

Title: Patient and companion concerns when receiving a dementia diagnosis: An observational study of dementia diagnosis feedback meetings.

Authors

Penny Xanthopoulou¹ (corresponding author)

p.d.xanthopoulou@exeter.ac.uk

Jemima Dooley¹

j.m.b.dooley@exeter.ac.uk

Ilaria Meo²

meo.1322242@studenti.uniroma1.it

Nick Bass³

njbass@HCPs.org.uk

Rose McCabe¹

R.McCabe@exeter.ac.uk

1. University of Exeter, Medical School, Exeter, UK
2. Sapienza University, Faculty of Medicine and Psychology, Rome, Italy
3. University College London, Division of Psychiatry, London, UK

Corresponding author at: University of Exeter Medical School, College House, St Luke's Campus, Exeter, EX1 2LU, UK

Abstract

Receiving a diagnosis of dementia is a life-changing event and can cause strong emotional reactions. The aim of this study was to examine patient and companion concerns expressed during dementia diagnostic feedback meetings. Sixty consultations between 19 healthcare professionals (HCPs), 60 patients, and 59 companions were video-recorded and transcribed. Concerns were operationalized as expressions that conveyed worries, fears, or unpleasant emotions. Concerns were identified from the transcripts and were (a) content analysed according to topic (b) coded as *elicited* by the HCP or *volunteered* by the patient or companion, and (c) coded according to whether the HCP *encouraged* or *discouraged* elaboration of the concern. A total of 249 concerns were identified, with an average of 4 concerns per consultation. There were three areas of findings: (a) Patients and their companions were concerned about the symptoms of dementia, receiving a diagnosis (e.g. shocked, confused), and were frustrated because of their symptoms. Other concerns related to patients' mental and physical health, and prognosis; (b) HCPs elicited more patient than companion concerns and 43% of the total concerns raised. They mostly elicited concerns aligned with the agenda of diagnosis feedback: dementia symptoms, reaction to diagnosis, and mental health. Concerns about physical health or prognosis were mostly volunteered; (c) HCPs were more likely to encourage elaboration when they elicited the concern. Concerns about family (e.g. caring for/loss of family members) and mental health were encouraged most often. Nearly 40% of concerns were discouraged by the HCP changing topic, with concerns about prognosis most commonly discouraged. The findings suggest that there were a wide variety of concerns at dementia diagnosis, many extending beyond the experience of dementia symptoms. Doctors focused mostly on patients' rather than companions' concerns. Avoidance of concerns about prognosis demonstrated delicacy in discussing the deteriorating course of dementia.

Keywords: dementia, concern, communication, medical consultation

Background

Estimates show that 47 million people worldwide were living with dementia in 2016 and the number is steadily increasing (Prince *et al.* 2016). Due to government policy drives to increase dementia diagnosis rates, the number of people receiving a diagnosis of dementia has risen by nearly 20% in the UK (Hodge and Hailey 2015) and is increasing worldwide (Alzheimer Europe, 2016). Receiving a diagnosis of dementia is a life-changing event, which can cause strong emotional reactions (Amizandeh, 2007). The process from a person realising that they might have a problem to the dementia diagnosis itself can take up to 3 years (Chrisp, *et al.* 2011). Thus when people finally hear the diagnosis, while there may be some level of shock and denial, there are likely to be many concerns and information needs surrounding the condition and its management (Bunn 2015).

The way healthcare professionals (HCPs) elicit and respond to concerns expressed by patients, where concerns are defined as patient expressions that convey worries, fears, or unpleasant emotions, is an important part of medical communication (Zimmermann, Del Piccolo and Finset 2007). Although eliciting patient concerns might prolong the diagnostic appointment (McLean and Armstrong 2004), encouraging their expression can lead to improved outcomes, for example by improving engagement of patients in health services who might otherwise not engage (Zimmermann, Del Piccolo and Finset 2007; McCabe *et al.* 2002). This is particularly important in dementia, where involvement in support and activities can enhance quality of life and reduce behavioural symptoms

(Trahan *et al.* 2015). Additionally, research on cancer consultations has shown that not addressing patient concerns can have a negative impact on patient's subsequent psychological wellbeing (Brown *et al.* 2001). However, a review of the literature shows that HCPs do not always detect patient concerns and may sometimes discourage their disclosure (Zimmermann, Del Piccolo and Finset 2007). Various frameworks have been developed that explore doctor-patient communication, such as the Roter Interaction Analysis System (Agha, Roter and Schapira 2009) and the Verona Coding Scheme for Emotional Sequences (Zimmermann *et al.* 2011; Del Piccolo, Goss and Zimmermann 2005), and focus predominantly on dyadic interactions between HCPs and patients.

In dementia there are specific challenges to HCP-patient communication. Memory clinic consultations usually involve the person with dementia, their companion and the HCP, and this can create additional communication difficulties when the needs of both the patient and companion have to be considered (Robinson *et al.* 2010; Karnieli-Miller *et al.* 2012). Another challenge is the impact of dementia symptoms on communication. Dementia can involve language decline and comprehension problems (Blair *et al.* 2007), which can have practical implications for how doctors communicate, for example using long sentences with multiple clauses can be more difficult for people with memory difficulties to follow (Jones 2016). These factors can lead to the marginalization of the person with dementia in discussions about their health and treatment (Sabat 2005; Karnieli Miller *et al.* 2012).

Many studies examining the needs of people with dementia and their family companions after receiving a diagnosis highlight issues that arise in the post-diagnostic stage regarding lack of ongoing support from services (e.g. Black *et al.* 2013; van der Roerst *et al.* 2009; McCabe *et al.* 2016). Additionally, studies of how people experience communication of dementia diagnoses demonstrate that people do not feel they receive adequate diagnostic information (Abley *et al.* 2013; Bamford *et al.* 2004). People with

dementia and their companions report feeling that they did not know what to ask the HCPs in the diagnostic feedback meeting and that they felt that the concerns they did raise were sometimes disregarded (Manthorpe *et al.* 2013). However, there have been no studies directly observing the communication in dementia diagnosis meetings that has focused on what concerns people with dementia and companions are raising in these meetings, and how HCPs are addressing these concerns.

This study explored concerns expressed in HCP-patient-companion communication in specialist memory clinics during the dementia diagnostic feedback meeting. The aim was to identify the topics of the concerns expressed by patients and companions, whether HCPs elicit patient and companion concerns or whether they are volunteered, and how HCPs respond to these concerns.

Methods

This study was part of a cohort observation study: Shared Decision Making in Mild to Moderate Dementia (ShareD: 13/114/93). Data was collected in the form of video recordings from 9 specialist memory clinics over 4 NHS trusts (1 in Devon and 3 in London), from May 2014 to February 2016.

Setting and data collection

The participating memory clinics were all based in secondary care, so patients had been referred by their GP for assessment and diagnosis. Patients were asked to attend the appointment with a family member or someone who knows them well. The memory clinic process consists of history taking, cognitive assessment, and neuroimaging stages, which culminate in a diagnostic feedback meeting. In London, these stages took place in

separate appointments over a period of months. In Devon these appointments occur on the same day in one 4-hour appointment.

The HCPs delivering diagnoses in the memory clinics were identified in the participating trusts and contacted first by email and then by telephone. The consent rate was 88 per cent. Eligible patients who were due to attend a diagnostic feedback appointment with the participating healthcare professionals were identified by administrative staff before their appointment by review of medical records. The only exclusion criterion was that the patient does not require an interpreter to talk to the HCP. The patients received information about the study with their appointment letters. When the patient and their companion arrived at the clinic, a researcher approached them to discuss the study further and obtain written, informed consent. For patients without capacity to provide informed consent to participate (one patient in our sample) we followed the “Guidance on nominating a consultee for research involving adults who lack capacity to consent” (Department of Health 2008). Of 315 patients approached to take part in the study, 215 took part (62%), of which 101 were diagnosed with dementia. The first 60 consultations containing people receiving a diagnosis of dementia were selected consecutively from the larger sample for analysis.

The diagnostic feedback meetings were videotaped using two GoPro HERO3 cameras, and audio recorded to ensure maximum chance of quality audio capture. The researcher was not present to minimise observer effects. Recordings were transcribed verbatim, including additional features such as pauses, laughter and acknowledgment tokens (e.g. hm). The video recordings were used during coding when it was not clear from the transcript if the HCP was speaking to the patient or the companion.

Participant information

Nineteen lead HCPs, 60 patients (37 women, 23 men) and 59 companions were observed. Thirty-five patients were from London and 25 from Devon. Patients were aged from 52 to 92 years with an average age of 81 years. In 90 per cent of the consultations there was one companion present and in 8 per cent there were two companions present. The HCPs who delivered the diagnosis to the patient/companion were all HCPs, either psychiatrists or geriatricians. The range of patients per HCP was 1 to 6 (4 HCPs had one consultation recorded). In 12 appointments other HCPs (dementia advisors, nurses and medical students) attended the meeting and participated in discussions. The majority of the elicitations and responses were attributed to the HCP (80%).

Data analysis

Concerns were operationalized as patient expressions that convey worries, fears, or unpleasant emotions, identified inductively from the transcripts (Silverman 2006), and defined as issues topicalised by the patient or their companion including: physical health problems; mental health concerns (feeling worried, anxious, afraid, upset, frustrated, embarrassed); negative consequences of symptoms of dementia (i.e. irritating people, getting confused, feel like an idiot); associated dependency arising from symptoms; stigma and response to diagnosis (shocked, not prepared).

Patient and companion concerns were coded according to:

(1) Topic: Each concern was coded using content analysis (Schreier 2014).

(2) Whether they were elicited or volunteered: Concerns were *elicited* when the HCP solicited or facilitated their expression, usually through direct questioning (Zimmermann *et al.* 2011). Concerns were *volunteered* when patients or companions spoke about the concern uninvited. Elicitations could be topic specific, for example prompting the patient or their companion to talk about their reaction to the diagnosis “*what do you think about*

*HCP: so, I wouldn't feel like, I wouldn't worry too much about that
at this stage*

Responses discouraging elaboration were characterised by HCPs not providing space for the patient/companion to further elaborate on their concern, most often by providing a minimal acknowledgement followed by an immediate change of topic:

*Patient: you know what I mean, I grew up, if I see my mother and father I
would go into a fit and stuff like that*

*HCP: okay, alright, so I think that the most important thing you can
do to help your memory really is to stay off the alcohol*

Reliability

The coding was developed inductively in 4 analytic meetings between RM, PX and IM. A further 5 meetings took place to finalise the coding scheme, where there was discussion of 28 cases that were uncertain. For example, it could be unclear whether there was an expression of concern when patients, prompted by the HCP, were explaining symptoms:

Patient: "(memory) ain't like it was but it's not terrible". Discussions about specific symptoms that were responses to HCP enquiry and did not contain expression of concern were not coded. Additionally, there were cases where utterances across a number of turns related to the same concern. These were coded as one concern.

After the coding scheme was finalised, transcripts were coded by one author (IM) and a second rater (PX) coded 15 per cent (randomly selected) of the total 60 transcripts in order to establish interrater reliability. Cohen's Kappa (McHugh 2012) was calculated using Stata (StataCorp 2015). Overall agreement was 89 per cent (mean of the

agreement of individual weighted kappas): patient concern kappa = 0.73 (second coder identified 5 new concerns); companion concern kappa = 1; response encouraging elaboration (patient) kappa = 0.83; response discouraging elaboration (patient) kappa = 0.83; response discouraging elaboration (companion) kappa = 1; response encouraging elaboration (companion) kappa = 1.

Results

A total of 249 concerns were identified (see figure 1). An average of 4 patient/companion concerns per consultation were identified, ranging from zero to 17 concerns per consultation. In 54 of the 60 consultations at least one patient concern was coded, and in 36 of the 60 consultations at least one companion concern was coded. In 5 consultations there were no patient or companion concerns raised, however there were HCP invitations to elicit concerns in all these consultations.

Insert figure 1 about here

Topics of Concern

Table 1 presents the concerns expressed by patients and their companions. The most common concerns were in relation to the *dementia diagnosis* (n=31). This involved personal negative representations of dementia, e.g. “*I had a friend, they had a dementia and they ended up being very violent*” (C23). These also included responses to the word dementia, e.g. “*I hope I haven't got the thing you talked about, dementia*” (P34), and concerns raised as a result of the disclosure of diagnosis, e.g. “*I didn't think you were going to tell me this*” (P19). The next most common concern was about *dementia symptoms* – primarily regarding memory loss. This included worries about remembering

names and things that happened recently, e.g. *"say I watch Coronation Street you say what was it about half an hour after, I can't even tell you"* (P33), and companion anxiety about patients not accepting their symptoms, e.g. *"I think (patient name) doesn't want to admit that there is a problem as such"* (C27). Patients discussed concerns about the dementia diagnosis and dementia symptoms almost twice as often as companions.

Patients and companions discussed concerns about their family, including traumatic events that are relevant to their current situation, e.g. *"sometimes I feel really awful about (my brother's death)"* (P35). Concerns about the patient's mental health e.g. *"sometimes she does have these fearful attacks"* (C35), and *patient physical health*, e.g. *"it's no fun when you're in pain all the time"* (P21), were the only concern topics to be raised more commonly by companions than patients.

A number of concerns related to medication. These included concerns about new tablets, side effects, and how to manage treatment, e.g. *"I live on my own so I don't want any drastic treatment"* (P57). Additionally, both patients and companions expressed concerns about the *role of the companion*, the patient often with anxiety about being cared for, e.g. *"I hate being nursed"* (P82), and the companion expressing concern about their defaulted position as carer in the relationship, e.g. *"I do feel a bit inhibited on sort of going ahead with making plans for a long term carer"* (C83).

Some concerns were only expressed by patients. *Frustration with dementia symptoms* was common (n=25). This included concerns about losing competencies, e.g. *"they exasperate me and frustrate me, looking for a word"* (P24), and worry about the impact of their memory problems, e.g. *"when something happens or anything, I sort of afterwards think oh I've lost my cool"* (P79). Also, only patients expressed concerns about *prognosis* and how dementia would affect them in the future, e.g. *"what does the future hold for me?"* (P117), as well as concerns surrounding *lack of social connection*

e.g. “you can always go out for a walk but you see nobody at that time ‘cause all families are indoors you know” (P84).

Finally, *other* concerns involved topics patient and companion concerns that occurred infrequently and were thus grouped together. These included concerns about the patient’s difficult life, not liking visiting hospitals, a concern about the amount of information given to the patient e.g. “I think she won’t you know take all this in” (C101), smoking, and a patient concern about the disability determination services (DSS) examination e.g. “I had to go through an examination through that bloody DSS HCPs, well my God, the questions on there” (P33).

Insert Table 1 about here

Elicited and Volunteered Concerns

There were a total of 177 HCP elicitations of patient/companion concerns, 3 elicitations on average per consultation. There was one consultation where there was no elicitation of concerns by the HCP, but 6 patient and companion concerns were expressed.

Forty three per cent of the concerns in the consultations were elicited by the HCP. In 67% of these cases (29% of total concerns) the HCP’s topic of elicitation was on the same topic as the concern raised, for example in this discussion about the patient’s hallucinations (P31):

HCP: *tell me about them*

Patient: *yeah, well, I can’t really tell you about them because um
nobody else ever believes you*

The remaining 33% of elicited concerns (14% of total concerns) were a result of HCP elicitation that were non-specific in topic (e.g. *“how are things?”*), or in a small minority (7% of elicited, 3% of all concerns) concerns were a response to elicitation on a different topic, e.g. (P105):

HCP: do you have any questions about diagnosis or treatment?

Patient: not really. I've got real problems when, just recently when I lost my diary, financial details.

Some elicitation were addressed to the companion, for example, eliciting concerns about being a companion, e.g., *“I guess that you're the one Mr (name) who actually has to bear the brunt of all of this and all these changes”*; and managing on a daily basis e.g., *“do you have any worries about do you know managing from day to day”*.

There were 4 instances where the companion elicited a patient's concern, for example their reaction to the diagnosis: *companion e.g., “does it bother you... that the doctor's telling you have dementia I mean, does it frighten you?”*.

HCPs elicited some of the topics of concerns more often than others (see table 3). For concerns about the *dementia diagnosis, symptoms of dementia, and patient's mental health*, the number of concerns that were elicited by the HCP was roughly proportionate to the number of overall concerns elicited (around 40%). However, some of the concerns were more often volunteered by patients than elicited by HCPs. For example, out of the 28 concerns raised about *patient physical health*, two of these were directly elicited (with an elicitation on the same topic) by the HCP. Similarly, none of the concerns about *prognosis or lack of social connection* were directly elicited by the HCP. Another topic of concern that was mainly volunteered by the patient was about *frustration with memory*

problems, where 5 of the 25 concerns were elicited directly. Additionally, while the *role of the companion* was raised in 5 of 9 cases as a result of the elicitation, only two of these were results of direct elicitations about the companion role.

Seventy invitations to elicit concern were not followed up by a concern. These cases usually involved patients reporting that they were not concerned about the topic discussed – such as the following two examples (P31 and P117).

HCP: now is there anything that you're, any problems that you have that we haven't talked about?

Patient: I can't think of any

HCP: what about driving is that a concern for you?

Patient: it's not a concern for me at all but I haven't driven for ages,

HCP response to concerns

All 249 concerns were given a response by the HCPs. The majority (62%) were given a response that encouraged elaboration, while in more than a third (38%) elaboration was discouraged by HCPs (see fig. 1).

When concerns were elicited by HCPs, they were more likely to respond by encouraging elaboration of the concern (71%) than not (29%). On the other hand, when concerns were volunteered by the patient or their companion, HCPs were (comparatively) more likely to discourage elaboration of the concern (55%) than not (45%).

HCPs encouraged elaboration of concerns more often with some topics of concern than others (see table 2). Concerns about *family*, *patient's mental health*, and the *role of the companion* were encouraged over 80% of the times they were raised. Concerns about *frustration with memory problems* were encouraged in nearly three quarters of cases, and concerns surrounding *medication* were encouraged in two thirds of cases.

Concerns about the *dementia diagnosis*, *dementia symptoms*, and *lack of social connection*, were encouraged in over half of the cases they arose as topics of concern, but still discouraged in over 40% of cases. Elaboration of concerns about *prognosis* were discouraged in 77% of cases they arose.

Insert Table 2 about here

Discussion

There were 249 concerns across the 60 consultations. The majority of consultations contained at least one patient concern and over half contained at least one companion concern. Patient and companion's *areas of concerns* included: the symptoms of dementia, receiving a diagnosis, dementia symptoms, patients' mental and physical health, and prognosis. HCPs *elicited* more patient than companion concerns, and 43% of all concerns raised. Concerns elicited by the HCPs were mostly linked with the agenda of diagnosis feedback: dementia symptoms, reaction to diagnosis, and mental health. Concerns about physical health or prognosis were mostly volunteered. HCPs' *responses to concerns*, were more likely to encourage elaboration when they elicited the concern. Concerns about family and mental health were encouraged most often. Nearly 40% of

concerns were followed by doctors discouraging elaboration of the concern by changing topic and concerns about prognosis were most commonly discouraged.

Unsurprisingly given the setting of the dementia diagnostic feedback meeting, the majority of concerns were about perceptions of or reactions to the diagnosis, or concerns surrounding the symptoms. Previous studies have shown that the stigma of dementia can delay seeking a diagnosis (Speechly *et al.* 2008), which is demonstrated by the negative perspectives about dementia that were raised by patients and companions in the diagnostic meeting. The negative reactions to the diagnosis itself have also been found in other studies of dementia diagnosis delivery (e.g. Brooker *et al.* 2003; Derksen *et al.* 2006; Aminzadeh *et al.* 2007). The concerns raised around the patient's mental health, primarily around anxiety and low mood, also reflect studies of patient experiences of receiving a dementia diagnosis, with many patients experiencing stress when noticing the early stages of dementia symptoms (Samsi *et al.* 2014; Perry-Young *et al.* 2016; Cahill *et al.* 2008).

Concerns about the diagnosis and the patient's mental health were most often elicited by HCPs. This again reflects the context of the dementia diagnostic feedback meeting, where the HCP's agenda will include the need to discuss the diagnosis and the patient's symptoms (including in test result feedback). This is also demonstrated by concerns surrounding medication also being the most often elicited by HCPs, as prescribing cholinesterase inhibitors is indicated on receiving a diagnosis of Alzheimer's Disease. That HCPs are eliciting patient concerns about taking medication demonstrates an aim to involve patients in medication decisions (Stevenson, 2000).

That some of the most common volunteered concerns were around family issues and the patient's physical health reflects the impact of dementia on the wider family system and the presence of comorbid illnesses. The symptoms of dementia often occur

alongside other difficulties, both physical and psychological (Clague *et al.* 2017), with most frequent comorbid illnesses in dementia patients identified as hypertension, diabetes, coronary artery disease, chronic heart failure and stroke (Schubert *et al.* 2006). Having comorbid illnesses can negatively impact patient-HCP communication as research shows that patients with multiple chronic conditions report worse experiences in health care more frequently than those with one condition (Paddison 2015).

Additionally, studies have shown that a dementia diagnosis can have an effect on a person's social network: changing roles and responsibilities of the people surrounding the person with dementia, as well as impacting on the person with dementia's identity within that network (Bunn *et al.* 2012). While the role of the companion was not one of the most common topics of concern, this also reflects the wider impact of the diagnosis. It may be argued that patients topicalising concerns about physical health or family problems may demonstrate a lack of awareness of the significance of their memory problems (Karnieli Miller *et al.* 2012). However, these topics were actually raised more often by companions, demonstrating that they are not just being raised to avoid discussions of memory problems, but are occurring alongside and are of equal importance as concerns about memory.

That these types of concerns, which are less explicitly related to the dementia diagnosis, were not elicited by the HCP as often again reflects the HCPs agenda in the diagnostic feedback meeting. Research demonstrates that HCPs are under institutional pressure to cover certain topics within the diagnosis feedback (Bailey, Dooley and McCabe 2016) which may account for the fact they are not asking about wider social issues that may be concerning the patient. This is in line with previous research that shows that a lack of social connection and daily activities are the most common unmet needs after a dementia diagnosis (Black *et al.* 2013; van der Roerst *et al.* 2009). The fact that patient frustration about their memory symptoms were also volunteered rather than elicited in

the majority of cases also reflects previous research showing that HCPs avoid exploring emotional aspects of people's dementia symptoms (Zaleta and Carpenter, 2010). Given the call for patient centred care in dementia (Brooker 2003; Robinson *et al.* 2010), it may be that services need to take a more holistic approach in discussing dementia with patients and their companions at this early diagnostic stage, focusing not only on the condition itself but also on wider aspects of the patient's current situation.

When considering how HCPs respond to the concerns, concerns about psychosocial issues were encouraged in over 80% of instances, where concerns surrounding the diagnosis, symptoms, and medication were encouraged in 60-70% cases. Additionally, while the lack of social connection of the patient had not been elicited directly in any instances, it was encouraged in nearly 60% of cases where it was discussed. Therefore, once concerns have been raised, HCPs are digressing from the relevant topics of diagnosis feedback to discuss other matters concerning patients and companions.

Although the majority of concerns were followed by HCPs encouraging elaboration of the concern, nearly 40% were followed by HCPs discouraging further discussion of the concern. Additionally, HCPs were far more likely to encourage elaboration when they had initially elicited the concern. This HCP control of the communication has been described in other dementia healthcare settings (Sakai and Carpenter, 2011; Karnieli Miller *et al.* 2012), and is common across all HCP-patient interactions, which by their nature will be driven by the HCP in their role as a questioner and the expert in the interaction (Heritage, 2005). The fact the HCP directs the discussion of concerns in the diagnostic feedback is thus to be expected. In fact, given that studies of cancer consultations show HCPs do not explicitly invite patients to express concerns at all (Brandes 2015) and often actively discourage the disclosure of concerns (Zimmermann, Del Piccolo and Finset 2007), the fact that HCPs are engaging patients and companions in discussions of their concerns may demonstrate enhanced patient involvement

compared to other settings. However, research shows that patients and companions feel their concerns around dementia diagnosis are disregarded (Manthorpe *et al.* 2013), and thus there may need to be more effort to address concerns more often, despite other institutional pressures.

A key topic of concern that HCPs appeared to be avoiding was that of prognosis. While there were only 12 cases where patients raised concerns about prognosis, this was the only topic of concern where none of these cases were a result of direct elicitation from the HCP. Additionally, this was the only concern around which HCPs discouraged further discussion. HCPs have highlighted anxiety about discussing prognosis, specifically in causing a negative emotional impact on the patient at the early diagnosis stage, as well as uncertainty in predicting an individual patient's prognosis given the wide variability of the progression of dementia between individuals (Bailey, Dooley and McCabe 2016). This is not just an issue in dementia, but has also been discussed in oncology (The *et al.* 2000). However, given that patients are raising these concerns without invitation by HCPs, this is an area that may need to be addressed despite the challenges it presents. One of the key reasons for increasing dementia diagnosis rates is to encourage advance care planning in dementia (Brown, 2015). Given that a recent survey of people with dementia found that nearly half see planning for the future as an unmet need (Black *et al.* 2013), concerns about prognosis will need to be discussed explicitly in order to aid these discussions. Avoiding details about prognosis might lead to reduced opportunities for patients and their families to adjust their lives accordingly and aim towards attainable goals for the future (Fallowfield, Jenkins and Beveridge 2002; Hancock, 2007).

Lastly, the role of the companion's concerns is interesting, especially related to previous literature around the triadic nature of medical consultations in dementia (Dooley *et al.*, 2015; Karnieli Miller *et al.* 2012). That patient concerns occurred twice as often, and

were elicited over twice as often, than companion concerns potentially demonstrates that HCPs are oriented towards discussing the diagnosis with the patient rather than the companion as previous literature has suggested (Hasselkus, 1994; Karnieli Miller *et al.* 2012). That HCPs are eliciting patient concerns could be particularly beneficial for this population as people with dementia show reduced conversational initiation (Blair *et al.* 2007).

In many cases, companion concerns were similar to those of patients, particularly surrounding the dementia diagnosis. However, concerns that were not discussed by companions support previous findings that companions may withhold from entering discussions about certain topics with HCPs in order to save the “face” of the person with dementia (Dooley *et al.*, 2015). For example, the literature suggests that people caring for people with dementia find the lack of information about prognosis frustrating (Bamford *et al.* 2004; McCabe *et al.* 2016). However, they did not raise these concerns in the current data. Furthermore, in many previous studies companions report a burden of caregiving and not having enough psychological support (e.g. McCabe *et al.* 2016), but concerns about the companion role were rare. Companions also did not raise concerns about patient frustration with symptoms or lack of social connection. The fact that companions are avoiding these topics in the diagnosis feedback meetings, but commonly reporting them as major areas of concerns after the meeting, may be a form of “protective caregiving” – trying not to upset the person with dementia by talking about difficult topics with the HCP (Hasselkus, 1994). HCPs highlight these subtle aspects of the triadic interaction as a key challenge in dementia diagnostic feedback (Bailey, Dooley and McCabe 2016). However, research demonstrates the importance of considering the person with dementia and their companion as a whole unit in order to support the adjustments surrounding a dementia diagnosis (Robinson, Clare and Evans 2005), and thus strategies to meet the needs of both patients and their companions are an important area for future research.

Strengths: The analysis was based on real time video-recordings of people receiving a diagnosis of dementia rather than interviews and included a range of HCPs from multiple memory clinic services across urban and rural areas. Analysing transcripts in detail (turn by turn) facilitated comprehensive exploration of participation.

Limitations: There were some positive emotions expressed in the consultations, however, the low frequency did not lend itself to systematic coding. Video recording the consultations could have had an impact on the HCP-patient interactions. There could also be selection bias for the HCPs and patients who agreed to participate. The HCPs who agreed to participate may have been more interested in communication while the patients may have been more engaged in the memory clinic process. Reliability coding was conducted on 15 per cent of the sample and although there was high agreement across all categories, there was some variation across coders in identifying a patient concern.

Conclusions

Patients and companions expressed concerns about the symptoms of dementia and the accompanying frustration along with feeling shocked about receiving a diagnosis, alluding to negative portrayals of dementia. They were also concerned about non-dementia issues such as physical health and family, reflecting patients' holistic approach to medical consultations. Patient concerns were more often elicited than companion concerns, which is encouraging given the potential for patient marginalisation in the context of dementia. Avoidance of prognosis demonstrated delicacy in discussing future planning at dementia diagnosis.

Practice implications

For HCPs and other healthcare professionals involved in the dementia diagnostic process, it may be helpful to be aware of the types of concerns patients and companions express when receiving a diagnosis of dementia. This may help to proactively attend to these concerns and support long-term planning, thereby reducing anxiety for people.

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Tables and figures

Figure 1. Concern and response totals.

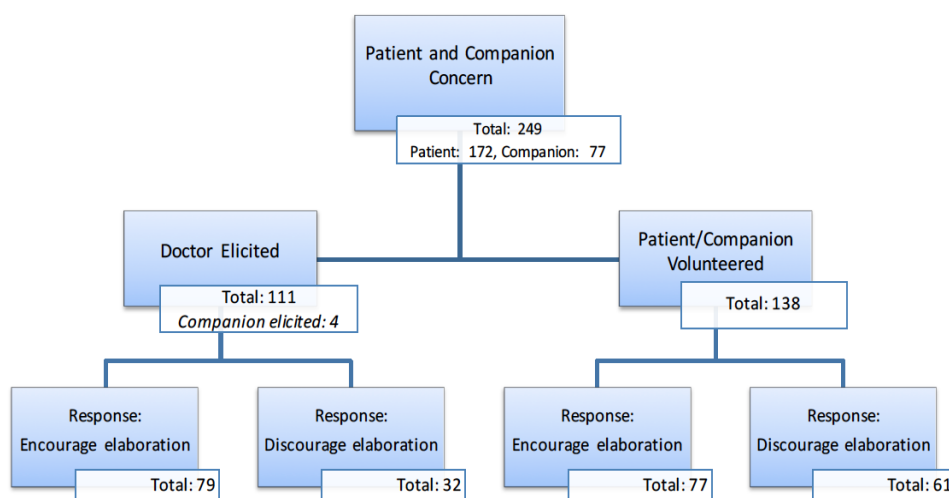


Table 1. Patient and companion concerns topics.

Concern Topic (frequency)	Patient Frequency	Companion Frequency	Definition	Examples
Dementia Diagnosis n=48	31	17	<ul style="list-style-type: none"> Stigma of dementia Personal experience of dementia: e.g. knowing someone else with dementia Reaction to the diagnosis: shocked, depressed, confused 	<p>"What's worrying me, all I keep seeing on the telly is people and they got, I can't even say the word because that upsets me" (P21)</p> <p>"I've seen people with it, I've been helping my neighbour two or three doors down and I've seen his, I was worried it was going to turn out like that" (C126)</p>

Symptoms of Dementia n=38	26	12	<ul style="list-style-type: none"> • Difficulty remembering things: e.g. dates, names, financial details, places • Worries about losing competence: e.g. spelling a word • Symptoms noticed by companion: e.g. difficulty understanding conversations • Patient not admitting problems 	<p>"I'm often asking you know, what's the word for" (P19)</p> <p>"I find the hardest thing is she won't accept that she's got memory (problems)" (C62)</p>
Family n=31	17	14	<ul style="list-style-type: none"> • Loss of family and friends • Concerns about leaving family and children alone after death 	<p>"I worry about my children and my wife" (P34)</p> <p>"We had a terrible well tragedy in the family, her brother" (C35)</p>
Patient Physical Health n=28	12	16	<ul style="list-style-type: none"> • Physical complaints: e.g. sleeplessness, tiredness, balance, visual problems. 	<p>"I don't know, I feel extremely tired, I can walk very short distance and then I have to sit down" (P24)</p> <p>"I am a little bit worried, in case there's a valve not working or something's blocked" (C66)</p>
Frustration with Dementia Symptoms n=25	25	0	<ul style="list-style-type: none"> • Negative impact of dementia symptoms: e.g. irritated, embarrassed, confused 	<p>"I feel also it must be very irritating for other people" (P19)</p>
Mental Health n=24	11	13	<ul style="list-style-type: none"> • Patient reporting psychological symptoms: e.g. stress, hallucinations, depression • Companion worries about patient psychological symptoms: e.g. anxious, confused, stressed 	<p>"But you see I am a stressful person, I'll just I get stressed" (P82)</p> <p>"I go round and she goes, oh I wish I was dead" (C06)</p>
Medication n=16	10	6	<ul style="list-style-type: none"> • Worries about side effects • How to manage taking tablets 	<p>"You make me worried really because I am on my own" (P57)</p> <p>"They must have picked up on the medication and giving mum a blister pack, for each day of the week, and the pills are already sorted so she doesn't have to juggle lots of different packets" (C102)</p>
Prognosis n=12	12	0	<ul style="list-style-type: none"> • Worries about the future: e.g. getting progressively worse or becoming violent 	<p>"because of late I have experienced a real deterioration and a steady worsening of my memory" (P24)</p>
Role of Companion n=9	5	4	<ul style="list-style-type: none"> • Patient concern about being cared for • Companion expressing concern over new caring role 	<p>"But you see I hate being fussed over" (P28)</p> <p>"Sometimes how can I say I don't get annoyed really but I think say I've just told you" (C23)</p>
Other n=11	8	3	<ul style="list-style-type: none"> • Difficult life • Don't like visiting hospitals • Too much information given • DSS • smoking e-cigarettes 	<p>"I was in the streets I was sleeping in subways, sleeping rough in (place) when my mother and father died" (P33)</p> <p>"I was a bit worried in case he might try to light them (e-cigarettes)" (C66)</p>
Lack of Social Connection n=7	7	0	<ul style="list-style-type: none"> • Reduced opportunities to go out: e.g. spouse cannot drive, worries about going out alone • Being alone 	<p>"I would like to get out of the house now and then" (P36)</p>
Total: 249	164	85		

Table 2. HCP elicitation and response by concern type.

Concern Topic (Frequency)	Percentage Elicited Separated by Patient/Companion	Percentage Elicited <i>Elicitation on Topic</i>	Percentage Response Encouraged Elaboration
Dementia Diagnosis n=48	64% patient 12% companion	46% (22) <i>On topic: 37% (18)</i>	59% (28) 21 patient, 7 companion
Symptoms of Dementia n=38	58% patient 27% companion	50% (19) 39% (15)	58% (22) 16 patient, 6 companion
Family n=31	53% patient 21% companion	39% (12) 29% (9)	81% (25) 13 patient, 12 companion
Patient Physical Health n=28	50% patient 25% companion	32% (9) 7% (2)	46% (13) 6 patient, 7 companion
Frustration with Memory Problems n=25	24% patient	24% (6) 20% (5)	73% (18)
Mental Health n=24	100% patient 23% companion	58% (14) 46% (11)	83% (9) 9 patient, 0 companion
Medication n=16	60% patient 33% companion	50% (8) 38%(6)	67% (11) 6 patient, 5 companion
Prognosis n=12	8% patient	8% (1) 0% (0)	23% (3)
Role of Companion n=9	60% patient 50% companion	56% (5) 22% (2)	89% (8) 4 patient, 4 companion
Other n=11	75% patient 33% companion	64% (7) 36% (4)	50% (5) 5 patient, 0 companion
Lack of Social Connection	57% patient	57% (4)	57% (4)

n=7		0% (0)	
Total: 249	53% patient	43% (29%)	62% (155)
	24% companion		