Glaucoma, Dementia and the Precipice of Care

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Dementia and Glaucoma

- The varying types of dementia are estimated to affect over 850,000 people in the UK.
- Glaucoma is estimated to affect around 600,000 in the UK; with 300,000 more undiagnosed.
- Both conditions expected to increase with ageing population.
- A study in Scotland suggested 24% of people now blind through glaucoma also had dementia.
- Symptoms and effects of dementia vary from person to person:
  - Difficulty in finding the right words.
  - Decline in mental ability and concentration.
  - Memory loss and forgetfulness.
The Research Problem

- Social Care Institute for Excellence: 45 percent of medicines prescribed in the UK for older people.
- However, up to 50 percent of the older UK population are believed to be non-adherent.
- Adherence behaviour studies have recently emphasised qualitative approaches.
- How does dementia affect the issue of adherence for glaucoma patients, carers and healthcare professionals?
Our Research Study

- Grounded theory approach
- Two research sites in Wales and Scotland
- Interviewed 23 patients suffering dementia and glaucoma
- Interviewed 22 lay carers helping those patients, as well as 9 healthcare professionals
- Further cohorts of those with glaucoma alone (n=6) and those with other non-dementia conditions (n=6) also recruited
- Only patients capable of consenting and who were willing to take part were interviewed
- Analysis of the interviews focussed on what may influence a person with dementia and glaucoma to be able to take their eye drops, and their medication more broadly
Our Findings

- Pandora Pound et al’s synthesis of qualitative adherence studies
  - Active acceptance and passive acceptance
  - Rejection and modification of medication regimens
- Adherence transitions related to:
  - The role of the carer
  - Relative importance of conditions
  - Attitudes towards medication and healthcare system
  - Importance of pre-established routines
Active Acceptance

- ‘Purposeful adherers’ (Johnson et al, 1999)

- Prerequisite for active acceptance is believing a prescription is necessary, effective and safe

- Often coincides with education on the nature of the condition being medicated and its potential consequences

*Your eyesight is very precious. I would rather go deaf than lose my eyesight. So, oh no, I put the drops in.* **WP15, Patient**
Passive Acceptance

- Adhere indifferently to medication; relinquish control to others
- Numerous accounts of medication being relinquished to others based on progression of dementia
- The role of medication management was generally assumed by lay carers or care home staff

*She was very much in control of it until...in the last two years...her understanding of things became less, and then to remember to do things...* WC06, Carer

*She wouldn't remember. Even when I go through, and she's decided to go to bed, I'll say I'll come and do her drops. If I didn't say that, they wouldn't be done.* WC03, Carer
Rejection or Resistance to Medication

- Accounts of rejection less prevalent within the sample
- Attitudinal factors important in those cases where there was resistance to medication; e.g. not taking the condition seriously

*R: She does it when she thinks about it. When you remember you do it, don’t you?*
*R2: I’m a bit naughty…*
*R: Because it isn’t giving her any trouble, she isn’t bothered with it, you know?*
*WC02, Carer (R) and WP01, Patient (R2)*
Modification of Regimens

- Modification implies active engagement from patients; not necessarily taking medication as prescribed

- As with, rejection and resistance, reports of modification were less prevalent than active or passive acceptance

- Healthcare professionals mentioned modification as a management strategy:

  I’ve got some patients who just can’t remember to do things in the morning…or vice versa…if you were just to say well do it all together rather than being fixed…I think that would make life a lot easier. **WH02, Optometrist**
Adherence Transitions

- Pound’s model identifies adherence categories; less clear on transitions between categories
- Active to passive acceptance commonly reported with dementia
- Length of transition reported as being related to several factors:
  - Attitudes towards medication and healthcare system
  - Relative importance of conditions
  - Importance of pre-established routines
  - Role of the carer
Attitudes and Beliefs in Value of Medication

- A key factor relating to adherence appeared to be beliefs in the value of the medication and the wider healthcare system.
- This was often founded on an understanding of the condition being medicated and its potential consequences.
- The study saw numerous reports of active acceptance of eye drops based on valuing sight.
- Other participants placed more stock on the healthcare system and its instructions:

  I: *Is it the fear of what would happen if you didn’t take your medicine?*
  R: *No, it’s just the fact that they say, “Take this”.*  
  *WP11, Patient*
Relative Importance of Conditions

- Management of multiple conditions offers potential for conditions to be prioritised:
  
  *Well, in fact, I don’t give her eyes a thought actually because they aren’t that important. No, it’s more like other things take priority over them at the moment.*  
  
  *WC02, Carer*

- Theme noticeable with conditions other than dementia:
  
  *You can pop off quickly with the heart and you don’t pop off quickly with glaucoma.*  
  
  *WPC01, Patient*
Pre-Existing Routines

- Pre-existing routines and the use of calendars or memory aids often coincided with a greater capability for a patient to manage their eye drops:

  “And she would really do it to the letter and would always take them, she used to say I have to take them the last thing of the day, so she would have them by the side of her bed, she would put them in and apparently the consultant had told her that she should put them in and she should hold her fingers in her eyes for 60 seconds…and she just literally did it to the letter”

WC06, Carer
The Role of the Carer

- The carer was an essential factor in slowing the deterioration of sight for patients. For dementia patients this was primarily in terms of acting as a substitute for memory:

“Yeah, he does it himself. I’ve got to tell him before we go to bed. I say don’t forget eye drops, in the fridge so, some nights even I go downstairs and he comes down, I say have you done it, oh no, he says, he’s got to go back and do them, but that’s all. I’m sure if I weren’t here he wouldn’t do them, I’m sure. And again I wonder it’s because he’s got used to me…he’s got used to me saying about it but I don’t know”

WC04, Carer
Conclusions and Recommendations

- Dementia can contribute to patients being forgetful over their eye drops
- Eye drops and glaucoma medication do not fit into memory aids such as blister packs
- The ‘precipice of care’ seemed more likely if both carer and patient had health issues
- Better recording of dementia diagnosis may aid communication in the eye clinic
- The Eye Clinic’s Liaison Officer may be helpful to patients with dementia
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