Open online education: translating dementia knowledge to non-traditional settings and students

Matthew T. K. Kirkcaldie, Aidan Bindoff, Lyn Goldberg, Andrew Robinson, James C. Vickers, Fran McInerney
Dementia has enormous social impact, particularly on partners caring for people with dementia in early stages, who lack knowledge and may become socially isolated.

In Australia and other countries, the aged care workforce lacks knowledge of the nature of dementing diseases and how they progress.

Part of the Wicking Centre’s funding mandate is to address these critical issues.
Wide internet access and new generations of easily-used devices like smartphones and tablets has democratised online resources. Education providers have developed an online market for self-education and upskilling. The advent of Massive Open Online Courses (MOOCs) has democratised access to quality education from recognised providers.
Understanding Dementia - FREE Online Course

Enhance your understanding of dementia online
The UD MOOC has been offered five times since 2013, attracting **90 635 enrolments**

Covers **The Brain, The Diseases, and The Person** via neuroscience, health and social science

Researchers and educators are interviewed, along with **interactive learning strategies**

Completion requires a passing grade of 70% on **three end-of-unit quizzes**
### Understanding Dementia structure

<table>
<thead>
<tr>
<th>Module 1 – The Brain (weeks 1-3)</th>
<th>Module 2 – The Diseases (weeks 4-6)</th>
<th>Module 3 – The Person (weeks 7-9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Normal brain anatomy</td>
<td>• How is dementia different to normal ageing?</td>
<td>• Dementia progression and staging</td>
</tr>
<tr>
<td>• Normal brain function</td>
<td>• Risk factors</td>
<td>• Living with dementia</td>
</tr>
<tr>
<td>• Pathology of dementia</td>
<td>• Early warning signs</td>
<td>• Dementia palliation</td>
</tr>
<tr>
<td>• Future directions of research</td>
<td>• Diagnosis</td>
<td>• Behaviours in dementia</td>
</tr>
<tr>
<td></td>
<td>• Dementia symptoms</td>
<td>• Dementia design</td>
</tr>
<tr>
<td></td>
<td>• Medical management</td>
<td>• Dementia-friendly communities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Strategies and therapies</td>
</tr>
</tbody>
</table>

**Discussion forums (weeks 1-9)**

- Social space
- Technical support
- **Ask an Expert**
• Participants’ background varies from primary school to postgraduate university level.

• Participants without a university education were just as likely to complete as those with.
### High engagement and completion

<table>
<thead>
<tr>
<th>Offering</th>
<th>Registrants</th>
<th>Completion</th>
<th>Int’l</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 2013</td>
<td>8 914</td>
<td>3 381 (38%)</td>
<td>12%</td>
</tr>
<tr>
<td>March 2014</td>
<td>15 329</td>
<td>5 684 (37%)</td>
<td>28%</td>
</tr>
<tr>
<td>October 2014</td>
<td>23 377</td>
<td>7 907 (34%)</td>
<td>42%</td>
</tr>
<tr>
<td>August 2015</td>
<td>22 983</td>
<td>10 266 (45%)</td>
<td>37%</td>
</tr>
<tr>
<td>August 2016</td>
<td>20 032</td>
<td>8 492 (42%)</td>
<td>33%</td>
</tr>
</tbody>
</table>

- **90 635** participants, **35 730** completions *(average 39%)*
- > 80% of registrants are **female** *(contrast to typical MOOCs)*
- Highest sustained rate of completion of a MOOC world-wide
- **Top 50** of world MOOCs, **#1 in Health/Medicine** *(Class Central)*
Monitored by **academic staff** and **answered daily**

**Labour intensive** process (engages ~10 academic staff monitoring and responding, for 9 weeks)

**Responses are very infrequently read** (usually 5-15 reads from tens of thousands of participants) – poor use of academics’ time and expertise.

**Questions frequently repeat** with minor variations
Asking this for clarification.

Most of us experience episodes of forgetting things. Like forgetting a sister's birthday, or forgetting to get some milk on the way home and so on. But then "remember that I forgot".

Is this process in a different part and pathway of the brain than the chronically affected Alzheimer's brain?
That's a great question, Teresa, and a very interesting topic to think about. We are used to describing memory as if it was a passive association between things, as if you're reminded of stuff whether you want it or not, but in some cases we actively choose what we want to remember, and deliberately try to keep something in mind for later. Everything that happens to us is evaluated, either involuntarily in the form of an emotional/stress response, or consciously because we know its importance. The emotional stuff links nicely to the likelihood that a memory will be formed (although not how good the memory is, it's been shown that people saying "I can remember exactly what I was doing when I heard JFK was shot / the World Trade Centre was attacked" are really only about as accurate as other memories of a similar duration). But the decision making side is a mystery, it's a high level process in which the brain is keeping an eye on its own functions, which is a lot to think about! The best we could do is to say it's a frontal lobe function, because people lose planning and organizational skills when they have frontal lobe damage, whether it's from injury or dementia. So in that case, a person with advanced dementia wouldn't be aware that they had forgotten something because of frontal lobe damage.

Another thing to think about is how one-way some memories are - I recognise lots of students but can't remember their names very often, but if you tell me a student's name it is usually easier to remember what they look like. So memory is not just association, but a very active organisation of useful knowledge.

Hope that helps.

Cheers,

Matthew.
oop's I forgot

posted 30 December, 2014 7:34 AM

Asking this for clarification.

Most of us experience episodes of forgetting things. Like for example, you can't remember where you left your keys or you forget to go to the store for groceries.

more

0 Unread 1 Replies 12 Views
Automating to scale up

We have plans to **greatly increase the reach of our educational offerings**, so we need to cope with large numbers of students.

“Ask an Expert” will not be **sustainable in its current form** if we have **hundreds of thousands of participants**.

➡️ **What questions should we address?**
Co-occurring semantic groups were identified in student posts for MOOC offerings 3, 4 and 5 using the R package **stm**, which computes structural topic models (Roberts et al., 2013; 2014; R core team, 2016), to meaningfully decompose the concepts embodied in text (Chang et al., 2009). Models were fitted for \( k = 5, 12, 15 \) and 24 topics.


Roberts et al. (2014) “stm: R package for structural topic models.” R package version 0.6 1.


Ten identifiable topics from the $k=15$ analysis

<table>
<thead>
<tr>
<th>Topic</th>
<th>Content Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appreciation of the course</td>
<td>(10.8%)</td>
</tr>
<tr>
<td>Dementia risk and onset</td>
<td>(8.8%)</td>
</tr>
<tr>
<td>Care and support</td>
<td>(8.8%)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>(8.5%)</td>
</tr>
<tr>
<td>Social and familial relationships</td>
<td>(7.5%)</td>
</tr>
<tr>
<td>Brain pathology</td>
<td>(7.3%)</td>
</tr>
<tr>
<td>Medications and treatments</td>
<td>(7.2%)</td>
</tr>
<tr>
<td>Guardianship and competency</td>
<td>(6.9%)</td>
</tr>
<tr>
<td>Preventing dementia</td>
<td>(6.8%)</td>
</tr>
<tr>
<td>Managing challenging behaviours</td>
<td>(5.4%)</td>
</tr>
</tbody>
</table>
We aim for participants to submit questions via a web interface which suggests similar questions and answers as relevant. The user can accept these as satisfactory or pass their question on to the expert panel. If successful, we may also create a standalone online Dementia Knowledge Bank to provide dementia info to the public between MOOCs.
The Wicking Centre has recently received an unprecedented **third round of sustaining funding** from the J.O. and J.R. Wicking Trust.

One goal for this third phase is **to reach a million people** with our educational offerings.

With this analysis and others like it, we will **develop tools to deliver dementia education to a broad base of people** and thereby help to achieve our social mission.
Hello Experts.. This has been a most enjoyable and informative course which has helped to consolidate a lot of what I already knew (but didn’t realise I knew it until now)...you have a great knack of drawing out previous experiences and making us think about things in depth without it seeming onerous. Thank you. I am quite sure I shall think of a question at some point and will then come back to this thought tree.
Anecdotally, often the “burning questions” that people want to ask before completing any of the course. Heredity is a common theme.

Frequent: dementia, peopl, diseas, life, suffer, earli, young

Exclusive: dementia, young, men, suffer, life, peopl, diseas

Is dementia more common in women and men? Also I read that people with blue eyes are more prone to suffer from dementia, is this true? [Intro]

Is dementia hereditary? Is there anything we can do now to stop us from getting dementia? Why do some people get dementia and others don’t? [Intro]
Care and support

Frequent: care, work, dementia, age, peopl, facil, carer
Exclusive: fund, train, provid, care, servic, facil, communiti

... Why is it that they deem it not as important to see that the caregivers and nursing staff are not looked after well, our wages being one of the biggest problems! People in the health systems are all under paid for what we are and what we are doing! Any ideas here? [The Person]
Diagnosis

Frequent: diagnosi, diagnos, earli, alzheimer, cognit, test, age
Exclusive: diagnosi, mri, treatment, diagnos, ect, cognit, stroke

What screening tools can you recommend that may help in the diagnosis of dementia specifically AD? I use MMSE, MOCA test, CDT, which of these is the most sensitive. please enlighten me. thank you.

If a patient has several heart attacks and strokes and well as carotid artery blockage(plague build up) and high blood pressure. What diagnosis is it vascular or Alzheimers?
Social and familial relationships

Frequent: year, mother, famili, live, home, time, friend

Exclusive: parent, sister, mother, visit, father, doesnt, longer

My grandmother has dementia, according to the doctor who took away her driving and can no longer live alone. However, she does not know that she has dementia. and is very cranky towards my mother (the caretaker). My grandmother live over 300 miles away, which means my mother is staying with her ... NOW, Grandma refuses to come up for the holidays, which means that my mother is unable to come up here.
Frequent: brain, bodi, memori, part, affect, cell, lewi
Exclusive: lewi, cortex, hippocampus, nerv, cell, dream, bodi

We’ve learned that in Alzheimer’s disease one of their hallmarker is the betaamyloid plaques inside the cell, and also in Lewy Body disease, the main neuropathological feature is the presence of lewy bodies. My questions is: What is the cause that origine this lewy bodies and how destroy the neuron? For example in Alzheimer’s disease researchers founded the bad functioning of betamyloid protein or tau-protein for neurofibrillary tangles. Thanks.
Frequent: stage, medic, effect, research, type, progress, find

Exclusive: stage, depress, effect, progress, drug, advanc, anxieti

There was mention of the limitation of drugs being used to help with the symptoms of the disease. It sounded like the maximum timeline for benefit was 12 months. My question: Is there any benefit in continuing these drugs after 12 months? Or is the benefit outweighed by the side effects of these drugs?
Guardianship and competency

Frequent: person, patient, famili, ill, make, wonder, support

Exclusive: patient, cultur, ill, popul, termin, person, legal

I know of a legal matter involving a person with dementia and her family members. In this matter, a “capacity” assessment on the person with dementia was to be performed by a Neuropsychologist instead of a Geriatrician. Can someone please explain to me why a neuropsychologist is preferred over a geriatrician in this kind of situation? I would think a Geriatrician's expertise would qualify him/her to perform such an assessment would it not?
Frequent: risk, div, prevent, activ, studi, brain, factor
Exclusive: div, diet, alcohol, oil, coconut, nutrit, gene

A recent study of diet and effects on Alzheimer's by Martha Clare Morris, PhD, a nutritional epidemiologist at Rush University, has 15 dietary components. Apparently closely adhering to the dietary protocol lowered the risk of Alzheimer’s by as much as 53 percent. One recommendation is to drink 200ml wine daily. As alcohol is a known class A carcinogen would grape juice be a better alternative? Would it be as beneficial?
Managing challenging behaviours

Frequent: resid, behaviour, nurs, manag, day, medic, home

Exclusive: aggress, agit, wander, bed, resid, behaviour, pmc

... As a Carer I witnessed different kinds of ... "Sundowning behaviour“. I have one resident who had risperidone to manage hs agitation. But after he had 2 consecutive falls, all of a sudden they ceased the risperidone. The situation right now is the resident displayed inappropriate behaviour, more resistive during adl's, agitated and verbally and physically aggressive. Do you think that the pill I've mention make his behaviour worse?