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‘If you sell your sickness, you will get its medicine’: Care and intrafamilial communication for chronic diseases in southern Ghana

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ABSTRACT

Knowledge of family health history can help to mitigate risk for chronic non-communicable diseases known to run in families. However, disclosure of disease or illness is not always a given. This paper explores the relationship between care and intrafamilial communication regarding chronic health conditions in Ghanaian families, drawing on concepts of generativity and reciprocity. Data were drawn from a qualitative description study on family histories and health. This paper analyzes four focus group discussions and two intergenerational family interviews conducted among 35 older adults and their adult children and grandchildren in the Greater Accra Region of Ghana. Data were analyzed thematically using an inductive approach and themes relating to care and intrafamilial communication were assessed for this analysis. Findings showed that intergenerational care can serve as a means to disclose and communicate family health histories while disclosure of illness serves as a means to receive and give care for oneself and one’s family. Furthermore, care services can sometimes be a barrier to communication of family health histories while concealment of disease and of family health histories and identities may be a form of care. Finally, intergenerational family health history discussions may prompt encouragement of care-seeking behaviors and preventive care. The results of this pilot study suggest avenues through which care arrangements could be capitalized on to promote the sharing of health history information within families to better manage chronic disease risk. In addition, they illustrate the potential for family health history discussions to further encourage care-seeking for chronic disease prevention.

Introduction

Family history of disease is a risk factor for several chronic ‘non-communicable’ conditions, including cardiometabolic diseases (heart disease, diabetes, stroke), cancers (breast, colorectal), autoimmune and atopic diseases (rheumatoid arthritis,

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Abbreviations: FGD, Focus group discussion; IGI, Intergenerational interview.

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asthma), neurological diseases (epilepsy, Alzheimer's disease) and mental illnesses (anxiety, depression, psychosis) [26,39]. In high-income countries where the utilization of allopathic medicine is high, patients are often asked about family health history to help identify whether they are at increased risk and to recommend early screening, genetic testing and/or lifestyle changes to manage risk. Thus, a growing literature in these countries has explored the transmission of family health history and interventions to increase family health history knowledge [5,10,16–18,20,21,23,26].

In the African context, where biomedical models of health and access to and utilization of allopathic medicine are less prevalent, the literature relating to family history of chronic disease is more limited; literature retrieved in searches often focused on hereditary conditions such as sickle cell disease and had less emphasis on the sharing and use of family health histories in care and prevention [1,13,19,24,27,32]. This paper analyzes data originally collected for a pilot study entitled, 'Family Histories of Chronic Disease in Coastal Ghana', in order to examine the relationship between various forms of care and intrafamilial communication around disease. The study was designed as a qualitative description study with overall aims to provide insights about: (1) whether family histories of health can provide useful insights into the occurrence of chronic disease in previous generations in coastal Ghana; (2) views and attitudes about family health history in coastal Ghana and (3) how coastal Ghanaians interpret certain chronic disease questionnaires.

The analysis presented in this paper utilizes data from focus group discussions and intergenerational family interviews conducted for the project in order to examine the issue of care in relation to intrafamilial communication about health and illness in the coastal Ghanaian context. Here, a variety of forms of care are considered [22]—intergenerational and kin care, chronic care, care within the formal healthcare system, preventive care and care-seeking behaviors.

Materials and methods

Author and project information

The 'Family Histories of Chronic Disease in Coastal Ghana' pilot study contributed to the *Chronic Disease in Sub-Saharan Africa* project at University College London. KAG is a social epidemiologist of Ghanaian heritage and is a passive speaker of Akan (Fantse/Twi). AdGA is a social psychologist of Ghanaian heritage who speaks Akan. MV is an historian of African health. The conception of the project was initially informed by the family histories passed down within KAG's own family from coastal Ghana.

Study site and sample selection

The sample consisted of adults living in southern Ghana who were not vulnerable due to cognitive impairment, mental disability or refugee status. We focused primarily on older adults aged 50 and above, as well as their younger adult children and grandchildren. Participants were recruited purposively using the researchers' networks, organizations and activities targeting senior citizens and snowballing techniques. The area of southern and coastal Ghana was selected for the pilot study because we believed that residents in this area would be more be likely to provide rich information on the study's original aims (health transitions, family histories and chronic disease). Coastal Ghana has had a long history of globalization. Centuries of trade with and colonization by Europeans—including significant involvement in the transatlantic slave trade—as well as modern-day globalization, have resulted in coastal populations with a range of historical sociocultural influences on diet, customs, education, language, healthcare, etc. [2,31]. This may therefore provide a rich area in which to study health transitions and family histories.

We similarly oversampled older adults to facilitate rich data collection for our research questions. Older adults have often been noted to be the repositories of both family histories and family health histories, including in Ghana [4–7,34,35]. Given the study's central interest in health transitions and the history of chronic disease in Ghana, older adults were recruited to provide a longer timeline of such histories and transitions. Thus, the sample is not representative of the Ghanaian population or coastal Ghanaian population, but purposive based on the aims of the study.

Participants were recruited in person through attendance at meetings and events geared toward older adults and in the community, or they were referred from the researcher's contact networks. Discussions took place in the Greater Accra Region.

Data collection

Fieldwork was conducted in Ghana from February through May 2019. Participants were given an information sheet or had the information sheet read to them. Written informed consent was obtained from participants and where participants were unable to give written consent due to lack of literacy or preference for verbal consent, a witness documented the consent.

Four focus group discussions (FGDs) and two intergenerational family interviews were conducted. Individual interviews were also conducted for the broader study but do not form part of this analysis. Interviews and FGDs were semi-structured and the guides were developed by KAG and reviewed by the other authors. English-language FGDs were facilitated by KAG while a master's level public health research assistant from the University of Ghana assisted in coordination and recording. Local-language (Gã, Twi) FGDs were facilitated by master's and PhD level psychology students/graduates from the University of Ghana who translated the questions. KAG was also present during and contributed to the facilitation of these discussions. The two intergenerational interviews (IGIs) were conducted by KAG. Discussions were audio recorded using Olympus DM-670 digital recorders.

Data analysis

Draft transcripts were produced by research assistants who were current or former postgraduate students in psychology or public health at the University of Ghana or by transcribers who had been employed previously by faculty at the Regional Institute for Population Studies, University of Ghana. KAG then reviewed and corrected all transcripts, doing strict verbatim transcription, verifying them against the audio and then redacting identifying information and familiarising herself with the data.

A thematic analysis was conducted using an inductive approach (Vaismoradi, Turunen, and Bondas, 2013). The authors independently read through the FGD and IGI transcripts and then KAG and AdGA came together to discuss broader themes in the data. KAG drafted an initial codebook which was discussed with AdGA and then further refined by KAG. KAG then conducted coding of the transcripts in Nvivo 12 and analyzed emerging themes relating to communication about chronic disease and health history in the context of care for this paper, applying the constructs of generativity, reciprocity and stigma to interpret the findings through a theoretical lens. Codes were classified into potential themes and categories which were then reviewed, refined and named.

Theory

Conceptual frameworks

The concept of generativity [4,25,35] was used to guide this analysis. Generativity was initially defined by psychologist Erik Erikson in 1950 and refers to a ‘concern in establishing and guiding the next generation’ [25]. It can be expressed through child-bearing and child-rearing, work and professional life or friendships and community participation. The drive for generativity is believed to become particularly acute in later stages of life [25,35]. In the Ghanaian context, generativity can also be expressed through achieving material success in life and achieving ancestorhood [35]. With regard to health, the communication of family health history information by older adults to their younger family members has been described as a generative act, designed to help ensure the health and well-being of younger generations of the family [4]. Similarly, in the Ghanaian context, van der Geest [35] discusses the gifting of wisdom by older adults, in the form of advice on how to behave and avoid trouble, on history and family history and on life experience, as an important expression of generativity among the Kwahu, an Akan ethnic group in southern Ghana. One should note, however, that such wisdom and advice may not always be relevant and useful to younger generations in changing times [35]. Nevertheless, generally in this context, an older person’s primary concern is the well-being of his or her family and his or her actions are judged according to how they benefit the family [34]. Thus, we analyze our findings around care and intrafamilial communication regarding health through a lens of generativity.

In addition, the concept of reciprocity has also informed our analysis. Van der Geest and colleagues identify reciprocity, or giving and receiving, as an important aspect of intrafamilial care in Ghana. This mutual assistance and exchange of care serves as a bond within biological families as well as within familial relationships among other groups that are not related by blood. Thus, reciprocity determines entitlements to care [34,36]. Reciprocity also serves as the ‘basis of culture and society’ (p.395) [35]. Tsai and Dzorgbo [33] describe reciprocity as central to kinship ties in Ghanaian families and providing a sense of security that help is available in times of need. This idea of reciprocity determining entitlements to care and forming a basis of society can be observed in the Akan proverb which says, *Obi hwɛ wo ma wo se fifir a, wo so hwɛ no ma ne dze tutu,* which roughly translates to, ‘If somebody cares for you until your teeth grow in, then you also care for them until their own [teeth] fall out.’

A final concept which also features in our analysis is stigma. Stigma as described by Goffman (1984) can be due to one’s character, culture or physical imperfections [14]. As defined by Deacon (2005), it refers to ‘value-based ideology that imposes moral judgements on others to affirm the ingroup’s safe and moral identity’ [11]. Disease stigma due to physical imperfections refers to the ‘negative social “baggage” associated with a disease that … is not justified by the medical effects of disease on the human body’ (Deacon 2005 as cited by [11]). While individuals can suffer stigma due to perceived deficits within themselves, others who are associated with these ‘defective’ individuals (e.g., family members) may also suffer what is referred to as courtesy stigma [11,14].

In a paper on kinship stigma (i.e., when family members stigmatise one of their own kin) experienced by sufferers of irritable bowel disorder (IBD), Dibley and colleagues describe the distinction between two types of stigmatising conditions [14]. One includes visible stigmatising marks (e.g., a visible condition, perhaps achondroplasia) in which one has become discredited. The other consists of invisible stigmatising marks or conditions (such as IBD), in which one is discreditable; in other words, there is the potential to become discredited if the hidden stigmatising features are revealed. The issue of visible versus invisible stigmatising conditions and discreditability is one which surfaced in the present study, as will be shown below.

Table 1
Participant characteristics.

	Size	Gender	Age group	Education level	Language of discussion
FGD1	14	Women: 12; Men: 2	45–49: 1; 50–54: 1; 60–64: 5; 65–69: 3; 70–74: 2; 75–79: 2	None: 2; Some primary: 3; Completed primary: 7; Some secondary: 2	Gã
FGD2	8	Women: 7; Men: 1	55–59: 1; 65–69: 4; 75–79: 2; Missing: 1	Some secondary: 1; University: 3; Postgraduate: 4	English
FGD3	4	Women: 3; Men: 1	70–74: 1; 75–79: 2; Missing: 1	Postgraduate: 4	English
FGD4	4	Women: 4	40–44: 1; 45–49: 1; 60–64: 1; 65+: 1	Some primary: 2; Completed primary: 2; Some secondary: 1	Gã & Twi
IGI1	3	Woman Woman Man	85+ 55–59 30–34	Some primary Postgraduate Postgraduate	English & Fantse
IGI2	3	Woman Woman Woman	80–84 50–54 45–49	University Postgraduate Postgraduate	English

Notes: 'FGD' refers to focus group discussion. 'IGI' refers to intergenerational interview.

Table 2
Categories and themes.

Care and disclosure
Care as a means to disclose family health history
Care as a barrier to disclosure of family health history
Disclosure of illness as a means to receive care for the ill
Disclosure as a means to provide preventive care for younger generations
Care and concealment
Concealment of illness as a barrier to care for the ill
Concealment of illness as a barrier to care for younger generations
Concealment as a form of care
Encouragement of preventive care-seeking through family health history discussions

Results

Participant characteristics

The analysis presented here draws on data from four FGDs and two IGIs. The four FGDs ranged in size from four to 14 participants. Two of these FGDs consisted primarily of participants with higher levels of formal education. The other two FGDs consisted of participants with limited levels of formal education and were conducted in areas of lower socioeconomic status. FGDs ranged from about 50 to 100 min in length. The IGIs each included three participants, consisting of an older adult woman and her younger adult children and/or grandchildren. They ranged in duration from about 50 to 80 min. Participant characteristics are presented in Table 1. Details have been suppressed to protect participant privacy.

Thematic analysis

Findings of this analysis are grouped into three broad categories. One is the nexus between care and disclosure. The second is the nexus between care and concealment; and the final category concerns familial communication to encourage care-seeking through family health history discussions. These themes are outlined in Table 2 and expanded on below.

Care and disclosure nexus

Care as a means to disclose family health history. Conversations with participants revealed that family health history and illnesses within the family were sometimes disclosed in the context of care, specifically in intergenerational care. This care was often mutual with family members caring for each other and offering reciprocity.

For example, in intergenerational and 'communal' households, grandmothers, grand-aunties or other older adult family members [collectively referred to here as 'grandparents' as was done by FGD participants] performed roles of helping to train their grandchildren and contribute to their development and formation. Meanwhile, the grandchildren also performed roles helping to care for their grandparents. As participants discussed, this arrangement was how households were customarily organized in the past [e.g., 'We grew up with three grandmothers in the same house…So their children and grandchildren, they were all in one house' (FGD2)]. It was through this process of mutual and reciprocal intergenerational care between older adult family members and children that information about health and illness in the family was sometimes disclosed and communicated.

For instance, in FGD2, participants debated whether in the past, family members explained what health conditions were present in the family and what to look out for. Many participants acknowledged that as children, they were generally not supposed to ask questions of adults and discussions of family matters were often kept from them. However, one participant recalled how she learned of her grandmother's diabetes as a child in the process of helping to provide care for this grandmother:

> P[1]: I will also say my grandmother also was diabetic and she explained to me. Of course, I didn't understand. Because she always took some tablets and I asked what that was and she tried to explain that it was for diabetes. (…) Because (…) I was the one who brought the (…)
>
> (…)
>
> P: …the pill box…Mhmm. Anytime (…) she had some tin, some Milo tin or some tin with some tablets in it. So, when she's eating or she's going to eat, then I will be the one to bring it. So, I asked one of those days. And it was explained…that she was diabetic.
>
> In this example, the act of the grandchild giving care to her grandmother by routinely bringing the grandmother's pillbox during meals facilitated and led to the disclosure of the grandmother's diabetes status.
>
> Other respondents in this FGD also described the relationship between children and grandparents and its role in the facilitation of intrafamilial communication and disclosure of family history, even if not specifically about health matters:
>
> "Sometimes it depends, too, on…those days…how close you are to the…grannies and the grandpas. You know, if you are very close to them, they send you, you go. Then story time you'll come and sit by them; they will be telling you stories. Ahaaaaaa! Then they—that's when they open up a bit about the family…but not deep about the health issues."

Care as a barrier to disclosure of family health history. While communal care arrangements could sometimes facilitate disclosure of family health history, in some instances, care was described as hindering the disclosure of family health history. This was noted particularly in interactions with the formal healthcare system. In FGD3, participants described how doctors sometimes refuse to reveal their patients' diagnoses to patients themselves:

P4 (woman, aged 75–79 years): Because if you go home and in the traditional setting, somebody is sick, and you ask, 'What's wrong with the person?'

P3 (woman, 75–79): He is just sick…

P4: They are *most* unwilling to talk about—they will talk in general terms,

(…)

P4: 'He is not feeling well.' 'Oh, she's losing weight.' 'Oh, she's not eating.' But what specifically *is* the problem? 'Oh, he's been to see *all* the doctors but they are not telling him or her what the problem is.'

(…)

P4: Because nobody–, the doctors don't tell… I think.

(…)

P2 (man, 75–79 years): Yeah, here they don't.

P4: And we don't ask.

(…)

P4: So, it's a two-way affair. They [doctors] don't tell. We don't ask. You understand?

KAG: Mhmm. Mhmm.

P1 (woman, possibly late 60s-early 70s): Mmmm. The doctors don't tell; I don't know why.

P4: Hmm. Oh [laughs] well my discussions, argument with some doctors, they'll say, patients are not interested.

In this example, Participant 4 suggests that healthcare providers themselves were perceived to obstruct the communication of health information by not fully informing patients about their diagnoses. She states that doctors say that 'patients are not interested'. This by extension can affect the ability of families to transmit health history for the benefit of family members.

Disclosure of illness as a means to receive care for the ill. While care can facilitate or hinder disclosure of family health history, disclosure of illness was also described as a means to receive care and treatment. On multiple occasions, participants expressed the sentiment that disclosure of health conditions within and outside families was important to facilitate care, while acknowledging that this ideal was not the reality in Ghana. Disclosure of illness was described as a means to various forms of care. In the first instance, it was seen as essential for the receipt of care for the individual suffering from the

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[1] 'P' signifies 'participant'.

condition. In addition, it was also seen as important for facilitating care in younger generations of the family, and therefore serving a generative purpose.

In IGI1, consisting of a grandmother, her adult daughter and adult grandson, the grandmother (an 85+ year-old woman with some primary school education) used a proverb to relay the importance of disclosure for care:

Daughter: [In Fantse to her mother ('Grandma')] I'm saying that today, here in Ghana, when it comes to your health and things, everybody keeps it to themselves. Nobody wants to talk about it.

Grandma: They don't talk about it.

Daughter: [Laughs]

Grandma: Yes. If you say it, I think it would be good, or…Uh-huh…

Daughter: [In English] Exactly. She says that it-it will be good (…) to say it. But you know, here, sometimes, they are afraid that if you say it, you'll be stigmatised, you know.

KAG: Mhmm. Mhmm.

Grandma: [In Fantse] No. You have to say it because they say that if you sell your sickness, then you'll get its medicine. You see.

Daughter: [In English] She's gived [*sic*] us a proverb.

Grandma: Mhmm.

Daughter: It says, if you sell your ailments, that's when you get medica—you get… Ah-hah.

Grandma: Mhmm.

KAG: Mhmm.

Daughter: [In Fantse] When you sell your sickness, you get its medicine.

Grandma: Ah-hah [with emphasis]. (…) But if you have it and you don't say it…

Daughter: [In English] Nobody can help you.

Grandma: [In Fantse] …that one, that is—that is serious. (…) So, if you are unwell in any part of your body or you see that you have some illness somewhere, you have to say it immediately and go to the hospital so that they can help you quickly.

Here, the participants describe the reality of the situation in Ghana, that the stigma surrounding health issues discourages people from disclosing their illness. The grandmother then relates the proverb, '*Ɛ tɔn wo yareba, ebɛnya no ho edur* (if you sell/expose your sickness, you'll get its medicine)', to underscore why it is important to disclose sickness to facilitate care. The proverb is typically used to signify that when you open up about your issues in general, you can get their solutions. It uses metaphors of sickness and medicine to convey this message. In the context of these discussions, however, the sickness and medicine metaphors become literal because the message can apply not only to broader problems but to health problems as well.

In FGD4, conducted in Twi and Gã, the oldest participant used the same proverb when describing the stigma surrounding discussing health issues to illustrate the importance of disclosure for receiving care.

P2 (woman aged 65–69, possibly older, with some primary education): [When it comes to] [P]eople's health matters, it's not everyone who talks about it, or am I lying?

[P*articipants in agreement*]: Yes.

P2: If you are suffering from an ailment and you don't say it, you'll die (…) If you don't tell people about your illnesses for someone to help you, you'll die (…)

Facilitator: My mother here [referring to the older participant] was saying something that if you are sick and you don't say it …

P2: Yes, if you are sick and you don't sell it—if you sell it, you'll get someone to buy it from you.

Facilitator: Can you please explain that to us for the sake of the research?

P2: Yes, what it means is that, as I'm here, I may be sick and if I don't tell my sister here about it and I hide it within me and I faint somewhere, I'll be responsible for my own death. If I had told her, maybe she might have put me in a car and taken me to the hospital for me to get cured but because I didn't say it, I lost my life. So, I'm responsible for my own death.

P3 (young woman, early 40s): There may be a medicine that she can show you in order for you to be cured.

Similar sentiments about disclosing chronic and other illnesses to receive appropriate treatment were expressed by participants in other FGDs even when the exact proverb was not used. For example, in FGD1, participants asserted that family members *did* talk about their illnesses and the reason given for doing so harkened back to the proverb:

Facilitator: Thank you. When you were growing up, did any of your family members or grandparents talk to you about the sugar-related diseases, hypertension in your family?

P: They used to talk about them.

Facilitator: They did?

P: Yes.

(…)

P: In the family, they talk about it, so when I got hypertension, they were like 'really?'. They discussed them.

(…) [Discussion about types of diseases people talked about]

Facilitator: Why are you saying they talk a lot about sickness?

P: Everyone is looking for a solution for his or her sickness. That's why they talk about it…

The link between disclosure and care was also reinforced in FGD2 through the converse example, when the male participant suggested that concealing illness may not be unreasonable if it's not in a care context: 'If you have a (…) certain sickness, and maybe, it is not the doctor, it is not the one who is going to care for you, what is the need to be…broadcasting? Or sharing it?'

Disclosure of illness as a means to provide care for younger generations. In addition to disclosure of illness being a means for personal care, participants also acknowledged that intrafamilial disclosure of chronic health conditions and family health history can help members of the next generation care for themselves. In IG1, the daughter gave an example of how the disclosure and awareness of her father's diabetes helped her to take up preventive health behaviors and also to advise her children to protect their health:

Daughter: And then, you know, if it's something that, you know, somebody, the family could have benefitted from knowing so that they would change, like a lifestyle kind of thing. Yeah…you know. Somebody like—I know that, my dad died of diabetes and it's in the family so I know I have to watch…watch my intake of some things. And I-I impress upon my children, you know. But, if (…) they kept it and nobody knew and (…) I kept eating all the *angoa* [oil] and the *sɔkyee* [fatty/rich foods]. I wouldn't know [with emphasis]. And I'll also end up in the same–

KAG: Mhmm.

Grandma: … [In Fantse] …yeah,… the sickness would, it would go up. It would—

This example demonstrates a view that intrafamilial communication and disclosure of health conditions can facilitate care not just for the individual with the disease but also preventive care for those generations below.

Care and concealment nexus

Concealment of illness as a barrier to care for the ill. On the converse side, participants likewise demonstrated how failing to disclose health issues for a range of reasons can become a barrier to an individual's care. In IGI2, the mother suggested this when her youngest daughter told her story of breast cancer:

Daughter 2: I think it was in *[late* 2010s*]*, yeah.

Daughter 2: I started seeing some…[*sucks teeth*]…deeper…She told you I had a surgery when I was young.

KAG: Mhmm…Mhmm.

Daughter 2: So underneath the scar, there was a growth.

KAG: Mmmm.

Daughter 2: And the growth kept…like, when it comes to your menstrual cycle, it keeps shifting.

KAG: Mhmm…Mhmm, mhmm.

Daughter 2: It becomes small; then it becomes big, like, from time to time.

Mother: Ooh, you see…at-at that time if you had told us, we would have removed it.

In this exchange, the mother laments that her daughter's keeping her lump from her family potentially prevented them from helping her to get better care earlier.

Concealment of illness as a barrier to care for younger generations of the family. Similarly, concealment was expressed as a barrier to care not just for the individual who was ill but also for subsequent generations of the family. An example of this came from FGD3, where one woman described the circumstances surrounding her late husband's death and how her children who were abroad needed information about his cause of death to give to their own care providers:

"Because my husband, my husband died of cancer. And then, the children are all staying outside. And then they came. (…) After the funeral and everything, when they were—they were about to leave, the—their uncle called and said, 'Ah, there is nothing we could do; your—your dad knew sh—he was going to die. So just take it like that.' But the children said, 'No, we want a full report from the doctor. We want to know.' Because over there when you say your dad died of a cancer, it's a big thing. What kind of cancer? (…) So, they have to get the full reports from the doctor and give it to them. So that when they go there and they ask them, they said their father died of a cancer, they know what kind of cancer –. Up until now, the family members were refusing to go and check from the doctors (…) You see, the parents—these elders, keeping health secrets, I don't know the meaning of that."

In this instance, the family's reluctance to get the details of their relative's cause of death from his care providers hindered his children's ability to receive full and appropriate preventive care abroad. This theme was also expressed in FGD2 in an exchange about concealment and Ghanaian families' refusal to conduct post-mortem autopsies on their relatives who have died:

P1[2]: …if you go to the hospital, *koraa*, the family says, 'Don't do post-mortem'….

P2: They don't want to know.

P1: 'I don't want to know.'

(…)

P1: So, because the person is dead already so…your post-mortem will not… But they forget that doing the post-mortem will give them…ah… insight into really the cause of the death…and it's something…

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[2] Numbers here solely for clarity to indicate that they are different respondents speaking.

P3: Yes.... Yes...which might affect the living.

P1: ...which might affect the living or try to do something which might affect the living or something...or benefit the living.

Another participant in FGD3 (woman, 75–79 years old) reflected on this issue in relation to her own care, an account which resonated with the other participants:

"And it's—to me, yeah it's-it's bad because then, for example, I see my doctor almost every three months and almost the question that she keeps asking 'Oh! Aunty *[Name]*, erh, is this something... is there any member of your family that has...?' (...) Then I'll just [laughs]... literally dash back and say, 'Doctor, did parents talk about what they had?'"

Concealment as a form of care. In some cases, concealment could also be interpreted as a form of 'care'. Participants expressed how avoiding stigma created incentives to conceal both individual conditions from others, as well as to conceal familial conditions from outsiders. A distinction between visible and invisible conditions featured in the FGDs and it is the invisible chronic conditions and the discreditability they may cause which drive the desire to conceal illness from others.

Participants described the ways in which concealment, particularly of familial conditions appearing among blood relatives, was employed to avoid courtesy stigma and to protect the identity of the family. Throughout the discussions, participants had noted that one of the main circumstances in which family health histories are discussed in Ghana is in the context of marriage. Though they noted that this practice is decreasing over time as marriages become more centered around the couples than around their families, family health histories of potential spouses were customarily investigated before marriage. If certain stigmatised conditions, particularly mental illnesses, were found to run in the potential spouse's family, the family member seeking marriage was advised against marrying into the affected family. Thus, concealment of family health histories and of familial conditions could be viewed as an act of 'care', protecting one's family from stigma. Likewise, this concealment could be viewed as an act of generativity, by facilitating marriage and therefore the continuation of the family.

An example of concealment to avoid courtesy stigma can be seen in an exchange in FG2:

KAG: OK. OK. So, what do you think are some of the reasons why people don't like to... share...like family health information—or wh-why—what?

P3: Maybe...

P1: The main reason...

P2: Stimgatization.

P1: ...you don't know, yourself ...

P2: Yeah.

P3: Even...Basically. Illiteracy

P: Exactly.

P: Illiteracy. Illiteracy.

(...)

P3: And if you know but you don't want to share.

P2: And then two, stigma

P5: Why? Why don't you want to share?

P4: Stigma.

(...)

P2: The moment it goes out...

P4: So, you see...

P1: So they will tell you, 'Ah! Please don't tell anybody.'

P2: [Laughing]

P1: Don't go spreading to people that, 'Oh, in your family, we have this'.

P2: 'We are not the only family that have illness'.

In this conversation, stigma is identified as a reason individuals and families conceal illness. The participants proceeded to discuss specific stigmatizing conditions, raising the example of HIV/AIDS stigma and how it is not only HIV/AIDS that people try to conceal but also conditions such as cancer and sickle cell disease:

P2: Sometimes they can actually divide it into more serious illnesses and (un)serious illnesses (...) The serious illnesses that should—nobody should hear about it.

P4: What are the serious illnesses?

P3: Which are they?

P2: Those ones that they think can bring disgrace to the family.

P4: Like? Like?

P2: Like maybe...erh, cancer, like sickle cell or something.

Here, protecting the family name against disease stigma motivates concealment of family health history and could therefore be viewed as an act of 'care'.

Encouragement of care-seeking through family health history discussions

A final theme about intrafamilial communication in relation to care that emerged from the intergenerational interviews was the way in which the family health history interviews led to the encouragement of care-seeking in the family. During the course of both intergenerational interviews, older family members communicated encouragement of care-seeking behaviors in their children and grandchildren, which seems to have been prompted by the act of discussing these health history issues with family members.

In the first family, for instance, both the grandmother and the daughter urged their younger child/grandchild to seek preventive care to protect their health. In this family, hypertension, diabetes and prostate cancer were among the chronic diseases discussed as running in different branches of the family. At one point in the interview, the daughter expressed concern about why her son had stopped going for regular check-ups and as the conversation progressed, the grandmother then described why it is important for them to go for regular health checks.

Grandson: Well, I think the-the strange thing honestly, just…because I fel—I feel like because maybe I was young then and I was living at home, I was way more health conscious when I was younger.

KAG: OK.

Grandson: I've been back what…eight—seven, eight years now… and the only times I've gone to do physicals is when I go back to *[foreign country]*.

Daughter: Yeah.

Grandson: Like, I don't do physicals here…

KAG: Yeah.

Grandson: …which is…a problem, you know.

Daughter: But, why don't you do the physicals here? You could have…

Grandson: No, but, honestly, I think sometimes when you're in the culture,…

Daughter: Yeah.

Grandson: …your mind also—

(…)

Grandma: [In Fantse] I'd always tell them [referring to her children and grandchildren] that we/they should look for a doctor in *[City in Western Region]* (unintelligible).

Daughter: [In English] At least the physical, you know, yearly physicals and then dental.

(…)

Grandma: [In Fantse] There are good doctors here in Ghana, so you don't have to just sit there.

So here, we see the two older generations of the family engaging in generative acts through intrafamilial communication by encouraging the younger generations of their family to seek healthcare.

In the second family which was also introduced earlier, the discussion revolved around episodes of cancer among both immediate and extended family members. As the oldest daughter was describing a cancer scare she had, her mother took it upon herself to remind her daughter to seek preventive care:

Daughter 1: She put the needle in, [makes onomatopoeic sound imitating action of needle going in], and then she started sucking it out. And then, the shadow kept getting smaller and smaller and smaller… and there was nothing.

(…)

Daughter 1: (…) She said, '…That's it. It's gone. It-It's just a liquid…build up, umm, in your mammary glands…'

KAG: Mmm, OK, OK.

Mother: How did it build up?

Daughter 1: '…So, I mean, you've had kids; you've breastfed…sometimes it…'

KAG: OK…Yeah.

Mother: You better start having—You better start going for mammograms, oo.

Daughter 1: Ah! Ma, what are you taking about? This is…almost twenty years ago.

Mother: Yeah, but you still do it.

Thus, the act of discussing family health histories through the IGIs prompted older family members to remind and encourage their children/grandchildren to engage in preventive care in these families where a history of chronic disease was noted.

Discussion

Discussion of results

Through these FGDs and IGIs, participants confirmed the existence, at least in the recent past, of reciprocal care arrangements in their families as described by van der Geest and Coe in their work in Ghana [9,34,36]. Grandparents in the household participated in the upbringing of grandchildren, which can be considered a generative act of contributing to the well-being of younger generations. Grandchildren similarly would run errands or perform tasks for their grandparents and in return would be provided with stories and knowledge about the family. Such stories were also an expression of generativity. Similar to van der Geest's observations in Kwahu, 'As we have seen, the gift of wisdom not only rewards the young for the affection and care they show to the older generation, it also reassures the elders that they will outlive themselves in their words of wisdom that the young take on board and will hand over eventually to their successors' (p. 395) [35].

This reciprocal caregiving relationship and communication between grandchildren and grandparents often occurred when grandchildren were young, pre-adolescence [34], as was also suggested in our participants' accounts. Further, this intergenerational caregiving process sometimes provided an opportunity for intrafamilial communication about chronic diseases that may have a familial component, such as diabetes. Ashida and Schafer [4] and Koehly et al. [18] report that reciprocal exchanges of social support between family members have been associated with the communication of familial disease risk and may determine the extent to which older adults share family health history information with other family members. Similarly, our findings suggest that caregiving roles in the family can be a means for transmission and disclosure of family health history. If such communication affects risk perception, it may assist in generative activities by providing awareness of health issues which the younger generation will need to look out for [37].

While intergenerational care in the household was shown to sometimes facilitate disclosure of family health history, other forms of care, notably in the formal healthcare setting, were sometimes noted as hindering intrafamilial disclosure when medical staff did not fully inform patients about their health status and diagnoses. In this way, these forms of care could stifle attempts at generativity and intrafamilial reciprocity by depriving individuals of knowledge about their own health issues which may affect other family members. This revelation highlights issues regarding patients' rights to their medical records in Ghana. In a review of Ghanaian legal documents, Norman et al. concluded that patients' access to their medical records is more of a privilege than a right and that the lack of national legislation on health records complicates the issue [29]. Similar accusations of medical staff withholding full information about diagnoses and treatment have been recorded among cancer patients in Kenya [28]. This is an issue that may warrant further investigation.

Our analysis also illustrated how disclosure of illness was perceived by participants as being critical to facilitating care for the affected individual. Several participants alluded to the proverb, 'If you sell your sickness, you get its medicine' to underscore this. This proverb is one of a number of Akan proverbs dealing with the importance of disclosing problems [Other similar proverbs include, 'Covered up things get eaten by mice' and 'If you keep your wound covered, it becomes infected'].

The exchanges about this proverb in FGD4 showed the reciprocal nature of disclosure of illness in relation to care. 'Selling' or disclosing an illness to a literal or figurative family member means that someone can 'buy' it from you and provide you with care (e.g., taking you to the hospital for treatment) or with a cure (e.g., medicine). The act of disclosing one's illness to one's families can therefore be considered a care-seeking behavior or form of self-care. While many participants noted that stigma inhibited people from discussing their health issues with family members and others, in some communities such as in FGD1, the search for care, cure and solutions seemed to motivate individuals to talk about chronic illness within their families.

Other research on health communication in families seems to support this motivation for disclosing illness. Ersig and colleagues [15] found that in families at risk for hereditary colorectal cancer, respondents were more likely to discuss their risk with people from whom they receive advice. Though theirs was a quantitative study and did not explicitly study motivations, it suggests that when discussing their risk with others, respondents may be seeking help in deciding how to address their risk [15]. Another study on disclosure of results of genetic testing for Alzheimer's disease in the U.S. found that participants were more likely to communicate their results to family members when they had greater optimism about cure, prevention and treatment strategies for Alzheimer's [3]. Although again not directly studying motivations, this study also suggests a link between disclosing risk or illness and hope regarding care and cure. Similarly, Dennis-Antwi et al. [12] reported that parents of children with sickle cell disease in Kumasi, Ghana chose to disclose their child's illness to people who could be sources of support or who could help their child receive better attention. These individuals included neighbors, close friends, parents, in-laws or health workers who had become like family [12].

Furthermore, as one FGD participant asserted in the present study, it may only be those who are caring for someone (such as the person's doctor) who need to know that person's health status. In other words, disclosure of illness may be necessary for care but may not be necessary otherwise. In the case of the medical profession, this view aligns with norms regarding patient privacy, although some have suggested a role for healthcare professionals in encouraging patients to disclose genetic risk to family members [8]. In addition, in the present analysis, disclosure of chronic health conditions within families also served as an expression of generativity through which older generations could facilitate care for their younger family members. As previously noted, research by Ashida and Schafer [4] has likewise characterized disclosure of family health history by older family members as a generative act.

Discussions with participants similarly revealed the ways in which concealment of illness within families was a barrier to care for the affected family member. In other settings, research on conditions such as sickle cell disease and HIV/AIDS has shown that attempts to conceal disease status because of stigma can sometimes lead to the avoidance of care or treatment [19,36]. Participants in this study highlighted how concealment of illness was not only a barrier to one's own treatment but also potentially threatened generativity within the family, by creating missed opportunities for older family members to help their younger kin address potential risk for cancer and other conditions. Nevertheless, concealment of family health history could also protect the family from stigma, thereby ensuring the continuity of the family through marriage, et cetera. In this regard, concealment of family health history could be viewed as an expression of 'care' and an act of generativity.

Research from Ghana and elsewhere has also noted concealment of disease to protect families from stigma, although it can sometimes hinder care. As Dennis-Antwi et al. [12] described in their work on lay perceptions of sickle cell disease, Goffman's original conceptualisation of stigma was relational and therefore must be understood within social contexts. In the Ghanaian setting, where illness is sometimes assumed to be acute and children are expected to be an investment and outlive parents, they reported that parents of children with sickle cell disease may conceal and deny the child's illness or refuse care to avoid stigma for the child as well as courtesy stigma as the child's parent. Nwanonyiri et al. [30] also found that family caregivers of children with sickle cell disease in the U.S. chose not to disclose the condition beyond close relations to protect the child, and themselves as parents carrying the trait, from judgement. In the Kenyan context, Mulemi [28] reported that some cancer patients concealed histories of chronic illness in their families to avoid associated stigma. Similarly, in the British setting, Yates and Gatsou [38] observed that some children hesitated to disclose parental mental illness to support services in order to avoid their family being judged negatively. Thus, concealment of illness could obstruct care but also be an expression of care and concern for family members by protecting them from stigma.

Finally, discussions of family health history through intergenerational interviews led to encouragement of preventive care-seeking behaviors in our study. During these discussions, older relatives prompted their children and grandchildren to go for health screenings and check-ups, thereby also expressing their care about younger relatives and performing a generative act. This result has implications for health promotion efforts in that it may suggest that intergenerational family health history discussions could be used as a tool to encourage disease prevention activities. Research by Ashida and Schafer in the U.S. context (2011; 2015) has similarly found that older family members were more likely to encourage cancer screening in families with hereditary cancer syndromes and that older family members were particularly important motivators of health screening in families. Furthermore, receiving family health history information from a parent was associated with sharing family health history with more family members. The authors suggest that therefore, older family members could be targeted as lay health advisors to increase participation in screening within families at greater risk [4,6].

Limitations

There are several limitations to this study. Men were underrepresented in the sample and those with low socioeconomic status were generally underrepresented in the interviews. Thus, findings are not representative and may differ in a sample with a different distribution of sociodemographic and socioeconomic characteristics. For example, some of the relationships between care, communication about illness, family history and intergenerational relationships in families may differ by gender so a larger sample of men may have allowed gender issues to be explored in a way that could not be done in the present sample. In his work among the Kwahu of Ghana, for instance, van der Geest [34] commented that the relationship between grandparents and grandchildren appeared to be stronger between grandmothers and granddaughters. Likewise, U.S. research on health information communication in families has found an association between female sex and the gathering and dissemination of health information [18]. Further research into gender dynamics, as well as socioeconomic dynamics, of health history communication in southern Ghanaian families is therefore warranted.

In addition, participants' conceptions of family were not explicitly explored. Participants were allowed to interpret 'family' personally. Therefore, further research to understand how participants conceive of family and to distinguish between different types of 'family' may enrich the interpretation of results. For instance, some may consider or emphasise family history and family health history on either the maternal or paternal side and some may consider nonbiological relatives, as has been found in research among some Samoan-Americans [26]. The conceptions of 'family' in family health histories could be explore further in this setting.

Furthermore, there may be benefit in exploring these issues in other geographic regions of Ghana such as the middle and northern belts of the country. Because this study was designed as a pilot study, the data collection was purposive and was limited to coastal Ghana for the purpose of studying health transitions. However, the research revealed that examining these issues in other regions of Ghana may provide additional insights and allow for comparisons.

Finally, while the IGI findings suggest that explicit family health history discussions could be an avenue for older family members to encourage preventive care among younger relatives, it is unclear whether such discussions can also elicit similar responses if held on their own. It is possible that the presence of the researcher led to social desirability bias and prompted the older family members to make those statements. Further research may be needed to examine whether self-directed intergenerational family health history discussions could also prompt encouragement of care-seeking in families.

Conclusion

This analysis examined material from FGDs and IGIs conducted as part of a pilot study on family histories of health in coastal Ghana in order to describe ways in which intrafamilial communication about health intersects with care in Ghanaian families. We found that intergenerational care sometimes facilitated the disclosure of illness and family health history and that this disclosure may be motivated by norms of reciprocity and a desire for generativity. However, in other circumstances care could also hinder disclosure, including in the formal healthcare system. We also found that disclosure of illness within and outside of families was recognized by participants as important for facilitating care and treatment of illness. However, avoidance of stigma often motivated the concealment of familial conditions and of individuals' illnesses or relatives' causes of death. Thus, intrafamilial communication about health conditions may not happen as desired. Finally, we observed that older family members may communicate support for their children's and grandchildren's engagement in care-seeking behaviors during the course of intergenerational interviews of family health history. This can be seen as an expression of generativity and 'care', particularly where the family may have a history of chronic disease.

To increase awareness of family health histories in Ghana so as to better manage risk for chronic diseases and improve health outcomes, it is important for families, healthcare providers and society to better understand how familial and formal care arrangements and factors such as generativity, reciprocity and stigma may influence the disclosure and concealment of illness and disease status. Understanding the dynamics of disease stigma and courtesy stigma when it comes to familial conditions and capitalising on generative desires and norms of reciprocity in families could help to inform public health interventions to improve family health history knowledge and thereby promote well-being in Ghana. Such interventions may include multilevel anti-stigma interventions [11], public awareness campaigns and encouragement of intergenerational family health history discussions.

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Ethics statement

Ethical approval for the project was obtained from University College London (UCL)'s Research Ethics Committee (14281/001) and the Noguchi Memorial Institute for Medical Research Institutional Review Board at the University of Ghana (#042/18-19).

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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