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Review article:

Behavioural and psychological symptoms in dementia: is it the next challenge for clinicians in the Middle East?

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الأعراض النفسية والسلوكية عند المرضى المصابين بالخرف:

هل هو التحدي القادم للأطباء في منطقة الشرق الأوسط؟

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Abstract

Dementia is a neurodegenerative disease of the brain in which there is a disturbance of higher cognitive functions. The rates of dementia as well as the financial burden are increasing worldwide. Dementia is an area of growing concern in the middle income countries where the numbers of elderly populations are rising. Moreover, behavioural and psychological symptoms of dementia are difficult to manage in a system based only on a pharmacological treatment because of the lack of evidence for specific medical intervention and the current concerns raised regarding the use of antipsychotics in dementia. The current medical profession in the Middle East should be prepared for this coming challenge, therefore, an urgent need for education and training among mental health workers is mandatory to develop a culturally sensitive multidisciplinary approach to deal with this multi-factorial problem.

Declaration of interest: None

Key words: Dementia, middle income countries, behavioural and psychological symptoms, antipsychotics.

Dementia - the growing problem

Dementia is a neurodegenerative disease of the brain, which can manifest itself in a multitude of clinical presentations. It can be defined as a syndrome in which there is a disturbance of the higher cognitive functions. These can include memory, language, calculation and executive functio¬ns[1].

The prevalence and incidence of dementia appears to be growing, with an ever-increasing older adult population. The World Alzheimer Report 2009 estimated that 35.6 million people worldwide would be living with dementia in 2010 and that this number is expected to be nearly double every 20 years, with 115.4 million being predicted by 2050[2]. A significant proportion is thought to be due to increased rates of diagnosis in less developed countries like within the Middle East as well as continued high rates from other countries[2]. Dementia will have a cost of 1% in gross domestic product and, if this was equated to a country, its size is estimated to be between Turkey and Indonesia, which would be ranked 18[3]. Data from the UK would appear to follow this worldwide trend. Currently, there are approximately 700,000 people with the diagnosis of dementia but this is set to rise to about 1.4 million over a 30 year period[4]. Relative to other parts of the world, studying the older adult population in the Arab world has been bare, despite the fact that older adults aged 60 years and above in 2000 – 2005 represented about 6.5% of Arab populations in North Africa and around 6.6% in Western Asia. Added to that, by the year 2050 these percentages will be around 19.4% and 17.8% respectively [5]. In the Middle Eastern countries, like Egypt, data is much more limited but a rise in the elderly population is expected. In Egypt, 5% of the population was over the age of 60 years in 1950. That figure rose slightly to 6.3% by 2000, but it is predicted to increase to 11.5% by 2025 and 20.8% by 2050[5]. This would be a 200% increase in a 100 year period6. If it is presumed that the pattern of prevalence for dementia in Egypt is similar to UK (approx. 5% between ages of 65-80 years[3]), then it could be estimated that 500,000 people will have a diagnosis of dementia from the 100,000,000 population expected in 2025[6]. In the first Alzheimer conference in the Arab world, the president of the Alzheimer's Association of Lebanon declared that there are 30.000 cases of Alzheimer disease in Lebanon and potentially 1.5 million cases throughout the Arab countries, figures that necessitate more serious actions to help patients with such a disease. Moreover, she stated that associations dedicated to the disease were immensely underrepresented in the Arab world with Lebanon and Egypt the only established members of international organizations [7]. A study on Alzheimer's disease, conducted in Northern Lebanon, found that the disease is present in 12 % among those aged 50 years and above. The same authors concluded that little effort was made to raise the importance of such a problem[8]. In 2007, Jordanian researchers concluded that there was a sort of neglect towards the disease in Jordan and lack of awareness to seek early specialist help if there were a decline in memory. Only moderate to advanced cases are presented to psychiatrists and/or neurologists for further help [9].

The impact on the population and its country as a whole will be significant. In the UK, dementia costs the National Health Service around £20 billion a year[3]. National reports suggest only 40% of people

with dementia ever receive a diagnosis with great variation in the assessment and management around the different regions of the country[3]. This highlights the need for improved general awareness not just in the UK, but around the world and the Middle East. It is evident that dementia is still perceived as 'part of normal ageing' particularly in the developing world but this is still also identified within the UK. The National Dementia Strategy for the UK cited this false belief and that of 'nothing can be done' along with the associated stigma attached as important reasons as to why people do not seek help[10]. Being given a diagnosis is important and enables the person and family to have more understanding about the disease and its prognosis. It also allows for measures and support to be instigated, which could potentially help prevent emergencies and crisis admissions to either medical hospitals or respite beds in the community. It has been reported that rates of admission to care in the UK could be reduced by about a fifth[3]. Consequently, it is recommended by the World Alzheimer Report 2009 that 'low and middle income countries like the Middle East should create dementia strategies based on enhancing primary healthcare and other community services whilst high income countries such as UK should focus on and develop national dementia action plans with designated resource allocations[2].

In the Middle East, traditionally, most of the dementia care will fall on family members especially daughters and daughters-in-law due to lack of care homes and presence of stigma. But the changing demographics in the Middle East including family structure and work force could lead to a real challenge in arranging care to people with dementia especially in the presence of behavioural problems.

Behavioural and psychological symptoms in dementia (BPSD)

In 1999, it has been explained that behavioural and psychological symptoms in dementia (BPSD) 11 is a generally accepted term that encompasses a wide range of clinical manifestations, which can be challenging to a cursing, making strange noises), physically non aggressive (pacing, repetitive mannerisms, inappropriate dressing) and finally physically aggressive (hitting/ kicking out, grabbing people or things) [12].

BPSD is not a core feature when considering the definition or international criteria (i.e. ICD-10 or DSM-IV) for a dementia syndrome[13], but it has been identified since its earliest descriptions. In the 19th Century, Esquirol observed that 'Demence Senile' was accompanied by emotional disturbances[12]. It is common with point prevalence estimates ranging from 60-80% and a cumulative risk of around 90% across the course of the illness[14]. Symptoms don't always occur alone and tend to accompany the anticipated cognitive decline. BPSD is often the first indication of a problem and the reason behind an individual's initial referral to primary care[4,13]. It is a significant part of the clinical workload within an old age psychiatry team and seen in a range of different environments including psychiatric hospital wards, care homes and other community settings[13]. Managing these behaviors is therefore imperative as even though dementia is progressive and terminal, it is expected that individuals can live on average between 7 to 12 years following initial diagnosis[14].

BPSD is thought to affect most people with dementia at some point in their illness. In the care home environment, studies have shown that it can occur in up to 90% of individuals with different symptoms being more evident at different stages of the illness[12]. The International Psychogeriatric Association (IPA) collation of studies indicates that affective disorders are more likely to present earlier on in the natural course of the illness with depression being reported in up to 80% of individuals in care homes and mania 3-15%. Agitation and psychotic behaviors tend to feature later when an individual has a more moderately impaired cognitive function. Therefore, the IPA reported that the frequency of these features vary greatly - delusions 20-73%, misidentification 23-59%, hallucinations 15-49% and aggression up to 20%[12].

Importantly, however, both psychotic and affective disorders are less prevalent in advanced stages of dementia as are the majority of the other behavioural and caregiver and distressing for the patient. It can be divided psychological symptoms[12] variation between the different types of dementia, with visual hallucinations being more commonly associated with Lewy Body dementia and impulsivity, hypersexuality and verbal outbursts associated with Fronto–Temporal dementia12. In 2007, the Jordanian study on the psychiatric presentation of dementia found that the most prevalent complaints were behavioural problems 63.04%, followed by cognitive impairment 30.43%. Furthermore, mood problems, personality changes and sleep disturbances were21.7%, 15.22%, and 10.87% respectively 9.

The exact cause is unclear, but it cannot be assumed that BPSD is only the consequence of the dementia illness itself.

The Royal College of Nursing in the United Kingdom estimates that only 10% of challenging behaviors is a consequence of dementia with 90% occurring in response to care practices or environmental factors[15]. Recent epidemiological studies have shown that behavioural and psychological symptoms are more common in people with dementia, but there are a significant proportion of mood disorders, apathy, irritability as well as persecutory ideations in a comparable population of people without dementia[12]. It is therefore multifactorial and likely due to a combination of the illness, the environment, physical health,

medication and interpersonal interactions[16].

BPSD can resolve itself spontaneously, persist or even gradually worsen in severity with wandering and agitation being the most enduring behavioural symptoms in patients with dementia particularly Alzheimer's over a two year follow-up period[12]. Thus, this can have a significantly negative impact on both the individual with dementia and the carers in the different community environments. Researchers indicated that BPSD could result in premature institutionalization, increased costs of care and significant loss of quality of life[17]. Psychotic manifestations, aggression, wandering and anxiety tend to be the most intrusive and difficult to cope with whereas crying, apathy, swearing and repetitive questions are common but less likely to lead to institutionalisation[12]. This is important when considering how best to manage this significant problem. It is known that the majority of people (66%) with dementia live in the community cared for by family members[6], which can lead to a number of problems including high levels of carers burden and depression[14]. In the UK alone, a third of people with dementia live in care homes and two thirds of people in care home have a diagnosis of dementia[3]. In Egypt, 90% of the elderly (either with or without a diagnosis of dementia) are cared for by their families and to date there are only 84 elderly care homes[6].

Antipsychotic use in people with dementia

Traditionally antipsychotic medication was developed to treat the positive symptoms of schizophrenia and bipolar affective disorder[14]. Randomized control trials comparing the effectiveness of atypical antipsychotics against a placebo show Risperidone and olanzapine to be the most effective treatment for psychosis, physical aggression, and agitation[15]. These findings have led to antipsychotic medication being prescribed to relieve behavioural and psychological symptoms in dementia. Generally, these treatments are being used off license as few or no pharmacological treatments have appropriate approval in the majority of countries[14]. In the UK, there are no drugs licensed for specifically BPSD, although there are licensed indications for drug treatment including psychosis and aggression[15]. Recent evidence regarding antipsychotic use in people with Alzheimer's type dementia in placebo controlled trials shows antipsychotics to have a modest but significant benefit towards aggression over a 6-12 week period but no demonstrable benefit for aggression or other behavioural symptoms over 6-12 months[15,16]. CATIE- AD study, 2006, included 421 patients with Alzheimer's disease and psychosis, aggression, or agitation who were randomly assigned to receive Olanzapine, Quetiapine, Risperidone or placebo for up to 36 weeks. It concluded that the adverse effects offset advantages in the efficacy of atypical antipsychotic drugs.[18]

Consequently in the UK, Risperidone is the only antipsychotic medication with a relevant license[14]. However, there are restrictions on its use, which is in accordance with the National Institute for Health and Clinical Excellence-Social Care Institute for Excellence (NICE- SCIE) guidelines 2007[19] indicated such as treatment for moderate to severe Alzheimer's dementia with persistent aggressive behaviors. Moreover, they reported that it should be prescribed as a short term measure when individuals are unresponsive to other non- pharmacological approaches and or when risks of harm to self or others are high[17]. Guidance from the Royal College of Psychiatrists in the United Kingdom indicates that if antipsychotic medication is deemed necessary then the '3 T approach' is best practice. This stands for target (the drug treatment i.e. antipsychotics should have a specific target symptom i.e. aggressive behaviors), titration (starting with lowest dose and increasing in slow increments) and finally time (medication should be time limited) [16]. In the case of atypical antipsychotics, they should not be prescribed for longer than a six-week period[9] without appropriate review from a clinician. Any decision taken to continue the medication should then be made on a case by case basis taking into consideration both the risks and benefits of the drug, reasons recorded clearly in individual's notes and monitored regularly[16]. Importantly, there are situations where atypical antipsychotics may need to be continued. These include people experiencing persisting BPSD, where it is felt severe adverse consequences may occur if discontinued or where no alternative approaches are suitable. However, it has been shown that if individuals on antipsychotics can remain relatively symptom free for at least three months successful withdrawal is possible[20]. It is advised that atypical antipsychotics should be discontinued gradually unless the individual is experiencing particular adverse effects[16].

However, antipsychotics are not recommended to individuals with mild to moderate Alzheimer's or other types of dementia due to the significant risks impacting on an individual's quality of life in the longer term[14]. Side effects of antipsychotic medication are well documented and consist of sedation, dizziness and Parkinson like symptoms, which can lead to falls. They may also accelerate cognitive decline[11]. The effects on each individual is variable, however it is likely that people with the diagnosis of dementia may be identified as high risk when considering factors such as age, physical co- morbidity and potential drug interactions[14]. In 2004, there was an alert to all clinicians from the Committee of Safety and Medicine in the

United Kingdom regarding use of Risperidone and Olanzapine in people with dementia. Data has shown an increased risk of cerebrovascular adverse events ranging from strokes to transient ischemic events. This was a three-fold increase from 1.1% to 3.3% typically over a 12-week period and those at most risk appeared to be individuals over the age of 80 years old[21]. The Food and Drug administration in the United States of America reported an independent analysis in 2005 reinforcing that when compared to placebo medication, atypical antipsychotics had a two-fold increased risk of all-cause mortality[22].

The Time for Action report 2009 indicated that around 180,000 people with dementia are treated with antipsychotics across the UK per year and it is thought that up to 36,000 possibly perceive some benefit from them14. When the report considered negative effects relating to antipsychotic use, it was highlighted that use at this level would lead to an additional 1,800 deaths and 1,620 cerebrovascular adverse events[14]. It is likely that the majority of these individuals reside in care homes with high complex and clinical needs including persistent BPSD and although antipsychotics are indicated in some cases, a high proportion of these residents are being inappropriately prescribed the medication[15]. Explanations for this include prescriptions for the wrong reasons; for example depression, incorrect dosing or lack of review following prolonged administration. The All Parliamentary Group on Dementia estimate up to 70% of prescriptions were found inappropriate in care homes, which has a huge economic impact on the National Health Service in the UK costing approximately £80 million per annum[15]. In 2008, the Management of Dementia in Care Homes Bill in the UK was read which requested better regulation and protocols for monitoring and reviewing antipsychotic medication for people with dementia in care homes. Data from the Arab countries on the use of antipsychotics are limited. The 2007 Jordanian study reported that medications which were prescribed for demented patients were as follows: antipsychotics (65.22%), acetylcholineesterase inhibitors (26.09%), antidepressants (19.57%), anxiolytics (8.7%), and hypnotics (4.35%) 9. Furthermore, the Northern Lebanon study in 2010 found that 50% of Alzheimer patients were receiving treatment, but 90% of those who were treated did not show any improvement [8].

Alternative non-pharmacological treatment options

Behavioural and psychological symptoms in dementia are best managed by non-pharmacological approaches particularly if mild to moderate in severity and should be the first line options in an individual's treatment plan according to NICE SCIE guidelines 200719. BPSD is multifactorial and likely factors, which cause, exacerbate or relieve the non-cognitive symptoms, will be specific to an individual. This has been recognized by the National Framework for Older People (Department of Health 2001) and the All Parliamentary report on dementia which states that people with dementia need more individualized support and emphasis being placed on promoting 'person centered' dementia care15. The assessment itself should take in consideration the person's physical health, mental health, undetected pain, medication notably any recent changes and side effects, cultural and religious beliefs, psychosocial factors and their physical environment19. The general approach, once the BPSD has been identified along with the potential antecedents and consequential events, is to tailor a care plan with realistic goals and continually monitor and alter if necessary[7,19].

The physical environment is important to the person with dementia and it has been recognized that it must be adapted to ensure it is constant, familiar and stress free[12]. It has been generally accepted that the use of soft lighting is more calming for an individual along with carpets to absorb sound, and good use of pictures. The distress to care providers caused by wandering could be alleviated by certain modifications; for example, accessibility to areas for walking within a care home environment with digital locks or artificial partitions[12]. At homes the use of assistive technology could be indicated in the form of electronic alarm systems or consideration of GPS type tracking systems if patients are able to consent. Maintaining an individual's temporal environment both during the day and at night is also beneficial to reducing BSPD[12]. It is necessary for a regular, consistent routine to be adhered to by the care givers and any necessary changes to be incorporated into an individual's life slowly. The International Psychogeriatric Association collated report on BPSD indicates that sleep patterns are affected by both temporal and physical environments as well as from biological factors. Increased activity and exercise during the day is thought to improve circadian rhythms and hence sleep patterns and quality of life impacting on reduction in challenging behaviours[12].

Research into non-pharmacological interventions is limited but it has been found that depression/apathy/ wandering/ pacing and repetitive questioning/ mannerism are most responsive to this type of management[12]. NICE-SCIE guidelines 2007 and research highlight that possible treatments that could be considered for BPSD are aromatherapy, multisensory stimulation, and therapeutic use of music and or dancing, animal assisted therapy and massage[19]. Cochrane database systematic reviews have been undertaken with reality orientation having the strongest evidence for demonstrating benefits in BSPD[12]. Music has a strong research base suggestive of being beneficial in managing BPSD; however, when collated together, the Cochrane Review concluded that it was unable to establish a statistical significance[12]. Background music has been found to reduce anxiety in a variety of medical illnesses

ranging from post-operative areas to obstetric wards and evidence suggests that music should be to an individual taste and culture for it to be at its most effective [12]. However, when considering any type of approach, it will clearly depend on its accessibility and availability, as well as an individual's preference. Dementia care homes are also fulfilling their roles and now implementing a daily activity schedule incorporating both physical and social therapies, which have been evaluated and show a reduction in behavioural and psychological symptoms and the need to use psychotropic medication[23]. The need for external support and education to the care homes and families has also been recognized and recommended to aid a potential reduction[14, 19].

Psychological interventions for individuals are also important in attempting to allay BPSD[19]. People with dementia particularly in the early stages will still have insight into their illness and the knowledge of the progressive, terminal nature of the disease. This can lead to heightened anxiety and a grief type reaction to their loss of higher cognitive functions, which can potentially be reduced by individual or group psychotherapy[12]. Evidence also suggests that family therapy can have a significant impact on both the patients and caregivers well-being although, like other therapies, it may require adaptations with disease progression[12]. Family therapy can allow issues within the family to be expressed and resolved within a safe environment which offers the potential to reduce agitation. Practical matters, for example, finances can be sorted along with understanding and acceptance of role changes and the new family dynamics[12].

Conclusion

Dementia is a growing health problem with a rapidly growing population. BPSD is difficult to manage in a system solely based on a medical model because of the lack of evidence for specific medical interventions and the current worries regarding the use of antipsychotics in dementia. Alternative therapy could offer some help, but again the evidence is not clear. However, there is a great need to develop a multidisciplinary approach to deal with this multi-factorial problem. Education and training for medical, nurses and social care forces are essential. The authors believe that the current medical profession should prepare for this coming challenge.

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الملخص

الخرف هو مرض عصبي انحلالي يصيب الدماغ بحيث يؤدي إلى اضطرابات في الوظائف المعرفية ذات الكفاءة العالية. إن أعداد المصابين بهذا المرض وكذلك العبء المادي الناتج عنه بازدياد في كافة دول العالم. هذا بالإضافة إلى أن هذا المرض أصبح موضع اهتمام في مناطق العالم ذات الدخل المتوسط، كما إن أعداد كبار السن بازدياد أيضاً. إن الاضطرابات النفسية والسلوكية الناتجة عن هذا المرض متعددة الأشكال وطرق العلاج متنوعة ومن الصعب علاجها في ظل نظام علاجي إذا ما اعتمد فقط على العلاج بالعقاقير الطبية وخاصة إنه لا يوجد دليل طبي قاطع يثبت فعالية أية منها لغاية الآن، هذا بالإضافة إن لها تأثيرات سلبية ومحاذير متعددة من استعمالها. إن الهيئات الطبية في مناطق الشرق الأوسط يجب أن تكون مستعدة وهذا يتطلب ضرورة الإسراع في تدريب وتثقيف العاملين في مجال الصحة النفسية لغايات إنشاء فرق طبية متخصصة تتناسب مع حضارتنا للتعامل مع هذه المعضلة الطبية متعددة الأسباب.

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