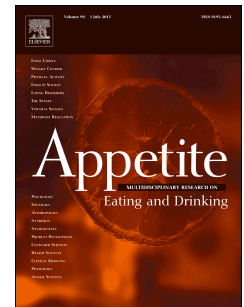


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Exploring perceptions of eating with dementia: Findings from a massive open online course

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List of Abbreviations

MOOC	Massive Open Online Course
UD-MOOC	Understanding Dementia Massive Open Online Course
STM	Structural Topic Modelling

2.1 Title Page

Exploring perceptions of eating with dementia: findings from a massive open online course.

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Abstract

People with dementia are at high risk of malnutrition as a result of progressive symptoms that affect eating. Maximising opportunities to enhance nutrition and strategies to encourage eating are a crucial part of providing care. Caregiver knowledge and a person-centred approach to eating is essential to reduce symptom burden and maintain quality of life. There is currently limited research investigating first person perceptions of eating with dementia, particularly beyond small sample sizes. Therefore, this paper aims to explore community perceptions of how best to encourage eating for people with dementia using findings from an online course. Within the *Understanding Dementia* Massive Open Online Course, responses to the following statement were collected: 'If I had dementia, the things that might help me to eat include...'. A total of 3,651 participant responses were collected from the 2018 and 2019 course enrolments and analysed using structural topic modelling and secondary thematic analysis. The majority of participants were female, tertiary educated Australians over 50 years old. A third were paid caregivers. Thirteen topics were isolated from topic modelling that can be reduced into six broad categories: food type personalisation, meal choice, meal presentation, eating environment, eating assistance and end of life nutrition. Participant responses demonstrated diverse awareness of important aspects to encourage eating in dementia. Findings support the need for improved uptake of nutritional strategies in practice and education on eating with dementia to support caregivers.

Keywords: dementia, eating, perception, qualitative, massive open online course

Introduction

Dementia is a progressive condition which gradually reduces an individual's ability to complete activities of daily living and remain independent (Gale et al., 2018). The range of complex physical and behavioural symptoms that may present along the trajectory of dementia negatively impacts eating and drinking, manifesting in states such as dysphagia, changes in appetite and sensory disorientation to food (Ikeda et al., 2002). Eating habits can be influenced by many facets of lived experience, including cultural and social backgrounds (Chang & Roberts, 2011). Furthermore, eating has an important role in many areas of wellbeing and can be the means through which people participate in activities, socialise and experience joy. If a person is unable to engage in eating this is likely to create a sense of fear or loss, especially if this coincides with higher care needs, such as in the case of dementia (Hammar et al., 2016).

Compromised eating ability increases the risk of poor nutritional health, malnutrition, dehydration, delayed wound healing, a decline in mobility and overall greater risk of early mortality (Watterson et al., 2009). According to a report from Dietitians Australia, up to 50% of people with dementia living at home and in formal care in Australia are malnourished (Dietitians Australia, 2019). Patient-centred care approaches that consider food quality (Puranen et al., 2015), meal assistance (Simmons et al., 2001), dining environment (Habib et al., 2017) and sociocultural needs (Odenrants et al., 2020) have been identified as central components to avoid negative nutrition-related health outcomes in dementia.

Providing an environment which supports eating can be considered just as relevant as ensuring the nutritional content of meals, given that even a highly nutritious meal has no nutritional impact if it is not consumed (Hobbins, 2016). Good nutrition in dementia not only requires access to appropriate food but adequate support to overcome the symptomatic challenges that hinder food intake (Leslie et al., 2013). Evidence suggests that ensuring families, caregivers and others who may become involved in caring for those with dementia understand how to best support nutritional health, contributes to reduced dependence and improved quality of life for people living with dementia (Ball et al., 2015). The primary decision making and facilitation of quality nutrition practices often falls to those involved in the care of people with dementia and therefore this cohort was the key focus in this study (Odenrants et al., 2020).

Despite a wealth of evidence to suggest the considerable impact of decreased eating on health outcomes in dementia and the benefits of specific approaches, uptake of practices to encourage eating does not always occur in both residential aged care and home environments (Beattie et al., 2014; Lea et al., 2019; Mole et al., 2018). Although there are many factors at play, this is partially a result of poor knowledge of nutrition, contrasting perspectives about best care and limited caregiver reserve to face situational barriers in paid and unpaid settings (Faraday et al., 2019; Keller et al., 2015). Previous research into knowledge of improving eating in paid settings suggests that identification of malnutrition is low (Mole et al., 2019). Paid caregivers, including health professionals in residential aged care, may not have sufficient knowledge of how to approach eating challenges in the context of the unpredictable behavioural and physical symptoms seen in dementia (Beattie et al., 2014; Lea et al., 2017). Informal caregivers, such as family and supportive community members, may have misconceptions about risk of malnutrition and are more likely to feel challenged by poor eating (Fjellström et al., 2010). A systematic review of education programs aiming to improve general or practical knowledge of dementia deployed for dementia caregivers found these programs appear to improve knowledge but not necessarily change care outcomes and rarely address interventions to encourage eating (Rea et al., 2019).

Knowledge alone is not attributable to behaviour as seen in many health-related activities, as a result of numerous barriers (Field et al., 2014). Additionally, perceptions, experiences and attitudes can affect an individual's confidence in understanding and therefore the likelihood of seeking further education (Radecki & Jaccard, 1995). However, understanding different viewpoints and lived experience provides a multidimensional understanding of how knowledge may be translated into practice (Radecki & Jaccard, 1995). Therefore, exploring the way in which caregivers perceive eating with dementia may provide novel information about the likelihood of applying knowledge in practice and improving care. Limited research is available on the application of knowledge and perspectives towards improving eating in dementia and the other potential roles of eating behaviours in the life of someone with dementia, such as routine and meal rituals. Furthermore, past exploration of perspectives of nutritional care in dementia has been limited to small samples, making it difficult to draw dependable conclusions about understanding of dementia and perceptions in whole communities.

This study aimed to explore community perceptions of how best to encourage eating for people with dementia. Gaps in knowledge of best care for people with dementia have been identified in

dementia caregivers (Pleasant et al., 2017) and previous authors have suggested anonymous open-ended questioning as a useful evaluative strategy for research to collect rich, unrestricted data (Robertshaw & Cross, 2019). The design of this study allowed for examination of caregiver perspectives, as opposed to knowledge, through open-ended discussion. Studies within dementia care have identified the need to measure how caregiver knowledge actually affects practice (Pleasant et al., 2017); exploring perspectives and using a discussion stem framed from a first-person viewpoint such as in this study may contribute to understanding what people are most likely to put into practice based on reflection on their own life experience and viewpoint, rather than knowledge of what they accept to be best practice.

Method

Design

This study used a qualitative descriptive approach, with structural topic modelling used to support analysis of a large textual dataset. In most cases, when a research question is explored through participant experience, the findings can then be adapted to target interventions or knowledge improvement (Colorafi & Evans, 2016). For these reasons, a qualitative descriptive design suits this study well, as it allows for exploration of perspectives on encouraging eating in dementia, without the need to develop theories beyond the data available. This combination approach of qualitative analysis and structural topic modelling has been used to explore similar data in online course environments (Borchard et al., 2022; McNerney et al., 2018).

The Understanding Dementia Massive Open Online Course (UD-MOOC) is a free, 7-week online course developed by the Wicking Dementia Research and Education Centre and The University of Tasmania. First delivered in 2013, this globally accessible course offers the opportunity to improve awareness and knowledge of dementia, whilst allowing the opportunity for peer discussion, with the aim of enhanced care and quality of life for those with dementia (Eccleston et al., 2019). This course provides a useful avenue for collecting information from a diverse learning group and what they consider important for people living with dementia. Given the volume of data available, this study used a quantitative structural topic modelling approach to explore the qualitative dataset. Topic modelling assists in deriving major topics from large collections of qualitative material and has proven beneficial in past MOOC research (McNerney et al., 2018).

Data Collection

MOOCs are gaining momentum in research as an informative and highly accessible means of collecting information about knowledge, perspectives and attitudes of a broad cross section of participants (Laurillard, 2016; McInerney et al., 2018; Robertshaw & Cross, 2019).

In the last module of the UDMOOC, an interview-style video introduced participants to common symptoms of advanced dementia, including dysphagia. The interview included discussion of basic practices that may improve eating including food modifications, maintaining meal temperature and basic feeding assistance as well as the contraindications for tube feeding. Participants were able to access a link to an external document that explained the nature of dementia onset and undernutrition, as well as environmental and social considerations to promote eating (Alzheimer's Disease International, 2014). During the course, participants were presented with a case study involving a man with dementia who would not eat his meals for cultural reasons, followed by suggestions to encourage food intake, including considering cognitive or mechanical deficits and consulting family about cultural needs. The following question was then posed to participants, *"Imagine you have dementia, poor eyesight and have perhaps lost your sense of smell (anosmia). What could be done to improve your desire and ability to eat?"*. They were then invited to voluntarily contribute an ending to *"If I had dementia, the things that might help me to eat include..."*. Due to the way in which this discussion board was framed, participants were able to reflect as if they themselves had dementia, therefore creating the opportunity to collect rich information about a range of topics related to eating.

Participants

This study draws information from an international community sample from 2018 and 2019 UD-MOOC enrolments. A total of 49,670 people participated in the UD-MOOC across the two-year period with 38,816 (78.1% of entire cohort) of these consenting to participate in research by selecting "yes" to their data being used for research purposes. This included discussion board contributions and demographic information (Table 1). Providing a response to discussion boards was optional. A total of 3,651 participants (9.4% of UD-MOOC consenters) posted in the diet and dementia discussion board and were included in analysis (Table 1). Typically, those who have provided care in a paid or informal capacity for people living with dementia rather than those diagnosed with dementia are participants in the UD-MOOC (Eccleston et al., 2019). The experiential learning of this care population has been shown to influence their knowledge of dementia and

perceptions of care (McInerney et al., 2018; Borchard et al., 2022).

Data Analysis

Discussion board responses were deidentified and any personal names anonymised by a MOOC administrator prior to data handling. Due to the size of the data set, a two-step approach was used to explore the discussion board responses: structural topic modelling, followed by thematic analysis, an approach used to analyse MOOC responses previously (McInerney, 2019). Demographic data were analysed using descriptive statistics, with chi-square tests performed to compare UD-MOOC participants who responded to the discussion board with those who did not. This analysis was completed using IBM SPSS Statistics 26 software (IBM Corp, 2019).

Structural Topic Modelling

Structural topic modelling (STM) utilises a computerised algorithm to identify co-occurrence of words and phrases within text (Blei, 2012). Topic modelling allows for primary analysis of large qualitative samples to render a dataset that would otherwise be unwieldy to dissect and analyse meaning from (Bakharia et al., 2016). This analysis technique derives semantic meaning from words appearing together and uses this information to generate a series of topics which describe the data set. STMs were fitted using the '*stm*' package in R (version: 4.0.2, released: 2020) (R Development Core Team, 2013; M. Roberts, Stewart, & Tingley, 2018). Four structural topic models (containing 9,12,15 or 18 topics), were assessed and compared using the '*stmQuality*' package (Bindoff, A 2018), which were crafted by an experienced statistician (AB). The 15-topic model was selected and agreed by three authors (IG, KD and EL) based on the exclusivity and semantic coherence of topics within the model. Each topic was defined by keywords with the highest probability of occurring in that topic as well as words that discriminated between these topics. Fifty exemplar responses within each topic were then thematically analysed.

Thematic Analysis

Structural topic modelling produces themes from large data sets but does not assign real-world meaning or retain response integrity given the responses are fragmented during the modelling process. Therefore, further interpretation through secondary thematic analysis was used in this study by examining exemplar responses. The 15-topic model chosen was scrutinised by reading participant responses aligned to the topic. One topic repeated the discussion board stem phrase, thus did not constitute a meaningful response set, and one topic did not reveal clear semantic

meaning or a definitive theme and were excluded from further analysis. The remaining 13 topics were reported based on the interpreted themes. Direct quotes from participants were reported to highlight themes within responses and further grouped into six overarching themes based on similarities in the context of eating. Each direct quote is presented with participant gender (F = female, M = male), age (number) and caregiver status; for example (F, 67, non-caregiver). Reflexivity bias was considered given author interpretation of response meaning was necessary (Finlay, 2002). A reflexive journal was kept throughout analysis and response meaning in the context of the UD-MOOC. Authors conferred on the meaning ascribed to a given topic until consensus was reached.

Results

Analysis of participant demographics found that most were female (89.6%), Australian (73%), over 50 years old (62.6%) and had completed tertiary education (80.7%); however there were diverse age groups and education levels represented in discussion board participants, as for all UD-MOOC participants (Table 1). There were differences between the demographic characteristics of discussion board participants compared to UD-MOOC participants who did not participate in this discussion board. This was particularly the case for age, with discussion board participants being older than other UD-MOOC participants ($p < .001$). Discussion board participants were most likely to identify as paid caregivers (33.7%) followed by non-caregivers (26.1%) (Table 1).

Table 1: Demographic information for diet and dementia discussion board participants and all other UD-MOOC participants.

	Discussion board participants (n = 3,651)	Other UD-MOOC participants (non-participants in discussion board) (n = 35,165)	p value
Characteristics	n (%)	n (%)	
Gender			p < .001
Female	3,273 (89.6)	30,738 (87.4)	
Male	367 (10.1)	4,322 (12.3)	
Other/ N/A / Prefer not to say	11 (0.3)	105 (0.3)	
Age (years)			p < .001
- Below 30	240 (6.8)	6,552 (19.0)	

- 30-39	390 (11.1)	6,748 (19.6)
- 40-49	688 (19.5)	7,300 (21.2)
- 50-59	1,172 (33.2)	9,597 (24.5)
- Over 60	1,037 (29.4)	5,382 (15.6)
Education (highest level completed)		p < .001
- Grade 10 and below	333 (9.2)	2,791 (8.0)
- Grade 11 and/or 12	331 (9.2)	3,488 (10.0)
- Diploma / Certificate / Associate Degree	1,198 (33.2)	11,241 (32.3)
- Bachelor's degree	958 (26.5)	10,566 (30.3)
- Postgraduate	792 (21.9)	6,764 (19.4)
Caregiver Status		p < .001
- Paid caregiver	1,231 (33.7)	14,662 (41.7)
- Unpaid caregiver	663 (18.2)	4,626 (13.2)
- Both (paid and unpaid)	802 (22.0)	7,801 (22.2)
- Non-caregivers (neither paid or unpaid)	953 (26.1)	8,064 (22.9)

Thirteen unique topics emerged from topic modelling and were analysed based on the nuances in meaning of response data. The topics are presented under descriptive thematic headings in order of highest relation proportion within the whole data set, as determined during topic modelling (see Figure 1). The included topics were then further analysed and organised into six descriptive theme groups based on thematic similarities (see Table 2).

Table 2: Structural topic modelling output words associated with each of the fifteen topics presented with theme group, interpreted theme and description.

Structural Topic Model			Topic Interpretation	
Topic	Theme Group	Co-occurring topic words	Interpreted theme	Description
1	1	soft, pure, fruit, soup, fresh, mash, veget	Preferable foods and consistency	Soft foods and specific food preferences listed with emphasis on health benefit
2	1	sweet, cream, ice, chocol, dessert, glass, water	Sweet, pleasurable foods	Sweet food types in relation to desirability or health
3	-	eat, thing, dementia, might, includ, someon, want	Discussion board stem phrase	Repetition of discussion board stem (excluded)
4	1	food, small, favourit, amount, offer, finger, frequent	Small and frequent meals	Offering small, frequent meals often described alongside food temperature

5	6	will, stage, want, dementia, time, know, need	Changes to eating with dementia progression	Awareness of effect of dementia on eating needs, particularly in relation to healthful versus enjoyed foods
6	4	sit, good, peopl, comfort, love, nice, other	Comfortable, social environment	Physical features of dining environments and promoting socialisation
7	6	person, care, feed, patienc, life, dementia, understand	Medical nutrition decision-making	Artificial feeding perspectives and risk management
8	4	time, environ, assist, music, need, calm, rush	Calming environment	Relaxing dining environments with emphasis on encouragement but avoiding force
9	1	swallow, easi, food, chew, appeal, easili, easier	Diet for easy, safe swallowing	Swallowing safety and food modifications to suit condition
10	2	also, tasti, think, import, prefer, staff, home	Eating preferences	Respecting and providing eating choices
11	5	help, encourag, famili, use, food, mayb, might	Social encouragement	One on one physical and behavioural ques to encourage eating
12	5	make, dont, give, mouth, sure, spoon, get	Eating assistance and prompts	Suitable eating utensils and addressing other care needs before assisting (indirect assistance)
13	3	food, like, enjoy, serv, familiar, portion, look	Meal presentation	Presentation and familiarity of food important for meal enjoyment
14	3	plate, colour, can, cutleri, smell, use, see	Sensory stimulation	Sight, smell, touch and sound of food, utensils and the cooking process
15	-	meal, food, may, tast, textur, varieti, know	Unclear, mixed theme	Un-unified theme (excluded)

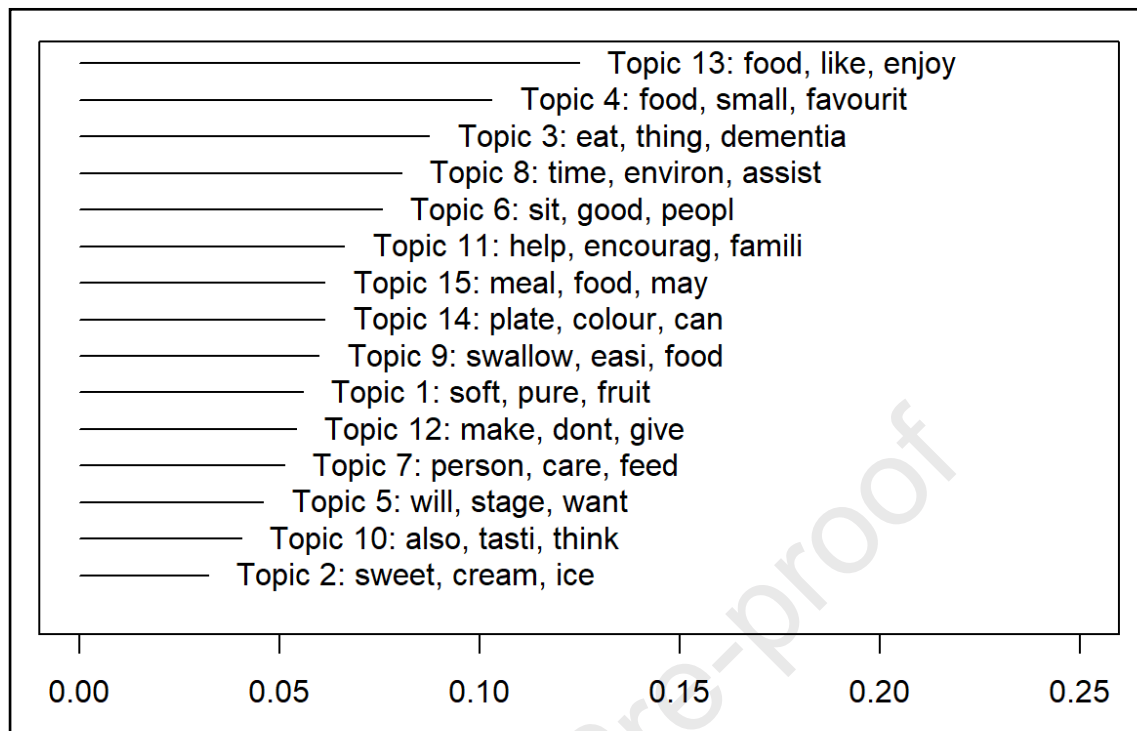


Figure 1: 15-topic model demonstrating the proportion (%) of each topic in comparison to the entire data set of responses.

The six themes developed during the thematic analysis process each represent and summarise the key concepts which participants identified and are detailed below.

Personalised Food Modifications

The relationship between dementia and commonly requiring dysphagia-friendly foods was identified: “... food easily [chewed] and swallowed, avoiding dry crumbly things that could be drawn in with breath...” (M, 68, non-caregiver). Altering meals in this way to include more dysphagia-friendly foods based on individual circumstance was explicitly noted by a small number of participants,

“A consult with a speech pathologist to assess swallowing reflex. A consult with a dietician to ascertain suitable meals to avoid aspiration. A diet of semi thick and thick consistency that is easy to chew in order to prevent inhaling food and fluids” (F, 57, unpaid caregiver).

There was a general consensus that small, frequent meals would be preferred, including cross-over into other topics: “Having small amounts, snacking” (F, 65, non-caregiver). Participants also regularly discussed the importance of food temperature to maintain the appeal of food: “Small amounts more

often. Keep hot foods hot and cold foods cold. Offer foods I grew up with, comfort foods” (F, 54, paid caregiver); *“Small amounts more frequently. Keep food warm”* (F, 71, unpaid caregiver).

Participants often listed their favourite foods as their entire response or did not explain their reasoning behind why certain textures may be preferable: *“... soft, creamy foods such as pasta, scrambled eggs, ice cream, milkshakes/smoothies, pureed foods ... Liquids could be problematic as could foods that require a lot of chewing such as meat and raw fruits and vegetables”* (F, 64, unpaid caregiver). Participants often listed texture preferences or what they perceived to be healthy: *“...If I had to have soft food I would want it to be the things that are already soft ie: soups, custards, scrambled eggs mashed potatoes gravy”* (F, 52, paid and unpaid caregiver). One participant appeared to see texture modified meals as not true food: *“...I would like to eat real food as long as I could, if not I would prefer smoothies made with fruits vegetables and protein powder”* (F, 53, paid caregiver).

Participants made regular reference to sweet foods. It was unclear whether sweet foods were simply enjoyed or if this was in recognition of a sweet preference often seen in dementia: *“Giving sweets/desserts to try even if I didn't eat my main meal because I might have a sweet tooth...”* (F, 49, paid caregiver); *“I would retain my sweet tooth, it means that if anything they feed me is sweet, or better sweet sour, or covered with chocolate (sugarless chocolate, this is) I would be glad of eating”* (M, 55, non-caregiver). Responses were divided between maintaining a healthy diet and eating any desirable foods: *“Soft attractive finger foods ... cake would be an ideal choice (subject to me not being diabetic!!!)”* (F, 46, paid caregiver); *“...I would eat all the foods I have to moderate in my diet for my heart health now”* (F, 58, paid and unpaid caregiver).

Meal Choice

This theme represented the need to respect eating choices and provide food options, with a strong focus on formal health care settings. For some participants, eating implements were an important preference to consider: *“I would NOT like to drink from a plastic cup at all”* (F, 59, non-caregiver). Other participants recognised memory retrieval through meals: *“Eating the meals I used to as a child. It would convey nice memories to me ...”* (F, 36, unpaid caregiver). Although preferred meal timing was not addressed in this theme or any other, in one rare instance, unlimited access to food was mentioned but was not obviously linked to dementia: *“Leave the good stuff out [on display]! Nothing disappears faster than what people can see”* (F, 37, paid and unpaid caregiver).

Meal Presentation

The importance of food presentation to encourage eating was clear in participant responses and this was often linked to familiarity: *"...make food look 'good to eat' and is presented in a way that makes it look like something I would enjoy"* (F, 45, non-caregiver). The association between food presentation and enjoyment was strong: *"the food would have to look appetizing and flavourful, offer foods that I always enjoyed eating"* (F, 44, physiotherapy assistant). This was described as 'known' or 'familiar food' by other participants but still with reference to presentation: *"Foods that I am familiar with and am known to enjoy. Present these in small attractive portions"* (F, 73, unpaid caregiver).

Participants considered the link between eating and sensory response and encouraging eating by adapting to circumstance. For example, one participant wrote that:

"If I have poor eyesight then good smelling food or poor sense of smell then attractive looking meals... where possible, touch I.e: give a piece of fruit such as an orange to peel, the touch, feel, sight, smell and action of preparing the food" (M, 51, unpaid caregiver).

Other responses appeared to consider the effects of dementia in more depth: *"Cups to be coloured to distinguish from table top... cooking smells to permeate space - encourages salivation and subliminal prompting food is coming... reducing distractions, movement, noise"* (F, 49, paid caregiver); *"Working with my hands before eating to stimulate procedural thinking... Not too much around the area I am eating... don't bring me multiple dishes all at once..."* (F, 56, paid caregiver).

Eating Environment

Participants had an awareness of atmosphere and surroundings as an important component of eating, with regular reference to music and aroma as promoters of calmness: *"...a very relaxed and non-stressful environment perhaps with background music and a carer who is calm, relaxed and non-judgemental"* (F, 67, non-caregiver). Promoting calmness was also regularly linked to encouragement and support to eat, suggesting that support was needed to create a peaceful environment for eating: *"Sitting in a relaxed and calm environment, with soft gentle background music playing, aromatherapy diffuser with relaxing fragrances and staff encouraging me to eat..."* (F, 56, paid caregiver). In comparison, environment was sometimes explored in terms of time allocated to eat and staffing: *"Being given enough time not being forced. Being given choice around what I was eating. Being encouraged and supported"* (F, 26, non-caregiver). Participants also recognised the

value of physical characteristics of a dining environment, such as lighting, ventilation, seating position and noise levels: *"Sitting upright in a chair in a calm and well-ventilated room near a window or door..."* (M, 49, paid caregiver). Participants tended to describe physical environment with a direct link to social company at meals, without necessarily providing meal assistance: *"Eating in a familiar place with good lighting, surrounded by people talking and laughing. Not stuck in a dark room on my own"* (F, 55, paid caregiver).

Eating Assistance and Prompts

Participants were aware of the potential need for assistance with eating, with a strong focus on utensil use; for example, *"If I can't recognize a spoon or fork, or know what to do with it, please allow me to eat with my hands..."* (F, 26, paid caregiver). One participant noted that a knife and fork would not be desirable in relation to cultural preference: *"...do not give me knife and forks but the chopsticks"* (F, 43, paid and unpaid caregiver). Assisting with pre-meal care activities, including oral hygiene, toileting and seating position, was seen as important: *"Good mouth care and oral hygiene. Please check that if I have dentures, then they are in, clean and fitting ok..."* (F, 50, paid caregiver). There was also frequent mention of allowing attempts to eat independently and with dignity before assisting: *"...Try to have patience with me. Don't talk to me like I am a baby...use a towel or bib so I don't make a mess on my clothes. Clean my face and hands before and after I eat"* (F, 60, paid caregiver).

Participants also suggested that active verbal prompts will improve eating: *"Talking to me and explaining what was in front of me, reminding me that I like this food, helping me eat... encouraging me to help myself to eat if I could"* (F, 54, non-caregiver). Social surroundings were perceived as an opportunity to encourage eating by observation and repeated prompting: *"It would be important that someone was patiently helping me, maybe describing the food and even eating a similar plate of food next to me at the same time, to encourage me to join in"* (F, 75, unpaid caregiver); *"It may be helpful for me to watch what others are doing and I may then try and mimic this activity"* (F, 43, paid caregiver).

Medical and End of Life Nutrition

An awareness of the changes to eating that may be required as a result of dementia progression was clear in participant responses: *"...what a person's favourite food was when they didn't have dementia may not be their favourite food now that they have dementia"* (F, 55, paid caregiver).

Further recognition of this change was noted by a participant who recognised the negative aspects of eating for some people living dementia: *"Eating will have no meaning or [significance] to me. It could even [prove] detrimental and frightening or even painful for me..."* (F, 53, unpaid caregiver). Dementia was recognised as a terminal condition and as a result, some participants questioned the encouragement of eating at all, raising important ethical issues. For example, one participant stated that *"To be honest, ... I find it strange that we continue to think up strategies to help people eat if their dementia is so far advanced their continence is no longer, the concept of eating is no longer - why keep them alive?"* (F, 35, paid caregiver). Other participants saw food as a meaningful part of life, even when eating was a potential risk to health, in recognition of the need to balance risk with quality of life. For example, one participant noted that *"...despite the risk of aspiration, my life and it's [sic] quality are enhanced through eating and drinking the things I love even though these may hasten me towards a palliative stage"* (M, 51, paid caregiver). Participants were concerned with offering foods that were enjoyed rather than traditionally healthy foods: *"Would it be that bad to just live off chocolate from this point on?"* (F, 38, paid caregiver).

Participants often combined personal stories and perspectives about medical nutrition support, rarely discussing in first person. Most participants agreed that enteral feeding was not useful in dementia: *"I never want a PEG [tube feed] under any circumstances ... I had my father in-law with a PEG ... It extended his life in my opinion, but not his quality of life. I had previously nursed people that also had a PEG. It is a sad medicalization of the natural progression of dying"* (F, 58, paid caregiver). One participant believed enteral feeding was favourable if all other encouragement failed, *"...especially once you start to lose senses and function of body organs... if the person is not able to eat either [by] themselves or because of the dysphagia not at all, PEG is better than nothing and may prolong that person's life..."* (F, 53, paid caregiver).

Discussion

Previous studies into the UD-MOOC have highlighted its benefit in improving awareness of dementia and comparatively high overall course completion rates amongst participants (Eccleston et al., 2019). The effect of knowledge gained from MOOC content prior to participants giving a response is an important consideration, with many concepts from the MOOC arising in the themes identified, such as food personalisation based on preference and ability and meal assistance. Even so,

participants were successfully able to demonstrate their awareness of concepts beyond MOOC content.

The discussion board analysed in this study encouraged participants to reflect on what may encourage eating if they themselves had dementia, which will be affected by experience and behaviours witnessed by people who care for people with dementia. From general observation of the responses, paid and unpaid caregivers had similar perspectives and awareness, which is not an uncommon finding in other areas of research into food and nutrition and dementia awareness (Beattie et al., 2014; McInerney et al., 2018; Robinson et al., 2014).

A person-centred approach to encouraging eating in dementia has been widely advocated in the literature (Keller et al., 2015; Mole et al., 2019). In contrast to other research into awareness of eating difficulties in dementia (Faraday et al., 2019), participants in the UD-MOOC were able to identify a range of person-centred eating practices, including social encouragement and feeding assistance, honouring preference and offering the chance to make informed medical nutrition decisions. This finding may be attributable to the large number of participants and various demographic backgrounds in the UD-MOOC study that provide an unbalanced comparison to many other qualitative studies in this area (Seaton et al., 2014). However, it may also be due to the way in which the discussion board was contextualised through a first-person perspective. Encouraging an empathetic viewpoint may have inspired a deeper person-centred mindset for participants when providing a response (Robertshaw & Cross, 2019). Considering the identified need for further education and practical knowledge for dementia caregivers, this first-person approach may suggest a useful strategy for future education to caregivers.

Personalised food modifications, such as offering soft textures, small portions and thickened fluids, were perceived as a valuable way to encourage eating. There was a strong link made between food modifications and swallowing safety, which is indeed a predominant concern in late-stage dementia (Payne & Morley, 2018). Some participants appeared to presume that meal alterations such as soft meals would be a requirement, suggesting participants perceived themselves as being unable to eat normal textures if they had dementia. This is an important finding given that previous research suggests unnecessarily changing food and fluid texture can potentially discourage eating as a result of reduced satisfaction and enjoyment of meals (Ball et al., 2015; Simmons et al., 2001). Participants were also concerned with prioritising food enjoyment over texture modifications to avoid choking, suggesting that there was consideration of the need to balance risk with quality of life (Dickins et al., 2018). In comparison, tube feeding was generally seen as an unwanted and burdensome intervention in dementia in the UD-MOOC cohort, which was briefly discussed in the UD-MOOC

content. Participant viewpoints on tube feeding concur with most recent literature of best practice, that suggests enteral feeding to combat the negative nutrition impact symptoms that are usually seen in advanced dementia does not improve outcomes in terms of dementia progression or mortality (Ijaopo & Ijaopo, 2019; Luk et al., 2017; Schwartz et al., 2014)

The theme that developed surrounding sensory considerations for eating was of interest given the context of the discussion board invited participants to consider having limited eyesight and sense of smell. Participants may have perceived that bright colours and stronger smells and flavours would intensify the eating experience for a person with dampened senses. A study that performed gustatory testing in 29 people with dementia confirmed functional taste declines in those with dementia (Minoru et al., 2020). However, these participants had a higher taste recognition threshold, particularly for sweet tastes, when compared to controls without dementia (Minoru et al., 2020). Similarly, gustatory testing conducted in those with dementia has shown that as dementia progresses, eating-related senses decline and it has been suggested that increasing the taste of meals would result in improved nutritional care and meal consumption (Sakai et al., 2016) This supports the finding that participants continued to see sensory stimulation as an important part of encouraging eating despite the possibility of senses being diminished.

The importance of food enjoyment and offering pleasurable foods was clear given many participants chose to share their favourite food types. Most participants were inclined to view weight loss as a negative occurrence in dementia. Past exploration of perspectives amongst paid caregivers in residential aged care has found that lack of knowledge and confidence exists in determining how much food needs to be eaten to avoid weight loss and malnutrition in those with dementia (Hammar et al., 2016). These same staff expressed feelings of rejection and guilt in seeking support from senior staff and their organisations. Multiple suitable considerations for encouraging eating were identified by participants in this study based on individual experience, however rates of malnutrition in those with dementia suggest that current eating strategies used in practice could be improved. This disparity may be related to multifaceted barriers including poor knowledge alongside aged care hierarchies and funding, two factors reviewed by the Royal Aged Care Commission in Australia (Royal Commission into Aged Care Quality and Safety, 2019).

Chronic disease may be viewed differently based on ethical standpoints of preserving health through nourishment as opposed to allowing enjoyment and likely hastening death (de Beaufort, 2007). Compared to food enjoyment, a smaller proportion of participants perceived the maintenance of a 'healthy diet' to avoid disease progression to be more important than enjoyment. This finding is not

unusual as research into spouses of those with dementia suggests many have a belief that certain foods should be avoided to manage weight and health (Fjellström et al., 2010; Puranen et al., 2015), despite evidence suggesting that lowering the risk of malnutrition should be a higher priority in dementia (Watterson et al., 2009). In addition, it is well known in the literature that sweet food preferences are common in dementia, suggesting higher eating enjoyment with foods typically considered as 'unhealthy' (Mariko et al., 2017; Sakai et al., 2016). These findings suggest that some participants considered healthy food the main priority whilst most perceived pleasurable meals a more important part of eating with dementia.

Assistance strategies such as the Montessori method can be used in dining environments to engage eating skills and maximise eating independence for those with dementia (Lin et al., 2010). Although these strategies were not specifically mentioned in responses from paid caregivers or any other cohort, these methods were often pointed to by describing the steps needed to eat and offering independent eating as a first choice, which has shown to improve individual satisfaction with meals (Lin et al., 2011). Evidence suggests caregivers in formal environments are often forced to prioritise those who need full physical assistance with eating or may not be able to assist due to time constraints in completing other daily activities (Murphy et al., 2017). This may indicate that those who may benefit from the verbal and physical prompt strategies raised by UD-MOOC participants may not be adequately supported. Apart from physical assistance, providing support to someone with dementia was also expressed through environmental and social supports that can enhance eating experience and the quantity of food eaten (Habib et al., 2017; Odencrants et al., 2020). Participants perceived factors such as meal presentation and physical eating environment to be important to encourage eating and were often mentioned in responses.

Participants identified the importance of familiar foods and social interactions, with regular reference to early-life and foods from childhood. Although this MOOC reached a global audience, most participants were Australian and, apart from country of residence, data on ethnic background were not collected. The link between familiarity, social interactions and cultural background was not an apparent theme that arose and therefore was not explored in depth in this study. Previous studies suggest that familiar food and surroundings for people with dementia can improve food acceptance (Hanssen & Kuven, 2016).

While preferred foods and food choices were regularly identified by participants, mention of preferred meal timing was a rarity, aside from suggesting frequent meals. Strict and undesired meal

timing has been linked to poor psychological wellbeing and a reduced sense of autonomy in formal settings for those with dementia, with communication about time expectations and attitudes of nursing staff impacting eating habits (Wang et al., 2019). Previous studies found that caregivers were able to identify that inflexible meal times (Wang et al., 2020) and length of time between meals (Nell et al., 2016) changed level of meal satisfaction in those with dementia. These salient themes from the literature, that were not commonly raised by participants in this study, may suggest contrasting priorities of UD-MOOC participants. Instead, their interests focussed on encouragement through priorities such as food familiarity, meal choice and well-presented food.

Limitations

Unlike using thematic analysis alone in a qualitative study, researcher bias was alleviated by using quantitative structural topic modelling as a primary analysis tool, which developed topics algorithmically without initial interference from researchers (Brookes & McEnery, 2019). This two-step analysis method allowed for investigation of an abundant, diverse sample and large-scale analysis of perceptions. This analysis style, combined with an open-ended approach, created a rich pool of data in which to explore perceptions of dementia in the context of eating. There were however some limitations for this study. People who participate in MOOC discussion boards have been described as more active and may therefore represent a subset of opinions (Mustafaraj & Bu, 2015). It is important to note that the very action of participating in the UD-MOOC shows that participants have a pre-existing interest in dementia and in increasing their level of understanding of dementia. Additionally, because of the way this discussion board was framed, the responses given do not reflect all participant awareness of the topic of diet and dementia, rather their perception of what is important within the specific scenario presented. Participants were also able to view other responses in the discussion board before posting their own response, introducing potential confirmation bias (Robertshaw & Cross, 2019). Although not without its benefits, as it enables participants to build ideas from others, this may inherently interfere with individual posts. Nonetheless, the range of responses obtained suggest this was not the predominant approach to formulating responses. Lastly, although many participants self-identified as caregivers when providing demographic information, data were collated from all eligible participants which included those not currently providing care. The approach of this study was to consider all participants as potential caregivers as any individual can be or may in future be a caregiver. Overall, the aim of gaining an understanding of perspectives from a broad group rather than complete knowledge sets from individuals was successful in this study.

Conclusion

In conclusion, participants in the UD-MOOC were able to identify a diverse range of strategies to encourage eating that considered an array of person-centred practices that remain crucial to dementia care. Through envisaging themselves with dementia, data from these participants has enabled an understanding of what eating means to them and what they felt would interfere with this if they had dementia, a projection of their perceived experience. These perceptions become highly relevant for who these individuals currently or may care for and their care giver strategies.

Further investigation into education needs and opportunities to those both inside and outside of formal care environments may be warranted. This study provides grounds for introducing mainstream access to education to improve awareness of eating strategies in dementia, whilst striving for a system that allows this knowledge to be maximised in practice. These findings may also provide insights for health professionals, especially dietitians, to inform targeted advice and training to other caregivers about improving eating in dementia.

Ethical Statement

This study is part of the evaluation of the design and delivery of the UD-MOOC and associated research into national and international perspectives on dementia approved by the University of Tasmania Human Research Ethics Committee (H0018595). Prior to commencing the UD-MOOC, participants agreed to the collection of de-identified demographic information. Those who also agreed to collection of additional data for research purposes provided written informed consent online for their data to be included. All consenting participants were allocated a user identification number to match demographical information to responses for analysis.

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Author Contributions

All authors have approved and agreed to the published version of this manuscript. IG contributed to the research plan, data analysis, interpretation of results and manuscript write-up. EL and KD contributed to the research plan, data analysis, interpretation of results and critical revision of the

manuscript. AB contributed to data preparation and generating structural topic models used in analysis.

Conflicts of Interest

The authors declare that there were no conflicts of interest.

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