

BMJ Open How is family health history discussed in routine primary healthcare? A qualitative study of archived family doctor consultations

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ABSTRACT

Objectives Family health history underpins genetic medicine. Our study aimed to explore language and patterns of communication relating to family health history observed in interactions between general practitioners (GPs) and their patients within routine primary care consultations.

Design Secondary analysis of patient and GP routine consultation data (n=252).

Participants Consultations that included 'family health history' were eligible for inclusion (n=58).

Primary outcomes A qualitative inductive analysis of the interactions from consultation transcripts.

Results 46/58 conversations about family health history were initiated by the GP. Most discussions around family health history lasted for between approximately 1 to 2 min. Patients were invited to share family health history through one of two ways: non-specific enquiry (eg, by asking the patient about 'anything that runs in the family'); or specific enquiry where they were asked if they had a 'strong family history' in relation to a particular condition, for example, breast cancer. Patients often responded to either approach with a simple no, but fuller negative responses also occurred regularly and typically included an account of some kind (eg, explaining family relationships/dynamics which impeded or prevented the accessibility of information).

Conclusions Family health history is regarded as a genetic test and is embedded in the sociocultural norms of the patient from whom information is being sought. Our findings highlight that it is more complex than asking simply if 'anything' runs in the family. As the collection of family health history is expected to be more routine, it will be important to also consider it from sociocultural perspectives in order to help mitigate any inequities in how family history is collected, and therefore used (or not) in a person's healthcare. Orientating an enquiry away from 'anything' and asking more specific details about particular conditions may help facilitate the dialogue.

INTRODUCTION

Family health history has been described as the first genetic test.¹ A family health history is defined as 'a record of health information about a person and his or her close relatives.

Strengths and limitations of this study

- The patient cohort was Euro-centric, and not fully reflective of the ethnic population of New Zealand (where the study was carried out).
- The extent to which the family health history information had been previously shared/documentated was not ascertainable.
- The study draws on range of routinely collected consultation studies with different purposes, and hence cover a wide range of general practitioner contexts, without specifically having a focus on family history.

A complete record includes information from three generations of relatives, including children, brothers and sisters, parents, aunts and uncles, nieces and nephews, grandparents, and cousins.' (National Institutes of Health, Genetics Home Reference). Such a detailed family health history is regarded as one of the most useful tools for risk assessment for common chronic diseases.² It is estimated that the relative risks and ORs for various cancers, stroke, type 2 diabetes and cardiovascular diseases is twice that for people with an affected first degree relative, and more than four times greater for many of these diseases if there is more than one affected first-degree relative.^{2,3} The value of health records from relatives has been recently demonstrated in research aimed at providing accurate predictions of disease risk: Truong *et al* showed that including health information from first-degree relatives of those with both genomic and health records, had similar accuracies in polygenic risk scores with 44-fold larger population samples consisting of only genomic data and health information.⁴ Several professional organisations have recently made recommendations that general practitioners (GPs) routinely, and opportunistically, collect family health history for three generations.^{2,5}

However, current evidence would indicate that there may be barriers to achieving this level of information, and approach to its collection, as family health history is widely reported as being both poorly and infrequently collected.^{6,7} Reported barriers to the collection of family health information include: poor reimbursement, provider's lack of time and expertise, lack of guidelines and adequate tools and limited functionality of electronic health information systems to capture and interpret data and unreliability of information provided by patients.^{8,9} The potential to improve healthcare by being able to act on family health history information is thus not being fully realised. This is important as access to genetic and genomic testing becomes easier and cheaper, available direct to the public and knowledge of family health history is imperative in wisely using this testing and interpretation of results.^{1,10,11}

The exploration of the practice of collection of family health history has tended to focus on the practical side, that is, to garner better understandings around the barriers and facilitators to its collection, and the validation and implementation of tools to collect family health history.^{2,11,12} How family health history is actually discussed in routine primary healthcare consultations has received less attention, and to our knowledge this is first study to observe conversations about family health history in routine primary care consultations. The aim of our study was to explore language and patterns of communication relating to family health history observed in interactions between GPs and their patients within routine primary care consultations.

MATERIALS AND METHODS

Data source

Consultation data were sourced from the Applied Research on Communication in Health (ARCH) Corpus

at the University of Otago, Wellington, New Zealand,¹³ and have been previously described.¹⁴ The Corpus houses a digitally stored collection of patient/practitioner consultation data that includes 458 videorecorded consultations, verbatim transcripts and selected medical notes.¹⁵

Identification of family health history consultations

The consultations analysed in this paper were derived from five different studies that comprise the ARCH Corpus; in none of these was family health history the focus (table 1). At the time of this study, the Corpus included 252 patient–GP consultations involving 36 GPs, collected between 2004 and 2018. The ARCH Corpus includes a Microsoft Access database populated with metadata including full demographic information about every participant, research site information and free-text content logs of each consultation. The logs were prepared by a research nurse according to a standard template and include information about the main topics discussed, outcomes of the consultation (including prescriptions and referrals) and a minute by minute summary of key events and content. The logs thus capture any complaint or topic mentioned incidentally in a consultation, in addition to the main presenting complaint(s). The database and logs link electronically to full verbatim transcripts (including time measurements in minutes) and the original audio and videorecordings to facilitate subsequent more detailed analysis, but the latter cannot be queried directly via the database.¹⁵

A query was run on the Microsoft Access database of the logs of each GP consultation in the Corpus using the keyword 'family health history' (table 1). The term 'family health history' was present in the logs of 71/252 individual patient consultations with GPs. Further review of the transcripts was undertaken and the consultations were excluded if family health history was not discussed.

Table 1 Overview of the study and number of patient–GP consultations where family health history was discussed

Study	Brief description of the original study	No of consultations included in the analysis	No of patient–GP consultations in original study
Diabetes Study	Tracking the contact of newly diagnosed patients with type 2 diabetes with healthcare professionals over a 6 month period	7	34
Interaction Study	Exploring clinical decision-making when rationing is explicit	11	58
Tracking Study	Exploring communication processes throughout a single complete episode of care of patients referred from primary to secondary care	31	125
Talking About Overweight and Obesity	When and how GPs and patients discuss excess weight related issues (or not) during routine consultations	6	19
Interpreting Study	Clinical risk and patterns of use and communication with/of interpreters	3	16
Total		58	252

GP, general practitioner.

Additional terms were also included at this time to identify if family health history was mentioned in another context and included ‘family history’; ‘family’; ‘whānau’ (family); ‘inherited’; and ‘condition’. It is possible that not all relevant consultations in the Corpus were identified; however, the purpose was to collate a relevant dataset adequate for the purpose of undertaking a descriptive qualitative analysis, and not to investigate the frequency of occurrence of family health history.

Patient and public involvement

Patients were not involved in any aspects of the study design, including plans for dissemination of the research findings. As part of the original consenting process, they would have been advised on the length of the time required to participate in the research.

Data analysis

Themes were derived iteratively using a qualitative inductive approach based on the verbatim transcripts of interactions between patients and GPs.¹⁶ Our overarching aim was to report on the emerging range of issues and communication styles without pre-conceived assumptions. SF (health services researcher) read all of the transcripts (n=71) several times and identified the conversation sequences that related to family health history, including the time in the consultation that it was first mentioned. A subsample of transcripts were read by RJ (GP and health services researcher). Twelve initial inductive themes were derived (table 2) that formed the coding frame, the transcripts were then reread and new codes emerged as preliminary themes. These themes were mapped across all of the transcripts, reread and recoded until no further themes emerged and the final themes derived (table 2). Where additional clarity or interpretive information was required, the videorecording of the consultation was reviewed. Initial interpretations of the themes were shared with the team and discussed in detail discussion between SF and RJ. MHS,

Table 3 Self-reported ethnicity of patients who participated in the original studies

Self-reported ethnicity	Frequency
New Zealand European	41
New Zealand European/Māori	2
New Zealand European/Cook Island Māori	2
Māori/ Samoan/UK/US	2
New Zealand European/Samoan	2
Samoan	8
Tongan	2
Assyrian	1
Chinese	2
Dutch	2
Dutch/New Zealand European	1
Indian	2
Italian	1
Somali	1
Sri Lankan	1
Thai	1
Total	71

a researcher with experience in interactional sociolinguistics contributed to an additional round of discussion and interpretation. The themes were discussed and agreed by consensus with all of the authors. The sociodemographic information of the 71 patients was reviewed after the first round of analysis and self-identified ethnicity reported in table 3 analysis by ethnicity was not undertaken.

RESULTS

Fifty-eight out of a possible 252 (23%) patient–GP consultations involved at least one mention of family health

Table 2 Thematic structure

Inductive codes	Preliminary themes	Final themes
Blindsiding	Open question	Non-specific line of enquiry
GP closed question	Closed question	Specific line of enquiry
GP contextualising	Health condition	
GP health promotion		
Knowing the GP		
Not knowing	Not getting very far	
Patient position		
Isolation		
Health condition	Why asked	
Lifestyle advice		
How asked	GP multitasking	Multitasking
GP position	Patient multitask response	

GP, general practitioner.

history. Since most patients came to the consultation with more than one reason for their visit, the resultant interaction between the GP and the patient was a dynamic exchange of information, often covering several points of discussion. The length of each individual consultation ranged from 6 to 37 min duration. Sharing or updating family health history was never the presenting reason for the consultation. In the 58 consultations, 46 conversations about family health history were initiated by the GP. Most discussions around family history lasted for between 1 and 2 min. Two overarching themes were developed from the transcripts that described how family history was raised, and then subsequently discussed, in the consultation—non-specific and specific enquiry; and one theme which related to the situational context, multitasking (table 2).

How family health history is raised in the consultation

The topic of family health history was presented initially to the patient in one of two ways, through a line of non-specific enquiry or through a specific context (table 4). Patients often responded to either approach with a simple ‘no’, but fuller negative responses also occurred regularly and typically included an account of some kind—for example, that the patient was unable to be certain or to provide the requested information (eg, explaining family relationships/dynamics which impeded or prevented their access to information).

Non-specific enquiry

A non-specific line of enquiry was initiated through prompt questions that were tilted towards a ‘no’ answer, typically asking the patient if there was ‘anything that runs in the family’ or if there was ‘anything in the family we should know about?’.

The introduction of the topic through this form of non-specific enquiry, while sufficient to initially engage the patient, elicited two opposite types of responses, one where the patient disclosed very little or one where the patient disclosed a significant amount of information.

Where patients responded by not disclosing any information, this often ended any further discussion about family history, with no further details being drawn out by the GP. Following this, the direction of the consultation tended to change abruptly into a different topic, as illustrated by the following interaction:

GP: ... and anything that runs in your family at all on either your mum or dad’s side?

PT: No not that I know of

GP: Nope

GP: Fine, and have you ever had a smear test?

(ARCH:TS GP08-17)

Those patients who responded positively to the initial response to the prompt to share ‘anything’ or discuss ‘any’ history did so by presenting a picture of family health that had personal meaning to them, and at the same time oriented to the doctor’s agenda by highlighting aspects that were clinically relevant. For example:

GP: I’ve got your details and medication, any history of

PT: Parents are in the seventies and still alive

GP: Good

PT: Apparently my grandmother ended her life in the gas oven at home so I guess she would have lived a long life if she hadn’t of done that

GP: Mm

PT: Grandfather on the other side was an alcoholic so that sort of explains why he’s dead

GP: Right

PT: The other set of parents are fine

GP: And the other grandparents

PT: Oh grandparents? One died on the operating table and um, he was sixty odd, and my grandmother would have been in her seventies as well I think’

At this point of the consultation, the GP changed to a more specific line of enquiry (inferably following a checklist) by asking about the occurrence of specific health conditions, and it followed as:

GP: Anyone had diabetes in the family?

PT: No

GP: And high blood pressure?

PT: No

GP: Um alcoholism it was your mother’s father or your father’s father?

PT: Oh my mother’s father grandfather, but it’s all largely hearsay

GP: Yep

GP: Any significant mental illness?

PT: No, we seem to be pretty straight up

GP: And familial degenerative disease, which I don’t actually understand what that means, so we’ll leave that blank

PT: Once again they’re all seventy they’re not in the mental asylums and they’re living in their own homes without nursing and wheelchairs so that’s pretty good

(ARCH:IS-GP02-08)

In this interaction initially it appeared that the patient wasn’t going to share family health history information by stating ‘Parents are in the seventies and still alive’, which suggests that they felt this was sufficient in describing a picture of family health. However, they went on to share more details, despite being prompted initially by a non-specific line of enquiry, with the patient disclosing that alcohol misuse and mental health conditions did exist in their family. Of note is that while this patient disclosed that a relative died by suicide, and that there was alcohol misuse, they did not appear to attribute this to poor mental health, instead discounting the reliability of the information passed down, by saying it was ‘hearsay’. After several specific questions about the occurrence of particular health conditions, the GP ended the enquiry by saying ‘And familial degenerative disease, which I don’t actually understand what that means, so we’ll leave that blank’ to which the patient augmented their initial response by stating ‘Once again they’re all seventy they’re not in the mental asylums and they’re living in their own homes without nursing and wheelchairs so that’s pretty

Table 4 Supporting quotes

Theme	Interaction	ARCH original study
Non-specific enquiry	<p>GP: Okay, and is there anything that runs in your family any medical problems at all? PT: In my family? GP: Yeah anything in your parents or brothers or sisters or grandparents? PT: No. PT: Er mum ...yeah she got asthma or something like that GP: Yep PT: Yeah yeah GP: Okay but you've never had any problems like this fine and do you drink any alcohol or smoke PT: No no GP: Well what about your family any um illness run in your family? PT: Um no GP: Um okay now what about bees GP: ... we'll examine you today and make sure that's okay. What about in your family any of those things run in your family at all? DA: Um nothing runs in the family... we, my aunt told me GP: ...anything that runs in your family? PT: Nope, my family's GP: Yeah good PT: My husband's well my ex husband's would be a different story GP: But your fam- there's no strong family history of any type of cancer or anything like that PT: Nope PT: Nothing GP: Fine</p>	<p>TS-GP08-01</p> <p>IS-GP05-05</p> <p>TS-GP08-21</p> <p>TS-GP08-23</p>

Continued

Table 4 Continued		ARCH original study
Theme	Interaction	
Enquiry through context	<p>GP: Any family history with bowel problems? PT: Um my aunty had bowel cancer but um that's all GP: How old was she when she got it? PT: She was late sixties GP: Right PT: But nothing you know my parents both died of smoking related diseases GP: Mm mm PT: So but apart from that there was nothing GP: Does anyone else in your family have diabetes? PT: No GP: Okay PT: No it's not in the family GP: Is um whether there's any significant family history of heart disease, anything there in your family? PT: Not sure about heart, so leukaemia's different isn't it? GP: Angina or heart, yeah PT: Yeah GP: Angina or heart attack, parents or grandparents PT: Yeah, my grandfather did have a heart attack GP: ...it's just a little, it's a small spot that's bleeding on your chest a bleeding spot on your chest, yep, there's no family history of skin cancer that I should be aware of or any skin problems? PT: Not that I know of GP: No that's fine, that's okay</p>	<p>TS-GP03-07a</p> <p>DS-GP19-02a</p> <p>IS-GP02-02</p> <p>IS-GP06-08</p>
Multiple conditions enquiry, and patient contextualising response	<p>GP: ...and anything that runs in your family? Any strong history of heart disease or cancers or blood pressure problems, diabetes, anything? PT: No GP: ...like that PT: Um no, nothing like that just my granddad PT: Yeah well my grandparents were pretty old when they died GP: Mmm PT: Um except for one, there was an accident so, yes nothing really pretty, pretty, pretty good genetics although I've got poor hearing from my mother's side but yeah I mean that's something I've known about for years, might need to get a hearing aid 1 day...</p>	TS-GP08-19
Enquiry through context – highlighting the unknown	<p>GP: Can I ask you a few more questions... is there any family history of any cancers in your family? PT: Um yes GP: Which ones? PT: On my father's side I don't know much, he was an only child with elderly parents so I never even met them and um so I don't know much about that except his cousin had cancer, um started with er testicles I think and then carried on um he's now passed</p>	DS-GP32-05_Taboo

Continued



indication that they would have been able to ascertain a more detailed family history if they knew they were going to be asked about it, nor did any patient say in the consultation that they would attempt to find out more. Once an estranged family had been raised by the patient, the GPs made no more enquiries to establish familial inheritance/occurrence, and the consultation was refocused to the individuals' health history.

Multi-tasking

In reviewing the video recordings, the GP could often be observed multitasking during the consultation (eg, looking at or adding to the electronic medical record, undertaking a physical examination), including at the time while asking the patient about their family health history. The patient was also expected to multitask, from having to think about answering more than one line of enquiry, and having to undertake tasks at the same time. The following excerpt exemplifies such an interaction:

GP: I will need your height and weight please as well, and do you have a family history of heart attacks or strokes? Without shoes please

PT: Um my mum she had a minor heart attack but she died um it'll be three years this year

GP: Mm hm

PT: Um from cancer

GP: Mm what kind of cancer?

PT: Um they're not really sure

GP: Stand here please

PT: Cos they don't know where it started

GP: Yeah

GP: Sometimes has that, okay, that's perfect

PT: Oh okay, what height am I?

GP: One fifty six

(ARCH:DS-DP32-08)

This consultation commenced with a 'so' to which the patient explained the reason for their visit. Within 1 min the GP had turned their back to the patient, and started typing. Two minutes into the consultation, the GP started experiencing problems with the computer (data entry) and said to the patient 'ahhh don't you hate computers?'. The patient in this instance did not appear relaxed, they were wringing their hands and swinging their legs under the chair. The topic of family history was raised approximately 5 min into the 13 min consultation, where the patient was given a statement of intent—that their height and weight would need to be taken, asked a question—about their family history, and an instruction—to remove their shoes. In response to the doctor's question about family history of heart attack or stroke, the patient disclosed that her mother had died 3 years ago. At this point the GP was not making eye contact with the patient, and during the explanation of what her mother had died from the patient was given another instruction to go and stand in a particular place. While family health history information was able to be shared, because it was done in a context of multitasking, it appeared to create a perfunctory transaction, rather than a discussion.

DISCUSSION

This paper reviewed how family history was discussed in a sample of archived primary healthcare consultations. To our knowledge, this study is the first to observe conversations about family health history in routine primary care consultations. The majority (46/58) of conversations about family health history were initiated by the GP. Most of these family history discussions lasted approximately 1–2 min. Patients were invited to share family health history through one of two ways; non-specific enquiry such as asking 'anything that runs in the family?', or in relation to a specific condition where patients were asked if they had a 'strong family history' of a particular condition, like breast cancer. The majority of patients responded to either approach by replying 'no' or premising the negative reply by explaining family relationships or dynamics which would impede or prevent access to such information. Of note is constraints of primary care consultations on family health history taking. 'Multitasking', and computer use also appeared to have an influence on how family history taking played out. These aspects have been noted in other areas of primary care performance and, once understood, strategies can be put in place to mitigate their impact.¹⁷

Sharing of family history information with family members and health-professionals is influenced by the sociocultural norms of the family it pertains to and the purpose for which the information is being sought.^{18–21} There are multiple meanings of 'family' and varying beliefs about what 'health' (and illness) means.^{19 20} Furthermore there are different reasons for collecting family health history information, for example, to establish genetic risk to identify which patients need referral for specialist genetics assessments²¹; to establish the prevalence of complex chronic diseases³; or to establish family systems genogram²¹ or potentially for all of the aforementioned reasons. However, if this is not established prior to the enquiry being made, the healthcare interaction may result in misaligned communication because there has been an assumed shared understanding of what is meant by 'family health history'.^{20 22} This was frequently observed in our study. While no patient questioned why family health history was being enquired about, there was no indication given by the GPs as to why it was being asked about. It is not possible to ascertain whether indicating the purpose of the enquiry would have resulted in more aligned discussions and this warrants further investigation.

As part of realising the use of family health history more routinely, there is an emerging expectation that people will collect their family health information through the use of online family health history tools.^{2 12 23} In 2010, the US Surgeon General suggested that Thanksgiving Day be also called 'Family Health Day' because families often get together, providing an opportunity to discuss and collect family health history from several family members.²⁴ In parallel the US Surgeon General released a free online tool for the collection of family health

history.²⁵ The use of family health history tools has been shown to improve the detection of inherited conditions and cancer in research studies.² However, there are considerations for the use of such tools in routine practice. As with other family health history tools, this tool reflects a narrow biomedical definition of the family²⁰ which raises questions about the relevance and potential acceptability of such tools for many families, including for those observed in our study. Multiple approaches that incorporate both social and biological/medical elements are likely to result in more equitable access to and greater benefit from family history information in healthcare.

In our study, enquiring about family health history lasted between 1 and 2 min. A ‘full’ family history includes three generations of relatives, health problems with age of onset for each family member, and age of each relative at death with cause has been estimated to take up to 30 min.²⁶ Dedicated consultations for the collection and documentation of family health history have been proposed as potential solutions to these system level constraints.² However, this approach could potentially create inequities in access to (and therefore benefit from) family history collection for those people who are unable to pay for and/or attend additional consultations.

In previous studies, GPs have reported that the information that patients do provide about their family history is unreliable.^{8 27 28} Our study demonstrates that the way GPs enquire about family health history may also contribute to the amount and type of information that is gathered. Another study exploring how GPs could meet patients unmet needs in acute care consultation found that changing the orientation of the enquiry by using the question ‘Is there something else you want to address in the visit today?’ led to significantly more unmet needs being eliminated than when GPs used the question ‘Is there anything else you want to address in the visit today?’²⁹ Although the paper reports a randomised controlled trial that was conducted in the context of eliciting additional concerns, but its relevance extends beyond this topic—the key point is that choosing ‘anything’ rather than ‘something’ in asking the question signals that that the expected answer is ‘no’. Hence this finding is relevant to history taking as well as problem presentation. It would be worth exploring if such attention to linguistics would help improve the collection of family health history. In a further study, when patients were asked to consider family health history, the addition of ‘extended’ to family health history yielded patients reporting positive family history for 8 of 11 medical conditions.²⁶ In our data, the abrupt shift in consultation topic after a negative initial response to family history is indicative of many interactions in primary care where there are competing demands in a checklist driven consulting environment.³⁰ With increasing expectations that family health history is collected, such communication devices may help to enhance interactions and obtain more relevant information

A limitation of this study is that the patient cohort was Euro-centric, and not fully reflective of the ethnic diversity of New Zealand (where the study was carried out). We have not undertaken any analysis by ethnicity, and this is warranted in future research. It was also not possible to ascertain the extent to which the family health history information that was shared was taken into account in any clinical decision making by the GP. Nor was it possible to ascertain whether other healthcare practitioners had had prior discussions with patients about their family history, or if this information had been collected and recorded elsewhere in the patient records. A strength of this study is that these examples are taken from a range of routinely collected consultation studies with different purposes, without a specific focus on family history, and hence cover a wide range of GP contexts.

This study has highlighted areas where inequities may arise with existing methods of routine collection of family health history. The opportunistic enquiry into family health history is more complex than asking if ‘anything runs in the family’ and, with attention to linguistic devices and acknowledgement of patient social and cultural norms, there is an opportunity to expand history taking to the point at which the history can become an effective genomic tool.

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approval for this study was given by the University of Otago Human Ethics Committee (Health) (H19/022).

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