

Laidlaw summer 1 reflective report

The title of my summer 1 research project was “Exploring Knowledge and attitudes of Irish care home staff on Lewy Body Dementia”. I decided to do this project because I have some personal experience of working in a nursing home and having a grandfather with dementia. From my experience of working in the nursing home, I felt that many staff didn’t have a lot of knowledge of the symptoms and behaviours associated with dementia, especially Lewy Body dementia. Lewy Body Dementia (LBD) is the second most common form of dementia after Alzheimer’s and can manifest with challenging behaviours and symptoms. Residents with LBD can be hard to care for as they may experience delusions, hallucinations, along with reduced mobility and many other symptoms. There are few treatment options for LBD, again making it harder for carers and families. For these reasons, I had an interest in knowing the level of knowledge of care home staff in Ireland on the subject.

I proposed to send out an anonymous online survey to consenting nursing homes in Ireland for staff to complete. This survey had approximately 20 questions, and tested staff on their knowledge of LBD.

My original timeline involved me sending out the survey in July. However, I submitted my application for ethics in June and it is still yet to be approved in the middle of October. This caused me to completely rearrange my timeline, and this reflection will outline the work I have done to prepare for sending out my survey, what I intend to do once I receive ethics approval, and the preliminary results from the field testing of my survey.

The first step in my summer of research was submitting my ethics application. As I had never done any academic research before, I had no idea where to start. I found it quite daunting at first as I had never done any academic research before, and many of the terms were new to me. I did some research on how to submit an application and which department to submit it to. I also had a meeting with a member of the Dementia Research Team in St James’ Hospital who had applied before. It was really helpful to get some guidance, and I met with her a few times to get some more advice. Another issue with applying for ethics approval was that the Ethics committee for the School of Medicine does not allow for any new applications to be submitted after the 1st of June, and my college exams did not finish until after that date. In hindsight, I should have been prepared for this, looked at those dates before and sent in the

application before the deadline. However, as I did not do this, I had to submit my application through the REAMs system. Another challenge arose when I found out that REAMs is not open for undergraduates, so I had to use one of my supervisor's accounts and submit it that way. I found the Laidlaw ALS group particularly helpful for working through the challenges I had with my ethics application as many of my other peers were also submitting applications.

Submitting my application for ethics was probably the least enjoyable part of my summer as it was quite long and repetitive. However, it was definitely a learning experience as it made me realise how important it is to plan for problems and have different plans in place if those problems arise. It also showed me how the life of an academic researcher can be frustrating if the start date of your project is dependent on how long it takes for ethics to be approved.

Another learning experience for me was learning about why ethics is so important in protecting participants. Even though my survey is very low risk, as it is anonymous and does not disclose any participant identifying information, ethics is still necessary to make sure that no questions are being asked that could cause participants any harm. Ethics becomes even more important when we look at larger scale clinical trials for new medications or interventions. I think that there should be a slightly faster system for low-risk surveys and a more accessible system for first time researchers, along with a committee that meets over the summer so researchers can continue over the summer and can get support if they need from admin staff.

The next step of my summer research was drafting and finalising the survey questions. I had a zoom meeting with a director of nursing of a care home which has specialist training in Lewy Body dementia, and also with a family carer of a person with LBD. This meeting was really helpful to gain their opinion on what is important for care home staff to know about LBD and allow them to have some input on the survey. It was very useful to get some feedback on the questions I had already drafted for the survey. Following this meeting, I had another look at the survey, made some changes, and then I met with my supervisor to get her opinion on it.

Once we were both happy with the survey questions, I inputted them onto Survey Monkey and I was then able to field test the survey with some participants. The participants were staff of different grades from a care home in Dublin. There were 16 participants ranging from

activities staff to domestic assistants and clinical nurse managers so it gave me a good insight into whether the survey questions would be accessible for all grades. I got feedback from these participants which was quite good, and no major changes were needed. However, I did learn from this that getting participants to 1) start the survey and 2) fully complete the survey will be a challenge. Having anticipated this, I plan to go in person to a number of different nursing homes and offering some training on LBD, in return for the staff completing the survey. This would not only increase participant numbers but would also be a good learning experience for myself.

Another challenge that I anticipate will be the data analysis of the responses of the survey. As I have mentioned already above, this is my first time doing any sort of research, so I have never done any data analysis before. To overcome any anticipated challenges, I will do some online courses in data analysis to gain a better understanding and can be prepared for when the results from the survey come in.

Although the sample size of the field testing was very small, I do have some results that give me an indication of what the results of the study will be. There were 16 responses-13 people fully filled out the survey. Only 4/15 had BA or higher and only 3/14 answered correctly to whether the terms dementia and Alzheimer's are interchangeable, even though 4 participants were at a grade higher than staff nurse. The responses indicate that the people know that there are other types of dementia, however few were able to give more than one form of dementia when asked to name them. Even though Lewy body dementia was in the title of the survey, only two people gave it as an answer when asked to name another type of dementia other than Alzheimer's. The most common answer was vascular dementia in response to this question, two people said they couldn't name another type and it was skipped by 4 people.

What I thought was interesting was that two out of thirteen people had never heard of LBD before, even though they all work in a nursing home that has residents with LBD. Around 75% of respondents had not received dementia training specific to LBD before and the average rating of how people rated their knowledge on a 0-10 scale was 2.6.

When asked about symptoms of LBD, most people were able to identify a few but nobody was able to identify all symptoms. Majority of people said they were unsure if they could

differentiate between a resident with LBD and Alzheimer's. Interestingly, 8/13 people either agreed or strongly agreed when saying that they feel comfortable caring for a resident experiencing hallucinations or delusions even though the average rating of knowledge was 2.6.

In relation to job satisfaction, most people said that they feel satisfied. Respondents mostly either agreed or were neutral when asked about how they felt about being appropriately trained to care for residents with different types of dementia. 9/13 people agreed that they could appropriately care for a resident with responsive behaviour, and 12/13 people said that they would sign up for LBD specific training if it was offered- which suggests that nursing homes would appreciate training if it was offered.

The field testing was helpful in giving me an insight to what type of results I should expect from the survey. When I complete the survey and data analysis, I plan to produce a poster which displays the findings in an engaging way. I will also produce a powerpoint presentation describing my research, which I hope to present to relevant stakeholders such as Lewy Body Ireland and Nursing Homes Ireland. My proposal for the LiA project ties into my research nicely- I hope to use the results to make a training workshop which Nursing homes can then use to educate their staff about LBD. I plan to give the workshop to one nursing home and track their improvement in their knowledge of LBD. I will need help from my supervisor to get in contact with relevant stakeholders, and I am interested in travelling abroad to shadow a specialist in LBD in order to increase my knowledge on the subject. My overall aim of both summers is to improve LBD knowledge in care home staff with ultimately improving quality of care for residents living with LBD.

My supervisor, Dr. Iracema Leroi, was very helpful through Summer 1. We had regular meetings, and she was easy to contact. She put me in contact with other members of her team that had specialist knowledge in different areas. This included a director of Nursing of a nursing home in Cork, along with a family member of someone with Lewy Body Dementia. Dr. Leroi also introduced me to members of her team that had gone through the process of ethics approval before, and I had regular meetings with them which helped me greatly.

My project experience so far has been both an achievement and a challenge. Applying for and receiving the Laidlaw scholarship has been a big achievement for me as this was totally

out of my comfort zone as I had never done any research before, and in my course there are very few assignments for me to practice academic writing. Along the same lines, putting in an ethics application was both an achievement and a challenge, as I discussed above. Another success of my summer was working as part of a team. It was really nice to have people to reach out to for support, and I have been given the opportunity to work as a blinded rater on a clinical trial for dementia. I would not have gotten this opportunity without Laidlaw, and it will definitely be interesting and a great learning experience for me. I also had the opportunity to sit in on consultations with Dr. Leroi with her LBD patients which allowed me to improve my knowledge on LBD, along with getting some good clinical exposure which will benefit me in relation to medicine.

Challenges of this summer that I have identified were time management, planning ahead and obviously gaining ethics approval. Time management was something I struggled on especially while I was still trying to complete college exams. I learned that I need to set small goals for myself in order to keep motivated. Planning ahead and anticipating obstacles was another element of the project that I found difficult, but it was a great learning experience overall.

In conclusion, I am delighted that I was awarded this research scholarship and grateful for all the opportunities that have come with it. I have learned a lot about myself, along with researching, LBD and leadership which will help me with many aspects of my life in the future.