

1 **“When someone becomes old then every part of the body too becomes old”:**
2 **experiences of living with dementia in Kintampo, rural Ghana**

3 Short title: Experiences of living with dementia in rural Ghana

4 Studies have suggested that in African countries, symptoms of cognitive decline are commonly seen
5 as part of “normal ageing” or attributed to supernatural causes. The impact of causality beliefs upon
6 help-seeking is unclear. Likewise, there is a lack of evidence relating to how families cope with living
7 with an older resident with dementia. Our study aim was to explore the sociocultural beliefs,
8 understandings, perceptions and behaviours relating to living with dementia in Kintampo, Ghana.
9 We conducted in-depth interviews with a total of 28 people, using a series of case studies among 10
10 older people living with dementia and their families. Results revealed that symptoms of cognitive
11 impairment were generally linked to inexorable bodily decline seen to be characteristic of “normal”
12 ageing. Stigma was therefore perceived to be non-existent. Whilst managing the costs of care was
13 often a challenge, care-giving was largely accepted as a filial duty, commonly shared among female
14 residents of large compound households. Families experimented with biomedical and traditional
15 medicine for chronic conditions they perceived to be treatable. Our findings suggest that whilst
16 families offer a coherent approach to the needs of older people living with chronic conditions
17 including dementia, health and social policies are at odds with this. In future, it will be important to
18 develop policy frameworks that: acknowledge the continued social and economic potential of older
19 people and strengthen the existing approach of families, optimising the management of non-
20 communicable diseases within primary care.

21 Keywords: Dementia, qualitative research, ageing, help-seeking, Ghana

22

23 Background

24 Longer life expectancy and lower fertility are changing the demographic profile of sub-Saharan Africa
25 (SSA), with the number of older people aged more than 65 expected to expand from 46 million in
26 2015 to 157 million by 2050 (I. A. Aboderin & Beard, 2015). Although the prevalence of dementia
27 was once thought to be lower in SSA as compared with high income countries (Guerchet et al.,
28 2010), a small but expanding epidemiological literature suggests that the prevalence may be similar
29 across different world regions (M. Prince et al., 2013), with the number of people living with
30 dementia forecasted to increase from 1.63 million in 2015 to 5.73 million by 2050 (Prince M, 2015).

31 There is a scarcity of knowledge relating to local understandings of dementia in sub-Saharan Africa.
32 Studies have suggested that symptoms of cognitive decline are commonly perceived to be either a
33 part of normal ageing (Ineichen, 2000) or attributable to supernatural causes (Mushi et al., 2014). It
34 has been suggested that those who attribute dementia to the supernatural may be more likely to
35 seek care from traditional and spiritual healers (Mushi et al., 2014; Uwakwe et al., 2009). Such
36 explanatory models are also likely to influence coping behaviours of older people living with
37 dementia and their families. Beliefs about causality may be linked to how communities perceive and
38 interact with people with particular conditions. For example, in traditional societies, belief in
39 supernatural causes has been linked to the stigmatisation of mental illness (Lauber & Rössler, 2007).
40 Although in traditional societies, it has been observed that older people were honoured and
41 respected (Chuks J Mba, 2007), there is some evidence that perceptions may be more ambivalent:
42 although longevity is associated with knowledge and wisdom and thus deserving of respect, old age
43 is simultaneously linked with sorcery and therefore associated with mistrust and suspicion (Faure-
44 Delage et al., 2012).

45 Non-HIV-related dementia has been absent from public health and policy agendas in SSA. It is
46 therefore important to consider the broader policy and practice context as this relates to older
47 people in general, as the most relevant background to our work. Indeed, older people in SSA have
48 generally been neglected by governments and non-governmental organisations alike (C. J. Mba,
49 2010). Although policy frameworks explicitly directed at ageing populations are beginning to
50 emerge, these have yet to effect change in policy and practice: health and social systems therefore
51 remain poorly equipped to meet the needs of older people. A lack of formal provision for the social
52 and economic impacts of ageing means that family and household networks remain the key sources
53 of social security in older age (Heslop & Gorman, 2002). However, it remains to be seen to what
54 extent rapid socioeconomic change associated with “modernisation” is undermining the social
55 processes which traditionally protect the material wellbeing as well as the social status of older
56 people (Heslop & Gorman, 2002). For example, it has been suggested that transitions from
57 subsistence farming to wage-based economies and an increased emphasis on formal education may
58 have contributed to a devaluation of the role of older people and the level of support extended to
59 them (I. Aboderin, 2004). Given that dementia is associated with high levels of dependence and
60 complex needs for care (Sousa et al., 2009), it seems plausible that people living with dementia
61 might be particularly vulnerable to any reduction in the level of family support extended to older
62 people, particularly in settings like rural Ghana, where there is very little provision from the state.

63 Ghana has one of the region’s largest populations of older people with 7 per cent of the population
64 estimated to be aged over 60 in 2010, expected to increase to 12 percent by 2050 (C. J. Mba, 2010;
65 WHO, 2013). People aged 70 years are eligible for free basic medical care under the National Health
66 Insurance Scheme and are exempt from annual fees. Ghana has a National Ageing Policy, the main
67 aims of which are to: strengthen community capacity to deliver healthcare for older people,
68 expansion of palliative care, the integration of comprehensive healthcare for older people and

69 incentivisation of specialist training in geriatrics and gerontology for medical students. However,
70 little progress has been made in the implementation of this policy, and the Ghana Health Service
71 lacks an implementation plan ((Kwankye, 2013; World Health Organisation, 2014). Little research
72 related to ageing and mental health has been carried out in this setting. Building on the work of the
73 Kintampo Health Research Centre (KHRC) and the work of the 10/66 Dementia Research Group
74 (DRG), we carried out a cross-sectional survey with a nested qualitative study among people aged 70
75 years or older in the Kintampo Health Demographic Surveillance Site (KHDSS). Our aim was to
76 explore sociocultural beliefs, understandings, perceptions, and behaviours relating to living with
77 dementia in Kintampo. Based on gaps in the evidence base, we were particularly interested to
78 explore: i) understandings and experiences of dementia, including beliefs about causality and stigma,
79 help-seeking behaviours; ii) care arrangements and the impact of caregiving.

80 Methods

81 We conducted in-depth interviews with a total of 28 people using series of case studies among 10
82 older people living with dementia and their families. The overall aim was to obtain multiple
83 perspectives on the experience of living with an older person with dementia (Crowe et al., 2011; Yin,
84 2009). This approach has been used successfully in the 10/66 DRG INDEP studies in Peru, Mexico,
85 China, and Nigeria (Mayston et al., 2014), and by other research teams in Tanzania (Mayston et al.,
86 2014) and Norway (Smebye, Kirkevold, & Engedal, 2012). The sampling frame was participants in our
87 quantitative cross-sectional survey who were identified as cases of dementia through a preliminary
88 processing of the data, using the 10/66 DRG short dementia diagnostic schedule (Stewart, Guerchet,
89 & Prince, 2016). The 10/66 DRG algorithm has demonstrated excellent validity in identification of
90 dementia cases in a wide range of low and middle income country settings (M. Prince, Acosta, Chiu,
91 Scazufca, & Varghese, 2003). It was not feasible to obtain a clinical diagnosis in the context of this
92 study. In settings where dementia is very rarely diagnosed in any part of the health system, a one
93 stage, culture- and education-fair screening tool is amongst the most feasible and valid means of
94 identifying dementia cases for the purpose of epidemiological research (M. Prince et al., 2003).
95 When compared against results of the original 10/66 DRG algorithm, the short-schedule version
96 attained sensitivity and specificity in detecting dementia that were equivalent to the high levels
97 obtained using the original algorithm (Stewart et al., 2016). Given the established validity of this
98 approach, as we would expect, distribution of cognitive test scores between our qualitative sampling
99 frame and study participants without dementia were consistent with differences identified in studies
100 carried out elsewhere in sub-Saharan Africa (Guerchet et al., 2010).

101 Setting

102 Our study was carried out in collaboration with the KHRC, in the Kintampo Municipality. Kintampo is
103 located in the middle belt of Ghana in the Brong Ahafo Region. It is a rural community, with farming
104 as the main economic activity (Owusu-Agyei et al., 2012). Kintampo is made up of 11 ethnic groups
105 with Akan the largest group, comprising 25.0% of the total population. The average size of a
106 household is 5 families, commonly resident within a compound made up of up to 10 separate blocks
107 clustered together. Researchers have begun to explore undertaking dementia research in the KHDSS,
108 which resulted in the translation of some components of the 10/66 Dementia Research Group
109 assessment prior to our work. However, ours is the first study to use these instruments to carry out
110 population-based research in this setting.

111 Sampling

112 Using the KHDSS register as our sampling frame, we identified 4222 people aged over 70 years at the
113 start of data collection. Our sample size calculation for the quantitative study (from which our

114 qualitative sample was drawn) was based upon an anticipated dementia prevalence of 10 percent. In
115 order to recruit the necessary 864 participants, we estimated that we would need to target older
116 people aged 70 years and above within an 18km radius of the KHRC. Older people were eligible to
117 participate if they: i) were verified in the KHDSS register as normally resident within catchment area
118 during the study period, ii) understood information about the nature and purpose of the study, iii)
119 agreed to participate and signed to acknowledge informed consent (thumb print with witness if
120 lacking the literacy skills to be able to sign), iv) understood and spoke Twi. We excluded older people
121 who were: i) not matched from the register, ii) verified in the KHDSS register but moved out of the
122 study area or deceased.

123 NA, SN and 4 field supervisors visited households identified from the register and introduced the
124 study. Information sheets and consent forms were verbally explained and left with households for
125 24 hours to enable potential participants to absorb and consider the information provided.
126 Interviews were arranged with those who consented to participate. Participants were informed that
127 their household might be selected to participate in a second qualitative interview. We completed
128 quantitative interviews with 761 older people and their key informants. The 10/66 DRG short
129 dementia diagnostic schedule identified 17 people with dementia (Stewart et al., 2016), which
130 formed the sampling frame for the qualitative study.

131 We purposively selected 10 households based on characteristics that we thought might influence
132 experiences of living with dementia, for example: sex, household size and structure, and age.
133 Selection criteria were designed to maximise diversity among our sample. Our sample size was
134 pragmatic, based on feasibility within the scope of our exploratory mixed methods study. We
135 anticipated that this sample size would enable us to get close to saturation on our a priori topics of
136 interest.

137 Recruitment and data collection

138 After completion of quantitative data collection and preliminary processing of data, two health
139 researchers (NA and SN), with backgrounds in social sciences (demography, qualitative research
140 methods) returned to households selected for participation in the qualitative study to carry out in-
141 depth interviews. In order to identify the key members of the household/family involved in practical
142 care work, decision-making or economic support, we carried out a relationship mapping exercise
143 with the head of household at the start of the interviews. We selected interviewees for participation
144 on the basis of findings from this exercise, where possible our aim was to interview the older person
145 themselves and the key people involved in their care. All interviews were audio recorded with the
146 permission of participants. Field notes (key words, phrases, events, observations) were taken to
147 supplement the data included in transcripts. Interviews were conducted from September to October
148 2015.

149 We used an adapted version of the 10/66 DRG INDEP study topic guide as a starting point for the
150 development of our topic guide. The aim of INDEP was to study the economic impact and needs for
151 care among older people in four low and middle income countries (Mayston et al., 2014). Given our
152 focus on the lived experience of dementia, causality, care arrangements etc. we amended the INDEP
153 topic guide to include Kleinman's explanatory model interview questions (Kleinman, 1980), in order
154 to elicit responses on these topics. We carried out interviews in a narrative style. We selected this
155 approach as a naturalistic way for interviewees to "tell their story" about the onset, course and
156 impact of dementia (Jovchelovitch & Bauer, 2000; Muylaert, Sarubbi Jr, Gallo, & Neto, 2014):
157 described by interviewees as "problems with memory, concentration and thinking which are serious
158 enough to affect day-to-day living". We also included prompts to probe for responses related to any

159 a priori topics of interest that were not covered in the narratives or where the interviewer felt the
 160 expansion of a particular theme would offer helpful insights, for example: asking about whether they
 161 had sought help for the problems described and their experiences of help-seeking for dementia.

162 Ethical approval was sought and obtained from the King's College London Research Ethical
 163 Committee (REC) and Kintampo Health Research Centre's Institutional Ethics Committee (IEC).

164 Analysis

165 We transcribed all the interviews verbatim from the local language (Twi) directly into English using
 166 Microsoft word. We anonymised notes/transcripts from the field by redacting identifying details
 167 after transcription. The data were managed using Open Code 4.0 qualitative software (University of
 168 Umeå, 2013). NA and RM read the data repeatedly and familiarised themselves with the content.
 169 We used a framework approach for our analyses (Furber, 2010; Ritchie & Lewis, 2003). The
 170 framework approach facilitates use of a priori codes derived from literature as well as enabling new
 171 codes to emerge from the data. It also allows within case analysis as well as facilitates identification
 172 of crosscutting themes (Feilzer, 2010; Gale, Heath, Cameron, Rashid, & Redwood, 2013). Given our
 173 defined area of interest we were keen to look at similarities and differences in perspectives within
 174 families as well as identifying commonalities across households. We selected initial codes and sub-
 175 codes with reference to published literature and a priori topics of interest. NA developed the initial
 176 coding framework, discussed and agreed with RM. Both researchers then independently applied
 177 framework to the dataset. Additional codes that emerged during our analyses were added to the
 178 framework. NA and RM then met to discuss their frameworks and coding. NA consolidated coding
 179 according to this framework. NA and RM met to discuss and mapped out themes.

180 Results

181 See Table 1 for a description of the characteristics of the households selected for qualitative
 182 interviews. Table 2. Describes categories, themes and sub-themes identified in our analyses and
 183 described in detail in our results.

184 Table 1. Household characteristics

No	Household code	Sex	Age	Co-residents	Primary caregivers	Household structure & arrangements
1	AS 0552	M	85	7	Spouse, son, & older grandson (not living in household)	Spouse, children & grandchildren
2	NN 0133	M	100	10	Spouse, & eldest son	Spouse, sons, nieces & other relatives
3	NN 0081	M	90	7	All	Spouse, daughter-in-law, grandchildren
4	AS 0533	M	73	2	Spouse & son (not living in household)	Spouse & tenant
5	OP 0088	F	85	10	Daughter and grandchildren	Daughters, grandchildren & great grandchildren
6	BB 0731	F	85	6	Daughter & granddaughter	Granddaughters & other tenants
7	PP 0010	F	77	9	Daughter and granddaughters	Daughters & grandchildren
8	AB 0075	F	80	6	Grandson	Daughter-in-law & 4 grandsons

9	AS 0815	F	82	8	Self, daughter-in-law & older grand child	Son, daughter-in-law & grandchildren
10	BN 0089	F	92	10	Self, daughter and grandchildren	Daughter & grandchildren

185

186 Table 2. Categories, themes and sub-themes

CATEGORIES	THEMES	SUB-THEMES
SYMPTOMS	Cognitive problems	Problems with language, getting lost
	Physical co-morbidities	Mobility, aches and pains, stroke, blood pressure, hearing/sight
UNDERSTANDINGS OF COGNITIVE SYMPTOMS	Ageing	Cognitive have no specific name, part of overall decline
	Grief	Grief perceived to be a precursor to onset of cognitive decline
	Witchcraft	Bewitchment caused cognitive symptoms
HELP-SEEKING	Biomedical services	
	Traditional services	Used in combination with biomedical/used because of perception of supernatural cause
COURSE OF COGNITIVE ILLNESS	Irreversible	
CARE ARRANGEMENTS	Gender	Decision-making
		Division of labour
ECONOMIC IMPACTS OF CARE	Income generation	Generally limited impact
	Multiple demands upon household finances	Costs of care occur in context of other crises- sickness, poor harvest, essential building works
	Indirect healthcare costs	Even with insurance, transportation, herbal medicine costs are problematic
	Uncertain illness trajectories	Future healthcare costs are unpredictable, which is problematic
STIGMA	Lack of stigma	Despite symptoms, older person is treated with respect

	Changing role	Value of older person as an advisor is reduced, physical work is replaced with more sedentary activities
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187

188 *Symptoms narratives*

189 *Mental decline*

190 The most common problems reported by family members were difficulties in holding a conversation.
 191 Caregivers of eight of our participants described changes in the ways in which older people
 192 conversed. Older relatives were more likely to: veer off topic or forget what they were talking about,
 193 lose concentration, say things that were perceived to be not meaningful or irrelevant to the
 194 conversation, or say things that were perceived to be disinhibited. For example:

195 *“That was not how she was ... but now she has changed ... [paused]... looking at how she used to be*
 196 *then and now are different ... also nowadays she says or does things that are not sensible ... some*
 197 *things that she would not say to anyone before, now she says them freely ...”* [HH OP0088, Daughter
 198 of older participant]

199 *“I can converse with her but sometimes she loses concentration and it is as if she has not heard what*
 200 *I have been saying or said at all or maybe she has forgotten what we were talking about...I don’t*
 201 *know...”* [HH AB0075, Grandson of older participant]

202 Other problems reported included forgetting words for objects or being forgetful or confused (n=4),
 203 losing things (n=2), getting lost (n=2), failing to recognise family members (n=1), unable to dress/go
 204 to the toilet/wash (n=1). Despite the absence of some of the more severe symptoms of dementia
 205 (such as aggression), participants clearly found these symptoms troubling. For example:

206 *“What is worrying is that he doesn’t sleep at night so we also don’t sleep. Often at times when there*
 207 *is a “dance” [music and drumming] going on at the town centre then he will want to go there and*
 208 *dance. When you are not awake or you do not see him going out then you are relying on outsiders to*
 209 *bring him back home when they see him outside at night ... [sighs] if nobody sees him then he walks*
 210 *around until someone who knows him brings him home.”* [HH NN0081, wife of older participant]

211 *Co-morbid physical health problems*

212 Caregivers often listed symptoms of physical health problems which co-existed alongside those
 213 associated with cognitive decline, such as: mobility problems (n=3); aches and pains (n=3); stroke
 214 (n=1); blood pressure (n=1); problems with hearing/sight (n=1).

215 *“At first she was able to go to farm and gather firewood even when you try to stop her, she will not*
 216 *mind you ... she was very strong ... she will fetch all the firewood a tractor brings as if three young*
 217 *men went to fetch that firewood. Now she cannot even come out of her room not to even talk of*
 218 *going to the farm to gather firewood. When you ask her, she complains of joint pains and that she*
 219 *cannot walk... that is how I got to know that she has changed ... then I already mentioned to you that*
 220 *when I tell her something immediately I come back to ask again she has forgotten about it. So that*
 221 *too I have seen that she has changed.”* [HH BB0731, Daughter of older participant]

222 *Making sense of mental and physical decline*

223 *Ageing*

224 Ageing was the factor most commonly understood to underlie cognitive symptoms, reported by
225 caregivers in relation to eight older relatives. One family specifically related the onset of symptoms
226 to the time of their mother's menopause. There was an understanding that the passage of time
227 inevitably led to the decline of the body and mind in humans, related with the wear and tear seen in
228 objects or decay witnessed in other natural things:

229 *"If there is a leaf which is very green and now it had turned yellow, you now start thinking 'when will*
230 *this leaf fall down'...we sometimes think...what will happen...but God alone knows the end"*

231 [HH NN 0081; Wife of older participant]

232 When asked what they called the condition associated with cognitive symptoms (eg. Difficulties
233 holding a conversation, losing thing, getting lost etc.) participants stated that they had no
234 specific word for this condition or someone experiencing these kinds of symptoms, rather,
235 "the only name we know is someone who has grown very old...'hangyena'" (HH AS0815; son of
236 older participant).

237 One caregiver of an older lady (her grand-son) clearly related her problems to deterioration
238 over time of the brain:

239 *"You know when you buy something new and you use it for a long time it becomes old...it does*
240 *not remain like you bought it. I think that is how the human brain is...when you are young it*
241 *works well*

242 *but when you grow old it does not work well...so when someone becomes old then every part of*
243 *the body too becomes old"*

244 [HH AB 0075; Grandson of older participant]

245 *Grief*

246 Grief related to the recent deaths of close relatives was thought to contribute to the onset of
247 cognitive symptoms according to three study participants (an older lady, and two caregivers for
248 different older participants):

249 *"It is not because I am aging that is why I am behaving this way...if you have eight children and four*
250 *of them suddenly die...now you only have four of them what will you do? When this girl's (referring*
251 *to a toddler on lap) mother died, five days later another one who lives in Kintampo also passed*
252 *away" 0089*

253 *Witchcraft*

254 Witchcraft was identified as a causal factor underlying symptoms by three participants: two
255 caregivers (for different older people) and one older participant. One of the caregivers believed that
256 although the older person had experienced a stroke, this event had been caused because the older
257 participant had been bewitched. The older person in question understood that his symptoms of
258 suddenly not being able to walk or talk were caused by a neighbour. For another caregiver, his
259 father's problems also had a supernatural cause:

260 *“hmmm what I can tell you is that at times he can go somewhere and someone will have to bring him*
261 *back to the house. Then there are some things in this house that he cannot lift but I noticed that*
262 *sometimes he will be filled with some powers and because he is not himself he tries to lift those*
263 *things like some easy thing...sometimes too he will run and climb very tall trees. That was when I*
264 *realized that something was wrong with him. So, I contacted my uncle at Baniantwe and he said that*
265 *at first the dwarfs wanted to possess him and he did not like it, so that is why he sometimes behaves*
266 *like that” 0533*

267 *Help-seeking*

268 *Biomedical services*

269 Participants reported that all of the older people in our qualitative sample had visited the hospital
270 since the onset of cognitive symptoms. Physical health symptoms were generally the impetus for
271 accessing health services. Cognitive symptoms were not generally reported to healthcare workers:
272 they were considered to be consistent with deteriorating health but not a sickness per se:

273 *“As I said before we took him because he complains of the stomach ache, pains in his knees or if he*
274 *has body pains ... that is what we go and tell health workers ... then they will give his medicine for the*
275 *ailments ...we have never reported his behaviour to the doctor ... we think its old age ... it is not*
276 *sickness so that is why we did not tell the doctor” [HH NN 0081; Wife of older participant]*

277 One caregiver reported mentioning to the healthcare worker the problems their father was having
278 with reasoning and conversation. The healthcare worker diagnosed high blood pressure, provided
279 medication for this and advised that alcohol and salt should be reduced in his diet. The cognitive
280 problems were not directly addressed and the family observed no improvements in these
281 symptoms In fact it was rare for the older person to receive a diagnosis for any of the problems
282 presented to the healthcare worker. More commonly, they were provided with medication without
283 further advice or information..

284 *Traditional medicine*

285 In five households, traditional medicine (usually herbal) was used in lieu of or in combination with
286 “white man’s medicine” to treat the older person’s health problems. Families evaluated both
287 treatment models in a similar way. If herbal treatments were found to be ineffective, families might
288 switch to biomedical treatments and vice versa. Sometimes herbal and biomedical treatments were
289 used in combination, with the aim of addressing different aspects of the same problem:

290 *“When it happened we were told that we can only use traditional medicine because of the nature of*
291 *the fracture ... and that is what we did ... we were told to put some herbs on the affected area after*
292 *we had massaged the area with a hot stone ...other times to I buy some drugs that works on the*
293 *bones for her to swallow” [HH BB0731; Daughter of older participant]*

294 In the two families who believed supernatural forces were the primary cause of cognitive symptoms,
295 although biomedicine was accessed for physical illness, traditional medicine was believed to be the
296 only appropriate treatment for this problem:

297 *“When it started he could not talk or walk...we did not send him to hospital to treat this kind of*
298 *illness...we only used the traditional medicine and we saw that there was an improvement because*
299 *he could walk...”*

300 [HH NN 0133; Son of older participant

301 *Course of illness*

302 Overall, it was generally acknowledged that improvements in symptoms of sickness of older relatives
303 (including those with a supernatural cause) might be partial and that it might not be possible to halt
304 natural decline. Generally, families aim was to treat what they could, in order to see an
305 improvement in the level of comfort of their older relative:

306 *"No...no...I don't believe it will improve...it will get worse...but maybe if we get medicine for her she*
307 *might feel okay"* [HH AB 0075; Grandson of older participant

308 *Care arrangements*

309 *Gender*

310 Female relatives were the hands on caregivers in all households. All of the men had wives who were
311 the primary caregivers. All six of the female participants were widows. Where there was a man
312 involved in day-to-day activities with the older person, they identified themselves as the primary
313 caregiver; in these cases, they made decisions about care and treatment and were responsible for
314 finances, arranged transport to healthcare appointments, supervised medication. But in each of
315 these households, the wife of the older person and other women in the household assisted the older
316 person with other activities of daily life: bathing, preparing food, dressing, toileting, ensuring they
317 were not left alone (for fear of getting lost). Being a caregiver for a husband was an integral part of
318 being a wife, and by extension, providing care for the older members of a husband's family was a
319 natural extension of this role as wife and daughter-in-law. Others became de facto caregivers
320 because of their geographical proximity to the older person and the absence of possible candidates
321 for the role. For example, a son who was a caregiver described how all of his siblings had relocated
322 to the city, leaving him and his wife as the only suitable caregivers for his mother; for one grand-son
323 who was a caregiver for his grandmother, the polygamous marriage of his father meant that he
324 spent several months of the year in the North of the country:

325 *"I can send her to the hospital and then call and tell him [his father] about it later...then he will tell*
326 *me what I should do or he will come if he has to be here."*

327
328 [HH AB 0075; Grandson of older participant

329 *Decision-making*

330 Whilst decision-making was a primary component of the role of male caregivers, some female
331 caregivers were both decision-maker and hands-on carer (usually daughters of the older person).
332 Some primary caregivers made unilateral decisions about treatment, informing those family
333 members not resident in the compound, but who might be expected to contribute financially to the
334 care of the older person, after the decision had been made and treatment accessed:

335 *"I will usually send him to the hospital first and then inform my other siblings later on... I will have to*
336 *look for money and send him...at times too my other siblings can bring a car from Kintampo to send*
337 *him to the hospital...we also have other relatives who help when papa is unwell. However, here in*
338 *this village I take care of everything and even his insurance."*

339 [HH AS 0533; Son of older participant]

340 In other cases, the approach to treatment and care was discussed by the family, with roles and
341 responsibilities, including financing, hands-on care and decision-making about treatment was jointly
342 agreed:

343 *“One person cannot decide on this issue. It was the decision of the family members that, where
344 Grandpa’s age has gotten to it is important we take good care of him. I mentioned this earlier on that
345 those who have travelled contribute their monies and send the foodstuffs we buy to them. My
346 grandmother is there with other family members so those living with him help him with his daily
347 activities ... when it comes to bathing, my grandmother is responsible; for his meals, it is my
348 grandmother. My uncle and my aunties ... they share those responsibilities and make sure that it’s
349 been taken care of...”*

350 [HH AS 0052; Grandson of participant]

351 *Division of labour*

352 In general, caregiving was a collective activity, with hands on care duties shared among the female
353 members of the large compound households in which the older people lived. Sometimes these
354 arrangements were co-ordinated by a primary caregiver but more commonly these arrangements
355 appeared to be more organic, with those most involved in care able to rely on supplementary
356 support as and when this was necessary:

357 *“Yes...since there are many of her grandchildren around the duties have been shared amongst them.
358 Initially when you tell them to prepare food they will be looking at each other not knowing who to do
359 what...when you do not mention someone’s name then they will be sitting down...so I met with them
360 and apportioned duties for each of them. The schedule is changed every three days to ensure that
361 each and every one is doing something”*

362 [HH BN 0089; Daughter of older participant]

363 *Economic impact*

364 *Income generation*

365 Where care needs were minimal and practical care was shared among many, the impact upon
366 income generating or subsistence activities was perceived to be limited:

367 *“Maame’s condition has not reduced the work I do in any way...even if I go to farm there is someone
368 who helps to care for her...we are many here so every time there is someone at home so if you are
369 not at home you are not worried. Maame also has many grandchildren it is not a problem to leave
370 her for a while and go to the farm to work...they take care of her needs...she can also do some things
371 for herself”*

372 [HH OP 0088; Daughter of older participant]

373 *Multiple demands*

374 Taking care of the older person occurred in the context of multiple demands upon family finances,
375 with the children of the older person commonly supporting their own young families. Given this
376 backdrop of already stretched finances, crises, such as poor harvest, sickness of a family member or
377 essential building works, were particularly challenging and commonly necessitated requests for
378 funds from family members outside the immediate household:

379 *“As you can see these days money is difficult to get...all of my other siblings are married and have*
380 *children to take cater for...they pay school fees and other things so in terms of money it is very*
381 *difficult to come by...but when this building almost collapsed it was my sister who gave us money to*
382 *rebuild and maintain it. When I also fell sick my sister gave me money to go to the hospital and they*
383 *told me it was high fever...you see when we were rebuilding the house I roofed the house and a nail*
384 *pricked me the time I was doing it but I did not tell anyone...my foot swelled and I could not wear a*
385 *shoe...”*

386 [HH AS 0533; Son of older participant]

387 *Indirect costs*

388 Most of the older people we interviewed had public health insurance (although in at least one case
389 this had lapsed). This was generally perceived positively by the families. However, transport and
390 herbal medicine remained a significant cost. Some of those who were uninsured reported that
391 economic constraints limited access to treatment:

392 *“I am talking of the means...that is money to send her somewhere for her condition to be treated...we*
393 *don’t have it...I am even talking about her eye problem, if I send her to the hospital they can treat her*
394 *...but I don’t have the means...if I had, I would look for treatment for her eye problem to go away so*
395 *that she can see well”*

396 [HH AS 0815; Son of older participant]

397 *Uncertain trajectories*

398 For this family, the uncertainty of the trajectory of the health of the older lady and the management
399 of future costs associated with illness was a source of concern:

400 *“we know that she will not live forever and she will die one day...she can live very long or even die*
401 *tomorrow but when she grows very old and has all kinds of small, small illnesses that is where the*
402 *problem can be...we don’t know when she will tell us this part is paining her and we two we don’t*
403 *have the means”*

404 [HH AS 0815; Daughter-in-law of older participant]

405 *Stigma*

406 When prompted as to whether they felt that they or the older person had ever been treated badly
407 because of the condition of the older person, participants universally responded that the community
408 treated the older person well and with respect. This was felt to be manifest in friends and
409 neighbours greeting the older person, asking how they were doing, coming to visit, sit and talk with
410 them. Getting lost, difficulties in having conversations, forgetfulness were accepted as symptomatic
411 of ageing when exhibited among older people, rather than “madness”. As such, older people
412 displaying these behaviours might experience some “teasing” from small children, but this was not
413 felt to violate the respect that was felt to be owed to older people:

414 *“Son: Sometimes some of the young people tease him but they are not disrespectful...”*

415 *Interviewer: “Please in what ways do they tease him?”*

416 *Son: “The way he speaks...always calling death and saying he will die, he will die, something small*
417 *then he will say he will die. I keep on telling him that he will not die. If he will die, then on the spot he*
418 *will die....right now we do not consider anything he says...even when he is asking you for money he*

419 will say give him “Simpoa” [previous currency that was being used]...so they make fun of him. Had it
420 not been that he is old we will say he is mad”

421 [HH AS 0533; Son of older participant]

422 Older people with these symptoms were routinely referred to as “childlike” by interviewees.

423 *Changing role of the older person*

424 This was linked to the transition in role of the older person, from being someone who was valued as
425 a confidante and advisor to being someone who needed to be taken care of and whose opinion was
426 regrettably no longer trusted or valued. This change was experienced as a loss by close family
427 members:

428 *“When she was a bit younger, I used to come to her for advice which was very useful when I followed
429 it...but now if I come and ask her for advice...what she will say does not bring anything good in my
430 life...I have realized I do not have anyone who will advise me again ...when I think about these things
431 then I begin to cry...that is why I say I am worried about her condition now”*

432 [HH AS 0815; Son of older participant]

433 Other aspects of the transition in the role of the older appeared easier for families to manage. For
434 example, although it was recognised that it was no longer possible for the older person to carry out
435 farming or go to market as they once did, the value of occupation was recognised by families and
436 older people were encouraged and supported to carry out alternative meaningful activities:

437 *“...she can do a lot of things on her own with her hands and when she is sitting down...you can see
438 her de-husking the maize for the poultry...”*

439 [HH AB 0075; Grandson of older participants]

440 Discussion

441 Our study was designed to examine experiences of dementia. However, we found that it was not
442 always possible or appropriate to separate experiences of dementia from those of other chronic
443 conditions. Consistent with qualitative research carried out in Tanzania (Mushi et al., 2014),
444 participants reported that they had no specific term for people living with dementia, rather they
445 were referred to as “hangyena”, translated as “very old”. Comparable with the metaphor of an old
446 car identified in a different qualitative study carried out among traditional and faith healers in
447 Tanzania (Hindley et al., 2016), participants in our study conceptualised problems associated with
448 ageing as accumulated “wear and tear” over time due to usage. Although within this holistic model,
449 participants sometimes made a distinction between body and mind (Patel, 1995) (linking symptoms
450 of cognitive impairment with wear and tear of the brain) dementia was not always the salient
451 element of participants’ experience. Participants viewed the health of older people holistically,
452 describing the overall collection of symptoms observed and responding to needs for treatment and
453 care (to which dementia contributed) as they arose. This reflects experiences of health and sickness
454 of older people and their families around the world, where multi-morbidity is common and broad
455 outcomes such as disability and needs for care are more salient and important to older people and
456 their families than diagnosis and aetiology.

457 Perceived aetiology did however play a role in shaping the character of help-seeking. As has been
458 found elsewhere, families who believed witchcraft to be the primary cause of cognitive symptoms
459 opted for traditional healing in the first instance (Dale & Ben-Tovim, 1984). However, families who

460 identified “ageing” as the primary cause tended to experiment with biomedical and traditional
461 treatments, switching services when a particular treatment was found to be ineffectual. Ultimately,
462 many of the symptoms of old age were understood to be untreatable and characteristic of
463 inexorable decline. Participants commonly located cognitive symptoms in this category. However, in
464 a setting where there is low recognition of chronic conditions associated with old age among health
465 professionals (de-Graft Aikins, Addo, Ofei, Bosu, & Agyemang, 2012), it is difficult to ascertain what
466 role this lack of services played in determining attitudes to help-seeking for chronic conditions,
467 including cognitive impairment. The impact of the absence of appropriate services and the perhaps
468 concomitant perception of the un-treatability of cognitive symptoms may have contributed to a lack
469 of focus upon cognitive deficits in interview narratives.

470 Some of our findings provide an interesting contrast with those from the 10/66 Dementia Research
471 Group INDEP study. In our site in rural Ghana, the work of caring appeared to be more seamlessly
472 absorbed into the daily tasks of the women within large family compounds than for women in Latin
473 America, China and Nigeria. Unlike among participants in our sites in urban Latin America, where
474 some women were beginning to challenge their de facto role as caregivers to older family members
475 (Mayston et al., 2014), none of the female caregivers we interviewed in Kintampo questioned their
476 status. In addition, in other settings, the stresses and strains of being a caregiver and attempting to
477 meet the costs of care were strong themes (Martin Prince, 2004; M. Prince et al., 2012), whereas in
478 Kintampo, although participants expressed concern for the health of their family member, any
479 adverse effects upon their own wellbeing were largely absent from our interviews. Only a minority
480 of our interviewees described caregiving as a major constraint on their income generation activities.
481 There are some obvious factors that may have contributed to these differences. It seems possible
482 that traditional gendering of roles and the salience of seniority and filial obligations remain more
483 strongly intact in this setting, retaining their influence in ordering relations and social actions
484 (Udvardy & Cattell, 1992) . Certainly, from our interviews, it seems clear that compound household
485 structures facilitated amicable distribution of care duties among many.. Interviewer field notes
486 suggest that although most of the older people interviewed displayed symptoms of cognitive
487 impairment, many of the signs and symptoms associated with severe dementia (eg. agitation,
488 aggression, incontinence) found to be particularly associated with strain elsewhere, appeared to be
489 absent (Ferri, Ames, & Prince, 2004). This may explain why cognitive symptoms did not appear to
490 significantly change the shape of care arrangements.

491 Finally, given that the primary activities in the region are farming and small trade, with low
492 participation in formal labour, particularly among women, the kinds of economic activities caregivers
493 were carrying out were more flexible and likely to be closer to home than the jobs and careers of
494 women living in urban Peru, Mexico and China (Mayston et al., 2014). Finally, health insurance
495 appeared to mitigate the worst impacts of the costs of chronic conditions for some. It was clear that
496 not all families were reaping the potential benefits of health insurance, although the reasons for this
497 were unclear. Although the Government of Ghana’s aim is equitable and universal access to a
498 package of essential healthcare, like elsewhere, coverage remains stubbornly low: less than 50%
499 among people aged older 70 years (World Health Organisation, 2014). Contributory factors include:
500 a large non-formal healthcare sector, rural communities made up of small towns with poor roads,
501 telecommunications which inhibit health service access (Agyepong & Adjei, 2008). Further research
502 is necessary to understand the specific barriers to accessing health insurance among older people,
503 although lack of awareness of fee exemption of those over 70 years from fees and equity of
504 enrolment for poorer people have been highlighted as potential concerns (Lagomarsino, Garabrant,
505 Adyas, Muga, & Otoo, 2012).

506 Although it was our aim to interview older people and their family members and older people
507 consented to participate, their voices are largely absent from narratives. Despite the fact that
508 research ethics committees commonly stipulate that researchers should ensure privacy during
509 research interviews, this is often not possible, due to a lack of private space and the cultural
510 inappropriateness of separating family members, particularly older people, for interview. In our
511 case, interviews were largely carried out as a collective activity. Our results inevitably reflect this,
512 with the Head of Household and main caregiver often the strongest voices. Although some older
513 people did contribute (and sometimes contradicted other family members), in general, family
514 members spoke on behalf of older people, even though, in many cases, it was clear to the
515 interviewer that the older person understood and was capable of participating in the interview. In
516 our view, this situation is unavoidable and is therefore something that researchers need to be aware
517 of as a potential influence on results rather than something that they should necessarily seek to
518 change. A key potential limitation of our study is the lack of clinical diagnosis of dementia among our
519 participants. We were unable to select participants on the basis of important clinical characteristics
520 such as sub-type and duration, which may have important effects upon the experiences of caregivers
521 and older participants. It is difficult for us to separate experiences which are a product of culture
522 from those which are a result of cognitive impairment. Nonetheless, given the proven validity of the
523 algorithm and its constituent instruments in other low income settings, we are confident that the
524 older participants in the qualitative study were, in fact, living with dementia. The symptoms of
525 cognitive impairment described in qualitative narratives by participants triangulate the results of the
526 10/66 DRG short dementia diagnostic schedule. In a region where despite rapidly rising numbers of
527 older people, and there is very little qualitative work designed to understand experiences of health
528 in older age, we believe that our exploratory study is an important initial contribution to the
529 evidence-base which will be necessary to develop effective policies and services in coming years.

530 Conclusions

531 Our findings demonstrate that families in Ghana have a coherent explanatory model for health
532 problems associated with older age, characterised as natural decline, within which beliefs about
533 symptoms related to cognitive impairment are nested. Alongside other related belief systems such
534 as gender roles and beliefs about the importance of seniority and filial duty, beliefs about health,
535 sickness and personhood in old age guide approaches to caregiving, help-seeking and the role of
536 older people. In contrast, social policies and the health system are at odds with the experience and
537 needs of older people and their families (World Health Organisation, 2014). It is important that
538 policies acknowledge the continuing social and economic potential of older people, including those
539 living with dementia, for example, the continued roll-out of social pensions, which have been found
540 to have a positive impact upon the socioeconomic status of the entire household where the older
541 person is resident (Heslop & Gorman, 2002). Specific challenges in the health system in Ghana
542 include: the lack of guidelines for chronic disease care, erratic supply of essential drugs and
543 equipment at facilities, lack of old age specialists, poorly trained healthcare workers with insufficient
544 knowledge of common chronic diseases (de-Graft Aikins et al., 2012). There is emerging evidence
545 that effective care for chronic diseases associated with old age, including dementia, can be delivered
546 by non-specialist workers providing outreach to older people's home from primary healthcare
547 centres in low and middle income country settings (Guerra, Ferri, Fonseca, Banerjee, & Prince, 2011;
548 Jotheeswaran et al., 2015). This approach is one potentially cost-effective means to rapid scale-up of
549 the services that will be needed to address the increase in chronic disease that will inevitably
550 accompany rapid population ageing.

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