

A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death

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Abstract

Study objectives—To develop a short form of an interview schedule used successfully in previous national surveys of care for the dying, and to investigate the effect of administering it by post on response rate, response bias and on the nature of responses to questions.

Design—Randomised controlled trial.

Setting—An inner London health authority.

Participants—Informants (person registering death) of random sample of cancer deaths between June 1995 and July 1996.

Main results—The shortened questionnaire (VOICES) has 158 questions. Response rate did not differ significantly between postal and interview groups (interview: 56% (69 of 123), postal: 52% (161 of 308)). Responders in the two groups did not differ in terms of their socio-demographic characteristics. Postal questionnaires had significantly more missing data, particularly on questions about service provision and satisfaction with services. Responses to questions differed between the groups on 11 of 158 questions. Interview group respondents were more likely to give top ranking responses to questions on service satisfaction and symptom control.

Conclusions—Postal questionnaires are an acceptable alternative to interviews in retrospective post-bereavement surveys of care for the dying, at least in terms of response rate and response bias. However, the increased costs of interview surveys need to be balanced against the fact that postal questionnaires result in more missing data, and possibly less reliable answers to some questions. Caution is needed in combining results from the two data collection methods as interview respondents gave more positive answers to some questions.

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nally ill cancer patients³ and fewer than a tenth of patients with non-malignant disease who die receive specialist palliative care.⁴ Patient surveys are therefore likely to give an incomplete picture of these services, favouring patients referred to palliative care while relatively well at the expense of iller patients, those who did not receive palliative care, and those who were not recognised as dying.

An alternative method is to collect information from bereaved relatives and friends in the months after the patient's death. This retrospective approach has been used in a number of influential palliative care studies.⁵⁻⁷ Although this method does have drawbacks, including uncertainty about the extent to which the views of bereaved relatives reflects those of the patients themselves,⁸⁻¹⁰ it does enable information to be collected on a complete population of people who die. This is not possible with a prospective study; doctors and nurses cannot accurately identify cancer patients with a short prognosis,¹¹ and are particularly poor at doing so for non-cancer patients.¹²

To date, retrospective surveys of care for the dying have been interview-based. However, self completed postal questionnaires are considerably cheaper than interviews,¹³ and need fewer trained staff to administer and analyse.¹⁴ Although response rate may be lower than in an interview survey,¹⁴ this is not inevitable.^{13 14} A postal questionnaire could, therefore, be a cost effective alternative to face to face interviews in retrospective post-bereavement surveys.

It cannot, however, be assumed that this method of data collection is acceptable to bereaved respondents, or that information collected in this way will be comparable to that collected in an interview survey. Although there is some evidence that respondents prefer to complete sensitive questions themselves rather than to be asked face to face by an interviewer,¹⁵ bereaved relatives may not find completing a questionnaire acceptable: they may prefer a face to face interview in which they have the opportunity to discuss their concerns and to talk about the deceased. In addition, although comparisons of postal questionnaire and interview surveys in maternity care and general practice have found little evidence that the mode of administration affects the nature of response^{13 14} this may not be true of bereaved relatives: family members may contribute more to the completion of postal questionnaires, or respondents may feel less

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A major obstacle to research and audit in palliative care is the dearth of reliable and valid methods of collecting information on patients and family outcomes.¹ The views of patients can be very difficult to obtain as many patients are too ill to be interviewed or to complete a questionnaire by the time they are referred to palliative care.² In addition, only half of termi-

Table 1 Characteristics of informants who completed a postal questionnaire or were interviewed, and of the deceased whose death they registered

	Interviewer group (n=69) % (n)	Postal questionnaire group (n=160) % (n)	df	χ^2	p Value
Relation between respondent and deceased					
spouse	35 (24)	33 (52)	2	0.1	0.9
relative	54 (37)	56 (90)			
other	12 (8)	11 (18)			
Age of deceased at death					
<55	17 (12)	11 (18)	4	3.2	0.5
55-64	12 (8)	19 (31)			
65-74	30 (21)	28 (45)			
75-84	29 (20)	29 (47)			
85+	12 (8)	12 (19)			
Sex of deceased					
male	48 (33)	49 (78)	1	0.1	1.0
female	52 (36)	51 (82)			
Social class of deceased					
I/II	28 (15)	31 (40)	3	3.2	0.4
IIIN	24 (13)	16 (21)			
IIIM	24 (13)	34 (45)			
IV/V	24 (11)	19 (25)			
Ethnic group of deceased					
white	90 (62)	92 (144)	1	0.2	0.6
non-white	10 (7)	8 (13)			

able to report socially undesirable feelings such as depression or anger towards health professionals when talking to an interviewer, for instance.¹⁴⁻¹⁶

We have therefore developed a short form of interview schedule used successfully in three previous national surveys,⁵⁻⁷ and have investigated by means of a randomised controlled trial, the effect of the administering it by post on response rate, response bias and on the nature of responses to questions on service used, and unmet need for and satisfaction with services.

Methods

A shortened version of the interview schedule used in the Regional Study of Care for the Dying (RSCD),⁷ itself based on that used by Seale and Cartwright,⁵ was developed. Specialist palliative care teams, doctors and nurses working in the acute hospital sector, GPs, and community nurses were consulted, together with purchasers, to ensure that what they perceived to be the most important aspects of service use, satisfaction and unmet need were included, and that it adequately reflected the multi-disciplinary nature of palliative care. The resulting questionnaire was piloted with bereaved relatives of patients who died while in the care of a local palliative care team, and views were sought from health care providers, researchers, and purchasers. The final questionnaire ("Views Of Informal Carers—Evaluation of Services" - VOICES) contained 158 questions printed on 28 pages.

A random sample of deaths was drawn from death certificates of residents in an inner London health district who died between July 1995 and June 1996 from cancer and whose death were registered by someone resident in the district, or living in adjacent districts. As previous work had shown that age and social class influenced response rate⁷ they were stratified by age and social class and randomly allocated to postal questionnaire or interviewer group. Random number tables were used to predetermine group allocation. For economic reasons the number of interviews was limited to 120; as a

lower response rate was anticipated in the postal questionnaire group¹⁴ an allocation ratio of two interviews to every five postal questionnaires was adopted.

In the RSCD 40% of the sample said hospital doctors' care was excellent. Sample size calculations for the present study suggested that to detect a significant difference at the 0.05 significance level with a power of 80% between this proportion and one of 60% a sample size of 80 completed interview schedules and 160 completed postal questionnaires would be needed. The RSCD obtained a 68% response rate for cancer deaths in Bloomsbury and Islington Health Authority (a predecessor to Camden and Islington). Response rates to postal questionnaires tend to be somewhat lower than in interview surveys.¹⁴ Assuming a 10 per cent drop in response rate, it was estimated that 414 deaths would be needed to obtain the desired sample size.

The person who registered the death (the informant) was contacted between six and eight months after the death. In the interviewer group, a letter was sent to the informant introducing the study and informing them that an interviewer would contact them in a few weeks. A contact number was given, and a refusal slip was included to enable the informant to decline to participate if they wished. In all contacts with informants it was emphasised that participation was voluntary, and that the interviewers would be willing to talk to someone else who had been involved, if the informant thought this was appropriate. After two weeks interviewers contacted the informants either by telephone, visiting, or by sending an appointment with a contact number, should the date or time be inconvenient. If necessary, the interviewer called in person at the informants' address on at least three occasions, each at a different time of day and on a different day of the week, leaving a contact number each time. Interviews were conducted in the respondents' homes.

In the postal questionnaire group a letter was sent to the informant explaining the study and informing them that a postal questionnaire would be sent in a couple of weeks. Again, a contact number and refusal slip were enclosed. Although it is not standard practice in postal questionnaire surveys to precede the questionnaire with a letter, this procedure was adopted after consultation with experts in bereavement to minimise the likelihood of causing distress to the bereaved family and friends. If no refusal was received within two weeks, a questionnaire and stamped addressed envelope were sent to the informant with a covering letter explaining that, if the informant felt that they were not the most appropriate person to complete the questionnaire, they could pass the questionnaire on to most appropriate person. If necessary, a reminder letter was sent, together with a questionnaire and stamped addressed envelope, approximately three weeks later, with a second reminder being sent up to three weeks after that.

Table 2 Comparison of amount of missing data on questionnaires completed by interviewers compared with the amount on postal questionnaires, by type of missing data

	Interview group (n=69) Mean (SD)	Postal questionnaire group (n=160) Mean (SD)	t	p Value
Number of questions omitted that respondent was eligible to answer	1.1 (1.4)	5.6 (8.7)	-6.3	<0.0001
Number of "don't know" responses	6.3 (7.8)	3.9 (5.7)	2.5	0.01
Total number of questions with missing data (omissions plus "don't know" responses)	7.4 (8.2)	9.5 (9.9)	-1.7	0.09

Table 3 Amount of missing data, by data collection method (interview or postal questionnaire) and type of variable I

	Interview group (n=69) Mean (SD)	Postal questionnaire group (n=160) Mean (SD)	t	p Value	95% Confidence intervals for difference
Factual questions about service provision (n=33)	0.9 (2.1)	2.6 (4.8)	1.6	<0.001	(0.7, 2.5)
Factual questions about symptoms (n=38)	3.1 (4.2)	3.2 (4.3)	0.1	0.9	(-1.3, 1.2)
Respondent's opinion of services (n=36)	1.3 (2.1)	2.0 (2.5)	0.7	0.03	(0.1, 1.4)
Respondent's opinion of symptom control (n=22)	1.1 (1.5)	0.7 (1.9)	-0.4	0.1	(-0.1, 0.9)
Respondent's opinion of patient's unmet service needs, and own experience of caring (n=23)	0.7 (0.9)	0.8 (1.7)	0.1	0.6	(-0.5, 0.3)

STATISTICS

Unless otherwise stated, all comparisons of categorical variables reported in the text were made using the χ^2 test, and are statistically significant at $p < 0.05$, using continuity correction where appropriate. Relations reported as exhibiting "near significance" have a p value of more than 0.05, but less than 0.10. Comparisons of continuous variables were made using the t test or analysis of variance, as stated in the text.

Results

RESPONSE RATE

Of the 431 informants who were sampled for this study, 230 agreed to participate, a 53% response rate. Response rate did not differ significantly between postal and interview groups (interview: 56% (69 of 123), postal: 52% (161 of 308)). Responders in the postal and questionnaire groups did not differ in terms of their relationship to the deceased, or the sex, social class or age of the deceased (table 1). Overall, responders did not differ significantly from non-responders in terms of the deceased's age, social class, site of cancer or relationship to the informant; the sex of the deceased did, however, differ between responders and non-responders (female: responders 52% (119 of 230), non-responders 39% (78 of 201), $\chi^2=6.7$, $p < 0.01$). There were no statistically significant differences between responders and non-responders in either the interview or postal questionnaire groups.

Informants in both the interview and postal questionnaire groups were invited to suggest another family member or friend to be interviewed or to complete the questionnaire if they felt this would be more appropriate. One

in 10 informants did this (interview group: 9% (6 of 69), postal questionnaire group 11% (17 of 161) $\chi^2=0.7$, $p=0.7$).

MISSING DATA: VARIATION BETWEEN METHODS

There were two types of missing data: firstly, an inappropriate missing entry, where the respondent had missed a question that they were eligible to answer; and secondly where the respondent chose the "don't know" response to a question. The number of variables on which there was missing data was compared across the two data collection groups (table 2). There was a statistically significant higher mean number of inappropriate non-responses in the postal group, while the interview group had a higher mean number of "don't know" responses. The higher mean number of combined missing answers in the postal group approached statistical significance.

All variables derived from the questionnaire were divided into seven types, according to whether the required response was based on fact or the responder's opinion, and the subject nature of the question. Tables 3 and 4 compare the total number of missing responses for each variable type. There were significantly more missing responses in the postal group than in the interview group for factual questions about service provision, and for questions asking the respondents opinion of services. The postal questionnaires were therefore less successful than interviews as a method for collecting information on the services received by the deceased, and on the respondent's satisfaction with services. There were, however, no other statistically significant differences between the groups.

Table 4 Amount of missing data, by data collection method (interview or postal questionnaire) and type of variable II

	Interview group (n=69) % (n)	Postal questionnaire group (n=160) % (n)	df	χ^2	p Value
Sociodemographic questions (n=3)					
No missing data	100 (69)	96 (154)	1	2.4	0.1
Missing data on one or more questions	0	4 (6)			
Reasons for lack of service provision (n=3)					
No missing data	80 (55)	81 (129)	1	0.1	0.9
Missing data on one or more questions	20 (14)	20 (31)			

DIFFERENCES IN QUESTION ANSWERS BETWEEN DATA COLLECTION METHODS

Variations in the type of responses given by respondents in the two data collection groups were explored to establish whether postal and interview surveys would give a different picture of use of, and satisfaction with, services.

Of 158 questions, 11 differed between the two groups at $p < 0.05$. Respondents who completed a postal questionnaire gave a statistically significant higher number of positive responses than those who were interviewed to questions on: whether the deceased was visited by a specialist doctor at home; if the deceased spent any time in a hospice in their final year; if the deceased said there was a place where they wanted to die; if the deceased suffered difficulty sleeping at home; if their symptoms were treated by a GP or specialist doctor; whether a pain/symptom control specialist had been involved in the care of the deceased while in hospital; if the deceased had suffered constipation while staying in a hospice; whether depressed or anxious deceased had had help with this. Respondents who were interviewed were more likely to report that the deceased had died in the right place, and that hospital control of breathlessness and loss of appetite were good rather than fair.

VARIATION IN RANKED RESPONSES

Whether respondents from the two data collection groups gave different responses to variables measuring satisfaction with services provided was investigated. This analysis was confined only to variables that required respondents to rank satisfaction with services or symptom control. All the ranked variables were recoded into three ranks: top, middle, and bottom. For those variables with four ranked categories, the "good" and "fair" categories were combined to form the middle group.

Multiple regression analysis was used to control for the total number of responses while comparing the number of top, middle, and bottom rankings between groups (table 5). The results show a significant difference between data collection methods in the number of top responses (for example, highly satisfied) and in the number of middle responses, but not in the number of bottom rankings (not at all satisfied). This confirms that respondents in the interview group were more likely to give top ranking responses, while respondents in the postal questionnaire group were more likely to give middle ranking responses.

KEY POINTS

- We developed a short version of a retrospective post-bereavement interview schedule used successfully in previous national surveys of care for the dying.
- We investigated the effect of administering this instrument (VOICES) by post on response rate, response bias, and on question answers.
- Postal questionnaires are an acceptable alternative to interviews in this context, at least in terms of response rate and response bias.
- They had more missing data, which needs to be balanced against the fact that interview surveys are more expensive.
- They may be better at enabling respondents to express dissatisfaction with care.

Discussion

Palliative care services have developed rapidly both in terms of quantity and diversity over the past 30 years,¹⁷ and continue to do so; recent developments include day hospices, hospice at home, and consultancy services. Although there have been a number of important evaluations,¹⁸ many questions about the acceptability and cost effectiveness of these services remain unanswered. More research into the needs of dying people, and into the effectiveness of services and therapeutic interventions, is urgently needed if service developments are to be cost effective and evidence-based.

Retrospective post-bereavement interview surveys have played an important part in furthering our understanding of the last months of life, in highlighting deficiencies in health and social service provision for people approaching death, and in evaluating palliative care services.⁵⁻⁷ Evidence from the limited number of studies that have investigated the validity of using bereaved respondents as proxy informants suggests reasonably good validity for service evaluations and for some symptoms, although accounts of pain may say more about the respondent's distress at watching the patient in pain than about the patient's subjective experience of pain.⁸⁻¹⁰ In addition, bereaved respondents' views have their own validity as it is these that live on. Retrospective surveys are the only way to collect information on a complete population of people who die, as many patients are too ill to participate in research or audit studies by the time they are

Table 5 Multiple regression analyses of differences between respondents in the interview and postal questionnaire groups in their choice of top, middle or bottom ranking options on questions measuring satisfaction with services or symptom control, controlling for the total number of valid responses on these questions

	Top ranked responses*			Middle ranked responses†			Bottom ranked responses‡		
	β	t	p Value	β	t	p Value	β	t	p Value
Data collection method (interview coded 1, postal questionnaire 2)	-1.2	-2.5	0.01	0.9	2.1	0.03	0.1	0.8	0.4
Total number of valid responses	0.3	9.6	<0.0001	0.5	0.0	<0.0001	0.2	6.9	<0.0001

*Multiple regression equation 1: $F(2,226)=46.1$, $p<0.0001$. †Multiple regression equation 2: $F(2,226)=126.8$, $p<0.0001$. ‡Multiple regression equation 3: $F(2,226)=47.9$, $p<0.0001$.

known to be dying. In the study reported in this paper we have investigated whether postal questionnaires can be substituted for face to face interviews in retrospective post-bereavement surveys, thus reducing the costs of such surveys and making this valuable methodology more widely accessible.

The first aims of the study were to investigate whether the response rate and response bias in a postal survey about the last year of life would differ significantly from those in an interview survey using the same measure. Neither differed significantly between the two groups, indicating that a postal questionnaire is a viable alternative to an interview in retrospective studies on care for the dying.

However, in 1990 the response rate in the RSCD in Bloomsbury and Islington district, the forerunner of Camden and Islington, was 62%, compared with 52% in the interview arm of the present survey. A major change in the design of this survey compared with its predecessors⁵⁻⁷ was that, rather than interviewers visiting the address of the deceased as given on the death certificate to begin a search for the best person to interview, the person who registered the death (the informant) was contacted. Deaths are often registered by adult children on behalf of bereaved parents, and as they may have been less interested in the survey topic or less involved in caring for the person who died this may account, at least in part, for the reduction in response rate. In addition, letters to informants were sent from a university department, in contrast with the RSCD in which letters to the deceased's address were sent out from participating health authorities. Although there is conflicting evidence about the effect on response of sending questionnaires from local GPs or health authorities rather than from university departments,^{19, 20} this may have influenced response rate in this study.

Given the evidence that response rates in both postal and interview surveys in inner city areas is likely to be low, the response rate in the present survey—although disappointing—is not surprising. What is important in relation to the study reported here is that it did not differ significantly between the interview and the postal questionnaire groups. Although more work is needed to investigate the effect of sending the questionnaire to the informant rather than contacting the address of the deceased directly on response rate, and to establish whether there is benefit in sending the questionnaire from a local organisation rather than from an academic department, these results demonstrate that, as far as response rates and response bias are concerned, administering questionnaires by post is a viable alternative to face to face interviews.

MISSING DATA

The postal questionnaires had more missing data than those completed by interviewers, particularly to factual questions about service provision and to questions asking respondents about their opinion of services. Other studies have also reported that interviews lead to less

missing data. This clearly needs to be balanced against the increased cost of interview surveys. Some missing data on the VOICES questionnaire appeared to be a consequence of the layout of the questionnaire and to the wording of questions. This highlights the importance of piloting postal questionnaires particularly carefully to reduce the amount of missing data.

RESPONSES TO QUESTIONS

Responses on 11 of the questions in the VOICES questionnaire differed significantly between the postal questionnaire and interview groups. A large number of statistical tests were carried out and seven or eight of these tests would therefore be expected to be significant by chance. Some caution is therefore needed in interpreting these results.

However, closer analyses of the questions to which responses differed between the two groups suggested that the interviewers had been playing a useful part in interpreting questions that were unclear to respondents. In particular respondents to the postal questionnaire were significantly more likely to say that they had had care from a specialist palliative care doctor at home or in hospital, and to report that the patient had been admitted to a hospice. We suspect that respondents who completed the postal questionnaires were often unclear about what was meant by specialist doctor or hospice and therefore provided inaccurate responses to these questions. The interpretation of the data is supported by comments written on questionnaire by respondents. One way of improving these questions may be to make them more specific by, for instance, naming the local hospice and by using terms to refer to specialist palliative care that are in common use locally.

The other group of questions that showed differences between the two data collection methods were questions about treatment of symptoms by GPs or hospital doctors. Respondents in the interview group were more likely than those in the postal questionnaire group to say that the symptoms had not been treated. We are unsure why these questions presented difficulties for respondents, but again think the interviewers must have played a part in helping respondents interpret these questions and to formulate their responses. The interviewers were both experienced in the use of structured questionnaires and understood the importance of reading questions as written and of not interpreting them to respondents. However, in the social context of an interview they clearly did do some interpretation of questions for respondents. The fact that interviewers do this is recognised to be one of the advantages of interview surveys.

In conclusion, the results of this study show postal questionnaires are an acceptable alternative to face to face interviews in retrospective post-bereavement surveys of care for the dying, at least in terms of response rate and response bias. They may, indeed, have an added advantage in that because postal surveys are cheaper, it is possible to have a larger sample size for a given cost, hence improving the variance of

estimates. However, particular care needs to be paid to ensuring that the wording of questionnaires are unambivalent and are understood by members of a target population, and, in particular, that respondents are helped to identify whether the deceased did in fact receive care from target services. Careful piloting and skilled design and question wording is needed to overcome these problems. Caution is needed in combining results from the two data collection methods, as respondents to face interviews give more positive answers to symptom control and satisfaction questions.

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