End of life care: a comparison of palliative patient symptom management in regional and rural community settings

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Illawarra Shoalhaven LHD

- Services a 250km coastal area directly south of Sydney
- Two distinct regions:

1. Illawarra, which is a regional metropolitan area, centred around Wollongong. The population is approximately 300,000. The main hospital is Wollongong Hospital. The palliative care unit is at Port Kembla Hospital and has 15 beds. The palliative care service has an on-call after-hours nursing service. PEACH packages are available to support patients at home in the last week of life

2. Shoalhaven, which is a largely rural area, servicing a population of approximately 100,000. The main hospital is Shoalhaven District Memorial Hospital, located in Nowra. The palliative care unit is based at David Berry Hospital, in the very north of the region and has 9 beds. Primary Health Nurses are on-call until 9pm. There is no after-hours nursing service. PEACH packages are not available

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District Palliative Care Service Issues

- The Illawarra is better resourced than the Shoalhaven
- The Shoalhaven has a third of the population, spread over a much bigger geographical area
- Referrals to the Shoalhaven palliative care service are increasing since the opening of the Shoalhaven Cancer Care Centre
- How does the service address Standard 10 of the PCA National Standards: Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography
- A study to compare symptom management and carer distress in the 2 regions could look at whether extra resourcing produces a better outcome and provide evidence for further resourcing in the Shoalhaven

The study

- Retrospective audit of PCOC assessments of all palliative care patients seen in the community, within the last week of life, by the PHNs, the palliative care CNCs and the after-hours palliative care nurses from 1st October 2014 until the 31st January 2015. All community palliative care patients seen or telephoned by nurses are supposed to have a PCOC assessment documented in the community health record - CHIME
- While retrospective, the PHNs and palliative care nurses across the LHD were informed about the study prior to the commencement date
- Symptom assessment scores for pain, nausea, breathing and bowels were reviewed
- Family/carer distress scores, where documented, were reviewed
- Place of death was noted

The study

PALLIATIVE CARE PHASE

Clinician rated

1. STABLE Symptoms are adequately controlled by established management
2. UNSTABLE Development of a new problem or a rapid increase in the severity of existing problems
3. DETERIORATING Gradual worsening of existing symptoms or the development of new but expected problems
4. TERMINAL Death likely in a matter of days
5. BEREAVED Death of a patient has occurred and the carers are grieving

Refer to complete Phase Definitions

RUG-ADL

Resource Utilisation Group – Activities of Daily Living

Clinician rated

For Bed Mobility, Toileting and Transfers

1. Independent or supervision only
3. Limited physical assistance
4. Other than two person physical assist
5. Two or more person physical assist

For Eating

1. Independent or supervision only
2. Limited assistance
3. Extensive assistance/total dependence/tube fed

Refer to complete RUG-ADL definitions

PROBLEM SEVERITY SCORE

Clinician rated

For the following 4 domains assess the severity of problems as;

0 = Absent; 1 = Mild; 2 = Moderate; 3 = Severe

PAIN: Record the severity of problems relating to pain

OTHER SYMPTOMS: Record the severity of problems relating to other symptoms.

PSYCHOLOGICAL / SPIRITUAL: Record the severity of psychological/spiritual problems of the patient.

FAMILY / CARER: Record the severity of family/carer problems.

Scores trigger referrals and more in-depth assessment

AKPS

Australia-modified Karnofsky Performance Status (AKPS) Scale

Clinician rated

100 Normal, no complaints or evidence of disease
90 Able to carry on normal activity, minor signs or activity
80 Normal activity with effort, some signs or symptoms of disease
70 Care for self, unable to carry on normal activity or to do active work
60 Occasional assistance but is able to care for most needs
50 Requires considerable assistance and frequent medical care
40 In bed more that 50% of the time
30 Almost completely bedfast
20 Totally bedfast & requiring nursing care by professionals and/or family
10 Comatose or barely rousable

SYMPTOM ASSESSMENT SCALE

The Symptom Assessment Scale describes the patient's level of distress relating to individual physical symptoms. The symptoms and problems in the scale are the seven most common; difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. The instrument is designed to be a patient rated tool but also allows for rating by proxy. Symptoms or problems, not listed, can be added in the blank row.

For accuracy and consistency, it is best for the patient to score symptoms on their own using the Symptom Assessment Scale Form for Patients.

A family member, carer or health professional can also use the Symptom Assessment Scale Form for Patients to assist the patient to rate how severe their distress is.

If the family member, carer or health professional is rating symptoms on behalf of the patient, it is important to look for signs of distress and rate accordingly.

Instruct the patient to consider their experience of the individual symptom or problem over the last 24 hours and rate according to how severe distress has been

A score of 0: means the symptom or problem is absent or there is no distress associated with that symptom or problem.

A score of 1: means the symptom or problem is causing minimal distress.

A score of 10: means the symptom or problem is causing the worst possible distress.

REASON FOR PHASE END - the reason this phase ended.

If the reason for phase end is discharge record the other assessment scores at the time of phase end

1. Change to Stable Phase
2. Change to Unstable Phase
3. Change to Deteriorating Phase
4. Change to terminal phase
5. Death
6. Bereavement Phase end
7. Discharge

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The study

Palliative Care Nursing Assessment

phone call

Phase:1

PCOC Assessment	SCORE	Comment
RUG-ADL (4 - 18)	4	
PCPSS - Palliative Care Problem Severity Score (0 - 3)	3	
AKPS - Australian Modified Karnofsky Performance Scale (10 - 100)	70	
SAS - Symptom Assessment Scale – patient rated (0 - 10) (enter below)		
Difficulty Sleeping	3	
Appetite Problems	1	
Nausea	1	
Bowel Problems	0	
Breathing Problems	3	
Fatigue	5	
Pain	0	
cough	4	

Plan /Treatment:

P/C to client, things remains the same. Getting relief from oxygen, settles any breathlessness well. Power cut 2 nights ago, pt called ambulance and went to ED for oxygen, advised them to ring and get a cylinder provided. Some nausea today, settled well with maxalon. P/C in 2 weeks, 17/12/14

The Illawarra

- 120 deaths
- 47 patients seen at home in the last week of life were evaluated
- Home deaths: 40 (33%). Average age 72. 55%female
- RACF deaths: 9 (7%)
- Deaths in hospital: 71 (60%)

- in palliative care unit PKH: 36. 11 patients were admitted in the last week of life

- in Wollongong Hospital: 17

- other hospitals: 18

- 3 patients who died at home had no PCOC assessment recorded

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The Shoalhaven

- 74 deaths (with a third of the population of the Illawarra, this was 61% of the number of deaths in the Illawarra)
- 22 patients seen at home in the last week of life were evaluated
- Home deaths: 15 (20%). Average age 74. 76% female
- RACF deaths: 8 (10%)
- Deaths in hospital: 51 (70%)

- in palliative care unit DBH: 30. 9 patients were admitted to DBH in the last week of life

- in Shoalhaven Hospital: 8

- in Milton-Ulladulla Hospital: 11

- in other hospitals: 2

- 8 patients seen at home in the last week of life had no PCOC assessment recorded

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The results

- There were more home deaths in the Illawarra, probably reflecting differences in both resourcing and geography
- There was no significant difference in the symptom management between the 2 regions with the average of all symptoms in the absent to mild range
- There was no difference in carer distress between the 2 regions, with the average rating being mild, but there was inconsistency in recording carer distress. Narrative descriptions in the notes suggest this rating was not reliable
- The average PCOC phase at the beginning of the last week of life was 2 (unstable) and the average phase of the last documentation of PCOC was 3 (deteriorating), suggesting inconsistencies in phasing in the community
- There were more PCOC assessments per patient in the Illawarra

The conclusions

- There were nearly double the deaths in the Shoalhaven compared to the Illawarra that would be expected for the population, highlighting the need for extra resources to support the primary care of the GPs
- There were inconsistencies in recording PCOC data
- There were inconsistencies in PCOC phasing
- Does the rural community have less expectation of medical services and tries to cope with the situation dealt to them?

The outcomes and conclusion

- Discussion with PHN NUMs re the importance of PCOC assessments for the community patients
- Education re PCOC phasing
- Shoalhaven statistics used in business case to have PEACH packages in the Shoalhaven
- Study needs to be repeated. Patient numbers and inconsistences in PCOC documentation and scoring make it difficult to draw any conclusions about resourcing affecting patient outcomes in the 2 regions, although it may affect the place of death, particularly the option to die at home.

Questions?

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