

SHORT REPORT

Improving the delivery of palliative care in General Practice: an evaluation of the first phase of the Gold Standards Framework

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Background: The Gold Standards Framework (GSF) was developed to formalise and improve the delivery of palliative care in the community. The framework consists of standards and a support programme to aid implementation. **Aim:** The aim of the study was to evaluate the first phase of GSF in terms of its acceptability to primary care teams, effectiveness in changing practice and professionals' views on the consequences for patient care. **Methods:** A prospective longitudinal comparative survey of 12 participating, 12 matched and 18 other practices included focus groups and questionnaires. **Results:** Participating practices reported that the GSF was acceptable and more. More standards were successfully achieved by the participating than matched practices. Registers, team meetings and co-ordinated care were thought to have improved communication, teamwork, patient identification, assessment and care planning. **Conclusions:** This small study suggests that the GSF appears to be acceptable and its early introduction to a few teams appears to have changed practice. Participants were positive about the effect on care. An evaluation of national uptake and further research into clinical outcomes is required.

Key words: palliative care, gold standards framework, supportive care, home death, family practice.

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Introduction

In a UK general practitioner's GP list of about 2,000 patients, there will be about 20 deaths a year, of which one quarter will be due to cancer.¹ Most cancer patients would prefer to be cared for at home for as long as possible and die at home if well supported.^{2, 3, 4} However, although 90% of the final year of life of cancer patients is spent at home, only about a quarter die there.^{5, 6} Reducing the numbers dying in hospital and decreasing emergency admissions is now becoming a focus of national policy.^{7, 8, 9} Successful care at home depends on factors such as support for carers, good symptom control, good communication and reliable service provision in the community. This includes the primary care team, nursing care, access to specialists, social support, night sitters, financial support and good co-ordination of care.¹⁰⁻¹² Interventions previously developed to improve community palliative care include team meetings and symptom control¹⁴ an audit schedule for monitoring palliative care standards,¹⁵ and patient assessment tools providing greater awareness of patients' preferences for place of death.¹⁶⁻¹⁸

The Gold Standards Framework (GSF), developed by one of the authors (KT), was described elsewhere¹⁹. The aim of this study was to evaluate the introduction of the GSF to volunteer practices in terms of its acceptability to primary care teams, effectiveness in changing practice and professional views on consequences for patient care.

Methods

Setting

Calderdale and Kirklees Health Authority in West Yorkshire included 311 GPs in 106 practices in urban and semi-rural settings. The study was undertaken between 2000 and 2001. A reference group of GPs, district nurses, consultants in palliative medicine, clinical nurse specialists and the Macmillan GP facilitator in cancer and palliative care (KT) met six times to agree the intervention and plan data collection.. Ethical approval was not deemed to be required by Calderdale Local Research Ethics Committee in October 2001.

The Intervention

Three key processes underlie the Gold Standards Framework:- to help primary care teams to: 1. *identify* palliative care patients, 2. *assess* their needs and preferences and 3. to *plan* ahead in response to these priorities.

The GSF is summarised in terms of the support implementation programme, set out in Table 1, as well as the six standards to be achieved set out in Table 2.

Table 1 here

Table 2 here

Study design and participants

The study included a prospective, comparative questionnaire audit of 12 practice teams participating in the intervention and 12 matched control practices chosen from volunteer practices. Practices were selected to represent differing sizes, urban/rural areas, training and non-training practices and Primary Care Organisations to provide two purposive samples for comparison. Another 18 practices were included in the survey following the intervention, to indicate how the participating and matched practices compared to other practices in the area at the end of the intervention. The questionnaire included questions with a yes/no format for quantitative analysis.

Focus groups of members of the participating practices were held at baseline and four months following the start of the intervention. These were run by an independent facilitator, videotaped and transcribed before thematic analysis. The first focus group, at baseline, made up of three GPs, one practice manager and eight district nurses, was asked to describe good and bad experiences of caring for the dying and to rank the key issues or barriers to improvement. The second focus group, which contained three out of twelve different members, was asked to rate these key areas before and after the introduction of the framework and to describe changes and whether the benefits were worth the effort expended.

Analysis

Fisher's Exact test was applied to questionnaire data, comparing participating and matched practices for achievement of the standards at six months. Data was

collected using Excel and analysed using SPSS version 10. Data in the form of focus group transcripts were analysed using the framework process of Tisser and a template method of theme based analysis was followed.^{20,21}

Results

Focus groups

The first Focus Group described good experiences of palliative care included examples of family involvement and support, communication, established relationships, and anticipated needs. Examples of bad experience included poor out-of-hours support for pain relief, disregard for patient and family requests, poor communication with on-call staff and with other services and emergency admission to hospital to die.

“The support that she got between all of us I think was the thing. She died at home which is where she wanted to be and we sort of managed to go with her wishes with no strings.”

“She suddenly deteriorated and this was in the evening over the weekend. An ambulance was summoned on 999 and she was admitted to hospital and died within 24-hours. I think that seems to be very undignified.”

The main issues in improving care of the dying in the community were nominated and ranked by the first focus group:

1. Communication, teamwork within and between teams, staff support and continuity of care out of hours
2. Advanced care planning.
3. Support for carers and families
4. Symptom control

In the second focus group at four months, participants reviewed conclusions from the first meeting and considered progress on the four issues. All participants rated these areas better since the introduction of GSF. Comments indicated that teams regarded changes as positive and worthwhile, here represented by quotes from three participants in the second focus group.

“It’s enabled me to do the job as District Nurse that I had always wanted to do.”

“we feel we are providing a better service for our patients.”

“We’re doing much of it already but it formalises and co-ordinates what we do.”

Questionnaire

The intervention practices reported a change in the use of registers, co-ordination of care and information given to carers.

Figure 1 here

The number of practices in the intervention and matched groups achieving the standards at baseline and at six months is set out in Table 3.

Table 3 here

Significantly more practices in the intervention group achieved each of the six standards compared to the matched group.

The position at follow-up including the achievement of standards by 18 other practices in the area is shown in Figure 2.

Figure 2 here

It appears that the practices in the matched group were similar in terms of achievement of the standards to the other 18 practices who participated in the survey at follow-up.

All intervention practices showed improvement and achieved at least four standards. Eight of them achieved all six. These changes were significantly less marked in 12 matched non-participating practices and, four months after the introduction of GSF, only one had achieved four standards, the majority having achieved only one or two

Discussion

The two methods used in this evaluation, were congruent and reflect the benefits of the intervention on the GSF practice teams. However, this was a small study and selection of the practices was not random. Therefore, it cannot be said that observed benefits are purely an effect of the intervention, independent of the characteristics of study practices. Although focus groups were independently

facilitated and transcribed, the growing enthusiasm for the work by the teams meant that they may not have been unbiased in their responses. One specific contribution that the GSF has made to the care of the dying is that it appears to facilitate at least the collection of data relating to the quality of care provision. All 12 participating practices were using the GSF one year later and now most practices in the study area are using GSF. Nationally, the GSF phased programme has been supported by NHS Cancer Services Collaborative, Macmillan Cancer Relief and currently by NHS End of Life Care Initiative in England. In Scotland, the GSF is supported by a new Opportunities Fund programme. Nearly 3000 practices throughout the UK have taken part, with every Strategic Health Authority, Cancer Network and a majority of Primary Care Trusts in England involved. Ellershaw et al developed the Liverpool Care Pathway for the dying²² to improve care in the last days of life – a modified version was later incorporated into later phases of the GSF as the ‘seventh C’. The NICE guidance recommends “an agreed framework or managed plan of care provided by the primary care team such as the Gold Standards Framework”²³ and wider implementation of GSF was recommended by the House of Commons Health Select Committee Report on Palliative Care July 04.⁸ Qualitative data on the later programme indicates that the GSF continues to change practice in an acceptable way.²⁴

This small study indicated that it is possible to develop some improvements in palliative care delivery by a limited number of primary care teams through the introduction of the Gold Standards Framework, backed by a support programme and some basic resources. However, further evaluation of the national

programme is needed to test the clinical and cost effectiveness of the GSF using patients and carer outcomes measures.

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Table 1 The Gold Standards Framework Support programme

- Information and education on the key tasks and ‘Gold Standards’
- Practice GSF Coordinator, Lead GP and practice manager attend information session with Facilitator and Palliative Care Specialists on implementation of GSF
- Practice visit from Facilitator to assemble register, discuss queries etc
- Resource materials provided ie register, templates, textbooks etc
- Monthly coordinator meetings, plus workshop with evaluation feedback
- Access to advice and support as needed
- Continued central support from Health Authority/PCT for sustaining of GSF

Table 2 Criteria for assessing the achievement of the ‘gold standard’ in the GSF Programme

1. **Communication** – the number of palliative care patients was known, the register was updated, and DS1500s given where appropriate.
2. **Co-ordination** – there was a nominated co-ordinator, had regular meetings (monthly/weekly) to discuss all palliative care patients and use a checklist of tasks.
3. **Control of symptoms** – use of a symptom control assessment tool and appropriate referral to specialist palliative care services.
4. **Continuity out of hours** – send handover form to the out of hours provider for each patient on the register and use/ aware of some of the services available out of hours.
5. **Continuing education** - some educational input, with a practice library or access to resources.
6. **Carer support** - specific support and information given to carers and a carer’s database in the practice for these patients

Table 3**Achievement of standards by intervention and matched practices at baseline and follow-up**

Standard	Baseline		Follow-up		Fisher's Exact Test Significance
	Intervention n = 12	Matched n = 12	Intervention n = 12	Matched n = 12	
Communication	4	1	12	3	p<0.0005
Co-ordination	4	1	11	1	p<0.0005
Control of Symptoms	2	0	9	1	p<0.0015
Continuity	8	7	12	7	p<0.01
Continuing Education	10	7	12	7	p<0.05
Carer Support	0	1	11	1	P<0.0005

Fig 1 A before and after comparison within Intervention practices .

Percentage of intervention practices achieving each gold standard at baseline and follow-up

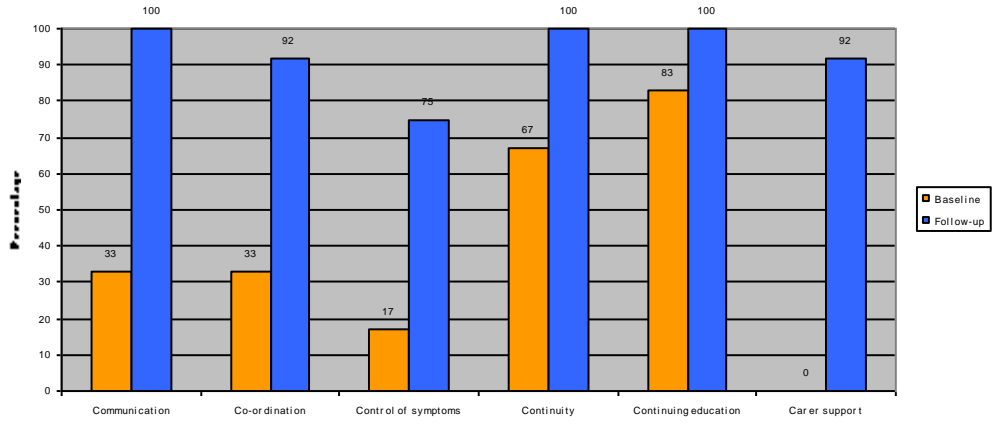
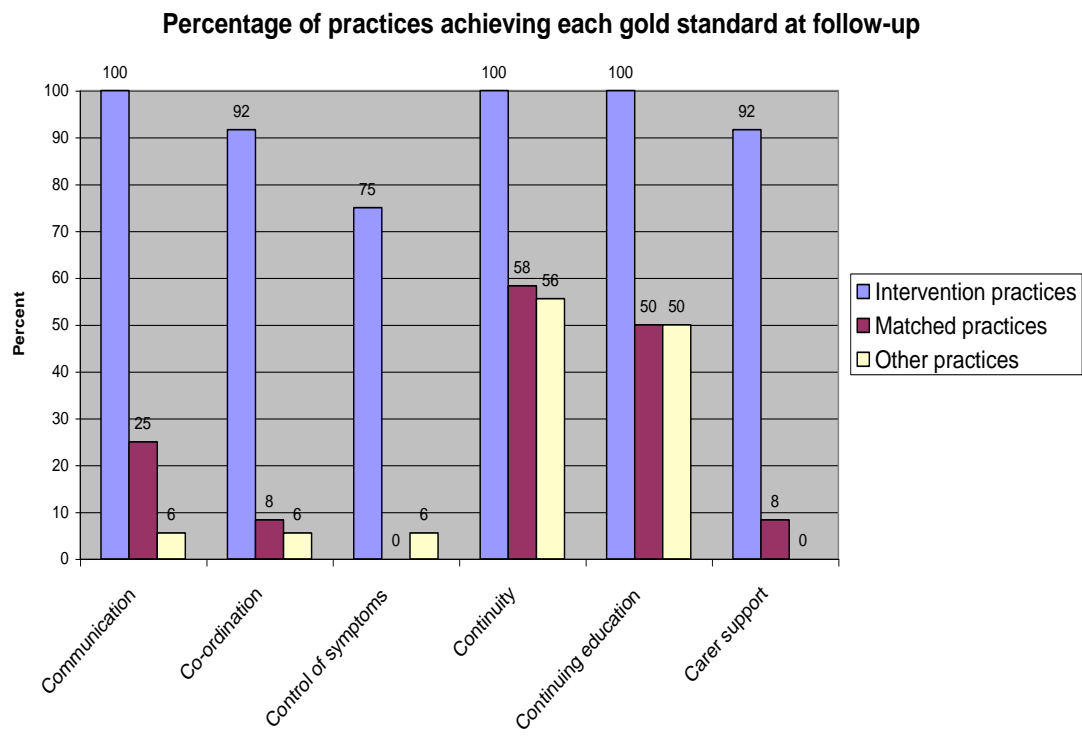


Figure 2



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