



Short Report: Experiences of an Unsuccessful Ethical Application Process Involving Research on a Sensitive Topic

Suicide in Older People in Rural Areas

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Introduction

In 2006 the NSW Institute of Rural Clinical Services and Teaching (IRCST) within NSW Health initiated and commenced an innovative program, the Rural Research Capacity Building Program (RRCBP), to provide opportunities for rural clinicians to increase their research skills and be supported in the process.

As a member of the 2006 RRCBP the author undertook the development of a work related research project relating to suicide prevention in older people. The rationale for undertaking any research in health care is based on the concept of Evidence Based Practice. The importance of having up to date evidence to support clinical practice is well documented. It is also important to have local rural evidence to support rural practice. Localising suicide data and investigating the rural contextual issues that impact on particular communities and groups of people is important in the development of any intervention, prevention or promotion strategy.

Suicide across the lifespan has been identified and recognised as a major public health issue by the World Health Organisation (WHO) (in O'Connell et al 2004) and is a tragedy no matter which age group is affected. Rates of suicide are also reported as being higher in rural than metropolitan areas (Hirsch 2006). While suicide is an issue across the lifespan it has been proposed that the ageing of the population will see an increase in suicide numbers and rates for older people.

Research Plan

A comprehensive literature review on suicide in older people and in rural areas revealed several gaps in the information available regarding contextual data on suicide in older people from a rural region. Few studies, if any, had been completed in rural areas about older people and suicide. The evidence available on suicide in rural areas was predominantly relating to farmers and younger people.

From consultation with the GSAHS Population Health Unit it was determined that approximately 50 people over 65 years of age had died by suicide in the rural region covered by the health service from 1999 to 2005. A research proposal was then developed which aimed at undertaking a thematic analysis of Coroners files for those 50

people to illuminate possible contextual information that could inform the development of mental health promotion, prevention and intervention strategies.

The anticipated outcomes of the research were considered to include:

- the development of local evidence base data to inform and improve rural clinical practice with older people at risk and with mental health issues;
- strengthening the capacity and capability of health and community services staff to identify and respond to older people at risk of depression and suicide;
- informing the development of aged mental health promotion, prevention and education programs in the health service;
- having local evidence will make it more meaningful to the communities which the health service works with and bring it home that suicide in older people is a local issue and reinforce that prevention is everyone's business.
- Adding to the literature and improve knowledge on suicide in older people in rural areas
- Highlight other questions that need to be answered or further areas of research that need to be undertaken in this area

General

It could be argued that there is sufficient information in the public arena already on suicide in older people generally and for rural communities without having to undertake additional research that may cause discomfort to the relatives of the deceased. However, there is still a need to have local and up to date evidence to support and inform the work that is being done and for future development of effective programs and strategies. It is also important to have research based in rural areas taking into account the rural environment as conditions and contextual circumstances are often very different to those in metropolitan areas where the majority of research has been undertaken.

Due to the sensitive nature of the topic and Ethics Committee concerns regarding the adequate supervision of a novice researcher with this type of research, the project also became the basis of a Masters Dissertation with two experienced supervisors appointed.

A number of challenges were faced by the author in attempting to gain Ethics approval for the research proposal. Overall the Ethics application process took 12 to 18 months with the research proposal being submitted to the local Ethics Committee three times and with several changes made to the proposal as a result. Ultimately, the Ethics Committee chose not to approve the project.

Alternative strategies were investigated in order to forward the research at a future point in time, and a further limited literature review was carried out regarding the ethics process and issues pertaining to confidentiality in rural research, consent and privacy, and the public interest.

While it was recognised that the topic of suicide may be a sensitive issue to some in the community, it was surprising how the topic and the need to gain consent were issues perceived very differently by the various stakeholders involved. All parties appeared to be advocating on behalf of the subjects and their families but from different perspectives, though legally it was the Ethics Committee's view that prevailed.

With any sensitive research, particularly in rural areas, it is imperative that confidentiality and privacy be preserved as much as possible. De-identification of cases alone is often not sufficient in rural areas to mask the individuals/community involved. This can often leave rural researchers in a dilemma as to how to ethically undertake research and disseminate their findings.

Results

While the research was not able to be undertaken, there have still been some outcomes from the project that can be described.

We know that

- older people in rural areas do take their own lives,
- the majority of older people taking their own lives in the GSAHS are male, which is consistent with state and national suicide trends
- there is a definite gap in the literature and evidence regarding contextual information dealing with suicide of older people in rural areas.
- a general list of risk factors for suicide in both older people and rural communities have been ascertained from the literature
- the main risk factor for suicide in older people is depression (from urban studies).

The literature also implied that a consequence of the ageing of the population could see increased suicide numbers and rates in older people, and this has implications for rural communities which are ageing. The review also highlighted the need for more evidence based practice in rural areas as well as providing a basis for further work required in the area.

While the author found the ethics process quite frustrating and inconsistent at times, the Ethics Committee feedback was also a positive as it constantly challenged the reasoning behind the choice of particular methodologies and provided suggestions about alternative ways of obtaining the information that may not previously have been considered.

Based upon the author's critical analysis of their ethics application process the following are some of the learnings and suggestions that have resulted from this.

1. Become familiar with Ethics application guidelines and what they mean and use them in your application. The NHMRC guidelines are a useful tool to consult in this.
2. Learn the language or jargon of the Ethics process and quote it back to them. Sometimes the meaning of words is interpreted differently by the Ethics Committee to what you had intended. By using the Ethics language then misunderstandings regarding concepts and methodology is minimised.
3. The importance of mentors and supervisors for their advice, assistance and guidance along the way is invaluable, not only for navigating the process but also for ensuring that you are trying to answer your research topic in an ethical way. This is especially important for novice researchers when undertaking research on sensitive topics. Also use the Ethics Committee themselves and/or their Executive Officer for their advice and to clarify issues you are not sure about.

4. Effective time management is essential when endeavouring to combine a busy work and clinical role with added research responsibilities
5. Explain everything and with little jargon. The Keep It Simple principle certainly applies. Don't assume that members of the Ethics Committee know what you are talking about or have a background in your area of expertise, or that they understand the importance of the research topic to your field. They often don't.
6. While trying to explain everything adequately it is still important to be as concise as possible in writing the application. Ethics Committee members usually have several applications to consider and little time to do so before the next meeting. The easier it is for committee members to read and comprehend the application the better.
7. The Ethics process certainly assists one to forward plan with the proposed research project. It is important and necessary to think about and consider what it is that you want out of the proposed research, how you are going to achieve this, expected outcomes, what tools and research methods will be utilised, consent issues, and how to maintain confidentiality and privacy of subjects. The Ethics application form and process certainly requires one to have considered these issues and be able to articulate them.
8. Be familiar with conditions regarding confidentiality, consent, and privacy, particularly with sensitive topics, and ensure that your reasoning for the research being in the public interest is tight and outweighs the need for privacy.
9. Having a sound strategy for the securing of information and data both during and at completion of the project is important, as is being able to elaborate on this within the ethics application form.
10. It is important to not be too focussed on doing the research in a particular way. Keeping an open mind is valuable as there may be other ways of obtaining the information that you hadn't considered. Often Ethics Committees provide valuable feedback regarding your research proposal with suggestions and requests for modifications before they approve it.

On the other hand if the research methodology chosen for the project is what you consider the best option for your needs after considering various alternatives then clearly outlining and justifying the methods chosen is vital.

The importance of having a good research design, methodology and process in place is vital to both being able to effectively answer one's research topic question but also for carrying out the research in an ethical way. An integral part of the preparation of the research proposal is deciding on the theoretical framework and methodologies that the research project is being built upon. This is where the author found their involvement in the RRCBP and the education and knowledge imparted being invaluable, as was the assistance provided by the CSU research supervisors.

Conclusion

Due to the research project on suicide in older people in rural areas not gaining approval from the local Ethics Committee, this project ultimately evolved into two separate investigations. The first being an exploration of the literature surrounding suicide in older people in rural areas, and the second an examination of ethics concepts and processes.

While the suicide literature review did establish that there is a growing amount of information regarding suicide in older people generally, this research was predominantly based on urban cohorts. The rural suicide literature dealt mainly with farmers and young people with little, if any, reference to older people over 65 years of age. What the review did highlight, though, was the need for more evidence based practice in rural areas as well as providing a basis for further work required in the area.

As Davis et al (2008) contend, “Comparative studies on retirement, health promotion, community participation, health seeking behaviour, health services are needed to better understand the complexities of the ageing experience across different types of rural communities and support healthy ageing”. Including mental health issues and suicide in these studies is vital to having an overall picture of the context and environment of older people in rural areas. Having this information will aid the development of a range of health promotion and intervention programs focusing on the needs of older people in different regions and assist to enhance their overall health and wellbeing, and their increased resilience.

Both the review of the ethics literature and the experience of going through an unsuccessful ethics application process have greatly increased the author's understanding and knowledge of the process and issues involved. As a novice researcher this was an invaluable experience and with hindsight the lessons learned will certainly assist with any future research projects they are involved in, and it is also hoped that this reflection and the insights gained will aid other novice researchers in their research journeys.

References

- AUSTRALIAN GOVERNMENT (2007) National Statement on Ethical Conduct in Human Research, Canberra
- DAVIS, S. & BARLETT, H. (2008) Healthy Ageing in Rural Australia: Issues and Challenges. *Australasian Journal on Ageing*, 27, 56-60
- HIRSCH JK (2006) A Review of the Literature on Rural Suicide: Risk and Protective Factors, Incidence, and Prevention. *Journal of Crisis Intervention & Suicide*, 27, 189-199.
- O'CONNELL, H., CHIN, A. V., CUNNINGHAM, C., LAWLOR, B. & CONNOLLY, N. (2004) Recent Developments: Suicide in Older People. *British Medical Journal*