Write an individual critical reflection regarding your experience of choosing methods and methodologies to address your research problem and answer your research questions.

(2000-2500 words)

Briefly describe your research problem and research question/s:

In Australia, dementia affects almost 1 in 10 people aged 65 and over (AIHW 2016). The vast majority (70%) of people with dementia live at home (NCCMH 2007, Alzheimer's Australia 2012 & 2014). Formal services in the community can assist people with dementia and their carers to remain at home through the provision of 'respite' services or substitute care (My Aged Care 2015), however, the overall proportion who use respite and other support services is low (Bruen & Howe 2009; Phillipson et al. 2014). This study is a carer survey to establish the current knowledge, attitudes, usage and need for different respite services by carers. The collection of this information will gain an understanding of the information needs about respite services for carers of people with dementia, so that they can be better supported in their role.

This study will answer the following research questions:

- What is the current knowledge of, attitudes towards, and information seeking behaviours about respite, of carers of people with dementia living in the community in the Illawarra and Shoalhaven regions?
- What is the perceived and evaluated need for, current use of, and intentions to use respite services of carers of people with dementia living in the community in the Illawarra and Shoalhaven regions?

Describe the method/s and methodology you have chosen and why they are appropriate to address your research problem:

The study proposes a **mixed methods research methodology** to measure the knowledge, attitudes, behaviours and levels of need related to the use of respite, of carers of people living with dementia in the community. It will also explore in-depth with carers the issues need and barriers to accessing respite. A mixed methods designs is appropriate as the combined data integration is useful to generate 'unique insights into multifaceted phenomena related to health care quality, access, and delivery' (Fetters, et al. 2013).

The research will consist of two phases:

- a **quantitative cross-sectional survey** will support valid estimates of the desired measures, assuming appropriate sampling response rates **(**Ragaini, 2019) to measure knowledge, attitudes, behaviours and levels of need (n=250),
- Follow-up **semi-structured interviews** with a **purposive sample** (n=20) of carers recruited from the larger survey sample will support in-depth exploration of the phenomena (Liamputtong, 2020), in this case of respite.

Sampling: For Phase 1, a **convenience sample** (Tranter, 2019) of carers of people with dementia living in the community will be recruited. This is appropriate as there is no register that identifies persons living with dementia, so no population frame available for random sampling.

Recruitment: Carers will be distributed the self-completion paper survey via local community service providers and carer support groups. A target of 250 participants is proposed (from n=500 coded surveys distributed within the Illawarra - Shoalhaven Local Health District). To be included a person must live in the region and self- identify as a primary carer for a person with dementia who is also living in the community. For Phase 2, a purposive sample (n=20) of carers from the larger survey sample will then be recruited to take part in a semi-structured

interview. At the end of the survey, respondents will be asked to indicate their willingness to take part in a follow up interview.

Describe the data collection tools you have proposed and explain why they are appropriate:

The **self-complete quantitative survey tool** will incorporate **two validated measures** to assess carers' need for respite: Problematic Behaviour scale (Pearlin et al. 1990) and Family Caregiver Self-efficacy for Managing Dementia (Fortinsky et al. 2002). This will ensure accurate measures on levels of the exposure and outcome variables, and allow statistical examination of relationships between variables (Travers, 2019). **Anderson's Behavioural Model of Service Use will be used as a guide** to develop the surveys (Andersen, 1995). The design will aim to collect a large amount of data collected in a short time frame to maintain **low burden** on the respondents (Walter, 2019).

The **semi-structured interviews** are a **qualitative method** which use an **interview guide** (Travers, 2019). In this study it will support deeper exploration of respite needs and barriers to respite use. Questions will be developed after initial analysis of the survey, in order to **explore issues raised within the survey**. The survey and interview guide will also be reviewed by a carer advisory group who will be engaged throughout the research to improve the quality of processes and instruments (Synnot, Cherry, Summers et al. 2018). A semi-structured format holds advantages over an unstructured interview format as the unstructured format can generate much higher volumes of data and can move away from the topic area (Liamputtong, 2020). Face to face interviewing are also better for this population and topic than online or telephone interviewing as the researcher can build a stronger rapport with the participant, and be more alert to distress during the interview (Liamputtong, 2020). Both surveying and semi-structured interviews have been used previously in research with this population group and this topic (Phillipson et al. 2014). After analysis, participants will

be re-contacted and the researcher will discuss the findings from the interview as part of

member checking (Liamputtong, 2020) to ensure research integrity.

Describe how you will analyse the data:

Univariate and bivariate analysis of survey data (Ragaini, 2019) will be conducted using

statistical software, to estimate levels of knowledge, attitudes and need regarding respite, as

well as current usage of services. Interviews will be audio recorded and transcribed for

analysis. Thematic analysis (Liamputtong, 2020) of interview data will identify current

barriers and carers needs. Findings from both methods will be combined as part of data

triangulation to give a holistic exploration of the topic (Liamputtong, 2020).

Include a visual representation (e.g. flowchart) of your study design:

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Establish carer advisory group
            ↓
   Develop carer survey
            ↓
Distribution of n=500 carer
surveys  (Illawarra-Shoalhaven)
            ↓
Phase 1: Convenience sample  →  Phase 2: Recruitment of n=20
(Proposed n=250)                carers for follow up interview
            ↓                              ↓
Univariate & bivariate data   →  Develop interview guide
analysis                         questions
            ↓                              ↓
                                 Conduct Interviews
            ↓                              ↓
Write up results to answer    ←  Thematic analysis of transcripts
research questions
            ↓
Disseminate results to key
stakeholders
```
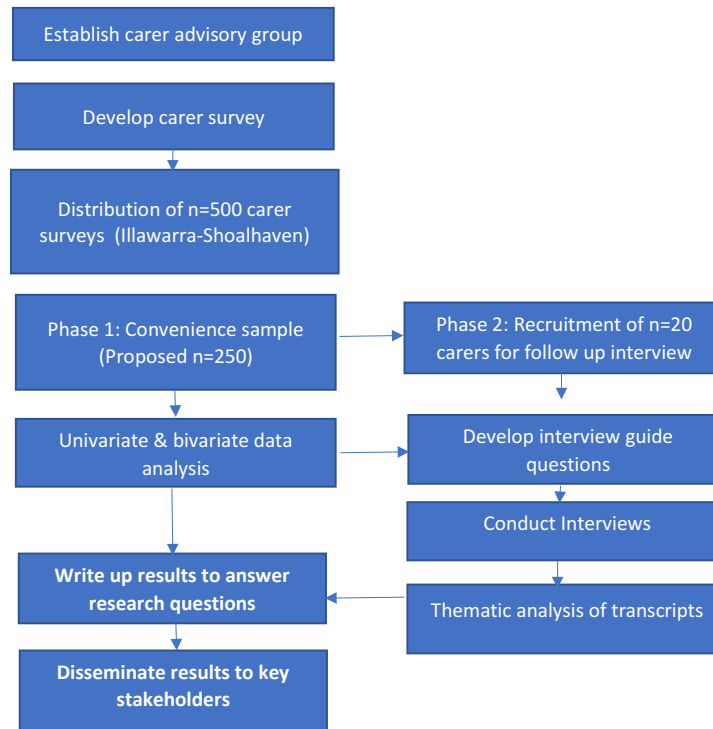
Figure 1: Proposed mixed methods research design

Explain the ethical considerations associated with the conduct of your proposed research plan and how they have been addressed in your study design:

Gaining informed consent is important to meet ethical obligations to participants (Banks, 2019). The Phase 1 survey will be a **self-complete, paper-based survey**, with consent assumed (**tacit consent**) if people complete the survey and return it. **Informed consent** will be ensured through the provision of a written **Participant Information Sheet (PIS)** outlining the nature of the survey questions, how data will be stored, analysed and publicised and emphasising that participants are under no obligation to participate.

For Phase 2, written consent will be required. Carers who express a willingness to participate in a face-to-face interview via their survey response, will be provided with an additional Participant information Sheet and will be required to provide written consent.

Another ethical consideration is the secure storage of participant data (NHMRC, ARC & UA 2007). Surveys and interview transcripts will be coded with a unique participant code and will be accessed only by members of the research team. Survey and interview data will be **confidential.** All survey data reported will be de-identified and reported as group statistics. All interview data will use pseudonyms and a participant ID to ensure confidentiality.

Minimising harms and maximising benefits is also a key ethical consideration (NHMRC, ARC & UA 2007). As the survey will cover sensitive issues concerning dementia and the impact of caring for someone with the illness, measures will be undertaken to **address the potential for psychological distress.** Carers will be provided with a 'Carer Support Services' information sheet on support services (government helplines) and local services which can provide support and advice. In addition to the support information, those who participate in interview will also be supported with a debriefing by the interviewer.

Research integrity will be supported through a Carer Advisory Group, and member checking in qualitative analysis.

Critically reflect on how your methodology, methods, tools and/or ethical considerations have been informed by two learning experiences and/or your personal, social and cultural context:

Below I reflect on two learning experiences and discuss how these, in addition to my personal social and cultural context have influenced my choice of methods and methodologies to address my research problem and how they informed my final research plan.

Learning Reflection 1: Choosing a methodology and research methods

In Week 3, following completion of Module 4 (Intro to Methods and Methodologies) as well as my own self-directed readings I posted the following Learning Reflection:

What? *Starting to think about methodologies this week was essential to me as a new researcher and started me thinking about what kind of researcher I wanted to be. I was drawn to quantitative methodologies as my background as a physiotherapist emphasised evidence-based practice informed by clinical trials and quantitative measure. The Module also introduced the concept of 'levels of evidence'.* ***So what?*** *I began to search for literature to understand more about my variable of interest for my study – the levels of knowledge, attitudes and needs about respite.* ***Now what?*** *This made me realise I needed to do some more independent research to work out what level of evidence I could hope to achieve in my study'(My Reflective Learning Post, Edited, Moodle, Week 3)*

In week 4, I also completed Modules 5 and 6 regarding Quantitative Methods and Methodologies and Qualitative Methods and Methodologies and I also participated in Workshop 2.

I continued to review literature around quantitative research. Helped by Module 5 on quantitative methods, I found that a cross-sectional study was probably the design best suited as it is: 'fast and easy to conduct, can provide accurate estimates of prevalence, and provide initial information of associations and risk factors' (Module 5, slide 6). However, the design has weaknesses in terms of bias if response rates are low, and should be used with a random sample (Ragaini, 2019). This challenged my thinking, as much of the research I was

reviewing used a cross-sectional design, but many did not appear to have a random sample. Does this mean these studies are not valid? I need to discuss this with my tutor and do some further reading to inform my final study design.

My discussions with my tutor and my further reading (e.g. Walters 2019) helped me to understand that while a random sample would be ideal, often social research has no means of gaining a random sample which needs knowledge of the whole population. The design is therefore still valid for this type of research, although it is important to try to maximise your response rates (Ragaini, 2019). This made me realise that whilst it is important to conform to scientific method as close as possible, compromise is allowed, and it is still valid for me to propose a cross-sectional design.

Learning Reflection 2: ReThinking my study design and meeting my target population needs

In my Week 7 reflection, I continued to reflect on my journey as a researcher, and how my learning experiences were challenging my beliefs and previous assumptions about what made for 'good' research. An edited version of my online reflection is included below:

What? In Week 4 I attended the Workshop about Methods and Methodologies and in week 5, I also completed the modules on Decolonising Methodologies and Research Ethics.

So what? These two modules and the Workshop discussed being aware of the 'extent to which your research design is inclusive of the needs of your population of interest' (Workshop 2, slide 29), made me think about my preference for the 'scientific method' of quantitative research. They challenged my feelings of the superiority of quantitative methods. The idea of collaborative methods and engaging populations in the whole research process and participating fully as co-researchers struck a chord.

Now what? *I realised that I needed to do some more research to understand whether there was a way I could collaborate more with carers to design my study and also how I might be able to include their voice more* (*My Learning Reflection, Edited, Week 7*).

As a health professional I am used to being the 'expert' and informing my patients/clients of what they need to do. While person-centred care is the goal, the reality is still a power imbalance. The discussion from Zyphur and Pierides (2017) on ethics in quantitative research where they discuss a strict adherence to scientific method as '*less important than the 'relational validity' of a study where the researchers develop a relationship between the relevant purposes and ethics of real world problems, with appropriate practices and discourses'*, made me re-think my study design and I decided to also incorporate some in-depth interviews where people are more able to discuss their needs and barriers. I concluded that this would also help my study to differ from those already identified in the literature. By incorporating semi-structured interviews, I feel I am allowing a stronger voice for carers to increase the 'relative validity' of my quantitative measures. I also decided to work with an advisory group of carers to help design both the survey and interview questions as another method of increasing my collaborative research practices (Khodyakov et al., 2013).

Write a concluding summary:

HAS941 has challenged me on what constitutes 'best evidence' in research and practice, providing me with a more nuanced understanding of the strengths of quantitative and qualitative approaches. I have also had to step back from a professional stance of 'expert' to allow a real voice to people within research, through adjusting research methods to suit my population and involve them more in the considerations of my study design and methods. Critical to this learning journey is the understanding of 'ethical research' as not just processes or standards involving ethics approval, participant information sheets, consent and

confidentiality – but rather a way of thinking and critical reflection on what is right for the target population, that starts at the lens through which we view a research 'problem' through to the analysis and dissemination of results. This learning experience has allowed me to grow as a values based ethical researcher.

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