

You don't know if you don't ask: Implementing a patient reported outcome measure in a Specialist Palliative Care Service



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Background

- Patient-reported outcome measurements (PROMs) play an increasingly important role in health care in allowing patients to assess the effect and quality of their care.
- We routinely collect satisfaction and symptom management data from our patients - Palliative Care Outcomes Collaboration (PCOC)
- But we have limited information on their experience of care

Background

- The POS measures are a validated family of tools in palliative care to measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs. Hearn, J., Higginson, I.J. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. Qual Health Care (1999) Dec; 8(4) 219-27
- The POS is available in 12 languages including English, Chinese, Dutch, French, German, Italian, Japanese, Norwegian, Portuguese, Spanish, Punjabi and Urdu.

Aims

- To invite the patient at discharge to complete the Palliative Care Outcomes Scale (POS) to understand their experience of care.

Results

- Patients were approached between September 2017 and February 2018.
- There were 364 separations with 211 deaths.
- Of the remaining 153 patients - 95 patients were discharged home - 26 patients were transferred to another hospital; 24 to a residential aged care facility; 7 were discharged whilst on leave; 1 discharged at own risk.

Results

- 119 patients were therefore eligible to participate in the PROMs study.
- Of these 30 patients were unable to complete the PROM because of cognitive impairment; confusion or spoke a language for which the POS had not been validated/translated.
- Of the remaining 89 patients discharged 56 completed the PROM - 63% response rate.

Results

- 57% were male
- 43% female
- 11% were from a Culturally and Linguistically Diverse background (n=6)
- The mean age was 76 years (sd 10.02, range 60-97)

Over the past 3 days, have you been affected by pain?

- Almost half the patients reported that they were not affected by pain at discharge (46.4%);
- 46.4% were slightly (n = 14) or moderately (n = 12) affected by pain
- 7.2% (n = 4) reporting they were severely or overwhelmingly affected by pain.

Have other symptoms e.g. nausea, coughing or constipation seemed to be affecting how you feel?

- A third of patients (n = 17) did not report other symptoms affected how they felt
- 30.4% slightly
- 25% moderately
- 8.9% (n = 8) severely or overwhelmingly affected.

Have you been feeling anxious or worried about your illness or treatment?

- Half of the patients (50.9%) reported not feeling anxious or worried about their illness or treatment;
- 17% occasionally;
- 13.2% sometimes
- 7.5% (n = 4) patients reporting that they were anxious or worried most of the time – “often affects my concentration” and
- 11.3% (n=6) reported they were completely pre-occupied by worry or anxiety.

Have any of your family or friends been anxious or worried about you?

- Almost half (45.3%) of patients reported that their family or friends were not anxious or worried about them;
- Over a third 32.1% sometimes/occasionally
- 13% (n=7) patients reporting their family/friends were worried most of the time and
- 9.4% (n=5) always pre-occupied with worry about them.

How much information have you and your family or friends been given?

- The majority of patients (85.5%) reported that they were given full information/as much as they wanted.
- 3 patients reported that they were given information but it was hard to understand;
- 3 that they were given information on request but would have liked more
- 1 person reported they were given very little information

Have you been able to share how you are feeling with your family or friends?

- The majority of patients reported they had been able to share how they were feeling with family/friends (71.2%);
- 15.4% reported most of the time
- 4 patients could only occasionally/sometimes share their feelings
- 3 patients not at all.

Have you felt life is worthwhile?

- The majority reported that they felt life was worthwhile (60.4%)
- A third most of the time (27.1%)
- 3 patients reporting sometimes/occasionally
- 3 patients reported that they did not feel life was worthwhile.
- Missing data (n = 8)

Have you felt good about yourself as a person?

- Around half (51.1%) reported feeling good about themselves as a person all the time
- 33.3% most of the time
- 4 patients sometime/occasionally
- 3 not at all.
- Missing data (n = 11) as some patients did not wish to answer (“that’s boasting”)

Have any practical matters resulting from your illness, either financial or personal, been addressed?

- The majority reported practical matters resulting from their illness, either financial or personal had been addressed (61.5%)
- 23.1% reporting they did not have any practical problems.
- 7 people reported problems were in the process of being addressed
- 1 patient that they were not being addressed.

What have been your main problems in the last 3 days?

- A third of patients (33.9%) reported no problems in the past 3 days.
- Other main issues identified:
 - Constipation or diarrhoea (n = 7)
 - Painful injections (n = 4)

Next stage

- In considering recommendations for the implementation of the PROMs we are guided by the 8 Steps identified in “Guidance on the implementation of Patient Reported Outcome Measures (PROMs) in clinical palliative care
- With a focus on the POS “family of measures” produced by the European Inter-sectorial and Multidisciplinary Palliative Care Research Training. These 8 steps are as follows:

- Step 1 Select patient, setting and timing
- Step 2 Determine which questionnaire to use
- Step 3 Design processes for reporting results
- Step 4 Choose a mode for administering/scoring the questionnaire
- Step 5 Identify the goals for collecting PROMs
- Step 6 Identify aids to facilitate score interpretation
- Step 7 Develop strategies for responding to identified issues
- Step 8 Evaluate the impact of measuring PROMs on practice

Immediate response

- Patient pain scores now reported at morning meeting
- Policy on bowel management reviewed
- In-service education on issues identified in open-ended questions e.g. painful injections

Chart Audit - Follow-up

- 12 patients (21% of study participants) reported severe or overwhelming levels of pain, other symptoms or anxiety in the last 3 days prior to being discharged.
- 1 of 4 patients with high level of pain was also affected severely by other symptoms. The majority (3 out of 4) patients with high levels of pain also had high anxiety.
- Some (3 out of 8) patients with high levels of other symptoms also had high anxiety.

Chart Audit - Follow-up

- By examining each of the patient's record, we found out possible sources of the patients' pain, problems with other symptoms and anxiety.
- The problems resulted from disease progression or complications and some were able to be managed with medications.
- Symptom Assessment Scale (SAS) and Problem Severity Score (PSS) were then reviewed to examine each patient on this study.

Chart Audit - Follow-up

- SAS scores and PSS Scores on pain and other symptoms reflected accurately on the severity of symptoms felt by the patients.
- The majority of PSS scores on Psychological/spiritual and Family/carer were **not found** to match the depth of concerns felt by the 12 patients in this study.

Conclusion

- More involvement from Pastoral Carers and/or Social Workers in the assessments of psycho-social aspect of care may provide a more accurate response to patients' concerns and will guide us to improve our care for the patients.
- Acknowledge time of discharge is in itself anxiety producing
- PROMs will be collected over next 12 months at admission and discharge and comparing patients reports to clinician assessment

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