Comparison of cause of death coding on death certificates with coding in the Royal College of General Practitioners Oral Contraception Study

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SUMMARY A comparison has been made between the coding of the cause of death by (a) the Royal College of General Practitioners (RCGP) during the Oral Contraception Study and (b) the Office of Population Censuses and Surveys (OPCS) or the General Register Office for Scotland (GRO) on death certificates for the same subjects. Broad groupings of the *International Classification of Diseases (ICD)* showed close agreement between RCGP and OPCS or GRO coding for all deaths which occurred from the start of the Oral Contraception Study in 1968 up to December 1978. Moreover, where discrepancies occurred there were no systematic differences between ever-users of oral contraceptives and non-users. Detailed examination of discrepancies in the coding of the causes of those deaths included in the RCGP publication of October 1977¹ shows that our previous estimate of mortality risk associated with oral contraceptives would not be materially altered by the use of death certificate information.

In October 1977, the Royal College of General Practitioners published analyses of the distribution of deaths recorded in its ongoing, long-term, prospective Oral Contraception Study, which began in 1968.¹ It was noted that the total mortality rate in women who had ever used the pill was increased by 40% and was accounted for by an increase in deaths from circulatory diseases of one in 5000 ever-users a year. The cause of death used in the analysis was that reported by the participating general practitioners (GPs) and was coded by C.R.K. and subsequently checked by V.B. Because of the importance of these findings, it was felt necessary to investigate the extent to which the conclusions might be altered if information from death certificates was used instead. Since the analysis of October 1977, additional deaths

have been reported in the Oral Contraception Study, and these provide an opportunity to make a general comparison of the cause of death reported by the GP with that supplied and coded by the OPCS or the GRO, referred to hereafter as the registries.

Method

The design of the Oral Contraception Study has been described in detail elsewhere.² Briefly, 23 000 pill takers and 23 000 controls, who were matched for age and marital status, were recruited over a 14-month period in 1968–69. Controls who later became oral contraceptive users were included in the taker category from the time of change. Ex-takers who resumed the use of oral contraceptives were,

thereafter, excluded from the analyses published so far. At six-monthly intervals each GP reports on the occurrence of illness, pregnancy or death, and on the details of oral contraceptive use in the study population.

For all deaths the GPs are asked to report the causes in the same format as required for the death certificate. The underlying cause of death is assigned by C.R.K. based upon the description given by each GP, supplemented by information relating to previous medical history gathered during the study. This cause of death is then coded using the *International Classification of Diseases (ICD)* 8th revision.³ Once coded, the information is stored on computer. Before analyses of mortality are begun, each code is checked by an independent observer. For the purposes of the present comparison, this second stage of checking has not been undertaken for those deaths not included in the analyses published in October 1977, since this could not have been done without being influenced by the information on copies of the respective death certificates which are now available.

Copies of the death certificates were obtained by applying to the GPs who, in order to maintain confidentiality, forwarded the name and address at death of relevant patients either to the OPCS in London or to the GRO in Edinburgh. By arrangement with these offices, personal details of the patients were blanked out on the photocopies of the death certificates sent to the RCGP. Because of the small number of subjects in Northern Ireland, it was decided not to involve the separate National Health Service Register maintained there.

Information on a death certificate relating to the cause of death is supplied by either a coroner or a doctor, who may be the patient's own GP or another medical practitioner attendant at death, such as a hospital doctor. Subsequent assignment and coding of the 'underlying cause of death' at the registries is performed by trained staff. The concept of an 'underlying cause of death' is that formulated by the World Health Organisation, and instructions about the assignment of underlying cause are included in the *ICD* manual.³

The *ICD* includes about 1000 three-digit categories. These are aggregated into various lists, for example the 'A' and 'B' lists with 150 and 50 categories respectively. In this paper the *ICD* codings of deaths available since the start of the Oral Contraception Study have been compared at the three-digit, the 'A' list, and the 'B' list levels. The 'B' list classification, which is the most aggregated, generally provides the best agreement.⁴ Since these broad groupings are sufficiently specific for most epidemiological purposes, many of the comparisons

presented here are confined to the 'B' list codings. Codes which are discrepant at the 'B' list level have been individually investigated to determine possible reasons for the differences. Because of our particular interest in circulatory deaths, more detailed analysis of these has been performed using the 'A' list codings. Differences between ever-users (takers and ex-takers) and non-users (controls) have also been examined. The deaths discussed in the publication of October 1977 have been analysed separately to determine whether the use of OPCS codings would impair the validity of the original conclusions.

Results

TOTAL DEATHS FROM START OF ORAL CONTRACEPTION STUDY UP TO DECEMBER 1978

(a) Comparison of all death codes

By December 1978, a total of 249 deaths had been recorded in the study. Death certificates were unobtainable for 44 of these because GPs did not respond (16 cases), the deaths occurred in Northern Ireland (three cases), or the death certificates could not be traced by the registries (25 cases). As shown in Table 1, of the 205 deaths available for analysis, 171 (83%) were coded to non-violent causes and 31 (15%) to violent causes, including suicide, by both the RCGP and the registries; in three cases (1.5%) the death was coded as non-violent by the RCGP and violent by the registries. (The details of these are listed in Table 2). Of the 171 non-violent deaths, the three-digit *ICD* codes were identical in 122 (71%), the 'A' list codes were identical in 143 (84%), and the 'B' list in 150 (88%). All the 21 cases (12%) which were discrepant according to the 'B' list are shown in Table 2.

The 31 accidental and violent causes of death coded by both the RCGP and the registries were compared according to the four 'B' list categories relating to external causes of injury. Complete coding agreement between the RCGP and the registries

Table 1 Comparison of deaths attributed to violent and non-violent causes by RCGP or OPCS/GRO

	RCGP STUDY		Total
	Non-violent causes (ICD 000-796.9)	Violent causes (ICD E800-E999)	
OPCS/GRO			
Non-violent causes (ICD 000-796.9)	171	0	171
Violent causes (ICD E800-E999)	3*	31	34
Total	174	31	205

*Patient numbers 15595, 16328, 30279 (see Table 2 for details).

Comparison of cause of death coding

Table 2 List of the 32 cases with discrepant coding at 'B' list level (total cases = 205)

Study number	Place of death	Cohort	Necropsy	Certifier	RCGP	ICD	OPCS/GRO	ICD
05765	Home	Ever-user	Yes	Other	1a Suicide, poisoning (Mandrax)	E950	1a Pulmonary haemorrhage b Prolonged unconsciousness c Arvynol poison (suicide)	E980
*06389	Hospital	Control	No	GP	1a Paroxysmal tachycardia b Paralytic ileus c Hysterectomy	560	1a Paroxysmal tachycardia b Paralytic ileus c Hysterectomy (fibroids)	218
*06444	Home	Control	Yes	Other	1a Duodenal ulcer, intestinal obstruction pyloric stenosis	560	1a Intestinal obstruction b Adhesion due to chronic duodenal ulcer	532
*09477	Home	Ever-user	Yes	Coroner	1a Suicide (hanging)	E963	1a Asphyxiation by hanging (suicide)	E953
*10695	Hospital	Ever-user	Yes	Coroner	1a Uraemia b Chronic renal failure c Malignant hypertension (Past history of hypertension since 1970 and malignant hypertension and uraemia since July 1972)	4003	1a Coronary insufficiency, Coronary atherosclerosis Malignant hypertension	4110
*14290	Hospital	Ever-user	No	Other	1a Peritonitis b Ischaemic colitis (GP's letter received subsequently: 'This patient died under general anaesthetic whilst having an operation to have a fibroid removed'.)	444	1a Shock b Faecal peritonitis c Ovarian cyst	220
*15595	Unknown	Control	Yes	Coroner	1a Renal failure b Ovarian cancer (Laparotomy for disseminated carcinoma of ovary one month before death)	183	1a Acute hepatorenal failure b Mercury intoxication	E980
*15773	Hospital	Ever-user	Yes	Other	1a Cirrhosis of liver and septicaemia b Chronic cholangitis c Congenital abnormality of intrahepatic bile ducts (Recurrent cholangitis since 1968)	571	1a Caroli's disease	758
16328	Hospital	Ever-user	Yes	Coroner	1a Massive cerebral haemorrhage Small liver nodules noted (no mention of fall)	431	1a Cerebral haemorrhage b Fall at work (open verdict)	E988
17332	Hospital	Ever-user	Yes	Coroner	1a Massive gastrointestinal haemorrhage b Acute gastric erosion c Peritonitis following partial gastrectomy	531	1a Massive gastrointestinal haemorrhage b Acute gastric erosion c Peritonitis	567
17565	Hospital	Ever-user	Yes	Coroner	1a Cerebral haemorrhage b Hypertension c Chronic nephritis (Past history of chronic pyelonephritis and hypertension)	590	1a Subdural haemorrhage b Hypertension c Renal artery stenosis	431
17910	Home	Ever-user	Yes	Coroner	1a Bronchial asthma b Diabetes mellitus (Past history of diabetes and asthma. Admitted to hospital four months before death with acute asthma)	493	1a Bronchial asthma b Diabetes mellitus	250
21534	Unknown	Control	Yes	Other	1a Suicide b Drug overdose	E950	1a Barbiturate overdose	E980
*23726	Hospital	Ever-user	Yes	Coroner	1a Acute cardiac failure b Paradoxical coronary embolism c Deep internal iliac thrombosis d Contraceptive pill, natural causes	410	1a Acute cardiac failure b Paradoxical coronary embolism c Deep internal iliac thrombosis d Contraceptive pill, natural causes	453

Table 2 (continued)

Study number	Place of death	Cohort	Necropsy	Certifier	RCGP	ICD	OPCS/GRO	ICD
23951	Hospital	Control	No.	Other	1a Rheumatoid disease b Leucopaenia, pericardial effusion, collagen disease	734	1a Acute renal failure II Rheumatoid arthritis	580
*25737	Home	Control	Yes	Coroner	1a Suicide (gas poisoning)	E870	1a Carbon monoxide poisoning (self-administered)	E951
25929	Hospital	Ever-user	Yes	Coroner	1a Overdose (History of puerperal depression and last child born 15 months before death)	E950	1a Poisoning by ingesting overdose Prothiaden with insufficient evidence to show intention	E980
*28008	Hospital	Ever-user	Yes	Other	1a Malignant neoplasm brain	191	1a Corpus callosum neoplasm	238
*30279	Unknown	Control	No	Other	1a Natural causes	796	1a Natural causes (asphyxia following inhalation of vomitus)	E911
31657	Hospital	Ever-user	No	Other	1a Disseminated sclerosis	340	1a Bronchopneumonia followed by respiratory failure II Multiple sclerosis	485
32755	Unknown	Ever-user	No	Other	1a Overdose paracetamol (Telephone conversation with GP revealed suicide)	E950	1a Acute hepatocellular failure b Paracetamol overdose	E850
*33967	Unknown	Control	No	Other	Cerebral haemorrhage	431	1a Cerebral haemorrhage b Benign hypertension c Obesity (gross) II Respiratory failure	277
35538	Hospital	Ever-user	No	Other	1a Crohn's disease	563	1a Pulmonary embolism II Crohn's disease	450
35587	Home	Control	Yes	Coroner	1a Pneumonia b Dystrophy myotonica (Past history of dystrophy myotonica for three months)	330	1a Congestive cardiac failure b Chronic bronchitis II Terminal bilateral broncho-pneumonia. Natural causes.	491
36142	Hospital	Control	No	Other	1a Decubitus ulcer b Septicaemia c Renal failure (Past history of hypertension and congenital deformity of legs. Sciatica. Coded hypertensive renal failure)	403	1a Chronic sepsis b Decubitus ulcer c Osteoarthritis	713
42101	Hospital	Control	Yes	Coroner	1a Head injuries	E929	1a Bronchopneumonia b Fractured temporal bone c Knocked down by motor vehicle when crossing road	E814
*42479	Hospital	Control	Yes	Coroner	1a Cerebral haemorrhage (No past history of renal disease)	431	1a Cerebral haemorrhage b Hypertension, cardiovascular disease c Chronic pyelonephritis right kidney	590
61015	Hospital	Control	No	Other	1a Chronic renal failure following unsuccessful renal transplant	582	1a Coronary thrombosis II Renal failure	410
*61375	Home	Control	No	Other	1a Septicaemia b Gastroenteritis	038	1a Septicaemia b Gastroenteritis	009
62075	Home	Ever-user	Yes	Coroner	1a Suicide by barbitone poisoning	E950	1a Barbitone poisoning by sodium amityl. Open verdict	E980
*66116	Hospital	Ever-user	No	Other	1a Subarachnoid haemorrhage b Berry aneurysm (Craniotomy four days before death)	430	1a Cerebral infarction b Spasm left middle cerebral artery c Aneurysm left cerebral artery	442
72859	Hospital	Control	No	Other	1a Hepatic failure b Infective hepatitis	070	1a Hepatic failure b Acute hepatitis	570

*Denotes those deaths included in the RCGP publication of October 1977.

The coded cause of death is shown in italics.

Comparison of cause of death coding

occurred in 23 cases (74%) and there were discrepancies in eight cases (26%); the details of these are also listed in Table 2.

In Table 3 non-violent deaths are analysed in respect of the availability of post-mortem information, the certifier of death, and the place of death. A comparison is made between the coding at the 'B' list level, in which there was agreement, and those codings which did not agree. Not surprisingly, there is good agreement in cases where the GPs completed the death certificates, since they also provided the information for the study. Discrepancies are most likely to occur when a necropsy is performed, when a coroner completes the death certificate, or when a death occurs at home.

(b) Circulatory diseases

There were 57 deaths coded as due to circulatory diseases by either the RCGP or the registries, or both. These were compared by the 'A' list categories. Table 4 shows that in 48 cases (84%) the RCGP

codes agreed entirely with the registry codes. There were nine discrepancies (16%), the details of which are listed in Table 2. There was no systematic difference between the RCGP and the registry codes. In four cases (7%) the RCGP coded a circulatory disease as the underlying cause of death, whereas the registries recorded a cause of death other than circulatory disease, and in three cases (5%) the registries coded circulatory disease as the underlying cause of death, whereas the RCGP recorded some other cause.

(c) Comparison of ever-users and controls

Comparison of deaths in ever-users (102) with deaths in controls (69) by non-violent causes showed that 71 cases (70%) and 51 cases (74%) respectively agreed at the three-digit level. Eighty-eight cases (86%) and 55 cases (80%) respectively agreed in the 'A' list and 89% and 86% (91 and 59 cases respectively) agreed in the 'B' list. Codings in 11% and 14% (11 and 10 cases respectively) were discrepant in the 'B' list. It is apparent, therefore, that discrepancies were no more likely to occur in ever-users than in non-users. Tables 5a and 5b show that there was no systematic difference between RCGP and registry coding in ever-users and controls, which is especially important in the case of circulatory deaths.

Table 3 Distribution of post-mortem information, certifier of death, and place of death in non-violent deaths by comparison of RCGP and OPCS/GRO coding at 'B' list level

	AGREED %	(No.)	DISAGREED %	(No.)	Total no. (= 100%)
(a) NECROPSY					
Performed	81	(44)	19	(10)	54
Not performed	91	(106)	9	(11)	117
(b) CERTIFIER OF DEATH					
Coroner	78	(25)	22	(7)	32
GP	96	(22)	4	(1)	23
Other	89	(103)	11	(13)	116
(c) PLACE OF DEATH					
Home	89	(33)	11	(4)	37
Hospital	84	(81)	16	(16)	97
Not known	97	(36)	2	(1)	37

DEATHS INCLUDED IN PUBLICATION OF OCTOBER 1977

Ninety-nine deaths were analysed in October 1977. Two deaths from complications of pregnancy were excluded at that time, together with 17 deaths from causes diagnosed before recruitment to the study. Table 6 shows the distribution of the 99 deaths by broad ICD groups according to the original coding by the RCGP (as tabulated in the October 1977 publication) and the registry codes on the death certificates. Death certificates were unobtainable in 15 cases. Full details of discrepant cases within the

Table 4 Comparison of deaths attributed to circulatory diseases by RCGP or OPCS/GRO, by 'A' list ICD codes

	RCGP STUDY						Other	Total
	A82 (Hypertensive disease)	A83 (Ischaemic heart disease)	A84 (Other forms of heart disease)	A85 (Cerebro- vascular disease)	A86 (Disease of arteries, arterioles and capillaries)	A87 (Venous thrombosis and embolism)		
OPCS/GRO	A82	1						1
	A83	1*	15				1*	17
	A84		3					3
	A85			25			1*	26
	A86			1*	1			2
	A87					3	1*	4
	Other			3*	1*			4
Total	2	15	3	29	2	3	3	57

*Patient numbers 10695, 14290, 16328, 17565, 35538, 33967, 42479, 61015, 66116 (see Table 2 for details).

specified groups between RCGP and registry codes are listed and asterisked in Table 2. It is apparent that the distribution of underlying causes of death is little affected according to whether RCGP or registry codes are used for analysis.

Discussion

There is good agreement (72%) between the RCGP and the registry death certificate at the three-digit level in the analyses of total deaths. Examination of the 'B' list discrepancies suggests that coding was usually compatible with the information given, although there are some errors. In 10 cases, similar wording was available to the registries and the RCGP. These were carefully reconsidered by the

registries. They concluded that, based on ICD rules alone, two had been miscoded by them and eight by the RCGP. The discrepancies are not surprising, since the registries used international rules to assign underlying cause of death, and the regulations are on occasion complex and may even seem contrary to medical knowledge. On the other hand, in assigning the cause of death the RCGP sometimes used information relating to the previous medical history which did not appear on the death certificate. For example, patient number 17920 who had a past history of diabetes mellitus and asthma was reported to the RCGP to have been admitted to hospital four months before death with acute asthma, which was, therefore, coded as the underlying cause of death. The death certificate listed: 1a Bronchial asthma; 1b Diabetes mellitus, and because of ICD coding regulations the latter was coded as the underlying cause of death by the registries. In this case the decision by the RCGP about the most important underlying cause of death was influenced by information not available on the death certificate. However, among the 205 deaths, such instances were uncommon.

Table 3 shows that a post-mortem examination was more likely to have been carried out in discrepant cases than in cases where coding agreed. An important reason for this is that post-mortem examinations are uncommon when the cause of death is obvious. For example, only 14% of women with cancer recorded either by the RCGP or by the registries had a necropsy, and yet there was 98% agreement on the underlying cause of death. Furthermore, post-mortem findings were not necessarily known to the GP when reporting on the cause of death, but this applied only to a small proportion of cases. Certain discrepancies appear to arise from subtleties of interpretation. For example, it is sometimes difficult to know whether the cause of death is accidental or not. In our study there are three cases (patient numbers 15595, 16328, and 30279) where the death was coded as non-violent by the RCGP and violent by the registries, although all three had been coded correctly from the information supplied. In all three cases post-mortem information was available. Patient 16328, who had a massive cerebral haemorrhage associated with a fall at work, illustrates that even at inquest it was not possible to ascertain which of the two factors was the underlying cause of death. However, such instances are so infrequent that they are unlikely to disturb the outcome of epidemiological analyses, but they could account for the higher percentage of discrepancies observed when coroners complete the death certificates, since they do not routinely inform the GP of their conclusions.

Table 5 Comparison of deaths in ever-users and controls as coded by RCGP or OPCS/GRO with special reference to circulatory deaths (ICD 390-458)

(a) EVER-USERS

	RCGP			Total	%
	Circulatory deaths	Violent deaths	Other deaths		
OPCS/GRO					
Circulatory deaths	41	0	2*	43	35
Violent deaths	1**	21	0	22	18
Other deaths	1***	0	58	59	47
Total	43	21	60	124	100
%	35	17	48	100	

*Patient numbers 17565, 35538

**Patient number 16328

***Patient number 14290

See Table 2 for details.

(b) CONTROLS

	RCGP			Total	%
	Circulatory deaths	Violent deaths	Other deaths		
OPCS/GRO					
Circulatory deaths	9	0	1*	10	12
Violent deaths	0	10	2**	12	15
Other deaths	2***	0	57	59	73
Total	11	10	60	81	100
%	14	12	74	100	

*Patient number 61015

**Patient numbers 15595, 30279

***Patient numbers 33967, 42479

See Table 2 for details.

Comparison of cause of death coding

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Table 6 Distribution of deaths analysed in October 1977 based upon original coding by the RCGP and OPCS/GRO codes on death certificates

CAUSE OF DEATH	ICD	(a) Original coding by RCGP*		(b) OPCS/GRO death certificates	
		EVER-USERS	CONTROLS	EVER-USERS	CONTROLS
All cancers	140-209	12	20	11	20
All diseases of the circulatory system	390-458	21	3	20	2
	400-429	10	2	9	2
	430-438	9	2	8	0
Accidents and violence	E800-999	12	7	12	8
	E800-949				
	E980	7	6	9	7
	E950-999	4	1	3	1
	E960-999	1	0	0	0
Other causes		2	7	4	7
Death certificate unobtainable, therefore unmatched		9	6	9	6
TOTAL		56	43	56	43

*Because of the distribution of unobtainable death certificates, the numbers in section (a) are not identical to those which appear in Table 1 of the RCGP publication in October 1977.¹

There was no evidence of bias in terms of circulatory disease, nor of oral contraceptive use or non-use. It should be emphasised that the occasional errors in the RCGP codings of deaths not previously analysed would have been identified and corrected at the second stage of validation.

Table 5 shows that the distribution of deaths analysed in October 1977 according to registry coding is very similar to the distribution reported with RCGP codes in both ever-users and controls. There is no reason why the unobtainable death certificates should be biased, and it seems reasonable to conclude that the previously estimated mortality risks associated with oral contraceptive usage would not be materially altered by use of death certificate information. This study, of course, is not a direct test of the accuracy of death certificates, because in 25 patients (10% of cases) the GPs themselves completed both the death certificate and the forms for the RCGP study. On the other hand, the coding of the underlying cause of death was independent.

There has been much debate on the inaccuracies of death certificates^{5,6,7} and their validity for the purposes of epidemiological research. Many variables are involved in arriving at any final code of death, namely certifier, available information, such as previous medical history and post-mortem report, and, finally, the coding regulations employed. The underlying cause of death assigned by the RCGP may represent a more realistic assessment than that coded

from the death certificate, by virtue of the availability and use of previous medical history. Nevertheless, the RCGP coding method, essentially a modification of ICD recommendations, would be neither practicable nor appropriate on a national scale. Where trained coders, rather than doctors, are involved, the systematic rules of the ICD are successful. Weaknesses in both systems do exist, and serve to demonstrate that perfection is impossible, even where post-mortem findings are available. In general, the errors described here and in other studies of cause of death certification only mirror what happens in clinical medicine. In certain subtle situations there is inevitably a choice of underlying cause. The assignment of the 'cause' may vary from one clinician to another and at different times, but the power of cause of death certification in research has repeatedly been demonstrated.^{7,8} The strong agreement between the 'B' list codes assigned by the RCGP and by the registries observed in this study is evidence of the effectiveness of both methods for analyses of the study data, and probably also for other epidemiological purposes.

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