Role of Specialist Care in Dementia

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There are 835,000 people in the UK who have dementia [1] at an annual cost to the UK economy of £26 billion. Most people with dementia live in the community with one in three living alone at home [2] with much of the care being met by unpaid carers [3]. Seventy percent of care home residents have dementia [1].

Dementia is an umbrella term that covers a multitude of diagnoses and problems from vascular dementia through to Alzheimer's disease via the fronto-temporal dementia and Lewy body disease.

Specialist care has a critical role in supporting primary care's role in management. Specialist care includes old age psychiatry, geriatric medicine and neurology.

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In addition non-medical specialties have a significant role. These include community psychiatric nurses, occupational therapists, psychologists and pharmacists. Physiotherapy and speech and language therapists can be a part of management and assessment. In this chapter we will describe the role of specialist care in dementia. There is no one model that fits the care pathways in dementia, and some of the collaborative models will be described.

23.1 Mental Health Care in Dementia

In the last 20 years, there have been changes in mental health services in dementia with expansion of multidisciplinary teams. Typical services for dementia in mental health are organised around a memory service, which functions to diagnose and treat patients and then signpost to other services.

Memory services do vary in structure and there is a national accreditation scheme in the UK (http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/qualityandaccreditation/memoryservices/memoryservicesaccreditation/msnapstandards.aspx).

Typically, patients are referred by primary care, less commonly by cross referral and in some centres can self-refer.

The changes in care have been brought about by the development of cognitive enhancer medications (of which there are 4 – donepezil, rivastigmine, galantamine and memantine) and innovation in psychological approaches. With the availability of generic medications in dementia, the role of primary care has been expanding [4]. In addition, there have been restrictions levied on psychotropic medications due to adverse effects in people with dementia, for example, stroke risk with antipsychotic usage.

Mental health services in dementia include old age psychiatry, community and inpatient psychiatric nurses, occupational therapists, psychology, support workers and social workers.

Specialist mental health services in dementia are primarily delivered in the community. In addition, there are day centres/hospitals in some services. For the more severe cases, there are inpatient services.

Diagnostic services are usually delivered by some form of memory assessment service so-called memory clinic [5]. However, these are sometimes delivered by neurologists and geriatrician more commonly in some healthcare systems, for example, the USA.

23.1.1 Psychological Approaches to Dementia Care

Mental health professionals have many contributions to the assessment, care and management of people with dementia and also to the support provided to dementia caregivers. Psychologists have an important role in neuropsychological assessment of dementia, and this is a highly specialised skill. The different dementias

(Alzheimer's, vascular, Lewy body, frontotemporal, etc.) may have a different neuropsychological profile [6–9]. It may be useful to take account of potential differences when working with people with dementia, but this is a very complex and challenging area for non-specialists.

Any dementia is likely to have a number of different consequences for the person with dementia and for those who care for them. There are obviously different dementias with different consequences for each individual and at different stages in the person's journey with dementia.

23.1.2 BPSD

In terms of behavioural and psychological symptoms of dementia (BPSD), mental health has a key role to play in working with informal and formal carers when dealing with behaviours that challenge in dementia. Behaviours that challenge cause significant distress to carers and can often result in a breakdown in care arrangements [10]. The first-line approach to treatment is recommended as nonpharmacological, because the potential benefits of antipsychotics are outweighed by the adverse effects evident from general use [11].

Understanding behaviour as having different functions for every individual psychologists, a key part of mental health services for dementia, has developed different ways of helping carers understand and respond appropriately to behaviour. Cohen-Mansfield and colleagues understand challenging behaviour in dementia as indicating an unmet need [12]. In the case of understanding a person with behaviour considered to be challenging in dementia, a psychological formulation-led individualised approach augments standard functional analytic approaches [10] by focusing on the person and the range of factors impacting upon them. As people with dementia may not be able to directly communicate their stress and distress in environments in many cases that are not under the direct control of an individual with dementia, individualised formulation-led interventions are going to be essential in order to meet the needs of the person with dementia [13].

Distress in Dementia Caregivers

Most care for people with dementia is provided within the family [14]. Strong evidence for psychological approaches (e.g. cognitive behaviour therapy, CBT) for dementia caregivers exists with a number of systematic reviews demonstrating that CBT is an efficacious approach [15–17].

Overall, the evidence for dementia caregiving suggests interventions are more effective when they are active rather than passive. While psychoeducation improves subjective wellbeing, it is effective in reducing distress *only* if it is active. CBT works best when used for more focal targets such as reducing caregiver depression and burden. As dementia is a deteriorating condition, interventions focused on one target may be less effective overall, and this is reflected in findings that only structured multicomponent interventions are effective in reducing and delaying institutionalisation [18].

Psychological Approaches for People with Dementia

Psychological therapists have often shied away from working with older people with dementia as they assume that such clients will be unable to engage in the process of therapy; however, this is disempowering of individuals and is contrary to the ethos of CBT. Many people diagnosed with dementia in the early stages will retain enough insight and capacity to engage in therapy as long as simple adjustments are made by the therapists to accommodate to any mild memory or communication difficulties [18].

At the post-diagnosis stage in the experience of dementia, there may be lot that an individual can benefit from psychological therapy as they come to terms with the implications of their diagnosis. CBT is especially appropriate with older people diagnosed with dementia because it is a structured problem-focused, present-oriented, evidence-based treatment making it straightforward to use, as well as effective in building coping strategies and skills that are empowering for individuals who are faced with challenges of living well with dementia.

Inspiration for tailoring CBT interventions for those with dementia can be drawn from CBT for chronic physical health conditions. Central to CBT for people with chronic health conditions is the concept that it is the individual's appraisal of their experience rather than the experience itself that is important in understanding how well they cope with an event. This is a standard concept in CBT. It is not the situation per se that causes an individual's problems; it is the personal meaning attached to the situation that determines its impact. In this way, two individuals may experience similar situations and report markedly different emotional responses. An individual's illness-related beliefs and illness-related behaviours are also likely to be important. How one views dementia will influence one's behaviour in response. Depressive attributions about how an individual with dementia characterises their problems may also be a useful focus for CBT interventions [19]. Thus, if an individual attributes all memory, reasoning or communication failures to the onset of dementia symptoms, this may be an overgeneralisation that may undermine an individual's self-confidence. Although people living with dementia have to deal with realistic challenges, nonetheless, individuals can endorse many unhelpful or erroneous cognitions that may make living with dementia much more difficult.

When working with people with dementia, there may be important data to be derived from understanding how an individual reacts in response to actual or real memory failings. A disproportionate reaction may leave an individual feeling more diminished as a competent person, and this may have an adverse approach on a person's cognition, affect and behaviour.

Evidence for the efficacy of CBT in anxiety and depression in dementia comes mainly from a range of small intriguing clinical trials and case studies. Mohlman and Gorman [20] note that treatment outcome for CBT for anxiety disorder can be compromised when clients have executive dysfunction (i.e. specific cognitive deficits in planning organising and reasoning abilities). If attention-training and enhanced self-monitoring in therapy are used to augment CBT, deficits can be overcome and enhanced treatment outcome achieved [20]. The evidence base for CBT interventions for people with anxiety or depression in dementia is summarised in Table 23.1.

Table 23.1 Table of psychological therapy for depression and anxiety in dementia, executive dysfunction and varying levels of cognitive impairment

Author(s)	Primary focus	Design	Intervention	Results
Teri et al. [21]	Depression in dementia	Open trial of 'Seattle Protocols'	22 BT and 19 control (this is intern report for Teri et al. 1997)	Treatment took place over 9 weekly sessions of BT (including carers in the intervention). 68 % of carers reported as clinically depressed at start. 20/22 PwD improved and carers' wellbeing also shows improvement. No change evident in W/L control group
Teri et al. [21]	Depression in dementia	Controlled trial	72 dyads: BT-PE, BT-PS, TAU and W/L. CGs involved actively	Both active treatments more effective in reducing depression than TAU or W/L. 60 % of participants in active BT conditions improved, whereas 70 % in TAU and W/L show no improvement. Carer's depression also improved significantly even though this was not directly targeted. Changes in depression in carers and PwD maintained at 6 months follow-up
Koder [23]	Anxiety disorder in dementia	Single cases CBT	2 cases	Two single cases of 82-year-old males with depression and anxiety. Treatment involved carers and positive effects were reported in both cases. Treatment was structured and time-limited in both cases
Scholey and Woods [24]	Depression in dementia	Single cases CBT	7 single cases	All participants met diagnostic criteria for depression and dementia. Individualised CBT protocol used without apparent difficulty. Overall significant difference in outcome in mood over treatment. 2/7 participants evidencing clinically significant improvement in mood using standardised mood scales (e.g. Beck Depression Inventory; BDI, Geriatric Depression Scale; GDS)
Walker [25]	Depression in dementia	Single case CBT	1 single case	71-year-old male living with spousal carer, both demoralised at intake. Treatment nonresponsive to ADM. Couple seen together for 16 sessions of CBT. At end of Tx and 12-month follow-up, cognition improved (MMSE) and anxiety improved (GHQ 32 at b/l, reduced to 5 at follow-up)

(continued)

Table 23.1 (continued)

Author(s)	Primary focus	Design	Intervention	Results
Burns et al. [26]	Depression in dementia	RCT	20 psychodynamic interpersonal therapy vs 20 TAU	While participants reported positive attitudes towards psychotherapy, there were no positive outcomes on any of the main domains of interest. Psychodynamic psychotherapy does not appear efficacious although treatment length (6 sessions) in this study is very short for this type of intervention
Carreira et al. [27]	Depression in varying levels of CI	Subgroup analysis of large RCT	52 participants with CI randomly compared IPT (35) to supportive clinical management (18)	The cognitively impaired participants receiving monthly IPT sessions fared better than participants receiving support clinical management. This surprising finding was contrasted with non-CI participants receiving the same interventions, and there was no difference. IPT seems to have potential as an efficacious psychotherapy with people with depression and cognitive impairment
Kraus et al. [28]	Anxiety in dementia	Single cases	7 cases	Treatment emphasises active self-monitoring by the clients (i.e. keeping a notebook handy to remember and monitor homework tasks, use of checklists to remain oriented to task and time). Emphasis on behavioural rather than cognitive change. Specific strategies used to enhance recall such as use of cues and other retrieval-based strategies
Kiosses et al. [29]	Depression in dementia	RCT (interim data)	15 PATH vs 15 ST	12-week home-delivered PATH (problem adaptation therapy); a behavioural problem-solving treatment was compared to 12 weeks of supportive therapy (ST) for people with depression in dementia. Carers actively involved in treatment. PATH participants reported 51 % greater improvement in depression compared to those allocated to ST

Table 23.1 (continued)

Author(s)	Primary focus	Design	Intervention	Results
Paukert et al. [30]	Anxiety in dementia	Open trial	9 intervention, 7 complete Tx	Six-month treatment with weekly session for first 12 weeks followed by telephone sessions. Carers active participants in treatment. Most participants reduced anxiety and depression, and carers concerns about PwD reduced over treatment
Arean et al. [31]; Alexopolous et al. [32]	Depression in executive dysfunction	RCT	110 problem-solving therapy (PST), 111 ST	Participants recorded moderately severe levels of depression and mild-to-moderate levels of ED. Randomly allocated to 12 weekly sessions of either ST or PST (a version of CBT focussing on problem-solving). Participants reported reduction in depression symptoms for both treatments. At week 12 (end of Tx), PST > ST (46 % vs 28 %) in terms of remission and response. No follow-up at end of Tx
Spector et al. [33]	Anxiety in dementia	RCT	25 CBT, 25 TAU	Randomly allocated to receive either CBT or treatment as usual (TAU). CBT participants reported reduction in anxiety and depression symptoms not experienced by participants in receipt of TAU. Gains maintained at 6 months after follow-up with CBT participants alone in reporting improvement in their relationships

From Laidlaw [18] with permission
ADM antidepressant medication, *BT* behaviour therapy, *BT-PE* behaviour therapy with psychoeducation, *BT-PS* behaviour therapy with problem solving, *CBT* cognitive behavioural therapy, *CI* cognitive impairment, *ED* executive dysfunction, *GAD* generalised anxiety disorder, *IPT* interpersonal psychotherapy, *PST* problem-solving therapy, *RCT* randomised-controlled trial, *ST* supportive therapy (counselling), *TAU* treatment as usual

23.2 Geriatrician

There is a considerable overlap between the geriatrician and the old age psychiatrist. As many as 50 % of older people with physical illness will have issues with recall and memory. For some, this will be little more than an irritation for others; it will indicate a more serious and underlying problem. Dementia or cognitive problems have been recognised as one of the geriatric giants for many years.

Older people with dementia may present to the geriatrician in a number of ways. These include an outpatient referral for diagnosis, a referral where the dementia is a comorbidity or a delirium or other acute or elective medical problem complicated by the presence of dementia. The role of the geriatrician is to exclude possible organic disease that may be the underlying aetiological factor and help the old age psychiatrist or general practitioner identify pseudodementia (hypothyroidism, metabolic disorders or depression).

Acute medical services are, at times, used as a service of last resort in an emergency to provide a place of safety. This is usual in the situation where there has been an exacerbation of the dementia by delirium or deterioration in behaviour due to disease progression or stress resulting in behavioural problems.

Delirium is increasingly common in older people with 60 % of those in post acute settings (including care homes) and 53 % of those in hospital, and failure to recognise delirium or consider the diagnosis can be fatal. People with dementia are 6–11 times more likely to develop delirium. It is the role of the geriatrician to recognise the presence of delirium and then to seek its cause. Increasing frailty, medication changes, constipation, urinary retention and a previous episode of dementia are some of the predisposing factors [34].

In this situation the geriatrician has to be able to recognise the underlying problem and work with the multidisciplinary team (including liaison psychiatry). Once the problem has been identified, not only must the aetiological factors need to be managed, but consequences also need to be recognised and managed. People may not have eaten or drunk for many hours or days, medication may not have been taken and the agitation and risk of harm need to be managed [24–36].

Behavioural and psychological symptoms of dementia (BPSD) or disturbed behaviour in the context of dementia will occur in over 90 % of people with dementia at some stage. The important role of the geriatrician is to recognise the underlying cause of the change in behaviour. The problem may again range from constipation and pain to a silent organic medical problem such as a myocardial infarction.

People with dementia are not only found on the acute medical wards, but are frequently occupying surgical beds, either due to the bed situation or because they have undergone surgery. The geriatrician is required to provide a liaison service to support the surgeons in the appropriate management of people with dementia.

Geriatric services also provide a liaison service to work with old age psychiatry to provide a medical input into the inpatient service to provide holistic care to review and manage any comorbid medical conditions [35].

Many older people live in care homes. Staffs in residential homes, in particular, are often poorly trained in dementia care, even if the primary focus of the home is dementia care. The geriatrician with the old age psychiatrist and the general practitioner need to work together to ensure appropriate management plans are in place to prevent inappropriate transfers of care.

People with dementia face repeated episodes of transfer of care to hospital from their care home or own home as the dementia deteriorates. There is a need to make

an assessment of the appropriate treatment/management so as not to increase suffering unnecessarily. Close working with primary care, psychiatry and care homes are required to ensure that appropriate anticipatory care plans are agreed and put into place. The PEACE documentation [37] and Gold Standards Framework [38] are examples of good practice. There needs to be a clinical recognition that a refusal to eat and drink may be part of the terminal decline and may be complicated by dysphagia. When dysphagia occurs resorting to enteral feeding is an inappropriate response. Carers need to be supported and encouraged to use oral feeding, recognising that this is a risk, but will provide comfort to the person with dementia.

Geriatricians access community nurses, physiotherapists, occupational therapists and speech and language therapists across the care pathway. They should also have links to old age psychiatry and neurology.

23.3 Collaborative Care as a Bridge Between Primary and Secondary Care

Optimising medical treatment in primary care for people with dementia needs integrative approach with specialists.

The underlying challenges in providing good medical care to people with dementia are similar across nations. The complexity of treatment and care needs cooperation between different professions and stakeholders. Amongst the tasks to be considered, medication management and drug safety plays an important role. For example, it has been reported that the incidence of hospitalisation in Germany due to potentially inadequate medication is 3,25 % with 205 of these being avoidable [39]. The action plan to improve drug safety in Germany (www.ap-amts.de) highlights interdisciplinarity and the knowledge of the entire medication are the key components of successful pharmaceutical treatment. However, in reality, each patient gets prescriptions from a variety of different physician specialists and is provided these medications by different pharmacies. There is no structural interface between those, so that potentially inadequate medication (Pim) and drug-related problems (DRP) are common. There has been the call for cooperation, for example, in the guideline 'multimedication' (www.pmvforschungsgruppe.de). In Germany, the general physician (GP) can serve as a gatekeeper for patients in primary care and the local pharmacies are well prepared to deliver their share in medication management. Since 2012, in Germany, medication management is part of the pharmacy rules of operation.

An innovative concept to overcome these interface problems is currently evaluated in the DelpHi trial following a successful US trial [40, 41], a cluster-randomised, population-based intervention trial. A dementia care manager (DCM), a specifically qualified nurse, is the function that is integrated into the healthcare system. The DCM works GP-based, with the GP screening patients for cognitive impairments and upon identification providing the DCM. The DCM visits the patient at home and amongst other topics conducts an extensive medication analysis. Using a

computer system, the DCM scans the barcodes of all medication present in the patients' household. The DCM notes medication plans, dosage, frequency, storage and adherence problems, according to a systematic assessment tool [42]. This information is summarised and given to the local pharmacist for evaluation, when the pharmacist participates in the study. For all other patients, the role of the pharmacist is provided by study pharmacists. They evaluate the medication plan, check for potentially inappropriate medication, drug-related problems and drug-drug interactions and provide pharmaceutical recommendations. This is done in a standardised way, and the DCM summarises the pharmacist's evaluation into a recommendation letter to the GP. The recommendation letter to the GP is basis for planning further treatment and care for the patient and is discussed between GP and DCM with the GP being able to delegate tasks to the DCM. Thus the GP is able to base his decision on systematically assessed and evaluated information and modifies pharmacotherapy and/or drug administration. The DCM, however, monitors the changes and is able to give feedback to the GP frequently. Results so far indicate that the structured and computer-supported assessment improves the identification of needs [43], however, not restricted or limited to medication. The interaction between GP and pharmacist has improved without adding too much on the work load on either profession. The function of a DCM is perceived as support and preliminary analysis shows an effect on medication as well.

The NHS has recently been piloted and was found unsustainable, and there was a need to redefine the role of case managers and better targeting of which people with dementia could benefit from collaborative care [44].

23.4 Role of Pharmacy in Dementia Care

23.4.1 Role of Community Pharmacists

Community pharmacists are amongst the most accessible healthcare professionals, on high-streets countrywide, and therefore could play a key role in supporting people with dementia and their family carers. It is acknowledged that community pharmacists are an underutilised resource; according to the NHS confederation, the 'NHS has historically undervalued the role that community pharmacists can play in improving and maintaining the public's health' [45]. However, as highlighted by Gidman et al. in a research conducted in Scotland, awareness of community pharmacists' extended roles is low [46]. The NHS is promoting community pharmacy with campaigns such as 'feeling under the weather' and in the report 'urgent and emergency care review' – 'we can capitalise on the untapped potential, and convenience, that greater utilisation of the skills and expertise of the pharmacy workforce can offer' [47].

Family carers are commonly housebound and home delivery services offered by community pharmacists can be valuable. Community pharmacists have a key role in supporting appropriate self-medication by people with dementia. Many over-the-counter (OTC) medicines possess anticholinergic activity and should therefore be

avoided in people with dementia [48]. There are a number of OTC medicines including Souvenaid and ginkgo products, which may improve memory, and community pharmacists are in an ideal position to advise people with dementia and older people, more generally, on the use of such products. The community pharmacist may be the healthcare professional that the family carer and person with dementia have most regular contact with. Community pharmacists can provide medicines use reviews (MURs). MURs are structured reviews for patients on multiple medications especially those patients who have a long-term condition [49].

Comorbidity is common in people with dementia, and community pharmacists can have a key role in supporting safe and effective management of medication both for the dementia and for any comorbidities [50]. However, preliminary evidence suggests that family carers, who commonly take on responsibility for medication management as the dementia progresses, lack appropriate support and find medication management challenging [51]. More research is needed on how community pharmacists can support family carers, including the usefulness of domiciliary visits that could include a medication review.

23.4.2 Medication Management Dementia Care Pathways

Pharmacists (community, secondary care, interface and prescribing support) all have roles to play in producing organisational and trust guidelines. Pharmacists are involved in drug and therapeutic committees (DTC). These committees are responsible amongst other things for improving drug use and evaluating drugs for the formulary list. Interface pharmacists provide the link between secondary and primary care, particularly around medication which may have a shared care protocol. These may be medications which started in secondary care and continue to be prescribed by general practitioners, for example, acetylcholinesterase inhibitors. The role of the clinical commissioning groups (CCG) pharmacists can involve, for example, cost-effective prescribing, medicines optimisation and many other aspects.

23.4.3 Specialist Pharmacy Services

Specialist pharmacy services are generally provided by pharmacy staff employed by mental health organisations and include both pharmacists and pharmacy technicians. Specialist pharmacists have diverse roles and responsibilities including:

- Developing secondary or cross sector guidelines, for example, the treatment of the behavioural and psychological symptoms of dementia (BPSD) [52].
- Attending ward rounds, case conferences and multidisciplinary team meetings to advise clinicians on the most appropriate medication regimen.
- Conducting individual one-to-one medication reviews.
- A supplementary or independent prescribing role.

- Counselling patients and carers on their medication regimen including potential adverse events and how to manage them. This may be one-to-one or in a group setting and include the supply of written information.
- Providing a medical information service and answering frequently complex queries from both health and social care professionals and members of the public.

Historically, pharmacy technicians have tended to have a mainly supply function and their roles have included dispensing. However, increasingly pharmacy technicians are developing a clinical function; a good example of such a role is medication reconciliation – when patients move between primary and secondary care. The Mid Staffordshire NHS Foundation Trust Public Inquiry highlighted the need for safe systems within healthcare, and recent research has identified the importance of this clinical role, delivered by pharmacy technicians, in improving patient safety [53, 54].

The Sainsbury Centre identified in 2007 the need for more investment in specialist pharmacy services [55], and such pharmacy practitioners need to receive appropriate training and support for this specialist, complex role. Specialist pharmacists can study for appropriate postgraduate qualifications at Aston University [56]; however, currently there is no such specialist qualification for pharmacy technicians. The College of Mental Health Pharmacy also provides support and runs training courses for both pharmacists and pharmacy technicians.

23.5 Conclusions

In the future, particularly with the contraction of bed numbers, specialists will need to work more within a community setting rather than in hospital services. One particularly innovative approach could involve joint working between primary care pharmacists and specialists to support GPs, for example, in the management of BPSD [57]. However, more research is required on the impact of such an outreach role for specialist dementia care pharmacists and potential for collaborative care between specialists and primary care [44].

Key Points

- Old age psychiatrists have a key role in making the diagnosis of dementia but will need to liaise with a geriatrician, the primary care team and social services.
- A number of models of care for the management of people with dementia have been proposed, including a collaborative care framework.
- Liaison between primary and specialist care should enable rapid access to support if a patient develops BPSD.
- Specialist pharmacists have a potentially important role in supporting medication concordance in patients with dementia.

23.6 Suggested Activities

- What is the role of mental health specialists in dementia in your healthcare system?
  - Is there a need?
  - Where do you fit into this system?
- What is the role of the geriatrician in managing people with dementia in your healthcare system?
  - Where do you fit in with the working of geriatric care in dementia?
- If a case management model was adopted, who could be a case manager in your healthcare system?
  - Could you be a case manager?
  - Where would you fit in with the working of a case manager?
- What is the role of the community pharmacist in supporting the management of people with dementia in your healthcare system?
  - How do you work with the community pharmacist in supporting the management of people with dementia?

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