Views of Healthcare Professionals in Primary Care About the Diagnosis and Management of Dementia

Keele University

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In conjunction with Healthwatch Shropshire

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Introduction

Healthwatch Shropshire is the independent consumer champion for health and social care in Shropshire. It was created under the Health and Social Care Act 2012 to work with service users and the public to listen to their feedback on health and social care provision in their area. They then act to influence those who commission, deliver and regulate health care on a local and national level to improve delivery of health and social care services to the local community[1].

Locally, Healthwatch Shropshire also aims to empower health and social care service users to achieve the most from their local services, by raising awareness of services through local or national events and literature[1].

Currently Healthwatch Shropshire is working with partners to refresh the current Shropshire Dementia Strategy Action Plan which expires in 2016[2]. This Action Plan will inform the future development of Dementia Services in the county to improve outcomes for patients.

Project Aim

The aim of this project was to investigate GPs' views about dementia pathways, with these being used to shape the new Dementia Strategy Action Plan for Shropshire, alongside those of other healthcare professionals, other organisations and people living with dementia and their carers.

Views of GPs were also sought from the neighbouring county of Worcestershire about their dementia pathway to identify any strengths and weaknesses of their dementia care which could be used in Shropshire too.

Project Method

In a joint discussion with Healthwatch Shropshire it was decided the best way to investigate GPs' views about the dementia pathway was by conducting semi-structured interviews. This allowed specific questions to be asked and key topics to be explored across all of the interviews that take place but also granted flexibility so the GPs could raise any points which the questions may not have considered[3,4].

Key areas were identified for further exploration in conjunction with GPs that allowed the stated project aims to be fulfilled:

- To better understand the dementia pathway and available services
- Barriers to a diagnosis of dementia and available services
- Gaps in the available services
- What they felt was working well and what could be improved

Based on these points and further discussions with Healthwatch Shropshire an eight item questionnaire was developed, all of which were open questions, to form the backbone of the semi-structured interviews. Prompts were also noted for each question to allow further probing of finer details which were encompassed by the question. At each stage GPs were encouraged to identify any recommendations for improvement or any initiatives that they had developed individually that might improve dementia care for the whole of Shropshire.

After running the first set of interviews with the GPs, a consensus emerged that other healthcare professionals, such as the care co-ordinators, were critical within the practice for delivering dementia care, so they were also interviewed. During each semi-structured interview the interviewer wrote notes about what the interviewees were saying, writing down key quotations as appropriate.

Once results were collated, a collective analysis took place identifying common themes and notable differences for each question. Based on these findings strengths and weaknesses of dementia care were highlighted with subsequent recommendations for the upcoming refresh of the Dementia Strategy Action Plan.

Results

Interviews were conducted in a total of four GP practices (three in Shropshire and one in Worcestershire). GPs and care co-ordinators/dementia leads (or their equivalent) were interviewed in all four practices. Despite interviewing at several practices there was remarkable agreement between the practices.

GPs in all of the practices were aware of a nationwide increased drive for earlier dementia diagnoses, and this awareness was mostly due to it being a part of the Quality and Outcomes Framework (QOF) system. However, there were mixed views about the push for an early diagnosis of dementia. Some GPs could understand why it was introduced, to allow for care to be put in place before a deterioration in the patient’s condition and for advanced directives to be organised. However, others thought it was unhelpful because people may not want to know if they have dementia as there are limitations on what can be done for the disease itself and being aware of it could be very distressing. Overall, GPs felt the benefits of an early dementia diagnosis would differ with different patient circumstances.

There were a variety of triggers to consultation which led to early diagnoses of dementia being made, these were common across all practices. These included memory loss, concerns about interference with activities of daily living, concerns from family members and opportunistic (i.e. presenting with something else). Similarly, all the GPs identified the same barriers to making an early dementia diagnosis. One GP told us that they felt the most important barrier was the patients' own beliefs about dementia including their fears that eventually they would lose their independence and end up in a care home. Other GPs also felt that patient's fears played a crucial role in delaying a diagnosis of dementia and that these included fears of becoming a burden, the impact on their independence and the stigma around the diagnosis. Another commonly identified barrier was the perception that memory loss is a normal part of ageing.

In both counties, once a GP suspected dementia, following a thorough history and use of an appropriate assessment tool, they were referred to a clinic which would use the Addenbrooke's cognitive examination to make a formal diagnosis of dementia. In Shropshire this clinic was called the memory clinic, whereas in Worcestershire it was called the Early Intervention Dementia Service (EIDS). One GP from the Worcestershire practice preferred the Shropshire service name as they felt EIDS caused undue anxiety about dementia when that may not be the diagnosis.

In all four practices, once a formal diagnosis of dementia was made care co-ordinators were then involved. Their role is to organise care for that patient by utilising all available options which would benefit the patient. Every single GP really appreciated the care co-ordinator and valued the work they do, greatly freeing up the GP for other work.

Generally, GPs were aware of the key services available, but it was the care co-ordinators who knew the greatest amount of detail. Both GPs and care co-ordinators felt there was a wide range of services available to those with dementia which were appropriate for those at different stages of their illness. Charities, such as the Alzheimer's society, provided numerous local services such as dementia cafés, peer support groups and art therapy sessions. Social services could organise carers to visit the patients at their homes allowing them to remain there; other carers include district nurses. For those with advanced dementia there were care homes, some which specifically cater for those with dementia. A common issue with these services, and the other ones, was the lack of availability. This was most likely due to the current economic climate and that all community services are underfunded. GPs raised the issue about organising services for cross-border patients as social services from one county would often deny it was their responsibility to provide care.

The practices were also implementing their own initiatives. One example of this is a Shropshire practice which provides its own information leaflets about dementia detailing information about what it means for the patient and also tackled some of the more difficult end of life issues in dementia such as do not attempt resuscitation (DNAR) forms and to expect changes in personality and appetite among others.

The important role of carers was recognised by all the interviewees. In all practices carers were coded as being so on their patient records. The impact of this varied between the practices. In one practice it meant having a lower threshold for treatment, such as giving antibiotics during an illness, whereas in others it allowed the GPs and care co-ordinators to organise respite care and ensure that additional care is provided in instances when the carer is unable to look after the patient with dementia.

Despite all of this, no one seemed aware of the Shropshire Dementia Strategy Action Plan and how it underpinned the local dementia care.

Recommendations

Based on the results of our project a number of key recommendations have been made which can be used to inform the development of the new Shropshire Dementia Strategy Action Plan.

- Healthwatch Shropshire should visit the locality meetings that involve multiple GP practices to raise awareness of the new Dementia Action Strategy Plan.
- The Dementia Strategy Action Plan should be made available on the CCG website alongside other local guidelines.

These two recommendations address the low awareness of the Dementia Strategy Action Plan amongst GPs and other healthcare professionals in primary care. By making the Dementia Strategy Action Plan available online it also means relevant healthcare professionals can access it at their own convenience.

- Care co-ordinators are recommended for all GP practices.
- Care co-ordinators should work with others with knowledge about local services for those with dementia.

Care co-ordinators are great assets to GP practices and free up significant time for GPs. This reduces their workload, allowing them to focus on providing other services that can only be provided by GPs. Care co-ordinators may also be unaware of all the available services and should be made aware of those working within dementia care. For example, Jan Roberts is the South Shropshire representative of the Alzheimer's Society and has extensive knowledge of services her charity provides and also what other services are available.

- There needs to be a continued drive to reduce the stigma and misperceptions about dementia.

Further education should be provided to the general public to encourage them to seek help about any concerns they have with regards to the symptoms of dementia, particularly memory loss. Healthcare professionals cannot do this by themselves but there are certain things that they can do, such as educating patients by providing information leaflets in their practice.

- GP's should meet and formally share their ideas for good practice in dementia care.

Furthermore, the results indicated novel ideas of good practice within each practice. Sharing these ideas would benefit patients throughout Shropshire. These ideas could be shared at the locality meetings.

Evaluation

The opportunity given to us as a group working on a project with Healthwatch Shropshire has been highly rewarding and enjoyable and we trust it to be a positive contribution to the wider project.

This project had a clear aim in providing GPs' views on dementia care and providing recommendations for the new Dementia Strategy Action Plan. As a group we have been utilised well to report GPs' views about dementia care, which has been highly useful for Healthwatch Shropshire as engaging with GPs can be difficult due to their already time-constrained, heavy workloads.

It was fortunate that one of the practices was not within the Shropshire borders, allowing a cross-border comparison for the strengths and weaknesses of how dementia care is carried out within a different trust. Working closely with Healthwatch Shropshire has meant that a questionnaire was designed that was agreed to be specific in finding out the required information. As a team, we have been able to contribute some important ideas and information.

Several areas have been identified for improvement; only practices from South Shropshire were used, using practices from the North of Shropshire would give a better representation of views across the County. Regarding the process of data collection, it was found that one of the questions used in the questionnaire lacked specificity, which could be amended to be more concise if the questionnaire was used in the future to compare GP's views.

Overall, we felt that our project was well conducted and that we were able to achieve our aims.

Handover and Future Development

Healthwatch Shropshire is aiming to complete the refresh of the Dementia Strategy Action Plan early next year. Therefore, the data for the refresh is currently being collected, meaning the next group would struggle to contribute to this particular project. However, it would be worthwhile for a future group to follow up the recommendations from the refreshed Shropshire Dementia Strategy Action Plan and measure whether there has been any change.

Acknowledgements

We would like to thank all of the GPs and other healthcare professionals who took part in our project and allowed us to interview them.

We would also like to thank David Latcham, the Information Officer from the local Alzheimer’s Society, to provide us with Dementia Friend training.

Last but by no means least we would like to thank Healthwatch Shropshire, especially Jane Randall-Smith, for giving us the opportunity to undertake this project and for being a great source of help and enthusiasm throughout.

References

[1] Healthwatch Shropshire. *About Us.*

http://www.healthwatchshropshire.co.uk/content/about-us (accessed 26/11/2015)

[2] Louise Jones. *Shropshire's Dementia Strategy 2014-16.*

https://shropshire.gov.uk/committee-services/documents/s3320/11%20Shropshires%20Dementia%20Strategy%20Version%203.pdf (accessed 26/11/2015)

[3] World Health Organization. *Semi-structured Interviews.*

http://apps.who.int/medicinedocs/en/d/Js6169e/5.4.html (accessed 26/11/2015)

[4] Whiting LS. Semi-structured interviews: guidance for novice researchers. *Nursing Standard* 2008; 22: 35-40

Appendix 1: Record of Engagement

Throughout the cluster project we were fortunate enough to work in conjunction with Jane Randall-Smith, the Chief Officer for Healthwatch Shropshire. Meetings were conducted on a Wednesday morning, and usually lasted 9am to 12pm. During one meeting, we were also privileged to receive dementia friend training from a representative of the Alzheimer's Society. In addition, we conducted semi-structured interviews with members of our respective GP surgeries.

Below are the dates on which meetings were conducted with our organisation:

Dates of Engagement	**Activity**
September 16th, 2015	Introductory session
September 23rd, 2015	Creating questionnaires
September 30th, 2015	Finalising questionnaires
November 4th, 2015	Discussing preliminary results + dementia friend training
November 18th, 2015	Discussing results
November 25th, 2015	Editing report
December 2nd, 2015	Run through of presentation

Appendix 2: Data Summary

Question 1: What is your awareness of the dementia care action plan?

- What was your awareness before we began this process?
- If you had not heard of this, how could awareness be improved?

1. Barely aware of its existence. Didn't know where to access it and doesn't remember having any meetings etc. to introduce it and discuss the key points. (DB)
    a. Should be put on the Shropshire CCG website with the other local guidance documents.
    b. When the new plan is rolled out, doctors must be told that this has occurred and preferably someone should take it to a meeting and explain what the key points and key changes are etc.
2. Not aware. (TB + PE)
    a. Aware of drive to increase diagnosis early.
    b. Would like face to face discussions to be briefed on new plan when it starts. To increase awareness.
3. Not aware (AK)
    a. Aware it's a priority
    b. Prefer if briefed in a GP away day when it begins so that people are more likely to listen than to read
4. Aware of multiple plans and initiatives, national, county council driven one, not aware of the action plan. (MS)

    a. Suggested that it is presented as a GP teaching day when it is first begun (MS)take care co-ordinators to the meeting beginning this plan as they perform a big role in co-ordinating care for dementia patients

<u>Question 2: How do you make an early diagnosis of dementia?</u>

- How do you identify these patients?
- What do you do when they have been identified?

1. Patients are identified via coding in the EMIS system so if anyone comes with a risk factors for memory loss, they are coded as ‘recall at risk of memory loss’. This tends to get run annually so that possible early dementia patients can get flagged up during consultations.
    a. The other major way is through opportunistic consultations, ie the patient has come for a medication review and someone also states there are some concerns about memory.
        i. This comes from the patient, family, locals, and practice staff.
    b. A key problem is the failure to change a code from ‘memory loss’ to ‘dementia’. This means that patients fail to be flagged up by the system for care plans etc.
    c. People with memory loss see the dementia GP local enhanced service.
2. Use answer a as above
    a. Medication problems/review, not taking the meds as regularly as they should - seen on EMIS

    b. Rural setting leads to increase awareness of individual’s circumstances.
    c. Do a 6CIT to assess memory.
    d. Get sent to the early intervention dementia service (memory clinic preferred name)
    e. Refers all patients in Shropshire to Worcestershire
3. Medication reviews, home visits, concerns from carers/relatives. Rural setting increased familiarity with patients.
    a. Through EMIS coding
    b. Refer to the memory clinic
4. Dementia DES (GP payment of £55 per patient on dementia records leading to emis review of risk factors to get on register. Target of 80%.
    a. QOF targets incentive. Dementia bloods and an action plan within 56 days of diagnosis .
    b. Opportunistic, family concerns, third parties (carers, homes, district nurse, self-referral
    c. Once identified, do a GPcog score and use this to decide whether to have an informal interview with carer if score less than 9. Less than 4 leads to dementia bloods for biological causes.
        i. Following review and bloods go to memory clinic for further investigations and CT scan then passed on to community mental health team for the old age for follow-up care.

Common Themes:

- Identified through a number of paths. Commonly opportunistic. Not easy to identify
- Incentivised by QOF payments.
- Sending to memory clinic for all practices for diagnosis.
- No single pathway
- No single screening tool to use. 6CIT, GPcog, MINI MENTAL STATE EXAM, clock test
- Low threshold for suspicion and entering the pathway

Recommendations:

- Develop a dementia template on EMIS for the consultation to identify risk factors and expedite process. (MS)
- Change name to memory clinic (TB), make it a patient friendly name, remove stigma.

Question 3: What are the barriers to recognising early dementia?

- Old age vs. dementia (normal vs. abnormal)

1. The main barrier is the patient themselves not wanting to be diagnosed as having dementia as they fear it will force them into a care home.
2. When patients are well looked after by family, not sure that early diagnosis helps.
    a. Family and patients see dementia is part of getting old so don’t act on it.
    b. Stigma of diagnosis, (beginning to improve with public awareness)

    c. Working across county borders makes it difficult to now the pathway and care services available.

3. Danger of medicalising small lapses in memory as dementia.
    a. Whether it improves the quality of care for patient if there still independent and functioning well.
    b. Cautious about labelling dementia too early
4. People resenting being questioned about their memory, leads to frustration
    a. Lack of training in recognising dementia in care homes etc. still think it is a natural part of aging
    b. Family and cares don't like to refer as it will upset patient. People don't like going from the child of patient to the carer.
    c. Recognition of link between dementia and dying
    d. Fear of monetary implications of dementia i.e. care home costs.

Recommendations:

- This can be helped by improving patient and family understanding of the disease and of the services available in the area
- Reduce stigma and public awareness that it isn't normal aging
- How to get people to come and engage with service, most often opportunistic
- Having a baseline memory test on over 65s so you can monitor for deteriorations

Question 4: What are the benefits and disadvantages of making an early diagnosis of dementia?

- Continuity of care, named GP

1. At this stage, the patient still is very independent and functioning well.
    a. Its beneficial at this point to begin introducing them to clubs and local services etc. as the social isolation makes the disease a lot harder to manage.
    b. They have an assigned GP
    c. The care co-ordinator is aware of them and may call on occasion. They get put on the frail elderly care register
2. Can make an advanced care plan, overall social issues are better dealt with as support and services can be put in place, can reduce risk factors fo harm.
    a. Stigma, people over involvement in life before the disease progresses to the point they need it. Limited medical intervention.
3. Allows for care plan. Can improve social situation. Can prevent falls and get OT involved, better quality of life. Gives the rest of the medical issues context in terms of how they cope with it.
    a. Medicalization, infringing patient autonomy to early and stigma. Limited treatment.
4. May have a biological cause that can be treated. Prevent secondary problems i.e. thyroid, early diagnosis allows early reviews and track progress and intervene. Access to social support and care services. Can recognise problems like taking tablets and looking after self. Can get financial support

a. Stigma, side effects form medication. Loss of independence. Possible withdrawal from society and depression. Premature Change of social role in family/ with friends.

Recommendations:

- Allows care planning and planning ahead.
- Goes to care co-ordinator after diagnosis to begin organizing care.
- Can treat medical causes identified.
- Financial aid
- Slow progression.
- Allows access to aid when needed.

Negatives:

- Early diagnosis allows care planning with patient still having capacity. Can still make decisions and consent for treatment (DNAR, lasting power of attorney etc).
- Public stigma.
- Can plan for when they need care so that people aren't pushed into tit to soon.

Question 5: How do you feel about organising care in the community for your dementia patients and is it affected by different patient circumstances?

- Longstanding patients, new patients and care home patients
- The referral process

- The service availability in the area
- Key question

1. Need support from social services if diagnosed late and there is a 1 month delay in the crisis team which is a long time if really struggling.
    a. Remember the availability of respite care in the area to give carers time to recover as well.
    b. The carers are coded on EMIS also so doctors can ask if they are coping.
    c. The referral is straight forward and relatively quick. The memory clinic is the single point of access and takes 4-6 weeks.
    d. This services provides the diagnosis then passes on to the elderly community mental health team
2. Have a PACT nurse (CCC). Do most of the organizing of care for dementia patients.
    a. A team effort. PACT, GP, social services, family.
    b. Social services very stretched in rural areas. Especially trying to discharge patients from local hospitals.
        i. Can't get social services if can afford to pay for carers. Have to have carers before entering a home. Can end up having carers when they would be better going straight to a residential home.
3. Care co-ordinator for organizing the social care. GP doesn't' have access, time and knowledge to arrange it in ten minute appointment.

    a. Team effort, need to involve OT, care workers, care home and relatives. Home visits are a good way of checking on patients. See I natural environment. Opportunistic.

4. Good link between CCC and GPs, GPs get diagnosis and then inform the CCC and send patient to see her.
    a. He organises care plan with patient and family. Organizes what they need based on this. Home support, OT, age UK reps. McMillan nurses.
    b. Coffee mornings in Ludlow, friendly neighbours, and exercise course at sports centre. All to do with getting out of house and engaged in community again.
    c. Lots of charitable and community care but it is stretched. Made worse by being very rural, a lot is based in Shrewsbury.

Recommendations:

- Very difficult to improve due to budget limits
- Care coordinator organizes the vast majority of community care.
- Problems with access are the biggest issue. Rurality and availability. Lots of services but difficulty getting a space within them.
- Jan Roberts from Alzheimer's society is a good point of information.
- Improve management of co-morbidities.

<u>Question 6: What links are there between GPs and services providers and what barriers are there to this?</u>

- Community mental health and the memory clinic

- New patients from out of area
- National support services
- Local support services

1. Patients from outside the area have great difficulty building working relationship and knowing what has previously been arranged.

Recommendations:

- There is good access to services, CCCs organize this.

<u>Question 7: How do you support the wellbeing of carers and what services are available to them?</u>

- What services are available
- What can be done further

1. -
2. Register carers on system and have an alert. Can flag up that if the carer is ill, then the patient may need extra support for this period as well.
    a. Admiral nurses, dementia café.
3. Same as 1 and 2
4. Mobile memory clinic services if patients can’t travel.

    a. Carers must have a physical and mental health assessment and the carers are now considered equal to the patient for support.
    b. Carers allowance, financial support and help with forms and applications etc.

<u>Question 8: What are you doing that is unique and beneficial for your patients</u>

- Local initiatives – including GP led services, documents and leaflets
- Personal experiences

1. Have their own end of life care plan, a pro-forma to go other issues that will arise as the dementia progresses. Can be done with patient and family when the patient can still be involved.
2. Do a lot more home visits for dementia patients than for others. Can check circumstances and can check if there are increased risks or problems coping.
    a. Having practice in rural areas leads to increased community awareness of patients, a good point of information about how patients are coping.
3. -
4. Continuity of care and seeing the same GP is beneficial, the GP template for dementia allows easier understanding off patient circumstances.
    a. Extending consultation time to 20 minutes for dementia patients

Appendix 3: Questionnaire

Introduction and our Project Outcome

I am a final year medical student from Keele University and today we are going to discuss dementia care services with an aim to identify the gaps in services, barriers to access and recommendations for improvements. This is part of a group project being done in association with Healthwatch Shropshire. We are doing this on the back of the current dementia care action plan coming up for review for 2016. Healthwatch Shropshire are canvassing the views of all interested parties in dementia care and as part of this GP opinions are being sought. We feel that GPs form an essential part of dementia care and would appreciate your involvement in the renewal process. Opinions from GPs outside of Shropshire will also be sought as ideas from their local services may be very useful.

About Healthwatch Shropshire

Healthwatch Shropshire is the health and social care champion for people and local communities in Shropshire. They help to ensure that everyone gets the best from their health and social care services – also that those services are good as they can be and work in a joined up way.

Their aim is to give patients, service users, carers and the wider public a real say in the way health and social care services are run. Their mission is to be the recognised independent voice of the people of Shropshire in seeking to improve their experience of health and social care services.

Questions

- For each question also consider improvements that can be made

Diagnosis and Initial Care Focus

Question 1: What is your awareness of the Dementia Strategy Action Plan?

- What was your awareness before we began this process?
- If you had not hear of this, how could awareness be improved?

Question 2: How do you make an early diagnosis of dementia?

- How do you identify these patients?
- What do you do when they have been identified?

Question 3: What are the barriers to recognising early dementia?

- Old age vs. dementia (normal vs. abnormal)

Question 4: What are the benefits and disadvantages of making an early diagnosis of dementia?

- Continuity of care, named GP

Management Focus

Question 5: How do you feel about organising care in the community for your dementia patients and is it affected by different patient circumstances?

- Longstanding patients, new patients and care home patients
- The referral process
- The service availability in the area
- Key question

Question 6: What links are there between GPs and services providers and what barriers are there to this?

- Community mental health and the memory clinic
- New patients from out of area
- National support services
- Local support services

Question 7: How do you support the wellbeing of carers and what services are available to them?

- What services are available
- What can be done further

Question 8: What are you doing that is unique and beneficial for your patients

- Local initiatives – including GP led services, documents and leaflets
- Personal experiences