care is provided by family and friends at home or within a nursing home or special hospice care facility. Staff at the hospice, including nurses, social workers, chaplains and volunteers as well as physicians, seek to address the needs of family members in addition to those of the patient.

Hospice care is appropriate when traditional medical care, so often focused on cure and length of life, is no longer the best way to serve the patient's interests. This may be when medical therapies no longer offer a benefit to the patient, or when the benefits are outweighed by their accompanying burdens.

While cancer is the most common diagnosis among hospice patients, increasing numbers of persons with end-stage heart, lung, liver and renal diseases and AIDS, are receiving hospice care. Approximately 210,000 persons at the end of life, together with their families, are estimated to be served annually by some 2,000 hospice programmes in the United States. (*These figures are from the time of publication. In the year 2001 more than 470,000 families were served by 2,277 hospice programmes.*)

Hospice and other health care delivery systems

A hospice is therefore a programme of care and not a building. It is so unique in terms of the health care delivery system it offers that it does not always fit into what already exists in terms of hospitals and nursing homes. Conflict may occur where traditional healthcare programmes take place in the same building as hospice care.

Traditionally healthcare does not respond in the same way as hospice care. For example, if a patient has a symptom problem and is unable to manage at home, the patient will tend to be hospitalized within a system which is primarily focused on diagnostic and life prolonging programmes. The hospice brings a new specialty of palliative care that has different methods of response. It takes a different mindset to allow a condition to take its own natural course. There is therefore an entirely different process within the chronic phase, i.e. within a nursing home, to the terminal phase in a hospice programme.

When a patient chooses to enter a hospice programme the patient elects a form of non-aggressive care and chooses to be kept comfortable within a natural process of decline. In palliative care one is treating the symptom instead of the disease. The disease is progressive and what one focuses upon is how to comfort both the patient and the family, as they cope with increased needs and imminent loss.

The traditional medical model deals with the patient and medical/ physical problem. The patient comes to the medical provider on the medical provider's territory. However the hospice provides care to patients wherever they are to meet their needs. The majority of care is carried out in the patient's own home and therefore the hospice offers care at the patient's invitation.

User profile example

A person may receive treatment for a serious condition which is treated aggressively. The treatment may do little to improve or combat the condition, the disease is progressing. The physician may at this point suggest that this is a potential hospice referral. Although the patient remains conscious, there may be nothing further that can be done as a cure, with recovery no longer an option. Yet the patient may have symptoms, e.g. shortness of breath, and may require assistance. Here the hospice can provide support to the primary care giver. It goes into the home with registered nurses dealing with symptom management and perhaps arranging for a volunteer to come in and help with the shopping or running errands. The role of the social worker

will be vital to work with the primary care provider (family member) during the transition from a curative to a terminal mode.

The setting for this hospice programme would be where that patient and family choose to be, within their own home. However for the patient who may not have family members, or whose family members do not live locally, this can often put a strain on any informal care giving network. In addition, some patients may suffer from difficult or unmanageable symptoms and unresolved pain. Family or friends may also require time for respite and need a place where their loved one can be cared for. The primary care giver may also be elderly, with medical problems of his or her own. The patient may be confined to bed thus placing further burdens on the primary care giver. For these reasons the patient and family need to know which options exist. The provision of an in-patient hospice centre can therefore be a resource and can add to the range of options for a patient's family and friends.

Theory

A comprehensive shift in thinking for both users and and design professionals is crucial for the development of patient focused care centres. A phenomenological design approach lends clues to the possibilities for the form of these environments.

The in-patient hospice concept in its present form is still evolving. As established in 1967 in England by Dame Cicely Saunders and in Connecticut in 1974, it has grown into a worldwide movement providing care for terminally ill people away from hospital. This fundamental premise runs counter to modern western thinking formed over the past two centuries, which views death as a failure and prefers the dying hidden from public view (Bauman, 1992).

Looking back

When we place the hospice movement in the context of other trends over the past 30 years a pattern emerges. The Americans with Disabilities Act (ADA), an extension of the Civil Rights movement and the Advance Directive laws operative in many states in the USA, can together be viewed as an attempt through legislation to transform our view of disabilities and people who have them. Under this legislation all public buildings in the USA must be made accessible and discrimination against a person specifically because of their disability is illegal. If the disabled person has specific rights, what are the rights of the dying?

Birth and Death

During the period since the inception of hospice, the ecology movement which has developed in the United States and Europe revived collective concern for the natural environment and reminded us that humanity is indeed part of the continuum of nature.

Birth and death are a part of the natural cycle of life. In the words of Sandol Stoddard:

> *'having accepted the realities of birth as a natural process to be celebrated and respected we are now bound, I think, to have a clear look at the process of dying'(Stoddard, 1978).*

This quiet revolution has also filtered through to the medical profession where childbirth procedures are becoming more informal and open to a mother's choice. Consequently the design of contemporary maternity wards is becoming increasingly influenced by natural and less medically invasive procedures. Yet an appropriate change in thinking in the form of in-patient hospice may be more difficult to effect because our attitudes toward dying are more deeply entrenched.

The modern view of dying

Although death is inevitable and natural, today we go about our daily lives oblivious to our own mortality (Rinpoche, 1992). the dying are mostly kept from public view in hospitals and nursing homes. BUt this is a relatively recent phenomenon. 'In Medieval times dying persons were seen as prophetic persons, voyagers and pilgrims' (Stoddard,1978). The medieval hospital was a place of respite for these weary travellers. Caring for the dying was a natural part of activities of daily life as caring for the elderly.

The modern rational view places humanity apart from, or above, other creatures and nature itself, displacing religious faiths or beliefs and dismissing as 'primitive' rituals which could not be explained with reason. For a few centuries now death has stopped being the entry into another phase of being which it once was: *'death has been reduced to an exit, pure and simple, a moment of cessation, an end to all purpose and planning'* (Bauman, 1992).

Modern medicine challenges the individual cause of death, if not death itself. Bauman (1992) has commented that to western society

> *'death was an emphatic denial of everything that the brave new world of modernity stood for. . . the moment it ceased to be tame, death has become a guilty secret. . . one does not address death any more as a phenomenon that is natural and necessary.*
>
> *Death is a defeat, a business loss. . .when death arrives it is considered an accident, a sign of impotence or misdemeanor. . .'*

The irony is that, simply put, without death there would be no philosophy, no culture, no religion. The inevitability of dying is the root cause of the need to find meaning in life meaning often found in transcendence of death. The tomb and the monument are powerful architectural topologies because they transcend the limits of a single lifetime.

Great enthusiasm exists for the design of monuments. For example thousands of architects, designers and laymen submitted designs for the Vietnam Veterans' Memorial in Washington DC and subsequently also for the Korean War Memorial. The Albert Memorial in London's Kensington Gardens was a proud testament of 19th century gothic architecture commissioned by Queen Victoria in memory or her dead husband. Yet this energy is devoted to the already dead rather than design for those who are dying.

It may not be coincidental that an extremely small number of designs for terminally ill people are recognized by the architectural community for design quality and contribution to the art of architecture. These projects are generally not considered as desirable or held to the same standards as other more prestigious building types.

Meaning

We have discussed several tendencies and movements coinciding with the hospice movement or in some way reconsidering modern notions. The period since the first hospice has also been a time of re-evaluation of modern architectural theory and the international style marked by Robert Venturi's book *Complexity and Contradiction in Architecture* (Venturi, 1963). The architectural community has in this period seen an extraordinary receptiveness to theory and philosophy. Karsten Harries suggests that this implies that architecture is in a period of uncertainty (Harries,1994). Architects have searched for meaning through semiotics, regionalism, historicism, and deconstructivism, but these ostensibly continue the rationalist basis of modern architecture.

Botond Bognar identifies two prevailing design approaches employed today: each in his view fails to account for the human experience relative to architecture. The first is that: 'productivist rationalism . . . limits architecture to the aspects of how buildings area constructed and how they work'. The second states that 'formalistic rationalism restricts architecture primarily to the aspects of how buildings appear visually' (Bognar, 1989).

The first approach, when paired with those modern attitudes dying people previously discussed, often leads to the following type of thought process in the design of a hospice room:

- start with the number of beds;
- determine the number of beds per room (say 2)
- align beds side by side
- the resultant room size and shape is a simple addition of standard bed dimensions and bed clearances as prescribed by codes and regulations;
- the rooms can then be arranged on two sides of a corridor for efficiency.

This solution is a variation of a typical hospital model. This approach is safer than raising questions about what will be going on in the patient rooms, or what will be necessary for an empathy for the occupants.

The second approach has led to solutions simulating the appearance or image of home. These solutions tend to rely on nostalgic and overly sentimental forms which may in effect appear unauthentic or trite. This approach tends to make us feel better about the prospect of death, without addressing the psycho-social and spiritual needs of the patient.

Embarrassment

There is often a peculiar embarrassment felt by the living in the presence of dying people. The range of words available for use in this situation is relatively narrow. Our verbal ineptitude with regard to dying is paralleled by our architectural ineptitude and embarrassment when designing places for people who are dying.

An example of this can be found in some in-patient hospice where visitors enter the vicinity through a carefully planned canopy or porte cochere, yet the patients are brought in via the service entrance. The deceased leave spectacularly ungraciously via the service doors which in some cases are near the refuse bins.

It has to be emphasized that the administration and care staff of all facilities are caring and dedicated and are generally years ahead of the design

community in terms of understanding the issues. Yet they depend upon design professions to provide the appropriate physical environment for care.

Silence

The architect Charles Moore once received a commission to design a house for a blind man. He was selected over several highly qualified architects for one reason. He was the only one to acknowledge his client's condition and discuss the implications of designing for a blind person. Architects must overcome the general reticence about dying in order to find truly appropriate and meaningful design solutions.

Alan Lightman provides us with a clue to the state of mind necessary: *'suppose that time is not a quantity but a quality, time exists but it cannot be measured. In a world where time is a quality, events are recorded by the colour of the sky, or the feeling of happiness or fear when a person enters a room. The time between two events is long or short depending on the background of contrasting events, the intensity of illumination, the degree of light and shadow, the view of the participants'* (Lightman, 1993).

Lightman's description implies that the potential for meaning in architecture lies in experience not abstraction. In a hospice we must not think of a door as a product selected from a catalogue, it is a threshold, a place where a son pauses before entering to see his father for the last time.

There is a silence for which we should strive. It is the silence which Juhanni Pallasmaa says '*turns our attention to our own experience–I find myself listening to my own being*' (Pallasmaa, 1994).

The next millennium

SInce 1963 Christian Norberg-Shulz has, in a series of theoretical books, thoughtfully outlined an approach to design exploring the psychic implications of architecture. 'After decades of abstract scientific theory it is urgent that we return to a qualitative phenomenological understanding of architecture. It does not help much to solve practical problems as long as this understanding is lacking' (Norberg-Shulz, 1979).

Case Study

The design of the Essa Flora, Hospice of Lancaster County, Pennsylvania begun in 1993 by R. M. Sovich, AIA and the firm, Reese Lower, Patrick and Scott

Architects, Ltd proved to be an opportunity to explore a phenomenological design approach.

In the design of each patient room an attempt was made to create a room with a center which could accommodate various activities, in a number of configurations controlled by one occupant, including solitude, gatherings or receiving guests, intimate discussions, dining, sleeping--napping, views to the outdoors and access to a private garden. Each room overlooks its own private garden and views from the bed were considered as well as how light enters the room. The rooms are oriented to provide direct sunlight when it is most pleasant but prevent harsh afternoon glare. The flexible room layout allows one to personalize, it is the domain of the patient. As the design of the room progressed it began to resemble a sachnissi, a special room in Greek and Persian houses 'used to receive guests, for business transactions. . . at times for sleeping or dining. . .rooms for being in' (Walkey, 1993) The patients' rooms are accessed via a series of family rooms linked en filade, thus preserving clarity of wayfinding without a corridor. The family rooms face and open onto courtyards away from the patient gardens.

The building inflects at the entrances to receive and welcome. It forms a dense cluster of elements enclosing two courtyards on the the site of a former pumpkin farm. In silhouette the long roof lines reach from the ground to the sky, and although clearly new, the form settles in comfortably with the agricultural-architectural traditions of the area. The building was completed in 1996.

Summary

The hospice alternative has taken root throughout the United States in just 20 years. It has taken that long to come to terms with the issues of organization, program and identity. The next 20 years will find the identity of hospice shaped by the qualities of the facilities presently planned and under construction. Will the next century produce thoughtfully designed patient focused environments supporting humane palliative therapies?

The provision of quality healthcare environments depends on many factors, not the least of which is finance, but it is also related to the needs of those requiring care and their care givers. The answer will depend on whether those who finance and administer healthcare programmes, together with the design community have the courage to listen and learn from dedicated hospice movement and really look through the eyes of the patient.

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Fig. 13.1 *Layout of a resident room at the Essa Flora Hospice of Lancaster County, Pennsylvania, USA. A phenomenological approach to the design of a patient room.*

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