Palliative Homecare support for terminal discharges

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Overview

• Background
• Aim of chart audit
• Methodology
• Findings
• Conclusion
• Discussion
• Questions and answers
A survey commissioned by the Lien Foundation showed that 77% of locals would rather die at home.

But government statistics show only 27% of deaths in Singapore take place at home.

Lien Foundation’s “Death Attitudes Survey” revealed 64% of Singaporeans view hospice palliative care as expensive, and upon knowing more about it, 80% are open to receiving hospice palliative care for themselves. Majority (82%) showed strong support for public education on hospice palliative care.
Terminal discharge

- When death is imminent, discharge home for the purpose of passing away at home has been termed “terminal discharge”.
- Death is expected to be within 1 to 2 weeks.
Locally, it is not uncommon for patients and their families to request for discharge home when the patient is in extremis.

About 100 cases of terminal discharges from hospital each year

Logistically challenging to organise for healthcare team in the hospital and the community. They also add to the stress experienced by patient and family members.
Terminal discharges may be initiated from the acute hospital, hospice or nursing home.

One of the main functions of the palliative home care service is to provide support for such patients and their families.
Aim

To study the resource utilization (contacts by telephone, visits, out-of-hours or within office hours) for patients who were terminally discharged, and to find out the type of support required for a smooth transition, from the institution to home, in their last hours/days.
Methodology

A retrospective chart review of patients admitted to a palliative homecare service over a six-month period (April to September 2013) was conducted.

Data collected and analysed
1. Demographics
2. Frequency and nature of contact
3. Support required by terminally discharged patients
Findings

Demographics

Twenty (14.1%) of 141 patients were terminally discharged during this period.

The mean age of patients was 73.2 years.

80% suffer from cancer.

15 Chinese patients, 4 Malay patients and 1 Indian patient
Findings - Duration of care

Duration of care ranged from 0 (passed away on day of first visit) to 40 days, with a mean of 8 days.

14 patients (70%) passed away within a week of referral.
Findings – Resource utilization

All families were contacted within 24 hours of referral.

- 7 (35%) were contacted within the first hour.

Mean number of phone calls made to each patient was 5.4.
Patients were visited at a mean of 2.8 visits per patient during the duration of care.
Resource utilization – Out-of-hours service

Not highly utilized with only a mean of 0.5 visits and 0.9 phone calls per patient

<table>
<thead>
<tr>
<th>After office hours call (N)</th>
<th>After office hours visits (N)</th>
<th>Reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>5</td>
<td>Wound dressing soaked with blood; bleeding from chest tube site; increased pain</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>Tubes dislodged (IDC, NGT); Terminal delirium</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>Status epilepticus</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>New case not seen; Symptoms - groaning, pain, secretions</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>Blood stained urine in IDC</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>Informed of demise</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>Pain</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>Enquiry</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>SOB</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>Agitation</td>
</tr>
</tbody>
</table>
Type of support during home visits - Physical

Number of patients

- Topping up continuous infusion drips: 3
- Nursing – management of tubes: 7
- Starting continuous infusion drips: 9
- Nursing – wound dressings: 10
- Caregiver teaching – ADL care: 15
- Medication titration: 15
- Preparing breakthrough medications: 17
- Caregiver teaching – medication: 20
Symptom management with medication use

- Assessment, reassessment of pt’s uncontrolled/distressing signs/symptoms
  - Pain control
  - Dyspnoea management
  - Throat secretions
  - Restlessness, terminal delirium
  - Fever reducing measures
  - Others: Bleeding; Urinary retention
- Intervene via pharmacological & non-pharmacological means
Main type of support during Home Visits: Medications

• Teaching caregivers how to administer s/cut medications according to needs (N= 20)
• Physical preparation of intermittent/breakthrough medications e.g. pre-filled syringes of medications, medications delivered (N= 17)

Caregivers have an important role to participate in symptom management.

Patients are often not able to take medication orally and sufficient supply must be present
Main type of support during Home Visits: Medications

- Amend, titrate, convert medications accordingly via suitable routes e.g. SL, PO, s/cut, PR, TD, TOP \( (N = 15) \)
- Starting \( (N = 9) \) or topping continuous medication \( (N = 9) \) infusions via portable battery operated pumps e.g. Baxter, CADD, Graseby syringe driver

Changes in patients’ conditions such that they are not able to take orally

Increase in symptoms at end of life which may not be observed / present prior to discharge
Main type of support during Home Visits: Nursing

• Caregiver teaching – ADL care (N = 15)
• Wound dressings (N = 10)
• Management of tubes e.g. Chest drains, IDC, NG (N = 7)

Most of the patients may be self caring or minimally assisted → Bedbound

Post-operative wounds and pressure ulcers
Drains often are remain insitu for symptom management
Type of support – Psychosocial, spiritual

- Emotional support: 19
- Loan of supportive devices i.e. beds, oxygen…: 4
- Financial support: 3
- Last hours preparation: 20

Number of patients
Main type of support during Home Visits: End-of-life advice

- Last hours preparation and advice (N = 20):
  - What to expect when death is near?
  - What can you do when these changes occur?
  - How do you know when death happens?
  - What do you do after death of your loved one?
  - Death certification

Practical advice

Emotional preparation for physical signs and symptoms of dying
Main type of support during Home Visits

Providing emotional & spiritual support (N = 19)

• Facilitating dialogue on patient/family need to openly communicate their inner emotions of their love, appreciation, apologies, forgiveness & goodbyes
• Assessing for high risk grief
• Bereavement support

Nearly all unless the contact is very short i.e. few hours to establish rapport. Usually referring source to support if needed
Main type of support during Home Visits: Advice/guidance/share

- Coaching & explanation such as nutritional component of care esp with reduced oral intake
- Sharing of resources/useful contacts e.g. renting/purchasing hospital beds, oxygen concentrators, engaging private nursing support
- ACP discussion, clarification, reaffirmation
Discussion

Terminal discharge is **resource intensive** for home care teams

- The evidence on cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers (is inconclusive from the recent Cochrane review (six studies) (Gomes et al, 2013)

- Some of these tasks may be difficult to measure or justify such as emotional support or simply ‘being there’ (Smith & Porock, 2009)
Symptom management and supporting caregivers in administering medication for their loved ones is the main key role of the palliative home care nurse.

- Although palliative specialist nurses do not provide hands-on care, palliative care nurses are skilled in symptom control (Lakasing, 2009).
- If the drugs are not in sufficient quantities to be available out of hours, symptoms in terminally ill patients may be uncontrollable (Beland, 2013).
Another main key role of the palliative home nurse is to **teach caregivers in providing ADLs care.**

- **Carers can be drawn into a role for which they are neither trained nor prepared and need advice from professionals on what to expect and the nursing tasks** (Eyre, 2010)
While the duration of care is short, it is still possible to provide **adequate psychosocial support** for the caregivers and families.

- **Experiences of caregivers in caring for a dying family member at home** (Carlander et al, 2010)
  - Challenged ideals in the situations they reacted, and feelings of insufficiency in caring role
  - Stretching their limits for privacy and intimacy
  - Interdependency such that dying patient’s expressed will has priority over their own needs
Case Study illustration

Mr LPC, 54 year old Chinese gentleman
- Chronic smoker: 2 packs/day
- Diagnosed: Advanced Ca Lung with large loculated right pleural effusion. Was in ICU for haemorhagic shock. Pericardial effusion
- Family & patient trying to accept terminal condition and Mr LPC very keen to return home.
- Terminally discharged from hospital on 12/7/13 with a flutter bag for chest drainage.
- Was visited by DPHC team on same day of discharge
- Length of stay with DPHC 27 days
## Snapshot of Mr LPC’s stay at home

<table>
<thead>
<tr>
<th>Days of Service</th>
<th>Date</th>
<th>Highlights</th>
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<tbody>
<tr>
<td>1</td>
<td>July 12</td>
<td><strong>First home visit (HV) by doctor &amp; nurse.</strong> Breathless – allay symptoms &amp; prepared s/cut injections (approx. 3 hours)</td>
</tr>
<tr>
<td>2</td>
<td>July 13</td>
<td><strong>On call dr activated and visited (HV) TWICE (0045-0115) and (0230-0330) for leakage at dressing site</strong></td>
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<td>3</td>
<td>July 14</td>
<td></td>
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<td>4</td>
<td>July 15</td>
<td><strong>Reviewed (HV) by dr and nurse for pain, constipation</strong></td>
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<tr>
<td>5</td>
<td>July 16</td>
<td><strong>Reviewed (HV) by APN for abdominal distension and topping up continuous morphine injections</strong></td>
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<td>7</td>
<td>July 18</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>July 19</td>
<td><strong>Reviewed (HV) by doctor &amp; nurse. Changed s/cut Morphine to Fentanyl patch</strong></td>
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<tr>
<td>9</td>
<td>July 20</td>
<td></td>
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<tr>
<td>10</td>
<td>July 21</td>
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<tr>
<td>11</td>
<td>July 22</td>
<td><strong>Reviewed (HV) by dr &amp; nurse – pain, constipation.</strong> Wheelchair loaned. Mr LKC expressed wish to visit S.E.A Aquarium in Sentosa with family</td>
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<tr>
<td>12</td>
<td>July 23</td>
<td>All contacts activated and correspondence made for the outing</td>
</tr>
<tr>
<td>13</td>
<td>July 24</td>
<td><strong>Mr LKC and family visited S.E.A Aquarium, RWS, made possible by DPH volunteers. Oxygen tank was available at all times</strong></td>
</tr>
<tr>
<td>14</td>
<td>July 25</td>
<td><strong>Reviewed (HV) by APN – Flutter bag changed. Staples at chest wound removed</strong></td>
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<tr>
<td>15</td>
<td>July 26</td>
<td><strong>Contacted CTVS re chest tube plan</strong></td>
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<td>16</td>
<td>July 27</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>July 28</td>
<td><strong>On call dr activated for leaking chest tube site. Resuturing done (0200-0330) (HV)</strong></td>
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<tr>
<td>18</td>
<td>July 29</td>
<td><strong>Appointment to see Cardiothoracic</strong></td>
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<tr>
<td>19</td>
<td>July 30</td>
<td><strong>Reviewed (HV) by APN for tightness at chest tube site. STO done to stich at back</strong></td>
</tr>
<tr>
<td>20</td>
<td>July 31</td>
<td><strong>Reviewed (HV) by dr for increasing pain at right chest tube site. Fentanyl patch dosage increased</strong></td>
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<tr>
<td>21</td>
<td>Aug 1</td>
<td><strong>On call dr called by family for pain not settling in spite of increased analgesia transdermally and orally. S/cut morphine re introduced (0550 – 0630) (HV)</strong></td>
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<td></td>
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<td>Visited again by dr for new pain – hepatic area (1600-1715) (HV)</td>
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<tr>
<td>22</td>
<td>Aug 2</td>
<td></td>
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<tr>
<td>23</td>
<td>Aug 3</td>
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<td>24</td>
<td>Aug 4</td>
<td></td>
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<tr>
<td>25</td>
<td>Aug 5</td>
<td><strong>Reviewed (HV) by nurse after discharge from DPH. On continuous infusion of Midazolam, Haloperidol, Morphine</strong></td>
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<tr>
<td>26</td>
<td>Aug 6</td>
<td><strong>Reviewed (HV) by APN – Increased breathlessness. Drowsy</strong></td>
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<td>27</td>
<td>Aug 7</td>
<td>Mr LKC passed away and CCOD was signed by DPHC doctor (HV)</td>
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Conclusion

This study has provided useful information on the healthcare resources, and the type of support required by the patients and their families when the patients are terminally discharged from hospital to home.
Conclusion

Future studies

• A longer duration of study period
• Comparing resources and support required for patients who are terminally discharged, and those who are already under home care services and their resources and support in the last 7 days of care.
References


Thank you
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