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Information management and quality of palliative care in General Practices: secondary analysis of a UK study

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Abstract

Palliative care seeks to improve quality of life for patients with terminal, chronic or life-long, illnesses. In the UK, most palliative care occurs in primary care, e.g., through General Practices. A recent national UK survey of palliative care within General Practices concluded that practices which utilized recognized initiatives to promote palliative care demonstrated better clinical care and higher perceived quality of palliative care. This paper reports on secondary analyses from this survey to investigate the management of information related to palliative care within practices. Relatively high levels of information provision to families and carers were reported, over two-thirds of practices reported having unified records for palliative care patients and over 90% of practices reported having a cancer/ palliative care register that was fully or mostly operational. Larger practices, those using the Gold Standards Framework (GSF) and practices using unified record keeping for palliative care, were independently more likely to give information or families and carers and were more likely to have a mostly or fully operational palliative care register. When testing for the relationship between measures of the structures and processes of information management and the perceived quality of care, as an outcome, within the practices, practices with a fully operational palliative care register and practices that had higher scores on the record-keeping scale were more likely to rate the quality of their palliative care as very good.

Keywords

General Practice; information management; palliative care; quality of care

1. Introduction

1.1. Background

The aim of palliative care is to improve the quality of life for patients with life-limiting and long-term diseases. Palliative care includes all aspects of care, including pain management, symptom control, psychological and spiritual support and is often provided by multidisciplinary teams in the UK. While palliative care is often associated with cancer, it care is also important for patients with other conditions, including chronic heart failure and neurological conditions. Within the UK, most palliative care takes place in primary care settings, e.g., General Practice or community health centres, delivered by primary health care teams with or without specialist input, although

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historically, hospices have been the setting for specialist palliative care. Palliative care has been given a low priority in the past but with people living longer it is increasingly important [1]. Improving palliative care has become a focus worldwide and the UK National Institute of Health and Clinical Excellence (NICE) has published guidance for improving palliative care for cancer patients [2]. In 2008, the publication of the End of Life Care Strategy by the UK Department of Health aimed to increase the profile of end of life care and to ensure patients receive high quality care [3]. The ageing population and the increasing demands for higher quality, personalised care are increasing health care costs. Historically, palliative care has been under-funded but is now being given greater priority.

Measuring quality of care is difficult and there is discussion on the best markers to use. The NICE report [2] highlighted the importance of information for decision-making and the need for cancer patients to receive adequate information. A recent national survey of the provision of palliative care in UK General Practices [4] concluded that practices that have systems in place that are in accordance with national guidance are more likely to provide clinical care that is in accordance with guidance. The study also suggested that the adoption of recognized initiatives to promote palliative care in General Practices was associated with better clinical care and higher opinions of the quality of palliative care that they provided. However, although data were collected on various aspects of the management of information and the information systems within the practices [4], the relationship between the attributes of the practices and the use of information and the relationship between the use of this information and the quality of palliative care provision were not explored.

1.2. Research aims and objectives

The aim of the research was to undertake a secondary analysis of this UK-wide survey of palliative care in primary care [4] to examine how information relating to patients receiving palliative care is managed in general practices. The objectives of the study were:

- To examine the structures and processes of information management for palliative care within primary care;
- To identify factors associated with these structures and processes in this context;
- To analyse the relationship between information management and quality of palliative care, as an outcome, within General Practice.

The paper is divided into a number of sections: section 2 provides background information for the interested reader, while section 3 describes the national survey and the analyses that were undertaken for this study. The results of the secondary analyses are presented in section 4 and are discussed in section 5.

2. Background

This part of the paper reviews recent policy on palliative care in the UK and its role in primary care, then proceeds to describe developments to improve the quality of palliative care and the role of information management in this area.

2.1. UK policy on Palliative Care

The 2003 End of Life Care Programme and the 2008 End of Life Care Strategy encouraged more consideration about the dying process and the quality of care provided to dying patients. The End of Life Care Strategy recommended the monitoring of care and evaluation of new initiatives. The End of Life Care Programme encouraged the use of initiatives including the Gold Standards Framework (GSF), Liverpool Care Pathway (LPC) and Preferred Place of Care (PPC). Stakeholders in the Programme felt it had encouraged a new way of thinking about palliative care and was an important start in improving care [5]. The NICE guidance for ‘improving supportive and palliative care for adults with cancer’ identified areas that are important for care and gave recommendations for changes to improve the service received by patients [2]. These include the need for patients and carers to be kept informed, for communication to improve and the resulting decisions to be recorded and for better information sharing between the healthcare team. This guidance also highlights the need to monitor and audit services to enable future developments [2]. These policy and guidance documents all identify the need to prioritise end of life care and enable patients to have a dignified death that meets their wishes. The guidance acknowledges that the quality of care is not consistent across the UK but notes that the profile of palliative care has been raised over the last 10 to 15 years. This has also been a general period of change for the NHS, beginning with the White Paper, “The new NHS: modern, dependable” [6], which laid out a plan to improve and modernize care to meet patients’ needs.

2.2. Palliative care in primary care

With the emphasis on giving patients choice over their care and place of death [3] and the majority of patients wanting to die at home [7], there is debate over the position of palliative care within primary care [8,9], with calls for maintaining palliative care in general practice [10]. The majority of patients do not need complex care delivered by a hospice but need well-trained staff delivering basic care. Patients may receive palliative care for over a year [11] and increased continuity of care has been associated with a decreased chance of dying in hospital [12]. GPs are in a position to build a relationship with patients and are better placed to meet the needs of family and carers as well [13].

Groot et al. examined the difficulties that GPs face in delivering palliative care in the Netherlands and found that bureaucracy and involving other care providers were felt to make care more difficult [14]. GPs felt more confident if they had more palliative care experience and were able to discuss care, suggesting that investment in general practice expertise can have a positive impact [14]. Although GPs may lack confidence in providing palliative care, GPs regard this part of their work as rewarding [15]. Mitchell reported that where communication was effective patients felt that GPs delivered good care in the community, but there was room for improvement compared to specialist palliative care [15].

Providing more resources to primary palliative care has been advocated [8], but it is recognized that it must be backed up with evidence, and further research is needed to ensure that community care is delivered appropriately and that primary care is not overlooked [16].

2.3. Initiatives to improve quality of palliative care

Several initiatives have been developed and General Practices have been encouraged to utilise them under the End of Life Care Programme [3]. The Gold Standards Framework (GSF) was developed to improve palliative care in general practice [17]: this was structured under 7 'C's, which include communication, coordination and continuity. These are all aimed at improving the organisation and information management of practices, and so improving the care received by palliative care patients. They aim to identify patients needing palliative care, meet the needs of the patient and plan and prepare for future care. The GSF also involves auditing care, so requires that information is recorded, collected and analysed to improve care [17].

One study assessed the efficacy of the initial implementation and reported that communication and advanced care planning had improved under the GSF [18]. Another study investigated the communication between GPs and district nurses within practices following the GSF [19]. Information sharing was considered valuable and generally felt to have improved since the implementation of the GSF. Informal communication was highlighted by GPs and suggested to be more important than formal meetings. It was also reported that staff felt that they provided high quality care without having implemented many of the features of the GSF. Although this was self-reported, it emphasizes the need to continue to assess the value of these initiatives. Dale et al. investigated the impact of the GSF and factors associated with any changes [20]. They found that the most change occurred in processes relating to coordination and communication. After 12 months over 90% of practices had a register for palliative care patients, when only 23% had a register at the start. They did not find any association between improvements and the size, type or location of practices. These authors concluded that the extent of improvements related more to staff motivation and the attitude of the team. The level of care is greatly affected by the enthusiasm of the staff involved [21].

A further initiative, the Liverpool Care Pathway (LCP), was developed to improve end of life care for patients. It is usually only used in the patient's last few days and ensures that the whole team record their notes in one place and gives guidance for continuing assessment of the patient [22]. The effect of the LCP in the Netherlands has been studied and was found to improve documentation and that, with symptoms also controlled better, it improved care for people who were dying [23]. A significant change in communication with the family was not found, but this was largely because communication was already reported as good before the LCP was used. The improvement in documentation supports the use of the LCP for organizing care and allowing the outcomes to be assessed. This is supported by a review of the literature [24], which concluded that integrated care pathways can improve the quality of team working in palliative care and contribute to continuity of care. The outcomes recorded in the LCP could be used for benchmarking and identifying areas for improvement [25].

2.4. Information Management

The NHS information strategy, 'Information for Health' [26], aimed to improve access to information for both health professionals and patients, and to provide information for those planning care. More recently, the Darzi review set out a plan to improve care within the NHS [27]. This highlighted the need for patient choice and access to information to make the best decisions. This involves information for care and reporting of outcomes to enable an assessment of quality and improvement to be made [27]. This showed that within the UK there is an increasing recognition that information is important and can enable an efficient and high quality service. Similarly, in the USA, guidelines have emphasised the need for better recording and access to patient information, and regular auditing of care [28].

Provision of information to patients and carers is increasingly being seen as improving care and empowering patients [27]. The amount of information desired by cancer patients varies according to the individual needs of the patient [29,30] and some information may be confusing so patients may rely on information given by their doctor. Older people may rely on GPs for information and consider that it is the role of the doctor to find the information for them [31]. Patients may be wary about bringing information to doctors and how this affects the role of patient and doctor. Information provision by GPs may therefore have an important impact on patients and carers who would not otherwise obtain information. However, cancer patients way wish to learn from the experience of other cancer sufferers [32]. When information is provided the quality may not always be high and so it does not necessarily improve decision-making [33].

A systematic review examining the information needs of carers within palliative care situations found that there are areas, such as pain management, that carers would like more information about [34] and that the quality of communication between health professionals and carers greatly impacted on the level of understanding and knowledge of carers. This suggests that both these aspects need to be prioritized to ensure that information is shared effectively, especially as providing better information was found to reduce carers' concerns and improve their handling of the situation.

A recent review highlighted the need to develop an evidence base to support the use of health informatics and health information management and to measure its effect on patient health and well-being and quality of care [35]. Donabedian, a leading figure of quality assurance within public health in the twentieth century, characterized the quality of health care and health services in terms of the structures (e.g. number of doctors in a health care unit), processes (e.g. number of hip replacements carried out over a period of time) and outcomes (e.g., hospital re-admission rates) [36]. Similarly, it is important to understand the structures, e.g., existence of cancer registers within a health service, and processes, e.g., the provision of information to patients and carers, associated with information and communication technologies (ICTs) and information management within health settings as these can have a bearing on the quality of care provided [35]. Taking this a step further, i.e., to analyse the relationships between the information structures and processes and health outcomes will help to develop an evidence base in health information management and health informatics. With this in mind, here we report on a study to examine the factors associated with the structures and processes of information management for palliative care within primary healthcare and examine their relationship with outcomes in terms of quality of care.

3. Methods

3.1. Introduction

This study undertook secondary analysis of data that had been collected and analysed previously as part of a national study of palliative care provision in the UK [4]. That study investigated the implementation of national guidance on end of life care in UK general practices. Questionnaires from 2096 practices were collected, giving a response rate of 60%. As well as being a high response rate for a postal survey, this gave us confidence that the sample was representative of the population of practices in the UK and that the results are generalizable to general practices throughout the UK. The full details of the data collection and findings have been reported elsewhere [4]. However, to give a full picture of this research for the secondary analyses described here, a description of the necessary relevant data is provided in section 4. This research used the data from the questionnaires to investigate further the information management aspects of palliative care.

3.2. Secondary analyses

Questions from the questionnaire relating to information management were used as the focus for the analyses. These related to the provision of information to family and carers (a measure of process), the development of a palliative care register (a measure of structure) and the extent of record keeping for palliative care (measuring both structures and processes) within the practices. The latter included six questions relating to how often the patient's wishes, spiritual beliefs, preferred place of care/death and details of families and their insights into the patient's conditions were recorded. The responses to these questions were used to create a record-keeping scale, the higher the score on this scale, the more often the practice included all the information in patients' records, and therefore, the more comprehensive was the record keeping. Data from a further question on to how practices rated their quality of palliative care were also utilised.

Descriptive statistics were used initially to examine the distribution of the data, before Chi^2 tests were used to test for associations between characteristics of the practices and the information-related variables, i.e., provision of information, the development of a palliative care register.

Variables that had a level of significance (*p* value) of <0.1 were entered into separate logistic regression models for the provision of information to families and carers and the stage of development of a palliative care register. A forced entry method of variable selection was used to identify the factors that were independent predictors of these two dependent variables.

A final series of analyses tested for the association between the information variables and the quality of palliative care and a final logistic regression model was used to identify which of these factors were independent predictors of quality of palliative care.

For those unfamiliar with this type of analysis, logistic regression is a statistical method of multivariate analyses, in which several independent, or predictor, variables are entered into a model to identify which are significantly, and independently, associated with a binary dependent, or outcome, variable. Odds ratios (OR), 95% confidence intervals (CI) and *p* values are calculated for each continuous independent variable, and for each category within a categorical variable relative to a reference category, in relation to the dependent variable. An odds ratio greater (less) than one indicates an increased (decreased) chance of the outcome of interest for each unit increment in a continuous variable, or increased (decreased) chance of the members of that category having the outcome of interest compared to members of the reference category. The 95% CI give the range within which the researcher can be 95% confident that the odds ratio lies. This is related to the *p* value in that if the *p* value is less than 0.05, then the 95% CI will not include unity, from which it can be inferred that the OR is significantly greater (or less than) than 1. Examples to illustrate this are described in relation to the results presented in section 4.2.

Variables were re-coded where necessary to ensure that the cell sizes were sufficient and to permit the use of binary variables for logistic regression. Statistical Pack for the Social Sciences (SPSS) was used for the analyses.

4. Results

4.1. Characteristics of the sample

The descriptive data from the 2096 practices have been reported previously [4], and are summarised here for completeness. Following exclusion of missing data, the data were analyzed for factors affecting information management for palliative care in general practices, for factors and the effect of information management on the quality of care received by palliative care patients.

Table 1 shows the characteristics of the practices within the sample. The majority of practices in the survey were located in England (80.8%). The mean number of patients per practice was 6769.7 (Standard Deviation (SD)=3956.43), and the mean number of GPs in a practice was 4.6 (SD=2.64). The highest proportion of practices was in urban areas (35.8%) and the remaining practices were fairly evenly split between rural (20.3%), suburban (20.8%) and mixed (23.1%). Half of the practices (50.4%; n= 1035) rated the quality of their palliative care as good and a further 23% rated it as very good.

Table 1: Number of practices located within each area of the UK

Variable	Category	N (%)
Country	England	1692 (80.8)
	Wales	94 (4.5)
	Scotland	235 (11.2)
	Northern Ireland	73 (3.5)
	Total	2094* (100.0)
Number of GPs	1	187 (9.0)

in practice	2	324 (15.5)
	3	338 (16.2)
	4	298 (14.3)
	5	277 (13.3)
	6	228 (10.9)
	7	154 (7.4)
	8	110 (5.3)
	9	69 (3.3)
	>10	103 (4.9)
	Total	2088* (100.0)
Type of area	Rural	422 (20.3)
	Urban	745 (35.8)
	Suburban	434 (20.8)
	Mixed	481 (23.1)
	Total	2082* (100.0)
Self-rating the quality of palliative care	Very poor	3 (0.1)
	Poor	31 (1.5)
	Satisfactory	515 (25.1)
	Good	1035 (50.4)
	Very good	471 (22.9)
	Total	2055* (100)

* Where the total is less than 2096, this is where some practices did not provide a response to this question.

Table 2 shows the responses provided by practices as regards their management of information. Most practices (72.0%) gave information to family and carers in some or most cases, but only 17.9% of practices gave information in every case. Approximately two-thirds of practices used unified records for palliative care patients and almost two-thirds of practices (65.8%) reported having an operational and up-to-date cancer register or supportive and palliative care register that was fully operational.

Table 2: Frequency of practices giving family and carers appropriate written information, having a unified record for palliative care patients and progress made to having a cancer register or palliative care register.

Variable	Category (recoded)	N (%)
Information provided to families / carers	In every / in most / some case(s)	1826 (90.0)
	Rarely or never	203 (10.0)
	Total	2029 (100)
Unified records for palliative care patients	No	661 (32.4)
	Yes	1379 (67.6)
	Total	2040 (100)
Progress made towards an operational and up-to-date cancer register or supportive and palliative care register	No register / Little progress	65 (3.2)
	Partly operational	140 (6.7)
	Mostly operational	505 (24.3)
	Fully operational	1369 (65.8)
	Total	2079 (100)

Table 3 shows the distribution of responses regarding the recording of information about palliative care patients and their families and carers within the practice.

Table 3: Frequency of practices recording information about palliative care patients and their families.

Care plans included in the records of palliative	In every case	422 (20.6)
	In most cases	718 (35.0)

care patients	In some cases	592 (28.8)
	Rarely or never	320 (15.6)
	Total	2052 (100)
Patients' wishes or spiritual beliefs concerning the dying process recorded	In every case	270 (13.2)
	In most cases	686 (33.6)
	In some cases	733 (35.9)
	Rarely or never	354 (17.9)
	Total	2043 (100)
Preferred place of care/place of death recorded	In every case	522 (25.5)
	In most cases	898 (43.9)
	In some cases	453 (22.1)
	Rarely or never	173 (8.5)
	Total	2046 (100)
Named family or carer with whom care can be discussed and coordinated recorded	In every case	679 (33.2)
	In most cases	944 (46.1)
	In some cases	341 (16.7)
	Rarely or never	83 (4.1)
	Total	2047 (100)
Family/carers' insights into the patient's condition recorded	In every case	303 (14.9)
	In most cases	879 (43.3)
	In some cases	631 (31.1)
	Rarely or never	215 (10.6)
	Total	2028 (100)
Evidence of impending death Recorded	In every case	412 (20.2)
	In most cases	1055 (51.8)
	In some cases	451 (22.2)
	Rarely or never	118 (5.8)
	Total	2036 (100)

The items in Table 3 were used to construct a scale measuring the total level of record-keeping on palliative care. This scale had good internal reliability (Cronbach's a = 0.775), and was used in the logistic regression model to predict quality of palliative care. However, in a linear regression model, the other variables relating to practice characteristics and information management had poor predictive power for this scale, accounting for only l3.2% of the variance in the record-keeping scale, and so are not reported further here.

4.2. Provision of information to family and carers

The variable recording whether the practice gave appropriate written information to family and carers of patients receiving palliative care was recoded into those practices who reported giving it rarely or never and those who gave it in every/most/some cases. χ^2 tests were used to measure the significance of any associations between whether information is given to family and carers and the practice characteristics and other independent variables. The frequency distributions for this are shown in Table 4.

Of the 14 variables detailed in Table 4, the following eight variables reached the threshold *p* value of <0.1 to be included in the logistic regression model: the presence of a GP with a medical post in hospice or palliative care within the practice (χ^2=3.75; degrees of freedom (df) =1; p=0.053), whether a practice has a GP holding a special interest post in palliative care (χ^2=3.45; df=1; p=0.063), use of the Preferred Place of Care initiative (χ^2=3.13; df=1; p=0.077), whether appropriate written information was provided for family and carers and the number of patients in a practice (χ^2 =21.29; df=1; p < 0.001), the number of GPs working in a practice (χ^2=26.91; df=1; p < 0.001), use of the Gold Standards Framework (χ^2=27.23; df=1; p < 0.001), use of the Liverpool Care Pathway (χ^2=7.19; df=1; p=0.007), use of unified record keeping=26.70; df=1; p < 0.001).

Table 4: Cross-tabulation of information provision to families and carers according to practice variables

		Practices that give family and carers appropriate written information, n (%)		
Variable	Category	In every/most/some	Rarely or never	Total

		cases		
UK area	England	1473 (90.2)	160 (9.8)	1633 (100.0)
	Wales	79 (88.8)	10 (11.2)	89 (100.0)
	Scotland	211 (90.2)	23 (9.8)	234 (100.0)
	Northern Ireland	61 (85.9)	10 (14.1)	71 (100.0)
Total		1824 (90.0)	203 (10.0)	2027 (100.0)
No. of GPs	1	145 (82.4)	31 (17.6)	176 (100.0)
	2	263 (84.8)	47 (15.2)	310 (100.0)
	3	295 (89.7)	34 (10.3)	329 (100.0)
	4	267 (92.7)	21 (7.3)	288 (100.0)
	5	242 (89.6)	28 (10.4)	270 (100.0)
	6	204 (92.7)	16 (7.3)	220 (100.0)
	7	133 (89.3)	16 (10.7)	149 (100.0)
	8	105 (96.3)	4 (3.7)	109 (100.0)
	9	65 (94.2)	4 (5.8)	69 (100.0)
	>10	99 (98.0)	2 (2.0)	101 (100.0)
Total		1818 (90.0)	203 (10.0)	2021 (100.0)
Macmillan GP Clinical Facilitator Post	No	1747 (90.0)	195 (10.0)	1942 (100.0)
	Yes	35 (89.7)	4 (10.3)	39 (100.0)
Total		1782 (90.0)	199 (10.0)	1981 (100.0)
Medical post in hospice or palliative care	No	1689 (89.6)	197 (10.4)	1886 (100.0)
	Yes	97 (96.0)	4 (4.0)	101 (100.0)
Total		1786 (89.9)	201 (10.1)	1987 (100.0)
Special interest post in palliative care	No	1679 (89.5)	196 (10.5)	1875 (100.0)
	Yes	106 (95.5)	5 (4.5)	111 (100.0)
Total		1785 (89.9)	201 (10.1)	1986 (100.0)
GP with a Diploma or Master’s in palliative care	No	1700 (89.7)	196 (10.3)	1896 (100.0)
	Yes	84 (95.5)	4 (4.5)	88 (100.0)
Total		1784 (89.9)	200 (10.1)	1984 (100.0)
Other managerial or academic post related to palliative care	No	1718 (89.8)	195 (10.2)	1913 (100.0)
	Yes	65 (92.9)	5 (7.1)	70 (100.0)
Total		1783 (89.9)	200 (10.1)	1983 (100.0)
Location type	Rural	372 (90.7)	38 (9.3)	410 (100.0)
	Urban	633 (88.2)	85 (11.8)	718 (100.0)
	Suburban	375 (88.9)	47 (11.1)	422 (100.0)
	Mixed	435 (93.1)	32 (6.9)	467 (100.0)
Total		1815 (90.0)	202 (10.0)	2017 (100.0)
GSF use	No	652 (85.5)	111 (14.5)	763 (100.0)
	Yes	1174 (92.7)	92 (7.3)	1266 (100.0)
Total		1826 (90.0)	203 (10.0)	2029 (100.0)
Use of LCP	No	1359 (88.9)	169 (11.1)	1528 (100.0)
	Yes	467 (93.2)	34 (6.8)	501 (100.0)
Total		1826 (90.0)	203 (10.0)	2029 (100.0)
Use of ACP	No	1666 (89.7)	191 (10.3)	1857 (100.0)
	Yes	160 (93.0)	12 (7.0)	172 (100.0)
Total		1826 (90.0)	203 (10.0)	2029 (100.0)
Use of PPC	No	1589 (89.5)	186 (10.5)	1775 (100.0)
	Yes	237 (93.3)	17 (6.7)	254 (100.0)
Total		1826 (90.0)	203 (10.0)	2029 (100.0)
Unified record Keeping	No	547 (84.9)	97 (15.1)	644 (100.0)
	Yes	1241 (92.5)	101 (7.5)	1342 (100.0)

Total	1788 (90.0)	198 (10.0)	1986 (100.0)

Variables that were significantly associated with the family/carers rarely or never being given written information were entered into a logistic regression model using a Forced entry method of variable selection. Table 5 shows the logistic regression model for the variables associated with information being given rarely or never to family or carers.

Table 5: Logistic regression model for factors associated with appropriate written information being given rarely or never to family and carers

Variable (reference category)	Category	Odds Ratio (OR)	95% C.I. for odds ratio Lower	Upper	*p*
No. of GPs		0.864	0.81	0.93	<0.001
GP with a medical post in hospice or palliative care (Yes)	No	1.662	0.59	4.70	0.338
GP with a special interest post in palliative care (Yes)	No	1.435	0.56	3.65	0.449
Demographic area (Rural)					0.266
	Urban	1.317	0.87	2.00	0.193
	Suburban	1.246	0.78	1.99	0.358
	Mixed	0.894	0.54	1.48	0.662
Use of GSF (Yes)	No	1.646	1.20	2.25	0.002
Use of LCP (Yes)	No	1.328	0.86	2.05	0.199
Use of PPC (Yes)	No	0.968	0.54	1.74	0.912
Unified record keeping in the practice? (Yes)	No	1.940	1.43	2.64	<0.001

Most of the variables in the model were not significantly associated with information being given rarely/never but if a practice did not use the Gold Standards Framework (GSF) it was more likely to give information rarely or never to families and carers (Odds Ratio (OR)=1.65; 95% CI 1.20, 2.25; p=0.002). Using the description of logistic regression, etc., provided at the end of section 3, this can be interpreted that practices not using the GSF were 1.65 times (or 65%) more likely to provide information rarely/never compared with practices that used the GSF. Further, we can be 95% confident, that this value lies between 1.2 times (or 20%) and 2.25 times (or 125%) more likely. As this range does not include 1.00 (or 0%), it can be assumed it is a significantly increased risk, this is confirmed by the very low *p* value.

Practices with no unified record keeping were almost twice as likely to give out information only rarely or never (OR=1.94; 95% CI=1.43, 2.64; p<0.001) compared with practices that did not have unified record keeping. The number of GPs within a practice was a significant predictor of providing information to families or carers (OR=0.864; 95% CI 0.81, 0.93; p=0.000): i.e., with each increase in the number of GPs in the practice there was a reduced (14% less) chance of information being given rarely/never. In other words, more GPs in a practice meant there was a greater likelihood of information being given in every/some/most cases.

4.3. Progress towards an operational register

The dependent variable, progress made towards an operational palliative care register, was grouped to identify factors relating to little or no progress, as shown in Table 6. The χ^2 test was used to analyse the level of significance of any relationships with practice characteristics or organization.

Table 6: Cross-tabulation of progress towards an operational patient register according to practice variables

		No. of practices (%) reporting the extent of progress made towards an operational patient register		
Variable	Category	No/little/partial progress	Mostly/fully operational	Total
UK area	England	180 (10.7)	1501 (89.3)	1681 (100.0)
	Wales	9 (9.8)	83 (90.2)	92 (100.0)
	Scotland	13 (5.6)	219 (94.4)	232 (100.0)
	Northern Ireland	3 (4.2)	69 (95.8)	72 (100.0)
Total		205 (9.9)	1872 (90.1)	2077 (100.0)
	<2000	14 (10.9)	115 (89.1)	129 (100.0)

	2000-3999	57 (12.9)	386 (87.1)	443 (100.0)
	4000-5999	51 (12.6)	354 (87.4)	405 (100.0)
	6000-7999	35 (10.0)	314 (90.0)	349 (100.0)
	8000-9999	25 (9.0)	254 (91.0)	279 (100.0)
	10000-11999	9 (4.1)	208 (95.9)	217 (100.0)
	12000-13999	6 (4.8)	118 (95.2)	124 (100.0)
	>14000	2 (2.3)	86 (97.7)	88 (100.0)
Total		199 (9.8)	1835 (90.2)	2034 (100.0)
No. of GPs	1	25 (13.5)	160 (86.5)	185 (100.0)
	2	49 (15.4)	269 (84.6)	318 (100.0)
	3	34 (10.1)	302 (89.9)	336 (100.0)
	4	37 (12.5)	260 (87.5)	297 (100.0)
	5	26 (9.4)	251 (90.6)	277 (100.0)
	6	18 (8.0)	206 (92.0)	224 (100.0)
	7	3 (2.0)	149 (98.0)	152 (100.0)
	8	3 (2.7)	107 (97.3)	110 (100.0)
	9	5 (7.2)	64 (92.8)	69 (100.0)
	>10	5 (4.9)	98 (95.1)	103 (100.0)
Total		205 (9.9)	1866 (90.1)	2071 (100.0)
Macmillan GP Clinical Facilitator Post	No	201 (10.1)	1789 (89.9)	1990 (100.0)
	Yes	1 (2.6)	38 (97.4)	39 (100.0)
Total		202 (10.0)	1827 (90.0)	2029 (100.0)
Medical post in hospice or palliative care	No	197 (10.2)	1736 (89.8)	1933 (100.0)
	Yes	5 (4.9)	97 (95.1)	102 (100.0)
Total		202 (9.9)	1833 (90.1)	2035 (100.0)
Special interest post in palliative care	No	197 (10.2)	1727 (89.8)	1924 (100.0)
	Yes	5 (4.5)	105 (95.5)	110 (100.0)
Total		202 (9.9)	1832 (90.1)	2034 (100.0)
GP with a Diploma or Master's in palliative care	No	196 (10.1)	1746 (89.9)	1942 (100.0)
	Yes	5 (5.6)	84 (94.4)	89 (100.0)
Total		201 (9.9)	1830 (90.1)	2031 (100.0)
GP any other managerial or academic post related to palliative care	No	197 (10.1)	1762 (89.9)	1959 (100.0)
	Yes	4 (5.6)	67 (94.4)	71 (100.0)
Total		201 (9.9)	1829 (90.1)	2030 (100.0)
Location type	Rural	44 (10.5)	377 (89.5)	421 (100.0)
	Urban	76 (10.3)	661 (89.7)	737 (100.0)
	Suburban	41 (9.5)	390 (90.5)	431 (100.0)
	Mixed	41 (8.6)	437 (91.4)	478 (100.0)
Total		202 (9.8)	1865 (90.2)	2067 (100.0)
GSF use	No	112 (14.1)	684 (85.9)	796 (100.0)
	Yes	93 (7.2)	1190 (92.8)	1283 (100.0)
Total		205 (9.9)	1874 (90.1)	2079 (100.0)
Use of LCP	No	170 (10.8)	1399 (89.2)	1569 (100.0)
	Yes	35 (6.9)	475 (93.1)	510 (100.0)
Total		205 (9.9)	1874 (90.1)	2079 (100.0)
Use of ACP	No	192 (10.1)	1712 (89.9)	1904 (100.0)
	Yes	13 (7.4)	162 (92.6)	175 (100.0)
Total		205 (9.9)	1874 (90.1)	2079 (100.0)
Use of PPC	No	186 (10.2)	1637 (89.8)	1823 (100.0)
	Yes	19 (7.4)	237 (92.6)	256 (100.0)
Total		205 (9.9)	1874 (90.1)	2079 (100.0)

Unified record keeping	No	115 (17.5)	541 (82.5)	656 (100.0)
	Yes	88 (6.4)	1285 (93.6)	1373 (100.0)
Total		203 (10.0)	1826 (90.0)	2029 (100.0)

Of the 14 variables detailed in Table 6, the following six variables reached the threshold *p* value of <0.1 to be included in the logistic regression model for level of progress towards an operational register for palliative care patients: location of the practice within the UK (χ^2=8.71; df=3; p=0.033), the presence of a GP with a Special interest post in palliative care (χ^2 =3.16; df=1; p=0.075), the number of GPs in a practice (χ^2 =27.10; df=1; *p*<0.001), use of the GSF (χ^2 =24.96; df=1; *p*<0.001), use of the LCP (χ^2 =6.39; df=1; *p*<0.001) and the use of unified record keeping for palliative care patients (χ^2 =59.75; df=1; *p*<0.001). A Forced entry method of variable selection was used. Table 7 shows the logistic regression model for the variables associated with level of progress towards an operational patient register for palliative care patients.

Table 7: Logistic regression model for factors associated with having made partial, little or no progress towards an operational palliative care register

		Odds Ratio	95% C.I. for odds ratio		Significance
Variable (reference category)	Category		Lower	Upper	
UK area (England)					0.009
	Wales	0.676	0.33	1.41	0.295
	Scotland	0.484	0.27	0.88	0.018
	Northern Ireland	0.240	0.07	0.78	0.018
No. of GPs		0.858	0.80	0.92	<0.001
GP with a special interest post in palliative care (Yes)	No	1.530	0.60	3.88	0.370
Use of GSF (Yes)	No	1.653	1.20	2.27	0.002
Use of LCP (Yes)	No	1.355	0.91	2.03	0.140
Unified record keeping (Yes)	No	2.843	2.09	3.86	<0.001

In the model, the number of GPs within a practice was significantly related to the progress made towards an operational register (OR=0.858; 95% CI=0.80, 0.92; *p*<0.001). As the number of GPs increased the likelihood of a practice having made little or no progress towards a register was reduced. Not using the Gold Standards Framework increased the chance of a practice having made little or no progress (OR=1.653; 95% CI=1.20, 2.27; *p*=0.002). If there was no unified record keeping, then the practice was 2.8 times more likely to have made little or no progress towards a register (OR=2.843; 95% CI=2.09, 3.86; *p*<0.001). The UK area within which the practice was located was significantly associated with level of progress made (*p*=0.009): a practice in Scotland (OR=0.484; 95% CI=0.27, 0.88; p=0.018) or Northern Ireland (OR=0.240; 95% CI=0.07, 0.78; *p*=0.018) was less likely to have made little or no progress, compared to practices in England.

4.4. *Self-rated quality of palliative care*

The final set of analyses was undertaken to determine the relationship, if any, between practices' management of information and how they rated the quality of care they provided.

1584 practices (77.1%) rated the quality of care they provided as Poor/satisfactory/good and 471 practices rated it as very good (22.9%). Table 9 shows the cross-tabulation of the provision of information to family and carers and the progress towards an operational register and the self-rated quality of palliative care. A significant association was found between provision of information to family and carers (χ^2=114.43; df=3; *p*<0.001) and between progress made towards a fully operational palliative care register (χ^2=44.95; df=3; *p*<0.001) and how practices rated the quality of their palliative care. If information was given in every case then a practice was more likely to rate their palliative care as very good. The variable recording the progress made towards a register was recoded to ensure that there were no small expected cell counts. There was a significant association between progress towards an operational register and how practices rate the quality of their palliative care (χ^2 = 44.95; df = 3; *p*<0.001). Practices with a register that was not fully operational were less likely to rate their care as very good.

A significant difference was found in the record keeping score for practices which rated their quality of care as very good and those that did not (t=-15.19; *p*<0.001). These variables were then entered into a logistic regression model to identify factors associated with very good palliative care.

Table 9: Cross-tabulation of information provision and quality of care

Variable	**Category**	**No. of practices rating their quality of palliative care (%)** **Poor/satisfactory /good**	**Very good**	**Total**
No. of cases where appropriate written information is given to family or carers	In every case	207 (57.2)	155 (42.8)	362 (100.0)
	In most cases	605 (77.3)	178 (22.7)	783 (100.0)
	In some cases	571 (85.6)	96 (14.4)	667 (100.0)
	Rarely or never	166 (84.3)	31 (15.7)	197 (100.0)
Total		1549 (77.1)	460 (22.9)	2009 (100.0)
Progress made towards an operational register	No register/little progress	48 (81.4)	11(18.6)	59 (100.0)
	Partly operational	121 (89.6)	14 (10.4)	135 (100.0)
	Mostly operational	424 (85.0)	75 (15.0)	499 (100.0)
	Fully operational	982 (72.7)	369 (27.3)	1351 (100.0)
Total		1575 (77.1)	469 (22.9)	2044 (100.0)

Table 10 shows the logistic regression model for information management variables that affect whether care is rated as very good. The progress made towards an operational palliative care register was found to be significantly associated with the rating of palliative care provision (*p* = 0.008). In particular, practices with a register that was only mostly operational were less likely to rate the quality of care as very good (OR = 0.671; 95% CI = 0.50, 0.91; p = 0.009) compared with practices with a fully operational register. Similarly, practices with a register that was only partly operational were less likely to rate the quality of care as very good (OR=0.49). The record keeping scale was also found to be significant (*p*<0.001), for each increment on the record-keeping scale, a practice was 1.25 times more likely to rate the quality of palliative care as very good (OR = 1.250; 95% CI = 1.20, 1.31).

Table 10: Logistic regression model of factors associated with practices' rating their palliative care as very good

Variable (reference category)		Odds Ratio	95% C.I. for odds ratio Lower	 Upper	Significance
Information provision					0.127
(in every case)	Rarely or never	0.804	0.59	1.10	0.170
	In some cases	0.709	0.49	1.03	0.067
	In every case	1.092	0.65	1.84	0.741
Progress towards register					0.008
(fully operational)	No register	2.342	0.70	7.84	0.167
	Little progress	0.922	0.39	2.19	0.854
	Partly operational	0.492	0.27	0.89	0.019
	Mostly operational	0.671	0.50	0.91	0.009
Record keeping scale		1.250	1.20	1.31	<0.001

5. Discussion and Conclusion

This study provides unique insights into the structures and processes of information management in relation to palliative care in General Practices across the UK and the impact these might have on the quality of palliative care as an outcome. The study included a large representative sample of practices from across the UK and the findings are therefore likely to be generalizable to the entire population of General Practices within the UK. Nevertheless there were some limitations with this particular study, particularly in relation to the data available.

5.1. Limitations

The original data used in this study were collected using a questionnaire sent to General Practices to investigate the progress made in meeting UK government guidelines on palliative care [4]. A series of questions was included in the questionnaire about information provision, record keeping and use of a register this paper reports on secondary analyses of these data, focusing on specific questions relating to the structure and processes of information management within palliative care. As mentioned in section 4.1, there was poor predictive power among practice variables for the scale measuring the level of record-keeping on palliative care, this may be because the of the specific questions asked about record keeping within the practices. A study whose primary focus was examining the use of information for palliative care within General Practices might have included more detailed questions on information provision, record-keeping, documentation of palliative care, etc., and, hence, the results reported here are not assumed to give a holistic view of the management of information for palliative care within primary care.

The high response rate obtained gives us confidence that these results are representative of the population of General Practices in the UK, although it is, of course, possible there was a positive response bias by those practices devoting more time and resources to the provision on high-quality palliative care. The questionnaire was based entirely on self-reporting, and questionnaires were completed by various staff, including GPs, practice managers and nurses, who might have quite different understandings of the palliative care provided by the practice. Although a pilot study indicated that the data obtained using the questionnaire were reliable and valid [4], it was not possible to check the accuracy of responses, e.g., on practice size, state of registers, etc., and some questions, e.g., on the quality of palliative care provided were subjective and open to interpretation. It is possible that staff who responded positively to questions on structures and processes for information management then responded more positively to the question on the overall quality of care provided, and a more objective measure of quality of palliative care would have been helpful.

The original study was conducted in 2007 and the picture might have changed since then, with practices developing their palliative care services and the structures and processes through which information is managed.

Despite these limitations, this study has provided unique and valuable insights into information provision, the use of record keeping and cancer/palliative care registers and the factors affecting these, as well as the relationship between these structures and processes and the quality of palliative care provided within primary care [35]. As noted above, a study asking more detailed questions about the way information is provided and managed and utilising other data on outcomes for palliative care patients, e.g., from the patients' perspectives, could give further insights into how structures and processes for information management could improve patient care.

5.2. Management of information

Over half (56%) of practices reported providing information to families and carers in every or most cases, more than two thirds of practices used unified records for palliative care patients and almost two thirds had a fully operational cancer register or palliative care register. These high levels of information provision and of unified record systems and registers observed in this study highlight the importance of managing information using appropriate structures and processes, if we think of these in Donabedian terms [35, 36].

Larger practices, in terms of the number GPs in the practice, were more likely to give information to families/carers and were also more likely to have an operational register of palliative care patients. Possible explanations for this are that practices with more GPs may have more capacity, and resources, to provide information and to collect information. Additionally, practices with larger numbers of patients are likely to have more patients receiving palliative care for the practice to consider it being worthwhile devoting resources to this aspect of care. Practices using the GSF also reported providing more information to patients and were more likely to have an operational register: this again could be related to the size of practice, in that larger practices had more capacity, and reason, to devote resources to palliative care provision. Farber et al suggested that doctors who spent more time delivering palliative care felt they were providing better care and doctors in larger practices might care for more terminally ill patients [37]. It has been noted that changes in palliative care rely on the enthusiasm of individuals in practices [5,21] and it may be that in a larger practice there is more likely to be a GP with the time and interest to advocate improvements. Use of the GSF also predicted information provision independent of size of practice, suggesting that, above and beyond the size of practice, use of the GSF may have positively influenced provision of information, perhaps because practices using the GSF were more aware of the value of information for family members.

Practices having unified record keeping were also more likely to provide information to families and carers and to have an operational register, independent of other factors. These findings may be a reflection that practices putting resources into palliative care provision look to improve the management of information in a number of ways, not just one, and approach improving palliative care within the practice in a holistic way. Progress towards an operational register was also significantly, and independently, associated with geographical location within the UK, in that practices in Northern Ireland and Scotland reported having made more progress. Unsurprisingly, when examining factors predicting the level of record-keeping, having a unified record system for palliative care was the best predictor, followed by participation in various end-of-life care initiatives. Again, the former finding may be an indication that practices investing in palliative care and in their information systems, do so in a number of ways, not just one.

5.3. Information Management and Quality of Palliative Care

While these findings are important for understanding the importance of the management of information for palliative care within primary care, they are, after all, only measures of structure and process, as defined by Donabedian [37], and do not give any indication of the impact on quality of patient care, or as Donabedian described it, outcomes. Our final analysis, reported in section 4.4, therefore, investigated the relationship between these measures of structure and process of information management and quality of palliative care as an outcome. Although there was a clear association between the provision of information to families and carers and the quality of palliative care in the initial analyses, this was not significant in the final logistic regression model. Therefore, although practices providing more information to families and carers generally have a higher quality of palliative care, these practices are more likely to have a more operational cancer/palliative care register and have a higher level of record keeping, and these factors are more important determinants of quality of palliative care. A possible explanation for this is that having these structures (e.g., a register of patients), and processes (in which details about the patient's wishes, spiritual beliefs, preferred place of care/death and details of families and their insights into the patient's conditions are recorded) in place give practices a better understanding about patients receiving palliative care and they therefore may feel better able to manage and care for these patients, resulting in a higher overall quality of care.

This paper therefore contributes to the evidence base for the value of health information management structures and processes in contributing to quality of care for patients.

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7. References

[1] National Audit Office. *End of life care*. 2008. London: The Stationary Office.

[2] National Institute for Clinical Excellence. *Improving supportive and palliative care for adults with cancer: the manual.* 2004. London: National Institute for Clinical Excellence.

[3] Department of Health. *End of Life Care Strategy – promoting high quality care for all adults at the end of life*. 2008. London: Department of Health.

[4] Hughes PM, Bath PA, Ahmed N and Noble B. What progress has been made towards implementing national guidance on end of life care? A national survey of UK general practices. *Palliative Medicine* 2010; 24: 68-78.

[5] Kennedy S, Seymour J, Almack K, Cox, K. Key stakeholders' experiences and views of the NHS End of Life Care Programme: findings from a national evaluation. *Palliative Medicine* 2009; 23 (4), 283-294.

[6] Department of Health. *The new NHS: modern, dependable*. 1997. London: Department of Health.

[7] Townsend J, Frank A, Fermont D, Dyer S, Karran O, Walgrove A, Piper M. Terminal cancer care and patients' preference for place of death: a prospective study. *British Medical Journal* 1990; 301 (6749), 415-417.

[8] Murray S, Boyd K, Sheikk A, Thomas K, Higginson I. Developing primary palliative care. *British Medical Journal* 2004; 329 (7474), 1056-1057.

[9] Levack P, Dryden H, Paterson F. Community palliative care services are not sufficiently funded. *British Medical Journal* 2005; 330 (7481), 42.

[10] Lloyd-Williams M, Carter Y. The need for palliative care to remain primary care focused. *Family Practice*, 2002; 19 (3), 219-220.

[11] Mitchell G, Seamark D. Dying in the community: general practitioner treatment of community-based patients analysed by chart audit. *Palliative Medicine* 2003; 17, 289-292.

[12] Burge F, Lawson B, Johnston G, Cummings I. Primary care continuity and location of death for those with cancer. *Journal of Palliative Medicine* 2003; 6 (6), 911-918.

[13] Murray S, Mitchell G, Burge F, Barnard A, Nowels D, Charlton R. It's time to develop primary care services for the dying. *Journal of Palliative Care* 2006; 22 (2), 115-116.

[14] Groot M, Vernooij-Dassen M, Verhagen S, Crul B, Grol R. Obstacles to the delivery of primary palliative care as perceived by GPs. *Palliative Medicine*, 2007; 21 (8), 697-703.

[15] Mitchell G. How well do general practitioners deliver palliative care? A systematic review. *Palliative Medicine*, 2002; 16 (6), 457-464.

[16] Murray S, Barclay S, Bennett M, Kendall M, Amir Z, Lloyd-Williams M. Palliative care research in the community: it is time to progress this emerging field. *Palliative Medicine* 2008; 22, 609-611.

[17] Thomas K. *Caring for the dying at home: companions on the journey*. 2003. Abingdon: Radcliffe Medical Press.

[18] Thomas K, Noble B. Improving the delivery of palliative care in general practice: an evaluation of the first phase of the Gold Standards Framework 2007; *Palliative Medicine*, 21 (1), 49-53.

[19] Mahmood-Yousuf K, Munday D, King N, Dale J. Interprofessional relationships and communication in primary palliative care. *British Journal of General Practice* 2008; 58, 256-263.

[20] Dale J, Petrova M, Munday D, Koistinen-Harris J, Lall R, Thomas K. A national facilitation project to improve primary palliative care: impact of the Gold Standards Framework on process and self-ratings of quality. *Quality and Safety in Health Care* 2009; 18, 174-180.

[21] Fox P. Continuity of care is paramount but needs to be tailored individually. *British Medical Journal* 2005; 330 (7492), 671.

[22] McNicholl M, Dunne K, Garvey A, Sharkey R, Bradley A. Using the Liverpool Care Pathway for a dying patient. *Nursing Standard* 2006; 20 (38), 46-50.

[23] Veerbeek L, van Zuylen L, Swart S, van der Maas P, de Vogel-Voogt E, van der Rijt C. The effect of the Liverpool Care Pathway for the dying: a multi-centre study. *Palliative Medicine* 2008; 22 (2), 145-151.

[24] Luhrs C, Penrod J. End of life care pathways. *Current opinion in supportive and palliative care* 2007; 1 (3), 198-201.

[25] Ellershaw J, Murphy D. The Liverpool Care Pathway (LCP) influencing the UK national agenda on care of the dying. *International Journal of Palliative Nursing* 2005; 11 (3), 132-134.

[26] Burns F. *Information for Health: an information strategy for the modern NHS 1998-2005*. 1998. London: Department of Health.

[27] Darzi. *High quality care for all: NHS next stage review*. 2008. London: Department of Health.

[28] National Consensus Project for Quality Palliative Care. National Consensus Project for Quality Palliative Care: Clinical practice guidelines for quality palliative care, executive summary. *Journal of Palliative Medicine*, 2004; 7(5), 611-627.

[29] Leydon GM et al. Cancer patients' information needs and information seeking behaviour: in depth interview study. *British Medical Journal* 2000; 320 (7239), 909-913.

[30] Rees C, Bath PA. The information needs and source preferences of women with breast cancer and their family members: a review of the literature published between 1988 and 1998. Journal of Advanced Nursing 2000 31(4):833-841.

[31] Henwood F, Wyatt S, Hart A, Smith J. Ignorance is bliss sometimes: constraints on the emergence of the informed patient in the changing landscapes of health information. *Sociology of Health & Illness* 2003; 25 (6), 589-607.

[32] Richardson A. et al. Learning from patients with cancer and their spouses: a focus group study. *Journal of Laryngology and Otology* 2002; 116 (12), 1028-1035.

[33] Godolphin W, Towle A, McKendry R. Evaluation of the quality of patient information to support informed shared decision-making. *Health Expectations* 2001; 4, 235-242.

[34] Docherty A, Owens A, Asadi-Lari M, Petchey R, Williams J, Carter Y. Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. *Palliative Medicine* 2008; 22 (2), 153-171.

[35] Bath PA. Health informatics: current issues and challenges. *Journal of Information Science* 2008; 34 (4), 501–518.

[36] Donabedian A. Evaluating the quality of medical care. *Milbank Memorial Fund Quarterly* 1966; 44 (3 Supplement), 166–206.

[37] Farber N, Urban S, Collier V, Metzger M, Weiner J, Boyer G. Frequency and perceived competence in providing palliative care to terminally ill patients: a survey of primary care physicians. *Journal of Pain and Symptom Management* 2004; 28(4), 364-372.