

One - Breathing Space, Rotherham

Prognostic indicators and advance care planning in chronic obstructive pulmonary disease (COPD)

The background to the service

Breathing Space is a unique nurse led facility in the heart of Yorkshire which was built in 2007 as a result of a partnership between the Coalfields Regeneration Trust, Rotherham Primary Care Trust and Rotherham Metropolitan Borough Council.

It is the largest multidisciplinary community based chronic obstructive pulmonary disease (COPD) rehabilitation programme in Europe. Originally the sole aim was to care for patients with COPD and this has now been extended to other chronic respiratory conditions. Its facilities include clinics for assessment and accurate diagnosis, pulmonary rehabilitation (for more than 400 patients a year) and a 20 bed inpatient unit dedicated to providing care for acute exacerbations.

At the time of joining NHS Improvement - Lung, the Nurse Consultant and Project Lead, Gail South, had identified that many of the COPD patients at Breathing Space had at least one of the Gold Standards Framework prognostic indicators often used to determine the last 12 to six months of life. This provided the catalyst for the service to look at the provision of end of life care and how this part of the pathway for patients at the facility could be improved.



Gail South (left) – Project Lead



The project aims and objectives

The main aim of the project was to advance the service delivery model for end of life care at *Breathing Space* as a choice for COPD patients and to support the carers of these patients during this difficult time.

The project hoped to answer some of the following questions:

- Are Gold Standards Framework prognostic indicators for COPD predicting death within 12 months?
- Are COPD patients with at least one Gold Standards Framework prognostic indicator (and their carers) interested in participating in Advance Care Planning?
- Do staff feel that patients with at least one Gold Standards Framework prognostic indicator are appropriate for Advance Care Planning?

- Do patients who have had Advance Care Planning achieve their preferred place of care and other goals?
- Do senior staff feel competent and confident at having these discussions after appropriate training?

What they did

A baseline audit was undertaken to determine whether there was any evidence to suggest prognostic indicators would be found amongst previous patients who were admitted to Breathing Space. This revealed 60% already had at least one prognostic indicator.

A paper audit form was then designed by senior staff to be used to capture any prognostic indicators present in patients attending assessment as an outpatient to the pulmonary rehabilitation programme and at time of admission during an acute exacerbation. The final page of the audit form asked the staff member responsible for admission to decide whether to initiate an Advance Care Planning discussion with the patient. This included giving information to the patient, notably the British Lung Foundation 'Guide to Coping with the Final Stages of Lung Disease' and an adapted version of The Whittington Hospital NHS Trust patient leaflet on 'Do Not Attempt Resuscitation'.

Patients and their carers were also given information about their 'Preferred Priorities for Care' (PPC) and asked if they wanted to complete any of the documents either on their own or with assistance from staff.

Breathing Space used a PDSA (plan, do study, act) approach during August 2011 to trial the form and they found quite quickly that one prognostic indicator was not necessarily an appropriate prompt for initiating this kind of discussion and therefore staff were documenting 'not appropriate'. The form was changed to use three indicators as the trigger point, and if senior staff felt it was not appropriate to initiate this discussion at this point, they were asked to document their reasons as to why.

A spreadsheet recorded all the data inputted from the paper audit forms collected. In conjunction with this project ten staff on the inpatient unit attended a preliminary training session on advanced communication skills delivered by a palliative care specialist. This followed a baseline audit of training skills amongst all staff.

Issues and challenges

Department of Health policy aimed at transforming community services meant that Breathing Space integrated with Rotherham Foundation NHS Trust in March 2011. This represented a challenge in terms of the continuity for the project as the then current provision of services was reviewed by the new host organisation. In order to mitigate this the senior team at Breathing Space involved in the integration ensured that staff at Rotherham Foundation NHS Trust were fully aware of the aims and objectives of the study and its progress by that date.

Locally the project lead spent a significant amount of time working on engagement and ownership of the project by the whole team. Continuing to have regular monthly meetings and emailing feedback to all team members has helped overcome communication barriers with staff who rarely spend time together due to changing shift patterns. Staff were also continually encouraged to comment on the project and data collection successes and difficulties.

Respiratory services also face their busiest time over the winter months and high admission rates and bed pressures have impacted on the progress of the project where the time could be dedicated to some of the data collection and administrative functions.

Talks with staff indicated that many of them felt a certain level of unease when asked to engage in an end of life care discussion with patients. In order to ensure staff felt empowered and skilled to undertake this sensitive and challenging task, ongoing training in communication skills and the development of clinical supervision strategies have given support to staff which has enabled reflective practice.

Key learning

The majority of patients who died during the period of the project had more than three Gold Standards Framework indicators present on their last admission, although overall staff felt the surprise question was perhaps a better predictor of death within a six to 12 month period. The 'surprise' question asks the clinician to consider whether they would be surprised if the patient were still alive in 12 months time.

Advance Care Planning materials used in this project received mixed responses from both staff and patients. The British Lung Foundation booklet contained too much information for some patients and was difficult for staff to use. Breathing Space have decided to create their own patient folder which can be personalised with bite size information on different elements of care which can be provided to the patient over a staggered period of time.

Not surprisingly many clinical staff felt very uncomfortable with end of life care discussions. Even when patients had three prognostic indicators present on admission, there were a sizeable number of audit forms where staff had indicated an Advance Care Planning discussion did not take place. This could have been for many reasons, some included: previous bad experiences, lack of confidence in the skill to address this subject, a pre-perception that it was not necessary and a fear of worsening the patients mental state by introducing the topic of dying. Although these issues are still apparent they are being addressed through supervision and training.

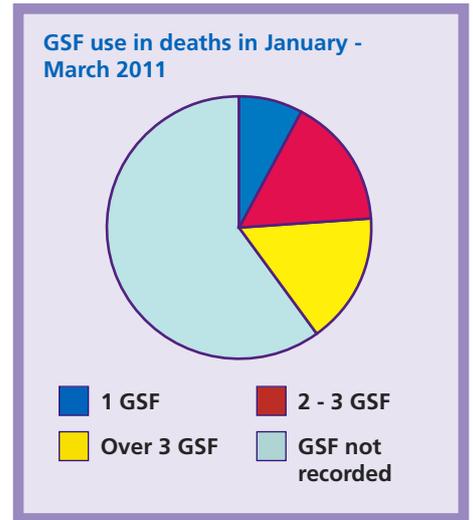
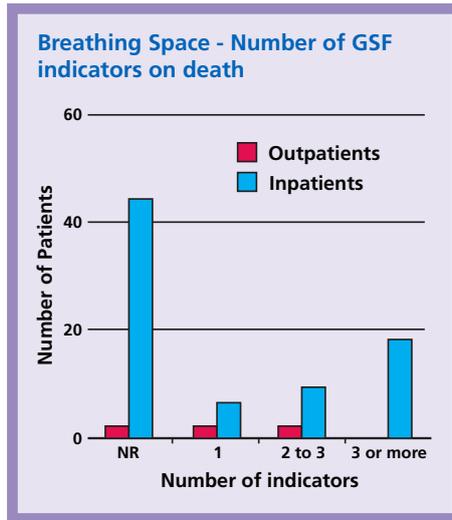
Perhaps less surprisingly, many COPD patients felt uncomfortable with the idea of end of life planning and some patients were distressed when the offer of Advance Care Planning was made available. Staff reflected on these incidents and concluded that in some cases an acute inpatient admission may not be the most appropriate time to initiate this kind of discussion. They are now considering the introduction of some general end of life care information during the weekly pulmonary rehabilitation sessions open to in and outpatients of the service.

Data

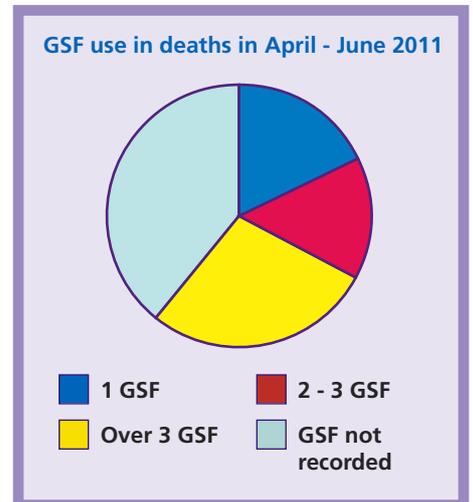
Between 1 September 2010 and 31 July 2011, a total of 683 patients with COPD were either admitted to the inpatient unit (606) or attended an assessment for pulmonary rehabilitation (77).

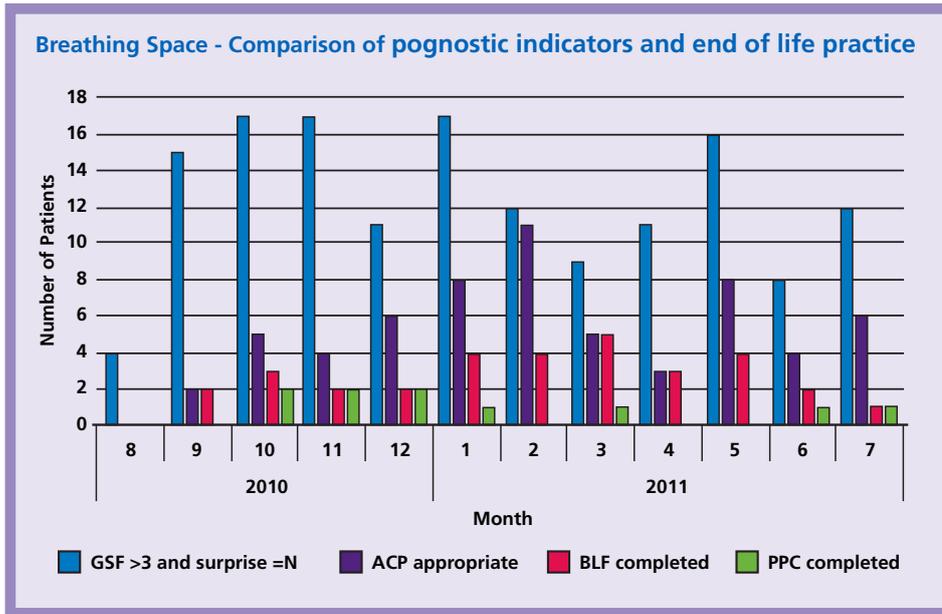
Overall 186 (27%) patients had at more than three prognostic indicators at time of admissions.

83 patients died since 1 September 2010 (76 inpatients and seven outpatients). Where recorded 18 out of 76 inpatients who died had more than three prognostic indicators, nine had two to three indicators and six had one indicator. Of the seven outpatients who died, three had two to three prognostic indicators and two had one indicator where it had been recorded.



However, there was a substantial improvement in the recording of the number of GSF indicators in patients who died as the project term went on.





Full year data from August 2010 to July 2011 is shown below with regard to the number of patients with three or more GSF indicators deemed appropriate for Advance Care Planning and those who went on to have the British Lung Foundation booklet given and a Preferred Place of Care recorded.

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