Keep all thee ‘til the end: Reclaiming the lifeworld for patients in the hospice setting

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Introduction

• “Hospice” has its root in the Latin “hospes” – describing the giving and receiving of hospitality.

• Cicely Saunders is widely accepted to be the founder of the modern hospice movement.
St Christopher’s Hospice, London
Cicely Saunders

- Gained experience caring for the dying at St Joseph’s Hospice in Hackney and St Luke’s Home for the Dying Poor.

- Wanted an institution that could combine this type of care with further scientific studies on the use of morphine.
Total Pain

• St Christopher’s aimed to be a holistic institution – providing care for families and the wider, non-medical needs of the patient.

• This reflected Saunders’ research on the concept of total pain.

• Total pain recognises that pain is not only a physiological experience, but is linked to spiritual, psychological and social dimensions.
Aims

• We aimed to investigate the dimensions of difference separating St Christopher’s apart from hospital care of the dying.

• This was in regards to social organisation and physical space – the overall environment of the institution.
Thematic Analysis

• A qualitative thematic analysis was undertaken on material from the Cicely Saunders Archive.

  ▪ The archive is held at King’s College London and consists of published works and notes, pictures, slides and photographs kept by Cicely Saunders throughout her life and archived after her death.
The scope of the archive echoes the full scope of Saunders’ work:

- How best to care for the dying medically
- Legal documents surrounding the construction St Christopher’s Hospice
- Publicity material for St Christopher’s Hospice fundraising activities
Materials Used

• The archive consists of 81 boxes which are categorised according to time period, material type, topic and geographic area. The time range of data available in the archive was 1953 – 2005.

• We used data from up to 1980 labelled “UK” - this was to keep the focus on the development phase of St Christopher’s.

• 31 boxes were selected for analysis.
Selection

• Selection of material within the boxes was done based around searches on selected themes:
  • Development
  • Environment
  • Philosophy
  • Need
  • Aim

• 15 out of 31 boxes were found to contain relevant material.
Selection within boxes

- Material concerning environment was then gathered from documents within the boxes.

- Environment was parsed as being both the physical construction of the building and interior spaces, and the organisation of time and people inside of it.
• Material that corresponded to these themes were gathered and recorded in a single document.

• Quotes gathered came from both formal and informal source material – the majority being from letters, notes for speeches or meetings and preparation for published pieces.
Themes

- Data was grouped into themes and sometimes combined to produce stronger categories.

  - Five themes emerged from the analysis of recurring text motifs –
    - (1) home/homelike
    - (2) community
    - (3) consideration of others
    - (4) link with outside world
    - (5) privacy
**Coding and Categories**

- An iterative process was used to define themes and extract data from this document.

- Themes were generated using open coding (Strauss and Corbin).
  - Open coding is an approach that begins with data, rather than hypothesis.
Open Coding and the Grounded Theory Approach

• When data is collected, it is marked with a series of codes at key points.

• These codes are then grouped into concepts and, when needed, further grouped into categories.

• From this, theories can then be built.
Grounded theory describes a full research process – from data gathering to analysis and theory generation – that is conducted in this way.

- True grounded theory also has other stipulations, such as:
  - Not recording the data gathered
  - Not conducting literature reviews before data gathering so as not to influence the process.
Home/homelike

- It was very clear that the use of “home/homelike” used referring to the environment of St Christopher’s was considered to be different to the care environment in a hospital.

- In many quotes this was used as opposition to how the hospital environment was described.
• "It has to replace home as well as hospital and the buildings should be designed with this in mind"

• "We believe that it is essential that these people should be welcomed into some kind of community that can replace their homes"

• "It is planned as something between a hospital and a home - combining the skills of one with the warmth and welcome, the time available and the beds without invisible parking meters beside them that belong to the other"
Community

• There was a great deal of thought on creating a community feel, and the idea of new bounds of normality was at the forefront of planning.

• At the time, patients with terminal illnesses were considered to be outside the remit of acute care hospitals and could find that they faced isolation from staff who considered them to be beyond help.
“a general ward is rarely the right place for them. The sight of them may frighten and depress others, and they become miserable as they see their neighbours improving while their own hopes are continually deferred.”

“The emphasis was placed on the ability to retain normal relationships without in any way compromising on the need for continuous and, where necessary, intensive care of the patient”
"We have planned wards rather than single rooms for we want there to be a community life for the patients."

“For the body: we strive for growing understanding and expertise in symptom control, for due regard to appearance and self esteem”

"There is great strength to be gained in the community of suffering and where patients are wisely placed they are often able to help one another”
Consideration of Others

- The role of relatives and friends was considered in planning St Christopher’s Hospice from the very beginning.

- Planning documents discussed enabling and encouraging the inclusion of informal caregivers in the day-to-day life of the hospice, a contrast to the very hierarchical hospital system.
• “Relatives might be enabled to stay and carry out quite extensive care for the patient (comparable to the admission of a mother with her child)”

• “We might keep one day free each week so that relations have no conscience at having a 'day off' ”
Links to the Outside World

- The idea of the hospice providing a link to the outside world was prevalent in the archive material.

- The physical construction of the building was the main concern within this theme.
EURO IMPACT

• “There would be a ward of 16 beds [...] all planned so that patients can see the life of the world outside and yet not have the light directly in their eyes”

• “Good public transport and a feeling of openness to the world outside are chief among the needs of any unit for terminal or long term care"

• "We would like to remember the original emphasis and that the care given by a Hospice was very much a part of life"
Privacy

• Though community and activity was an important concern in developing the workings of St Christopher’s Hospice, so too was privacy.

• This was mostly explored through remarks concerning the physical layout of the ward spaces.
"Space is planned for a change of scene for the patients, for silence and for privacy"

“Emphasis should be given to the need for spaces for private talk; these must be found”

“Preservation of the patient’s dignity and self-respect, with privacy, are essential to all, but especially to him whose illness subjects him to humiliating experiences”
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Discussion

• The structure of medical clinics has long been recognised as being intrinsic to the ability to treat.

• The construction of healthcare spaces has a distinct effect on patient care, and this has recognised repercussions in shaping the intended patient experience.
Heterotopia

- Hospitals are recognised as being a form of Foucauldian heterotopia; housing those who are considered to be deviant within “normal” society (Foucault, 1967).

- Hospices take this further still and act as a heterotopia for the hospital population in housing those who will not be cured.
Lifeworlds

- There is a difference in environmental need between patients who access healthcare for chronic and acute conditions.

- Habermas identified the concept of the lifeworld - an environment that may need to be created to sustain the holistic life of a subject in an institution.

- The separation of patient populations allows the construction of a different type of lifeworld.
• The themes within the analysis illustrate the different needs of patients at the end of life and how this is reflected through physical space.

• This creation of a new type of lifeworld reflected the social tenet of the concept of total pain - enabling “as full as possible” patient participation in the social sphere.
Other Institutions

- The same needs and processes are reflected in similarly total institutions.

- Oosterveld-Vlug (2013) explores the concept of dignity as experienced by patients in Dutch nursing homes.
  - Such institutions also serve the long-term and end-of-life patient population, and have similarly developed lifeworlds specific to these needs.
Implications Today

• Increasingly, facilities for longer-term visitors are also found and are constructed to mimic the scale and function of domestic homes.

• The modern patient is likely to receive treatment and advice from a number of settings - and this adoption of Saunders’ environmental values across institutions allows continuation of the chronic or terminal illness lifeworld beyond the boundaries of any one given institution.
Single Rooms vs. Wards

• The preference in recent years has been for single room facilities from the point of admission.

• This reflects consumer culture - where each patient and their family are able to control the temperature, light and airflow within their territory.
• There remains fear in facilities not solely comprised of single rooms that a patient enters a single room to die.

• This frames death as something to be feared and hidden away.
A 2011 systematic review on elderly inpatient deaths found a preference for small scale wards.

- Rowlands and Noble (2008) found that patients with advanced cancer appreciated a mix of single rooms and four-bedded cubicles depending on changing needs over time.

- Oosterveld-Vlug (2013) found that frail elderly patients in shared rooms reported feeling more secure than when they stayed alone.
Conclusions

• An institution of healthcare as a system is universalistic, and by nature directed to a high degree of instrumental rationality.

• In general it must be noted that in the planning of hospices in different countries and cultures, lifeworld characteristics vary more from one situation to another than the system characteristics.
• Concerns about the environment of end-of-life institutions have been instrumental in the evolution of palliative care.

• Saunders’ original concerns and ideas surrounding suitable environments for terminally ill patients have generally been developed and adapted to fit today’s more flexible culture of care.
The move towards single rooms is a significant departure from the intentions of St Christopher’s.

This may be a reflection of modern society, but the impact of separating dying patients further must continue to be assessed within the scope of the holistic dying experience.