

GOLD STANDARDS FRAMEWORK: IMPROVING COMMUNITY CARE

Penny Hansford, Helen Meehan

The Gold Standards Framework (GSF) is a model that enables good practice to be available to all people nearing the end of their lives, irrespective of diagnosis. It is a way of raising the level of care to the standard of the best. Through the GSF, palliative care skills for cancer patients can now be used to meet the needs of people with other life-limiting conditions. The GSF provides a framework for a planned system of care in consultation with the patient and family. It promotes better coordination and collaboration between healthcare professionals. The tool helps to optimise out-of-hours' care and can prevent crises and inappropriate hospital admissions. This article will describe the tool in both the primary care and the care home setting and provide a case example to demonstrate its use in practice. *Conflicts of interest: Penny Hansford none, Helen Meehan is the Lead Nurse on the National GSF Team*

KEY WORDS

Care of the dying
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Communication
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Few aspects of primary and community care are more important and rewarding than enabling a patient to die peacefully at home. Many GPs and district nurses feel that palliative care represents the best aspects of medicine and nursing, bringing together clinical, holistic and human dimensions of management. Caring for the dying and supporting patients near the last stage of life is an important and intrinsic area of community practitioners' work.

Penny Hansford is Director of Nursing, St Christopher's Hospice, London (p.hansford@stchristophers.org.uk), and Helen Meehan is National GSF Lead Nurse, National GSF Team, John Taylor Hospice, Erdington, Birmingham (helen.meehan@solihull-ct.nhs.uk)

Primary care teams deliver the majority of hands-on palliative and supportive care to patients and generally do this in a sound and effective way, especially when backed by specialist palliative care support (Mitchell, 2002). However, although there are many examples of good practice, end-of-life care can sometimes be uncoordinated, inconsistent and reactive, leading to a variable standard of care.

One means of improving the consistency and quality of care within the community is to use the Gold Standards Framework (GSF). The GSF is a model of good practice that enables a 'gold standard' of care for all people who are nearing the end of their lives. It is concerned with helping people live well until they die. It was developed within primary care and has been extended into care homes. This article will provide a general introduction to the GSF.

The development of the GSF

The GSF was developed by Dr Keri Thomas, a GP with a special interest in palliative care, with support from the Cancer Services Collaborative, Macmillan Cancer Relief and the National Lottery (Thomas, 2003). Its initial development was as a framework to be used in primary care. In 2004, it was modified

and reshaped for use in the care home (nursing) setting. Dr Thomas is currently the National Clinical Lead for the Palliative Care and GSF Programme.

The GSF has now been introduced to over a third of GP practices in the UK and is being used as a framework for patients with end-of-life care needs, regardless of diagnosis. Initial evaluation shows that its anticipatory approach to care has positive effects on pain and symptom control and that improved planning, particularly with regard to medication that might be needed out of hours, has enabled some hospital admissions to be averted (King et al, 2005). The GSF has been endorsed by the NHS End of Life Care Programme (www.endoflifecare.nhs.uk) and the National Institute for Health and Clinical Excellence (NICE, 2004). The Government's End of Life Care Strategy, due for publication later this year, will also confirm the GSF as a major tool for improving care at the end of life.

The GSF is not a prescriptive model but a framework that can be adapted according to local needs and resources. It enables teams to build on the good practice already present and provide coordinated care with a more patient-centred focus. It also improves

communication within and between teams. However, the GSF is only part of the jigsaw needed to improve end-of-life care across the healthcare community. Other important factors include:

- ▶▶ Improved advance care planning
- ▶▶ Better patient and carer support
- ▶▶ Communication skills
- ▶▶ Care in the dying phase
- ▶▶ Integrated care pathways (e.g. the Liverpool Care Pathway for the Dying Patient (LCP); Ellershaw and Wilkinson, 2003).

Table 1

The three key processes of the Gold Standards Framework

Identifies patients in need of palliative/supportive care towards the end of life
 Assesses their needs, symptoms, preferences and any issues important to them
 Plans care, particularly with regard to looking ahead for problems that might arise

The GSF in practice

The key strength of the GSF is that it improves organisational systems, communication and the competence of healthcare staff. If implemented effectively it can reduce inappropriate admissions to hospital for a patient's last weeks of life. The GSF is even more necessary now as the new general medical services contract for unscheduled out-of-hours' care focuses on dealing with acute emergencies and is less well placed for meeting the medical, nursing and social needs of dying people (Murray et al, 2004). Tables 1 and 2 list the three key processes of the GSF and its five goals.

The GSF has seven key tasks — the seven Cs. These are explained below.

Communication (C1)

A supportive care register is compiled by each primary care team or individual care home. This register should include

patients identified as having end-of-life care needs. Identification of these patients should be a multidisciplinary decision, involving the GP and nursing staff. The supportive care register is used to record, plan and monitor patient care at regular healthcare team meetings in the practice or care home. In a care home setting all residents are assessed using an ABCD traffic light coding system based on an expectation of prognosis:

- ▶▶ A (blue)=years+
- ▶▶ B (green)=months
- ▶▶ C (yellow)=weeks
- ▶▶ D (red)=days).

Coordination (C2)

A nominated coordinator within the primary care or care home team has designated responsibility as GSF coordinator to oversee the implementation and maintenance of the framework.

Control of symptoms (C3)

Patients'/residents' symptoms, problems and concerns (physical, psychological, social, practical and spiritual) are

Table 2

The five goals of the Gold Standards Framework (GSF)

The goals of the GSF are to provide high-quality care for people in the final months of life by:

- Ensuring patients are well symptom controlled
- Enabling patients to live and die well in their preferred place of care
- Encouraging security and support by better advance care planning involving the patient and their family
- Empowering carers through increased communication, listening and addressing issues proactively
- Educating staff and developing increased competence and confidence

assessed, recorded, discussed and acted upon, according to an agreed process. An anticipatory approach to prescribing, particularly in out-of-hours' situations, is essential to effective care.

Continuity (C4)

All relevant information should be handed over clearly to all involved professionals. This includes the use of an out-of-hours' handover form. This was developed in order that out-of-hours' doctors, nurses and ambulance services have the relevant information, including diagnosis, treatment, up-to-date medication, contact details of family/carers, and the views of the patient regarding care.

Continued learning (C5)

There needs to be a commitment to learning about end-of-life care and developing action plans to meet individuals' identified learning needs. Specialist palliative care providers should have a lead role in the delivery of education. In a care home setting attention must be paid to healthcare assistants who deliver the majority of the physical nursing care. Reflecting on past events, what went well and why, and what did not go well and why, can be a very effective way of learning (Wee and Hughes, 2007).

Carer support (C6)

The needs of carers have to be assessed and appropriate support provided. This includes:

- ▶▶ *Emotional support:* carers are supported, listened to, kept informed and encouraged to play as full a role in the patient's care as they and the patient wish. They are regarded as an integral part of the caring team
- ▶▶ *Practical support:* practical hands-on support is supplied where possible, e.g. provision of a night nurse, respite care, day hospice, equipment, etc.
- ▶▶ *Bereavement support:* practices/care homes plan support strategies, e.g. developing a bereavement protocol.

Meeting the needs of carers is an integral part of high-quality palliative care. Research shows that carers need information, practical help and emotional support (Payne et al, 1999).

Healthcare professionals should be mindful that carers are often unwilling to identify themselves as credible service recipients, as they do not feel they have a legitimate claim on resources (Harding et al, 2002).

Care in the dying phase (C7)

Patients in the last days of life (the terminal phase) are cared for appropriately, e.g. by using the GSF minimum protocol or by implementing the LCP, which encourages the health professional to consider systematically all aspects of patient and family care at this time. This includes stopping non-essential interventions and drugs, considering comfort measures, psychological and religious/spiritual support, bereavement planning, communication and care after death (Ellershaw and Wilkinson, 2003; Preston, 2007). The GSF minimum protocol is a checklist tool for care in the dying phase. It includes prompts for review of medication, notifying out-of-hours' health professionals and an agreed plan of care and communication.

National GSF programmes

There are currently three programmes of work within the GSF (Table 3).

GSF in Primary Care Programme

To date over a third of GP practices (3800) have registered with the national GSF Primary Care Programme. The spread of the programme nationally has been through development of resources and a cascade model of support, with the national team supporting primary care trust (PCT) leads/facilitators. The GSF national team currently supports over 200 GSF facilitators who lead on the development and implementation of GSF within PCTs. Many facilitators have held PCT workshops to support practices, and share information and learning in the GSF. These facilitators are employed by PCTs and many have been funded on fixed-term contracts to support implementation of the GSF. There is also a comprehensive national website, a facilitator's information pack and online support from the central team via email and telephone (see 'Further information').

There are currently four levels of adoption that define the process of implementing the GSF model in primary care. Some practices have implemented GSF to level 1, which includes the supportive care register and having regular practice meetings to plan proactively care for identified GSF patients. However, some practices have fully implemented GSF to level 4, working to all the standards (Table 4). These levels of adoption reflect the seven key tasks, or the seven Cs, of the GSF programme.

The impact of the adoption of the GSF into GP practices has been measured both quantitatively and

qualitatively, including evaluations from Warwick University (Munday et al, 2006). Evaluation of the GSF is ongoing and a more detailed record of national GSF evaluations to date can be accessed from the GSF website (www.goldstandardsframework.nhs.uk). Nationally, evaluation of the GSF in Primary Care Programme has consistently found evidence of improvements in:

- ▶ *Attitude, approach, awareness:* qualitative factors that underpin the culture of practice are hard to measure but are often the most valuable data
- ▶ *Processes and patterns of working:* practical system redesign processes

Table 3

The three programmes of the Gold Standards Framework (GSF)

- **Primary Care Programme:** a framework of multiple tools that can be adopted and adapted within GP practices and supporting community nursing teams to improve end-of-life care. The tools include templates for the supportive care register and advance care planning, assessment tools and guidance on implementation of the framework. It is currently funded through the NHS End of Life Care Programme. The resources are available on the GSF website (www.goldstandardsframework.nhs.uk)
- **GSF for Care Homes Programme:** a framework of multiple tools for end-of-life care in care homes (initially nursing only). These tools include: supportive care register templates; an advance care plan document which includes the residents' resuscitation status; ABCD coding guide to assessing the residents' prognosis; symptom assessment tools; good practice guide for GSF and care homes
- **GSF End-of-life Support Programme:** support for and development of improvements in end-of-life care, including generic tools (e.g. GSF prognostic indicator guidance) and development of local strategies

Table 4

Four levels of adoption within primary care (using the seven key tasks)

- **Level 1:** C1 communication and C2 coordination of care
- **Level 2:** C3 control of symptoms and assessment, C4 continuity of care with out-of-hours' providers and C5 continued learning and reflective practice
- **Level 3:** C6 carer support and C7 care in the dying phase
- **Level 4:** Sustainability of improvements made in end-of-life care through implementation of the GSF

that enable a more structured and formalised approach to provision of care

- ▶ *Outcomes:* reduction in hospital admissions and hospital deaths, more advance care planning discussions.

In 2007, practices registering to the programme have been using a new online 'After death analysis' audit tool. This is being piloted in 2007 in partnership with the University of Birmingham. As well as evaluation of the GSF adoption, the audit tool focuses on real patient outcomes in relation to end-of-life care. Examples of these patient outcomes include consideration of the following questions:

- ▶ Was an advance care plan completed?

- ▶ Did the patient die in their preferred place?
- ▶ Were the symptom control assessment tools used?
- ▶ Was an out-of-hours' form sent?
- ▶ Were anticipatory medications prescribed in the dying phase?

Primary care has a vital role to play in delivering palliative care. Through proactive planning, good coordination and communication, many GSF practices have been able to reduce the number of patients dying in hospital. However, these benefits of the GSF in primary care can only be realised fully when practices adopt all the standards and are working to levels 3 and 4.

Table 5 shows a reactive (pre-GSF) and proactive (post-GSF) patient journey.

GSF in Care Homes (GSFCH) Programme

The GSF in Care Homes (GSFCH) Programme is currently being implemented in over 400 care homes in the UK (Thomas, 2007). These are care homes that incorporate nursing care but the implementation programme will eventually include care homes that are residential. The GSFCH Programme follows the same aims and key tasks as the GSF in Primary Care Programme. The underlying philosophy of the programme is to enable residents to live well until they die. It is about quality of life as well as quality of dying. It also aims to make it more possible for the resident to die in the place of their choice, which for most would mean remaining in the care home. The GSF cannot be implemented effectively outside of this programme.

The GSFCH Programme includes three stages of implementation over a 1–2 year period. The three stages are preparation, implementation and consolidation. The preparation stage includes DVD information and awareness raising. The implementation stage involves four workshops. Workshop one gives an overview of the programme and covers the role of the coordinator and coding on the register. Workshop two concentrates on advance care planning, symptom assessment and managing out-of-hours' care. Workshop three covers education and reflection, carer, family and staff support and care in the final days. Workshop four looks at sustaining change, embedding the tool and developing practice.

The management of the GSFCH includes the support from a local facilitator. This is an ideal role for staff from a local palliative care team to be seconded into as they have specialist knowledge around end-of-life care and will be able to use this to educate the generalist staff. Ongoing facilitation and support is available from the central GSF team, via email, phone and website.

The consolidation stage of the programme will include an accreditation process for the care home. This will involve completion of a self-assessment

Table 5

Reactive (pre-GSF) and proactive (post-GSF; using the seven Cs) patient journey

Mr B: reactive patient journey

- GP and district nurse ad-hoc arrangements: Mr B's preferred place of care and death not discussed or anticipated
- Problems with symptom control causing high anxiety
- Crisis call out of hours: no plan or drugs available in the home
- Admitted to hospital
- Dies in hospital
- Carer given minimal support in grief
- No reflection by primary healthcare team on care given
- Inappropriate use of hospital bed?

Mrs W: proactive patient journey

- On GSF supportive care register: discussed at GSF local practice meeting (C1)
- Benefits advice and information given to patient and carer (C1, C6)
- Regular support, visits, phone calls: proactive care (C1, C2)
- Assessment of symptoms, partnership with specialist palliative care: customised care to patient and carer needs (C3)
- Carer assessed, including psychosocial needs (C3, C6)
- Mrs W's preferred place of care noted, communicated and organised (C1, C2)
- Handover form issued: care plan and drugs issued for home (C4)
- End-of-life care pathway/minimum protocol used (C7)
- Mrs W dies in preferred place of care: bereavement support, staff reflect/audit information, informs future care, team learn (C5, C6)

clinical governance checklist, an after-death analysis audit and an appraisal/visit to the care home. This process will be managed through the national team.

The *Case scenario* (see box) provides an example from a local care home in an early phase of introducing the GSF. This was a care home in which no deaths had occurred over the previous year as dying people who started to deteriorate were routinely admitted to hospital. As can be seen from the case described, the GSFCH can be used to change the culture of a care home. In this case the care home had felt unable to manage the care of a dying resident due to lack of confidence and competence. After the GSF was introduced the care home staff demonstrated that their skill set and confidence had increased. This enhanced the motivation and job satisfaction of the staff.

With its emphasis on education through reflection, coaching, mentoring and education in practice, the GSFCH Programme can improve staff confidence and provide practitioners with a greater awareness of their residents' needs. It has enabled many care homes to plan more effectively by having proactive conversations with residents about their resuscitation and place-of-care wishes. By assessing where a patient is in their illness trajectory, anticipating need, and prescribing medications in advance of being required, patients can be enabled to remain in the place of their choice. In addition, evaluation has demonstrated fewer deaths in hospital, better advance care planning, and improved coordination and communication between healthcare professionals, including the residents' GP (Clifford and Badger, 2007).

GSF End-of-life Support Programme: development of prognostic indicators

The GSF is fully adaptable for patients with a non-cancer diagnosis in need of end-of-life care. Correctly deciding who should be on the GSF supportive care register and identifying patients/residents with end-of-life care needs is fundamental to the effective

implementation of the GSF. About 1% of the population die each year (National Statistics Office, 2007), yet it is very difficult to predict or identify which patients may be in their last year of life (Oxenham and Cornbleet, 1998). The premise that the GSF is built upon is that if healthcare professionals can better identify these patients they will be able to provide more effective end-of-life care.

The GSF has developed prognostic indicator guidance, which has been endorsed by the Royal College of

General Practitioners (GSF, Royal College of General Practitioners, 2006). The guidance suggests a trigger question for when a patient might benefit from supportive/palliative care. The trigger question or surprise question as it has become known is: 'Would you be surprised if this patient were to die in the next 6–12 months?' This is an intuitive question and in answering it comorbidity, social and other factors need to be taken into account. For example, is the patient's functional status in decline? What is the patient's nutritional status?

Case scenario

Mrs F was discharged to a care home from hospital following a cerebrovascular accident. The care home was part of the GSF Care Homes Programme. On admission to the home Mrs F's prognosis was coded, i.e. a nurse assessed her possible prognosis, and she was placed on the GSF supportive care register as she was not expected to live many months. A proactive conversation took place between the care home staff, Mrs F and her two daughters. Mrs F and her daughters were clear that Mrs F did not want to go back into hospital and an advance care plan was produced. This is a document that enables a resident and staff to consider the resident's wishes about future place of care and treatment options. This forward planning can prevent unnecessary hospital admissions and enable the resident to be cared for in the place of their choice. Mrs F was referred to the palliative care team for symptom control.

Mrs F became increasingly frail and a month after entering the home she developed a severe chest infection. She could not take oral medication and needed to receive her medication via a syringe driver. The care home staff had recently received training in the use of syringe drivers and also in the care needs of people in the last days of life. Mrs F's family were supported during Mrs F's final days. Her daughters and grandchildren were with her when she died. Her death was very peaceful.

The end-of-life care training given to the home since joining the GSF had enhanced the staff's skill to care for patients. In this particular case the key was that they had recently been trained in the use of syringe drivers. They had the knowledge fresh in their minds and using the syringe driver in the clinical setting reinforced the learning they had gained.

Since this episode there have been a number of occasions where residents have been able to die in the home instead of being rushed to hospital. Therefore, the organisational systems and staff training have enabled other residents to have 'good deaths' in the home surrounded by family and the staff that know them. The Commission for Social Care Inspectorate (CSCI) inspector for the home recently commented that she was impressed by the new approach to end-of-life care evident in the staff, with new skills and greatly increased confidence being displayed.

The guidance also outlines specific indicators of advanced disease for each of the three main end-of-life patient groups, i.e. cancer, organ failure and elderly frail/dementia. The prognostic indicator guidance can be accessed through the GSF website given at the end of the article.

Palliative care specialists and the GSF

Palliative care specialists, including doctors, nurses and hospice staff, play a key role in the support and delivery of the GSF, and it is vital to involve them in the implementation process. Their central role in delivering and improving community palliative care services will be greatly enhanced by their support for primary care teams or care homes in using the GSF. Only by real collaboration between generalists and specialists will effective improvements in community palliative care be made.

At St Christopher's Hospice in South London, the specialist community teams are actively involved in introducing the GSF both into care homes and primary care and the hospice has first-hand experience of seeing what a positive difference this tool can make. It has created considerably stronger partnerships with primary care and opportunities for education and training. This has occurred not just through formal teaching sessions but through the regular GSF meetings when palliative care patients are discussed. For care homes, St Christopher's now has a clinical nurse specialist linked to each home and is working towards each of its community teams having a caseload of patients solely in a care home setting.

Conclusion

The GSF has been developed to support teams working in the community to deliver proactive, coordinated care for their patients. It helps to improve care by introducing the ideals of palliative care into standard practice and is a key part of improving end-of-life care for everyone. The GSF is only part of the solution to improving end-of-life care across a whole health community. Other developments include integrated

care pathways, advance care planning and the forthcoming national End of Life Care Strategy. However, the GSF can support and enable better care along the whole patient journey and contribute to an improvement in end-of-life care in the UK. **EOLC**

Further information

Administrator: Judy Simkins
National GSF Team
John Taylor Hospice
76 Grange Road
Erdington
Birmingham B24 0DF
Tel: 0121 465 2028
Email: judy.simkins@benpact.nhs.uk
www.goldstandardsframework.nhs.uk

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Key Points

- » The Gold Standards Framework (GSF) aims to enable teams to work proactively in order to anticipate patients' needs and reduce the number of end-of-life care crisis admissions to hospital.
- » The introduction of the GSF enables people to die in the place of their choice.
- » The GSF improves communication between patients, families and professionals.