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## How accurately do adult sons and daughters report and perceive parental deaths from coronary disease ?

Graham Watt, Alex McConnachie, Mark Upton, Carol Emslie, Kate Hunt

### Abstract

**Objectives**—To describe how adult sons and daughters report and perceive parental deaths from heart disease

**Design**—Two generation family study.

**Setting**—West of Scotland.

**Subjects**—1040 sons and 1298 daughters aged 30–59 from 1477 families, whose fathers and mothers were aged 45–64 in 1972–76 and have been followed up for mortality over 20 years.

**Outcome**—Perception of a “family weakness” attributable to heart disease.

**Results**—26% of sons and daughters had a parent who had died of coronary heart disease (CHD). The proportion was higher in older offspring (+18% per 10 year age difference) and in manual compared with non-manual groups (+37%). Eighty nine per cent of parental deaths from CHD were correctly reported by offspring. Only 23% of sons and 34% of daughters with at least one parent who had died of CHD considered that they had a family weakness attributable to heart disease. Perceptions of a family weakness were higher when one or both parents had died of CHD, when parental deaths occurred at a younger age, in daughters compared with sons and in offspring in non-manual compared with manual occupations.

**Conclusions**—Only a minority of sons and daughters with experience of a parent having died from CHD perceive this in terms of a family weakness attributable to heart disease. Although men in manual occupations are most likely to develop CHD, they are least likely to interpret a parental death from CHD in terms of a family weakness. Health professionals giving advice to patients on their familial risks need to be aware of the difference between clinical definitions and lay perceptions of a family history of heart disease.

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From a clinical viewpoint family histories are usually considered in terms of clinical events in relatives and the associated disease risks.<sup>5–7</sup> There have been few studies of how the general public perceive such information. In this study, we report the prevalence of parental deaths from CHD in a large cohort of families and the extent to which such deaths are perceived by adult sons and daughters as an illness or weakness that runs in their family.

### Methods

#### SAMPLE

This two generation study is based on 1477 married couples who took part in the Paisley and Renfrew (MIDSPAN) study in 1972–76 while aged 45–64<sup>8</sup> and who had at least one adult offspring living locally in 1996. Altogether 1040 sons and 1298 daughters aged 30–59 and living in the west of Scotland took part in a cross sectional survey in 1996 involving clinical measurements and a questionnaire, in which they were asked whether their parents and siblings were alive and, if not, the cause of death and age at death. They were also asked if they thought “that there are any conditions, weaknesses or illnesses which run in your family” and if so to specify the “illnesses or weaknesses”.

Mortality in the parental generation was established on the basis of linkage of participants in the original MIDSPAN studies to the General Register Office for Scotland (GRO) and regular reporting of death certificates by the GRO over a 20 year period up to the time of the 1996 survey of offspring. Deaths were categorised as attributable to “heart disease”, based on ICD9 codes 391, 393–8, 402, 404 and 410–429 appearing anywhere on the death certificate, and attributable to CHD, based on ICD9 codes 410–4 as the underlying cause of death.

Offspring social class was determined by applying the Registrar General’s classification to current or last occupations of sons and daughters in 1996; parental social class was based on paternal occupation in 1972–76.

#### ANALYSES

Sensitivity of offspring reporting of parental deaths was defined as the number of parents who were correctly identified as having died from “heart disease” or CHD divided by the number of parents who died from each cause. Specificity of reporting was the number of parents correctly identified as not having died of “heart disease” or CHD divided by the number who had died from another cause.

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In anticipation of new genetic markers,<sup>1</sup> there has been renewed interest in the recording of family histories of coronary heart disease (CHD) in clinical practice.<sup>2–4</sup> Family histories are thought to be useful both as indicators of familial susceptibility to disease, via shared genes, behaviours or environments, and as indicators of possible patient concern and motivation to adopt preventive measures.

Table 1 Numbers of offspring by parental and offspring ages when parent died from CHD

	Sons				Daughters				Total number of families
	<25	25–39	40+	Total	<25	25–39	40+	Total	
Father's age at CHD death									
<65	18	41	0	59	22	48	2	72	79
65–74	3	54	47	104	3	85	52	140	159
75+	0	7	21	28	0	9	30	39	48
Total	21	102	68	191	25	142	84	251	286
Mother's age at CHD death									
<65	4	14	0	18	6	20	1	27	27
65–74	0	23	33	56	0	26	25	51	62
75+	0	2	14	16	0	2	20	22	27
Total	4	39	47	90	6	48	46	100	116
Either parent died from CHD	30	140	94	264	43	169	116	328	376
Both parents died from CHD	5	12	0	17	13	10	0	23	26

The prevalence of parental deaths, the sensitivities and specificities of offspring reporting of parental deaths and the prevalence of a perceived family weakness attributable to heart disease are reported as percentages and were analysed by logistic regression. Thirty nine cases with a discrepancy between the respondent's and the GRO's reporting of parental vital status were excluded from analyses of perceived family weaknesses.

Logistic regression models included offspring age, gender and social class (non-manual or manual). Parental social class was not found to be significant in any of the models. Subsequently, the effects of parental age at death, offspring age at parental death, time elapsed since parental death and prevalence of a parental death from "heart disease" or CHD were investigated, and included if significant at the 5% level. Where both parents had died, average ages or elapsed times were used. Finally, interactions between significant main effects were considered by applying the model to subgroups of the data.

To account for correlation between siblings in each response, a bootstrap method was used to adjust the logistic regression models.<sup>9</sup> However, similar conclusions were reached by this method and the results of the unadjusted analyses are presented here.

Table 2 Prevalence of parental CHD and heart related death by offspring age and social class

Social class	Sons			Daughters		
	M	NM	Total	M	NM	Total
Parental CHD death						
Age (y)						
30–39	25/78	23/135	48/213	18/58	42/183	60/241
	32.1%	17.0%	22.5%	31.0%	23.0%	24.9%
40–49	61/238	84/342	145/580	51/163	131/574	182/737
	25.6%	24.6%	25.0%	31.3%	22.8%	24.7%
50–59	35/109	36/124	71/233	26/76	60/229	86/305
	32.1%	29.0%	30.5%	34.2%	26.2%	28.2%
Total	121/425	143/601	264/1026	95/297	233/986	328/1283
	28.5%	23.8%	25.7%	32.0%	23.6%	25.6%
Parental heart related death						
Age (y)						
30–39	26/78	33/135	59/213	21/58	57/183	78/241
	33.3%	24.4%	27.7%	36.2%	31.1%	32.4%
40–49	81/238	105/342	186/580	60/163	174/574	234/737
	34.0%	30.7%	32.1%	36.8%	30.3%	31.8%
50–59	49/109	53/124	102/233	38/76	88/229	126/305
	45.0%	42.7%	43.8%	50.0%	38.4%	41.3%
Total	156/425	191/601	347/1026	119/297	319/986	438/1283
	36.7%	31.8%	33.8%	40.1%	32.4%	34.1%

## Results

The age adjusted mortality rate for CHD in the 1477 fathers was 11.0 per 1000 person years compared with 12.0 per 1000 person years in 4779 other married men who took part in the original MIDSPAN study (who either did not have offspring in the study or who took part in the original study without their spouse). For mothers and 4642 other married women, the rates were 4.6 and 5.7 per 1000 person years respectively. In 18.4% of families both parents had died of any cause by 1996, compared with 24.5% of other couples who had participated in the original study.

Twenty nine offspring from 20 families reported themselves to be step-children or adopted and were excluded from further analyses. The study population comprised 1026 sons and 1283 daughters from 1457 families, who were aged 7–38 years when their parents took part in the original MIDSPAN study and 30–59 years when surveyed in 1996.

### PREVALENCE OF PARENTAL DEATHS FROM HEART DISEASE

Death certificates showed that 379 fathers (26.0%) died of "heart disease" including 286 (19.6%) with CHD as the underlying cause of death; for mothers the figures were 180 (12.4%) and 116 (8.0%), respectively.

CHD deaths occurred at a wide range of ages, from 51–86 years in fathers and from 52–83 years in mothers. At the time of bereavement sons were aged 12–58 years and daughters 9–55 years (table 1). Seventeen sons and 23 daughters had two parents who had died from CHD.

The prevalence of a parental CHD death was 26% in both sons and daughters (table 2). Prevalence was higher in offspring in manual compared with non-manual occupations (OR=1.37, 95% CI 1.12, 1.68, p=0.0021) and in older offspring (for a 10 year increase in age, OR =1.18, 1.01, 1.37, p=0.034).

### REPORTING OF PARENTAL DEATHS

Of the 647 sons with at least one deceased parent, according to death certificate records, 643 (99%) correctly identified the vital status of both parents; of 823 daughters with at least one deceased parent, 812 (99%) confirmed this information. Of the 379 sons whose parents

Table 3 Prevalence of perceived family weakness attributable to heart disease by offspring age and social class, and prevalence of a parental CHD death

Age	Social class	Sons			Daughters			All
		M	NM	Total	M	NM	Total	
30-39	Parental status							
	Alive/non-CHD death	4/52	12/107	16/159	6/38	17/140	23/178	39/337
40-49	CHD death	7.7%	11.2%	10.1%	15.8%	12.1%	12.9%	11.6%
	CHD death	4/25	8/23	12/48	7/18	17/41	24/59	36/107
50-59	CHD death	16.0%	34.8%	25.0%	38.9%	41.5%	40.7%	33.6%
	CHD death	12/173	26/255	38/428	13/112	63/434	76/546	114/974
Total	CHD death	6.9%	10.2%	8.9%	11.6%	14.5%	13.9%	11.7%
	CHD death	13/60	23/84	36/144	12/49	47/129	59/178	95/322
Total	CHD death	21.7%	27.4%	25.0%	24.5%	36.4%	33.1%	29.5%
	CHD death	7/74	7/86	14/160	7/49	18/164	25/213	39/373
Total	CHD death	9.5%	8.1%	8.8%	14.3%	11.0%	11.7%	10.5%
	CHD death	4/35	9/36	13/71	11/26	17/60	28/86	41/157
Total	CHD death	11.4%	25.0%	18.3%	42.3%	28.3%	32.6%	26.1%
	CHD death	23/299	45/448	68/747	26/199	98/738	124/937	192/1684
Total	CHD death	7.7%	10.0%	9.1%	13.1%	13.3%	13.4%	11.4%
	CHD death	21/120	40/143	61/263	30/93	81/230	111/323	172/586
Total	CHD death	17.5%	28.0%	23.2%	32.3%	35.2%	34.4%	29.4%
	CHD death	44/419	85/591	129/1010	56/292	179/968	235/1260	364/2270
Total	CHD death	10.5%	14.4%	12.8%	19.2%	18.5%	18.7%	16.0%

were alive in 1996 according to the GRO, 367 (97%) reported them both to be alive; of 460 daughters, 448 (97%) reported that both parents were alive.

#### REPORTING OF A FAMILY HISTORY OF HEART DISEASE

Altogether 89.1% of parental deaths from CHD were reported correctly by offspring. Older offspring reported this cause of death less sensitively, but the association did not reach statistical significance: for a 10 year increase in age, OR =0.68 (0.45, 1.02), p=0.065. Daughters' reporting was more sensitive, again without reaching significance: OR=1.59, (0.95, 2.65), p=0.078. The effect of offspring social class was not significant: for manual relative to non-manual occupations, OR=0.81 (0.48, 1.36), p=0.42. The specificity of offspring reports of parental CHD deaths was 86.3%.

#### PERCEPTION OF A FAMILY WEAKNESS ATTRIBUTABLE TO HEART DISEASE

Heart disease was the most commonly perceived type of condition, weakness or illness running in a respondent's family. In the whole population 12.8% of sons and 18.7% of

daughters considered that they had a family weakness attributable to heart disease. In both sons and daughters 47% of such cases were associated with at least one parental death from CHD (table 3). Some 22.9% of sons (202 of 881) and 20.7% of daughters (212 of 1025) who did not perceive a family weakness attributable to heart disease had at least one parent who had died of CHD.

Of those with at least one parental CHD death 23.2% of sons and 34.4% of daughters considered themselves to have a family weakness attributable to heart disease (table 3), compared with 9.1% of sons and 13.2% of daughters in families where neither parent had died from CHD. There was no difference between the proportions of maternal CHD deaths (24.3%, 43 of 177) and paternal CHD deaths (28.8%, 123 of 427) that were associated with a perceived family weakness attributable to heart disease.

The perception of a family weakness was lower in older offspring (for a 10 year increase in age, OR =0.82 (0.68, 0.98), p=0.034), higher in daughters (OR=1.56 (1.22, 1.98), p=0.0004) and slightly lower in offspring from manual occupations (OR = 0.80 (0.61, 1.04), p=0.089) (table 4). Relative to offspring whose

Table 4 Effect estimates (as odds ratios, with 95% CI and p value) from models of perception of a family weakness attributable to heart disease, based on all data and subgroups defined by gender, social class or prevalence of a parental CHD death

Effect	Subjects included						
	All	Sons	Daughters	Manual	Non-manual	No parental CHD deaths	≥1 parental CHD death
Age*	0.8 (0.7, 1.0)	0.8 (0.6, 1.1)	0.8 (0.7, 1.1)	1.0 (0.7, 1.4)	0.8 (0.6, 0.9)	0.9 (0.7, 1.1)	0.8 (0.6, 1.0)
Gender†	0.03 1.6 (1.2, 2.0)	0.2 —	0.1 —	0.96 2.0 (1.3, 3.0)	0.01 1.4 (1.1, 1.9)	0.2 1.5 (1.1, 2.1)	0.06 1.6 (1.1, 2.4)
Social class‡	0.0004 0.8 (0.6, 1.0)	0.04 0.7 (0.4, 1.0)	0.6 0.9 (0.6, 1.3)	0.003	0.02	0.01 0.9 (0.6, 1.3)	0.01 0.7 (0.5, 1.0)
One parental CHD death§	3.2 (2.5, 4.0)	3.1 (2.1, 4.7)	3.1 (2.3, 4.3)	2.3 (1.5, 3.7)	3.6 (2.7, 4.8)	—	—
Two parental CHD deaths	<0.0001 7.9 (4.1, 15.2)	<0.0001 3.5 (1.1, 11.4)	<0.0001 13.0 (5.4, 31.4)	0.0003 19.3 (6.4, 58.7)	<0.0001 4.3 (1.8, 10.3)	—	2.6¶ (1.3, 5.1)
	<0.0001	0.03	<0.0001	<0.0001	0.001	—	0.005

\*Age effect is for a 10 year difference in offspring age. †Gender effect is for daughters relative to sons. ‡Social class effect is for offspring in manual relative to non-manual occupations. §Parental CHD death effects (one or two deaths) are relative to offspring whose parents were either alive, or had died from a cause other than CHD. ¶Effect estimate for two parental CHD deaths is relative to one parental CHD death group.

parents had not died from CHD, those with a single parental CHD death had an odds ratio of 3.15 (2.47, 4.02,  $p < 0.0001$ ); for those whose parents had both died from CHD the prevalence of a perceived family weakness was again increased (OR=7.91 (4.12, 15.170,  $p < 0.0001$ ). In the statistical model confined to sons, perceptions of a family weakness attributable to heart disease were significantly less common in men from manual compared with non-manual occupations (OR=0.66 (0.44, 0.98),  $p = 0.038$ ) (table 4).

### Discussion

Despite increasing interest in the recording of family histories of heart disease in general practice, there have been few studies linking the prevalence, reporting and perceptions of such histories in the general population. This is the first such study based on a large general population cohort in which parental mortality has been monitored over a 20 year period. Although it was more difficult to renew contact with families where both parents had died, the study population includes a substantial number of such families. The study excludes offspring who had left the area.

Over the 20 year period 26% of fathers and 12% of mothers had died of "heart disease". Seventy five per cent of these paternal deaths and 64% of the maternal deaths had CHD as the underlying cause of death on their death certificate. The fact of death was reported correctly in 99% of cases and the cause of death was reported correctly in 89%, of deaths attributable to CHD.

Epidemiological definitions of a family history of heart disease are based on the fact of death and the associated disease risks.<sup>3-7</sup> Lay perceptions of a family history, however, depend in addition on the meaning and implications of deaths and clinical events as interpreted by individuals.<sup>10 11</sup>

Our study of lay perceptions was based on offspring reporting "a family weakness due to heart disease". This definition has some face validity, deriving from its strong association with parental deaths from CHD, the greater effect of two parental deaths and the greater effect of parental deaths from CHD on younger offspring.

A strength of the study is the high level of agreement between respondents' and the GRO's reports of parental deaths from heart disease. A limitation is that we have no data on non-fatal coronary events in family members<sup>12</sup> and on fatal events in family members other than parents and siblings (although only 10 sons and 8 daughters from 13 families reported a sibling, in all cases a brother, as having died from heart disease).

Qualitative research is underway to investigate the lay reasoning that underpins people's understanding of family histories of heart disease.<sup>13</sup> This suggests that while parental deaths are very important in the assessment of familial risk, people also take account of death and illness in other family members. Another quantitative study has demonstrated a strong relation between reporting of a family weakness

#### KEY POINTS

- About a quarter of men and women aged 30–59 may be expected to have at least one parent who has died of coronary heart disease (CHD). About 90% of deaths from CHD are correctly reported by offspring.
- Only one in four sons and one in three daughters with a parental death from CHD consider that they have a "family weakness" attributable to heart disease.
- Men in manual occupations are least likely to consider that a parental death from CHD indicates a "family weakness" attributable to heart disease.
- About a fifth of sons and daughters who do not consider themselves to have a family weakness attributable to heart disease have at least one parent who has died from CHD.
- Health professionals need to be aware of the differences between clinical definitions and lay perceptions of a family history of heart disease.

attributable to heart disease and numbers of both close relatives (parents and siblings) and more distant relatives (grandparents, aunts, uncles and first cousins) with the disease.<sup>14</sup> These observations help to explain why 9% of sons and 13% of daughters in the study whose parents had not died of CHD nevertheless reported a family weakness attributable to heart disease. The larger size of this category of offspring results in more than half of all offspring reporting a family weakness attributable to heart disease belonging to this group (table 3).

These data, and also the wide range of ages at which offspring experience parental deaths from CHD illustrate the heterogeneity of family histories of heart disease in the general population. This heterogeneity may be one reason why only a minority of offspring, comprising 23% of sons and 34% of daughters with at least one parent having died from CHD, reported a family weakness attributable to heart disease. There was no interaction between offspring and parental gender in how CHD deaths in parents were perceived.

While daughters and sons were equally likely to have experienced the death of a parent from heart disease, daughters were more likely to perceive such a death in terms of a family weakness. Our qualitative research suggests that while daughters who perceive a family weakness tended to have one parent who had died from heart disease, sons with this perception tended to have either two parents with heart disease or heart problems affecting their father and other relatives on his "side of the family" (unpublished data).

In the data reported here, it is of interest that men in manual occupations, who are at greatest risk of developing CHD, are least likely to perceive a family weakness attributable to heart disease (table 4), with only 17.5% of such sons reporting this perception (table 3).

However, this group also had the lowest prevalence of perceived family weaknesses from any cause. A possible explanation is that the greater exposure of men in manual groups to premature death in older relatives makes them less likely to identify specific family weaknesses. It is also of interest that 26% of men in manual groups who did not report a family weakness attributable to heart disease had nevertheless experienced at least one parent dying from CHD.

Our findings may not be directly relevant to current clinical practice concerning the ascertainment and management of people with a family history of premature heart disease. Current clinical guidelines for the definition of a family history of CHD are based on coronary events occurring in first degree relatives under the age of 55.<sup>15</sup> Only 1.4% of sons and 1.1% of daughters in this population had experienced a parent dying from CHD below this age. Higher proportions are likely to have parents below this age who have survived non-fatal coronary events. By its sampling criteria, the study also excludes parents who died of heart disease below the age of 45.

As understanding of genetic risk of CHD improves, however, it is probable that new definitions of family histories involving larger proportions of the general population will be introduced to clinical practice. Knowledge of a family history of heart disease is also important in relation to activities in cardiovascular health promotion, including attempts to influence individual behaviour. Our findings show that health care professionals need to be sensitive to variations in lay understanding and perception if they are to avoid dysfunctional consultations concerning CHD risk.

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