PALLIATIVE MEDICINE: MY CONTRIBUTION TO THE
DEVELOPMENT OF AN EVIDENCE BASE

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University of Newcastle
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**Declaration**

I hereby certify that this thesis is submitted in the form of a series of published papers of which I am a joint author. I have included as part of the thesis a written statement from each co-author; and endorsed by the Faculty Assistant Dean (Research Training), attesting to my contribution to the joint publications.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.

See Appendix 1

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Acknowledgements

This thesis has been an evolving (and at times arduous) journey. Like all journeys the final destination is not always where you think you will end up.

I would firstly like to acknowledge my supervisor - Professor Peter Ravenscroft. His gentle encouragement and feedback, has enabled me to reach this final destination. I would also like to acknowledge Professor Gerry Gleeson, who acted as a co-supervisor, until the journey changed direction a little, but in our talks I found a lot of help and inspiration.

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I am thankful that my parents valued giving their children a good education, and hope they learnt a bit along the way.

Finally I am grateful to all the patients I have cared for, who have taught me so much about life.
List of publications included as part of the thesis:


Medically Assisted Nutrition and Hydration


Clinical medications trials:


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Abbreviations:
ASCO - American Society of Clinical Oncology
DVT - deep vein thrombosis
ImPaCCT - Improving Palliative Care through Clinical Trials
MAH - medically assisted hydration
MAN - medically assisted nutrition
MANH - medically assisted nutrition and hydration
PACCSC - Palliative Care Clinical Studies Collaborative
PVC - Polyvinyl chloride
RCT(s) - randomised controlled trial(s)
Abstract:

Palliative Medicine is a challenging area of health care to work in and to perform quality research studies. The aim of Palliative Medicine is to apply the highest quality evidence to the problems encountered, taking into account the individual needs of the patient.

This thesis by publication consists of sixteen published, peer review articles, which have made an original and significant contribution to the knowledge base of Palliative Medicine. The first publication explored how much daily practice in Palliative Medicine was based on available evidence. It found that approximately half of interventions performed in an inpatient Palliative Care population were based on randomised controlled trials.

This led to research and publication in three different areas of Palliative Medicine.

The first was the difficult clinical and ethical dilemma of the use of medically assisted nutrition and hydration in Palliative Care. Two Cochrane systematic reviews were performed that found there were insufficient good quality studies to make any recommendations for practice with regard to the use of medically assisted hydration or medically assisted nutrition in Palliative Care patients. Three qualitative studies were undertaken, exploring the use of medically assisted nutrition and hydration at the end of life, in both the acute, and palliative care, setting. These found that Palliative Care doctors and nurses believed that medically assisted nutrition and hydration at the end stage of life rarely benefit patients and as long as adequate mouth care is given, patients do not suffer. However, family members do experience emotional distress in dealing with this situation. In the acute hospital setting the views of doctors in regards to medically assisted hydration represents a professional and personal struggle involved in attending to those who are dying and is accompanied by a discourse of uncertainty.
The second area of research was clinical medication trials, studying the use of a variety of medications in different clinical situations to examine their efficacy and safety. This was initially undertaken with prospective, observational studies. These found that a “burst” ketamine protocol was relatively safe and simple with a reasonable (50%) response rate. Further to this was the finding that a ‘burst’ triple agent approach was safe and effective during episodes of poorly controlled acute on chronic pain. The use of intranasal sufentanil was tested and found that it provided rapid onset, intense but relatively short lasting analgesia and it is an effective, practical, and safe option for breakthrough pain. Studies of medications used in syringe drivers were then performed using high performance liquid chromatography. The significant findings from the first study was dexamethasone and midazolam should not be combined in syringe driver solutions, as their combination leads to the significant loss of midazolam and perhaps more importantly this study also showed that cloudiness of a solution is not the only predictor of drug loss and that drug loss may occur even in solutions that remain clear at time of preparation. The second of these studies showed that there is significant loss of clonazepam when it is infused from syringe drivers through polyvinyl chloride tubing. The last of these studies related to medications found there was no association between the doses of opioids and sedatives on the last day of life and survival in an inpatient Palliative Care unit.

The final area was related to service delivery, and looking at how to improve quality of care. The first of these studies showed that the median length of survival (after enrolment on an Australian Palliative Care program) was 54 days. The final area of study was examining medication use in Palliative Medicine and produced a list of 20 essential medication as determined by Australian Palliative Medicine doctors, and the evidence in support of their use.
The implications of these findings as well as the future challenges of research are also explored in the concluding chapter. The underlying theme of this thesis is about contributing to the development of an evidence base in Palliative Medicine.