ADVANCE CARE PLANNING IN CANCER PATIENT- CAREGIVER DYADS

NATASHA MICHAEL
MBChB FRACP FAChPM MRCPI MRCHP MSc

A THESIS SUBMITTED IN FULFILMENT OF THE REQUIREMENTS OF THE DEGREE OF DOCTOR IN PHILOSOPHY (MEDICINE)

SCHOOL OF MEDICINE
UNIVERSITY OF NOTRE DAME, AUSTRALIA
JANUARY 2023
-Page intentionally left blank-
COPYRIGHT NOTICE

© The author (2022). Except as provided in the Copyright Act 1968, this thesis may not be reproduced in any form without the author's permission. I certify that I have made all reasonable efforts to secure copyright permissions for third-party content included in this thesis and have not knowingly added copyright content to this work without the owner’s permission.
TABLE OF CONTENTS

List of Tables ........................................................................................................ vii
List of Figures ......................................................................................................... viii
List of Abbreviations ............................................................................................ ix
Abstract .................................................................................................................. x
Publications prior to Enrollment ......................................................................... xi
Publications during Enrolment ............................................................................... xii
Declaration of Authorship .................................................................................... xiii
Acknowledgements ............................................................................................... xv

1. GENERAL INTRODUCTION ........................................................................ 1
   Explanatory Note ................................................................................................. 2
   1.1 Preface and Rationale for Thesis ................................................................. 3
   1.2 Research Aims ............................................................................................. 4
      1.2.1 Research Aim One .............................................................................. 4
      1.2.2 Research Aim Two ............................................................................. 5
      1.2.3 Research Aim Three ........................................................................... 5
      1.2.4 Research Aim Four ............................................................................. 5
   1.3 Content and Structure of Thesis .................................................................. 6
   1.4 Summary and Conclusion ........................................................................... 7
   1.5 References for Chapter One ......................................................................... 7

2. A REVIEW OF ADVANCE CARE PLANNING IN CANCER AND THE VIGNETTE AND DYADIC APPROACH ..................................................... 11
   2.1 Advance Care Planning .............................................................................. 12
   2.2 Advance Care Planning in Cancer and the Role of Palliative Care ........... 13
      2.2.1 Early Integration Palliative Care ......................................................... 13
      2.2.2 Uptake of Advance Care Planning in Cancer ...................................... 14
      2.2.3 Factors that Influence Advance Care Planning in Cancer ................. 15
   2.3 The Vignette Approach In Advance Care Planning .................................... 16
   2.4 The Dyadic Approach as a Consideration for Advance Care Planning ...... 17
CONTENTS

2.5 Summary and Conclusion.................................................................18
2.6 References for Chapter Two...........................................................19

3. FINDINGS FROM EARLY PUBLICATIONS.................................26

3.1 Understanding how Cancer Patients Actualise, Reject or Relinquish Advance Care Planning: Implications for Practice ....................................27
3.2 Cancer Caregivers Advocate and Patient and Family Centred Approach to A38dvance Care Planning.........................................................28
3.3 A Mixed Method Feasibility Study Feasibility Study of a Patient and Family Centred Advance Care Planning Intervention............................30
3.4 Exploring the Utility of the Vignette Technique in Promoting Advance Care Planning Discussions with Cancer Patients and Caregivers ..............31
3.5 Does Implementation Matter if Comprehension is Lacking? A Qualitative Investigation into Perceptions of Advance Care Planning in People with Cancer ........................................................................32
3.6 Summary and Conclusion.................................................................32
3.7 References for Chapter Three..........................................................34

4. RESEARCH FRAMEWORK AND METHODOLOGY FOR RANDOMISED CONTROLLED TRIAL AND SUPPORTING STUDIES ........................................................................................................37

4.1 The Medical Research Council Framework for Complex Intervention......38
4.1.1 Using the MRC Framework to Develop Complex Interventions for Cancer Patients.................................................................40
4.1.1.1 Exploring Theory.................................................................41
4.1.1.2 Testing Feasibility..............................................................42
4.1.1.3 Exploring uncertainties and refining the intervention............42
4.1.1.4 Implementation.................................................................42
4.2 Methodology for RCT and Supporting Studies………………………...43
  4.2.1 Research Design…………………………………………………….43
  4.2.2 Principles for Multi-Method Design…………………………….44
  4.2.3 Validity, Reflexivity and Ethics Approval…………………………44
  4.3 References for Chapter Four……………………………………………45

5. VIDEO DECISION SUPPORT TOOL PROMOTING VALUES CONVERSATIONS IN ADVANCE CARE PLANNING IN CANCER: PROTOCOL FOR A RANDOMISED CONTROLLED TRIAL ....................49
  5.1 Declaration by Candidate and Co-author Statement ..................50
  5.2 Preamble to Protocol Paper ..................................................51
  5.3 Protocol Paper........................................................................52
  5.4 Summary and Conclusion....................................................53
  5.5 References for Summary and Conclusions .............................62

6. PATIENT-CAREGIVER DYADS ADVANCE CARE PLAN VALUES DISCUSSIONS: RANDOMISED CONTROLLED TRIAL OF VIDEO DECISION SUPPORT TOOL ....................................................64
  6.1 Declaration by Candidate and Co-Author Statement ....................65
  6.2 Preamble to Empirical Paper One ..........................................66
  6.3 Empirical Paper One...............................................................67
  6.4 Summary and Conclusion....................................................78
  6.5 Reference for Summary and Conclusions.................................80

7. VULNERABILITY AND RESILIENCE: PHENOMENOLOGICAL ANALYSIS OF CANCER PATIENTS VALUES DIRECTIVES ..........................81
  7.1 Declaration by Candidate and Co-Author Statement ....................82
  7.2 Preamble to Empirical Paper Two ..........................................83
  7.3 Empirical Paper Two...............................................................84
  7.4 Summary and Conclusion....................................................95
  7.5 References for Summary and Conclusions.................................96
## 8. PATIENT-CAREGIVER COMMUNICATION CONCORDANCE IN CANCER – REFINEMENT OF THE CANCER COMMUNICATION ASSESSMENT TOOL IN AN AUSTRALIAN SAMPLE

- 8.1 Declaration by Candidate and Co-Author Statement ........................................ 99
- 8.2 Preamble to Empirical Paper Three .............................................................. 100
- 8.3 Empirical Paper Three .................................................................................. 101
- 8.4 Summary and Conclusion ............................................................................. 111

## 9. INTEGRATED GENERAL DISCUSSION

- 9.1 Integrated General Discussion ....................................................................... 114
- 9.2 Summary of Thesis Aims ................................................................................ 115
- 9.3 Overview and Synthesis of Main Findings ................................................... 115
  - 9.3.1 Protocol Paper ......................................................................................... 116
  - 9.3.2 Empirical Study One ............................................................................... 117
  - 9.3.3 Empirical Study Two ............................................................................... 118
  - 9.3.4 Empirical Study Three ............................................................................ 118
- 9.4 Key Findings from Thesis ............................................................................. 119
- 9.5 Strengths and Limitations of the Research .................................................. 121
- 9.6 Implications for Clinical Practice .................................................................. 122
- 9.7 Future Research Directions ......................................................................... 123
- 9.8 Concluding Remarks .................................................................................... 124
- 9.9 References for Chapter One ......................................................................... 125

## REFERENCES FOR ENTIRE THESIS

- ............................................................... 129

## APPENDICES

- ............................................................... 152
LIST OF TABLES
Table 4.1 Six core elements to consider at each phase of the research
Table 5.1 Components of an advance care plan/directive
Table 5.2 Predicted scenarios depicted in the Video Decision Support Tool
Table 5.3 Measures used pre and post VDST
Table 6.1 Sociodemographic, clinical and psychological characteristics of participants (patients and caregivers)
Table 6.2 Patient and caregiver attitudes towards ACP
Table 6.3 Cancer Communication Assessment Tool (CCAT)
Table 7.1 Questions asked in the values directive component of the ACP
Table 7.2 Development of the analysis schedule exemplified with codes, categories and subthemes
Table 7.3 Participants' demographic characteristics and details of completed ACP
Table 7.4 Existential postures of vulnerability and alternative constructive stances
Table 8.1 Participant demographics
Table 8.2 Concordance of cancer communication assessment between patients and their family caregivers
Table 8.3 Scale characteristics for CCAT items
Table 8.4 Concurrent validity of Cancer Communication Assessment Tool
Table 9.1 Key findings from this thesis
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 3.1</td>
<td>Patient reactions to ACP.</td>
</tr>
<tr>
<td>Figure 3.2</td>
<td>Shared Decision-Making Relational Elements.</td>
</tr>
<tr>
<td>Figure 4.1</td>
<td>MRC Framework for Complex Interventions.</td>
</tr>
<tr>
<td>Figure 4.2</td>
<td>Framework for developing and evaluating complex interventions.</td>
</tr>
<tr>
<td>Figure 4.3</td>
<td>Schematic representation outlining core studies and embedded studies.</td>
</tr>
<tr>
<td>Figure 5.1</td>
<td>Study procedure</td>
</tr>
<tr>
<td>Figure 6.1</td>
<td>Study procedure</td>
</tr>
<tr>
<td>Figure 6.2</td>
<td>Participant recruitment diagram</td>
</tr>
<tr>
<td>Figure 7.1</td>
<td>Study schema</td>
</tr>
<tr>
<td>Figure 7.2</td>
<td>Key expressed attitudes, priorities, and life goals</td>
</tr>
<tr>
<td>Figure 8.1</td>
<td>Participant enrolment</td>
</tr>
</tbody>
</table>
# LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACP</td>
<td>Advance care planning</td>
</tr>
<tr>
<td>EOL</td>
<td>End-of-life</td>
</tr>
<tr>
<td>CCAT</td>
<td>Cancer Communication and Assessment Tool</td>
</tr>
<tr>
<td>CCAT-P</td>
<td>Cancer Communication and Assessment Tool - Patient</td>
</tr>
<tr>
<td>CCAT-F</td>
<td>Cancer Communication and Assessment Tool - Family</td>
</tr>
<tr>
<td>CCAT-PF</td>
<td>Cancer Communication and Assessment Tool – Patient and Family</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>DASS-21</td>
<td>Depression Anxiety Stress Scale - 21</td>
</tr>
<tr>
<td>MEPOA</td>
<td>Medical Enduring Power of Attorney</td>
</tr>
<tr>
<td>MTDM</td>
<td>Medical Treatment Decision Maker</td>
</tr>
<tr>
<td>OR</td>
<td>Odds Ratio</td>
</tr>
<tr>
<td>PDMS</td>
<td>Preparation for Decision-Making Scale</td>
</tr>
<tr>
<td>QPL</td>
<td>Question Prompt List</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
</tr>
<tr>
<td>RR</td>
<td>Risk Ratio</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>UC</td>
<td>Usual Care</td>
</tr>
<tr>
<td>VD</td>
<td>Values Directive</td>
</tr>
<tr>
<td>VT</td>
<td>Vignette Technique</td>
</tr>
<tr>
<td>VDST</td>
<td>Video Decision Support Tool</td>
</tr>
</tbody>
</table>
ABSTRACT

For many, a cancer diagnosis signals death's inevitability and elicits much existential concern. In the quest for life prolongation, many are offered or seek life-sustaining treatments, fail to appreciate a declining trajectory and lack the opportunity to seek information or plan meaningfully for their future.

Advance care planning (ACP) provides an avenue for patients and their caregivers to plan for future care. ACP is defined ‘as a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care’ and is a key quality indicator in cancer care. An increased emphasis is now placed on exploring values and beliefs to ensure alignment with the choices made relating to treatment decisions and end-of-life desirables.

The uptake of ACP in cancer remains poor due to patient, caregiver, practitioner, and operational factors. For the clinician, the challenge remains as to how best to maintain hope, despite provoking and honest conversations. Increasingly, novel interventions are being developed to promote uptake in ACP. This includes the vignette technique (VT), whereby patients and/or caregivers are exposed to future scenarios in written or video material.

My studies were the first to explore the use of video vignettes to explore values conversations between patient-caregiver dyads. These studies described older participants as more likely to identify with ACP and values conversations, the importance of ACP in improving patient-caregiver concordance in communication and that cancer patients concurrently postured vulnerability and resilience, despite conflicting emotions and experiences.

I highlight that ACP requires contextualisation of individual situations and values and should focus on achieving meaningful outcomes beyond completing documents. Future research will focus on improving and measuring concordance in communication as an outcome for ACP and techniques to enhance ACP engagement in younger cancer patients.
PUBLICATIONS PRIOR TO ENROLLMENT TO PROVIDE CONTEXT TO THE CURRENT BODY OF WORK (ABSTRACTS SHOWN IN APPENDIX A-E)


PUBLICATIONS DURING ENROLMENT


DECLARATION OF AUTHORSHIP

Declaration
To the best of the candidate's knowledge, this thesis contains no material previously published by another person except where due acknowledgement has been made. This thesis is the candidate's own work. It contains no material accepted for the award of any other degree or diploma in any institution. As this is presented as a thesis by publication, further individual declarations of authorship signed by the candidate and co-authors are presented for each publication.

Human Ethics and Trial Registration
The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007, updated 2018). The proposed research study received human research ethics approval from Cabrini Health 09-27-02-17/Monash Health RES- 20-0000-112C and was assessed as qualifying for a Cross-Institutional approval by the University of Notre Dame (Reference Number: 2022-059S) (Appendix F). The study was registered with the Australian and New Zealand Clinical Trial Registry: No ACTRN12620001035910 (Appendix G).

This thesis includes four original papers published in peer-reviewed journals and refers to five previously published papers along the same theme of exploring advance care planning in cancer patients and caregivers. I was principally responsible for the development and execution of this study, the analysis of data, the synthesis of the results and the preparation of the manuscripts for publication. This was completed as a part-time student working at the Sydney School of Medicine, the University of Notre Dame, Australia and involved active collaboration with several clinical and research colleagues who are acknowledged as co-authors.
In the case of Chapters 4, 5, 6 and 7, my contribution to the work involved the following:

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Publication Title</th>
<th>Status</th>
<th>Student contribution</th>
<th>Co-author’s contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>VDST promoting values conversations in ACP: protocol of a RCT</td>
<td>Published</td>
<td>75%</td>
<td>C O’Callaghan, E Georgousopoulou: 5% each A Melia, M Sulistio: 2.5% each D Kissane 10%</td>
</tr>
<tr>
<td>5</td>
<td>Patient-caregiver dyads ACP value discussions: randomised controlled cancer trial of VDST</td>
<td>Published</td>
<td>75%</td>
<td>E Georgousopoulou, M Sulistio, A Melia, R Tuohy: 2.5% each G Hepworth 5% D Kissane 10%</td>
</tr>
<tr>
<td>6</td>
<td>Vulnerability and Resilience: Phenomenological Analysis of Cancer Patients Value Directives</td>
<td>Published</td>
<td>75%</td>
<td>X Symons 5% G Mendz 10% D Kissane 10%</td>
</tr>
<tr>
<td>7</td>
<td>Patient-caregiver communication concordance in cancer – Refinement of the CCAT in an Australian sample.</td>
<td>Published</td>
<td>75%</td>
<td>A Gorelik 5% E Georgousopoulou, M Sulistio, P Tee, K Hauser 2.5% D Kissane 10%</td>
</tr>
</tbody>
</table>

Sections of published or submitted papers have been renumbered to provide consistency in presentation within the thesis.

**Student Signature:**

Natasha Michael Date:

17/12
ACKNOWLEDGEMENTS

I acknowledge the funding received from the Australian Government Research Training Program Scholarship Program. I owe tremendous gratitude to several people for their unwavering support and assistance in enabling this Doctorate completion. Firstly, to Professor David Kissane, my primary supervisor, for his patience, thoughtfulness, and guidance. I enjoyed the many discussions we shared as we explored the narrative of this work, drawing from our shared experiences of patient care. I thank Professor John Eiseman for his guidance in the initial stages of work and Professor George Mendz for his subsequent support and great encouragement. I would also like to acknowledge the staff at the University of Notre Dame Research office, in particular Dr Craig Smith and the many administrative and support staff who assisted me throughout this process.

My clinical and research team at the Department of Palliative and Supportive Care at Cabrini Health have been generous in their collegiality and assistance, assisting with study design, participant recruitment and manuscript preparation. My early research years were enhanced by my working relationship and friendship with A/Prof Clare O'Callaghan and Professor Josephine Clayton, who were patient teachers and mentors. I want to acknowledge the enduring friendships of Julia Trimboli, Susan Sullivan, Julie Fleming and Xavier Symons. Their thoughtful conversations, warmth, support, and laughter have sustained me. A final word of thanks to Carmen Parvia and Monique Baldwin, who have assisted me greatly in finding the balance between my home and professional life.

Above and beyond all, I owe tremendous gratitude to my extraordinary husband, Eugene Tuohy, for his constant belief in me and my three beautiful children, Roisin, Alannah and Aine Tuohy, for the joy and pride they bring Eugene and me. Finally, to Dr Patrick Pillai - cancer patient, bone marrow transplant recipient and now cancer survivor, for being my 'muse' and quiet cheerleader.

This thesis is dedicated to my late father, Rex C.C. Michael, and my mother, Angela Jessie, for the many years of sacrifice they endured to ensure their children received the gifts of faith and an education that has enabled me to have a deeply fulfilling life and career.
CHAPTER ONE

GENERAL INTRODUCTION
EXPLANATORY NOTE

This *General Introduction* provides the preface for the body of work preceding this thesis, followed by the rationale for the research work undertaken for this thesis. It will provide an overview of the structure and content of the thesis, assisting with the reader's orientation to the area of research and the context in which it is undertaken.
1.1 PREFACE AND RATIONALE FOR THESIS

Cancer remains a significant cause of mortality and morbidity in Australia, with approximately 151,000 Australians diagnosed yearly and 490 dying from cancer daily.\(^1\) A combination of population growth and an ageing population will lead to an ongoing increase in the prevalence of cancer over the next decade.\(^2\) Additionally, there has been an increase in overall cancer survival, with at least 70% of all people diagnosed with cancer surviving for at least five years post-diagnosis.\(^1\)

The rise in cancer diagnosis has led to an increase in the use of disease-modifying treatments that extend the duration and options for treatment.\(^3,4\) There is therefore a concomitant increase in the use of futile cancer treatments in patients with limited prognosis and limited discussions on determining the ceiling of care for interventions such as antibiotics or cardiopulmonary resuscitation.\(^5\) This occurs at an increased cost to the healthcare system and no apparent benefit to patients.\(^6,7\) Patients and caregivers continue to report a poor understanding of their prognosis, treatment outcomes and choices regarding options for supportive and palliative care.\(^8,9\) In many instances, end-of-life (EOL) conversations are avoided to maintain hope and avoid distress.\(^10\)

Advance care planning (ACP) provides an avenue for patients and families to consider their options for the future. ACP is defined as ‘as a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care’\(^11(p.826)\) ACP is now a key quality indicator in cancer care,\(^12\) as defined in the quality metrics of the American Society of Clinical Oncology Quality Oncology Practice Initiative and the Centres for Medicare & Medicaid Services Oncology Care Model.\(^13,14\) These indicators recommend that ACP be initiated early and readdressed often in cancer patients. It encourages patients to nominate a key decision maker to communicate on their behalf if they are unable to communicate their wishes, complete a statement of values and make decisions regarding limiting treatments.\(^13\) There has been a growing focus on completing a Values Directive (VD) in ACP, recognising that patients' values and beliefs are the best predictors of the choices made relating to EOL goals and treatment decisions.\(^15,16\)

Despite the benefits cited for ACP, its uptake in the cancer population remains
CHAPTER ONE

low, with ACP interventions in cancer across a number of studies internationally increasing documentation rates from 15% to 30%-40%, but failing to achieve EOL care consistent with patients’ preferences. Novel interventions such as the use of video decision support tools (VDST) depicting scenarios of cardiopulmonary resuscitation and intubation have improved engagement with ACP. However, its development and use have never been tested in the Australian context. The inclusion of patient- caregiver dyads as participants in our studies was motivated by the increased recognition of the need to include caregivers in cancer communication to reduce the risk of communication discord and improve opportunities for shared deliberation.

1.2 RESEARCH AIMS

The overarching aim of this thesis was to further our knowledge of the issue of ACP in cancer patients. This body of work is an extension of previously conducted studies where we explored the use of the written vignette methodology to understand how cancer patients and their caregivers perceived ACP. With my colleagues, I subsequently examined the utility of the vignette technique (VT) in greater detail and finally conducted a longitudinal, mixed method feasibility study examining an ACP intervention which incorporated the VT amongst cancer patient-caregiver dyads.

In the four studies published in this thesis, I have expanded on understanding the use of the VT and methodology by converting written vignettes into video vignettes. I furthered our knowledge and understanding of ACP in cancer and the vignette methodology by designing a VDST that demonstrated cancer patient- caregiver dyads having ACP conversations that incorporate values-based ACP conversations. This was to align our approach with recommendations promoting value alignment in ACP. To address critical gaps in our understanding and the literature, this thesis had four overarching aims, as described below:

1.2.1 Research Aim One: To develop a protocol for a randomised controlled trial comparing the effect of a VDST depicting values communication with usual care (UC) in ACP in cancer.

The first aim was to design an RCT to examine the effectiveness of a VDST compared to UC
in completing ACP documents in cancer patients. This was addressed by:

1) The development of video vignettes for the VDST. The video vignettes were adapted from written vignettes used in previously published studies. I specifically adhered to suggested guidelines for preparing scripted video vignettes and focused on depicting patient-caregiver dyads in various permutations, discussing their values and EOL decisions.

2) I developed a protocol for an open-label, parallel-arm, phase II randomized control trial (RCT) comparing patients receiving a VDST intervention or UC. The protocol detailed the background issues pertaining to ACP in cancer and the importance of patient-caregiver communication in cancer and summarised the use of VDSTs in ACP. I subsequently detailed the development process of the video vignettes, sample size calculation, randomisation method and outcome assessments.

1.2.2. Research Aim Two: To compare the effect of a VDST depicting EOL values conversations between cancer patient-caregiver dyads with UC on ACP in cancer.

The second aim was to evaluate the effectiveness of video vignettes used as a VDST to model values-based ACP conversations between cancer patient-caregiver dyads and facilitate congruence in patient-caregiver communication. I hypothesised that the VDST is more likely than UC to facilitate ACP completion, improve understanding and perspectives on ACP, congruence in communication and preparation for decision-making. Unless there is mutual understanding, trust and agreement between the patient and caregiver regarding the patient's wishes, underlying discord will interfere with the execution of an ACP.

1.2.3 Research Aim Three: To examine the diversity of values, experiences and adaptations expressed in cancer patients' Value Directives.

The third aim was to explore, through textual analysis, the contents of completed VDs of cancer patients from our randomised controlled trial. I was interested in examining the diversity of values, experiences, and adaptations expressed in completing their ACP.

1.2.4 Research Aim Four: To examine the potential applicability of the Cancer Communication Assessment Tool (CCAT) within the Australian setting.

The fourth aim sought to expand the international psychometric validation of the CCAT by examining its potential applicability within the Australian setting. I sought to explore the early psychometric properties of the CCAT and conduct an exploratory factor analysis across heterogeneous tumour types.
1.3 CONTENT AND STRUCTURE OF THESIS

This thesis was designed as a thesis by publication in accordance with the requirements of the University of Notre Dame Australia School of Medicine. As such, incidences of unavoidable repetition are inevitable as the rationale and aim of each study are reiterated with each publication.

The thesis comprises eight chapters, including four published papers (one protocol and three empirical papers) and summaries of five previously published papers along the same theme. Sections of adjoining text have been included to ensure the coherence of the thesis. This chapter and Chapters two and three provide further context for the thesis.

Chapter one provides the rationale for the thesis and the research aims. Chapter two provides a synopsis of 1) ACP in cancer and identifies the gaps within the current literature, 2) the vignette methodology, 3) the dyadic approach and congruence in communication and the rationale for the use of a VDST, 4) the Medical Research Council (MRC) Framework for Complex Interventions\textsuperscript{25} and its utility in the design of this and previous studies. Chapter three summarises five previously published empirical papers\textsuperscript{9,21-24,26} by the candidate on the topic of ACP cancer. These papers provide the basis and the theoretical underpinning behind subsequent work undertaken for this thesis. The abstracts of these papers are provided in the Appendix of this thesis.

Chapter four comprises the published protocol for the subsequent RCT (paper entitled: Video decision support tool promoting values conversations in advance care planning in cancer: protocol of a randomised controlled trial\textsuperscript{27}). This paper outlines the study design, development of the VDST and chosen outcomes in detail. Chapter five comprises the published RCT (paper entitled: Patient-caregiver dyads advance care plan value discussions: randomised controlled trial of video decision support tool\textsuperscript{28}). This paper outlines the RCT that was conducted and the outcomes achieved.

Chapter six (paper entitled: Vulnerability and resilience: phenomenological analysis of cancer patients value directives\textsuperscript{29}) used qualitative methodology to explore the contents of the VDs completed in Chapter five. Chapter seven (paper entitled: Patient- caregiver communication concordance in cancer—Refinement of the Cancer Communication
Assessment Tool in an Australian sample\(^3\) sought to validate the CCAT in an Australian sample following findings of the RCT that demonstrated the benefit of ACP in improving concordance in communication. Chapter eight is the thesis's final chapter, providing an integrated general discussion. I summarise the main findings of the thesis and outline the strengths and limitations, the clinical and research implications and the potential direction for future studies.

In accordance with the University of Notre Dame's guidelines for a thesis by publication, the manuscript has been presented in the original publication format of the journal. However, the tables and figures within the manuscript have been renumbered to generate a consistent presentation and order within the thesis. References for each chapter and the published manuscripts are provided at the end of the chapter and manuscript, respectively. At the end of the thesis, a list of all references (from individual chapters and published manuscripts) is provided in alphabetical order.

1.4 SUMMARY AND CONCLUSIONS

This General Introduction provides a brief overview of the research context and rationale for the thesis. It additionally provides an outline of the research aims and an overview of the content and structure of the thesis. The following chapters provide an overview of critical aspects of the thesis content, a summary of previously published papers related to the thesis topic and four papers that form the main body of the thesis.

1.5 REFERENCES FOR CHAPTER ONE


CHAPTER TWO

A REVIEW OF ADVANCE CARE PLANNING IN CANCER
AND THE VIGNETTE AND DYADIC APPROACH
In this chapter, we provide an overview and synopsis of the literature of ACP in cancer and the vignette and dyadic approach in ACP. This was not undertaken as a formal narrative or systematic review as such but as an overview of the topics that will form an introduction to the thesis by publication of the four articles that are presented. For this review, I searched the following databases: MEDLINE, PsycINFO and Embase via OvidSP and CINAHL via EBSCO. Keywords and Medical Subject Headings (MeSH) terms included advance care planning, cancer, palliative care and dyads. In this chapter I will critique this body of work and demonstrate gaps in the literature that has led to the development of the body of work.

2.1 ADVANCE CARE PLANNING

“Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness”.¹(p.826)

The development and implementation of ACP as a public health initiative is proposed by the above statement, encouraging those without ill health to consider thinking about and discussing their future health wishes.² Surveys of the general population indicate that the most people want to discuss their end-of-life wishes and commonly initiate conversations with family members.³,⁴ However, the majority would prefer discussions to be initiated by health care personnel and timed to a serious life-limiting illness.³ The reported prevalence of ACPs or ADs in the general population ranges from 3% to 36%,⁵-⁷ with those over the age of 55, of higher health literacy, and with higher levels of dependency reported as more likely to consider ACP.⁸ There remains criticism as to the effects of ACPs including that the concept is fundamentally flawed, involves false promises and the inability of ACPs to direct end-of-life care.⁹ The challenge thus remains as to how to improve access and completion of ACP when physician engagement remains poor and uptake in the majority of cancer patients, pre and post diagnosis, remains poor.
2.2 ADVANCE CARE PLANNING IN CANCER AND THE ROLE OF PALLIATIVE CARE

Despite cancer patients articulating a desire for information around EOL options and prognosis, many with their families remain unprepared for their dying. EOL discussions remain limited in cancer, leading to the ongoing high cost of futile care and poor uptake of ACP. Barriers to effective communication in cancer around EOL matters have been well documented. They include time constraints, inaccuracies in prognostication, limited understanding of treatment intent, shortcomings in clinician's communications skills and poor patient health literacy. Additionally, cancer patients seek to maintain hope despite facing an advanced illness and resist conversations regarding their future care if introduced too early in the disease trajectory.

2.2.1 Early integration palliative care

Early integration palliative care was proposed to address the above issues in cancer care and to reduce the impact of futile and aggressive treatments on quality of life, financial hardship and the poor patient and caregiver understanding of treatment intent and outcomes. In the United States, the National Quality Forum and American Society of Clinical Oncology Quality Oncology Practice Initiative have defined aggressive cancer care as the following: receipt of chemotherapy within the last two weeks of life, intensive care within the last 30 days of life, more than one emergency room visit in the last 30 days of life and late referral to hospice/palliative care services. These recommendations and quality indicators do not refer to ACP or AD documentation or seek to benchmark patient choices as outlined in an AD against the stated quality outcomes. Additionally, as cancer treatment progresses with the use of immunotherapy or targeted therapies, it is appropriate that patients are sometimes admitted to intensive care or present to the emergency department to deal with treatment related toxicities or complications. These advances also preclude the early referral to palliative care in jurisdictions where access to hospice care is only available with cessation of all active treatment. Considering the above, it is plausible to suggest that with the advances of modern cancer care, some of the above quality indicators are worth reconsidering.

These variations can be exemplified by examining EOL outcomes in patients with pancreatic cancer, a cohort with high symptom burden and poor survival outcomes. In
America, chemotherapy use and admission of pancreatic cancer patients to ICU in the last month of life between the periods of 1992-1994 and 2004-2006 increased significantly from 15.5% to 19.6% (p<0.0001) and 8.1% to 16.4% (p<0.0001) respectively, despite the increased utilisation of hospice care.\textsuperscript{30} Likewise, a Swiss study of 231 pancreatic cancer patients found that 24% received chemotherapy in the last four weeks of life.\textsuperscript{31} Conversely, a retrospective population cohort study of 5381 Canadian patients with advanced pancreatic cancer found that involvement of palliative care services was associated with less chemotherapy treatment (OR 0.34, 95% CI 0.25–0.46), fewer ICU admissions (OR 0.12, 95% CI 0.08–0.18), reduced emergency department visits (OR 0.19, 95% CI 0.16–0.23), and fewer hospitalisations near death (OR 0.24, 95% CI 0.19–0.31).\textsuperscript{32} Additionally, an Australian retrospective cohort study of 278 patients who died of pancreatic cancer found that those who received late palliative care referrals (≤ 90 days before death) had 18.1% (95% CI 6.8–29.4%) more ED presentations and 12.5% (95% CI 1.7–24.8%) and more acute hospital admissions when compared to those who received palliative care earlier in their disease.\textsuperscript{33} Despite the benefits of early integration of palliative care and the opportunities it provides for conversations regarding future care and ACP, none of the studies of early intervention palliative care in cancer patients thus far have considered the completion of ACP as an outcome.\textsuperscript{34}

\textit{2.2.2 Uptake of advance care planning in cancer}

The overall uptake of ACP in cancer remains poor, with structured interventions increasing documentation rates from 15% to 30%-40%.\textsuperscript{35} However, studies continue to show that ACP interventions fail to achieve EOL care consistent with patient preferences.\textsuperscript{35,36} In the Australian context, a recent survey of 440 cancer patients and 265 support persons found that close to half had heard about ACP, and two-thirds had discussed their values and preferences with someone. However, only a third had completed formal ACP documentation and views varied about the preferred timing for ACP discussions (38.3% when cancer is curable and 20% at diagnosis).\textsuperscript{37} A study of ACP documentation in 458 older Australians with cancer reported that 58% self-reported document completion, but only 30% had an ACP in the records, with the majority (81%) of those who completed documentation expressing a preference for treatment limitation.\textsuperscript{38} A large multisite Australian RCT of an ACP intervention compared to UC offered to patient-family member dyads found that a formal
ACP intervention did not increase the likelihood of ensuring that EOL care was consistent with stated patient preferences. Finally an ongoing challenge faced in ACP is the variations in intervention design, delivery and outcomes measured for ACP in cancer. Interventions have been described as the provision of Question Prompt Lists, written clinical vignettes, documents and videos outlining details of ACP. Interventions are also delivered by a range of health professionals with heterogenous outcomes.

2.2.3 Factors that influence advance care planning in cancer

A systematic review of perceptions and experiences of patients, families and healthcare providers of cancer patients identified several salient factors that influence ACP in cancer. These included the relational aspect of ACP, with families acting as facilitators or barriers to ACP and the importance of the endorsement of ACP by a healthcare provider with whom there was a therapeutic alliance. ACP has the potential to cause distress and elicit existential anguish if introduced too early in the disease trajectory. It has been suggested in the first instance that one should assess readiness for ACP and that different components of an ACP should be offered at different points of a disease trajectory. Identifying triggers for ACP conversations, such as a change of treatment intent from curative to palliative, a change in functionality, or a significant clinical event, may assist further with considerations of timing for the introduction of ACP.

More recently, proponents of ACP have appreciated the importance of encouraging discussions around personal values in ACP. This suggests that a more person-centred ACP approach should be encouraged in cancer care. Personal values are individual conceptions of the desirable appraisals and actions that guide our attitudes and behavior and are recognised by patients as guiding their treatment and care choices such as the continuing or cessation of life sustaining treatment, or decisions pertaining to their preferred place of care. ACP interventions that incorporate a values-based paradigm remain underdeveloped. To address this unmet need, the Person-Centred Oncologic Care and Choices (P-COCC), which combines an informational care goals video with a brief patient values interview, was developed to help cancer patients consider future medical care in the context of their personal values and preferences. The P-COCC intervention addresses the internal (e.g., symptoms, psycho/spiritual values, and social relationship values) and external patient factors (e.g., family, the health care team, and medical care options). When tested in a pilot RCT of 151
cancer patients randomised to P-COCC vs video alone vs UC, P- COCC was reported as acceptable. However, increased participant distress compared with video-alone and UC study arms.42

The limited uptake of ACP and robust data from research may be related to the immature manner by which ACP interventions are developed and evaluated, and the lack of established practices for ACP within health systems.46 There needs to be more appreciation of the salient characteristics of ACP and the impact of psychosocial factors on outcomes. More recently, ACP has been viewed as a complex intervention, with several dimensions affecting the outcome.47,48 Thus, the measurement of a single outcome from the level of a single target group does not sufficiently depict how the intervention causes change and which factors influence the outcome.

2.3 THE VIGNETTE APPROACH IN ADVANCE CARE PLANNING
Clinical vignettes are a helpful tool for teaching and research in clinical medicine. They are essentially abridged patient reports and may summarise the relevant clinical history, examinations, investigation findings, and treatments.49 The VT was first established as a research tool to examine participants' perceptions, beliefs and attitudes, acknowledging that individual meanings and human behaviours are socially situated.50 When used in the research context, vignettes are usually hypothetical scenarios that are developed to elicit specific situations to which participants are invited to respond.51 Participants may be invited to describe how they may respond when faced with a particular scenario or be provided with several potential responses to choose from.

Clinical vignettes are commonly used to elicit views on EOL decision-making and are usually presented in written form.52-54 More recently, video decision aids or VDSTs incorporating video vignette methodology are acceptable to patients when used within the research context.55 In the context of ACP, VDSTs have been developed to depict diminishing health states and the nature of different treatment options. VDSTs have typically depicted simulated CPR, endotracheal intubation, or ventilation,56,57 with some others depicting didactic presentations on ACP or options of life-prolonging care, limited medical care and comfort care.45,47-49 A systematic review of ten trials enrolling 2200 patients to RCTs comparing a VDST for ACP with a comparator arm with no ACP VDST in adult cancer
patients aimed to examine the effect of a ACP VDST on life sustaining treatment choices.\textsuperscript{55} It found that patients who use a VDST were less likely to indicate a preference for cardiopulmonary resuscitation [pooled risk ratio, 0.50 (95% CI 0.27 to 0.95)], with moderate-quality evidence suggesting that VDSTs result in greater knowledge related to ACP standardised mean difference, 0.58 (95% CI 0.38 to 0.77)]. However, there were several limitations to this systematic review. This included variations in the definitions of life sustaining treatments (CPR and ICU admission) as well as the comparator arm (sham video, traditional methods of ACP decision support such as verbal description, pamphlets, usual care, or no discussion). Additionally, imputation methods were not used, thus including only patients with non-missing data (complete case analysis) in the meta-analyses. None of the studies reported on the congruence of end-of-life treatments with patients’ wishes or evaluated the effect of video decision aids when integrated into clinical care.\textsuperscript{55}

There has been limited if any, research that has incorporated patient-caregiver dyads in the use of VDSTs to consider ACP. When used effectively in written or video format, vignettes provide the opportunity for improved EOL communication about care preference. They may ensure that the surrogate decision-maker’s preferences more closely reflect patients’ wishes.\textsuperscript{56,57} Additionally, in the context of patients with serious illnesses such as cancer, the use of vignettes requires the presence of a skilled facilitator who can fully explore clinical concerns and provide guidance on prognosis, trajectory and treatment options.

2.4 THE DYADIC APPROACH AS A CONSIDERATION FOR ADVANCE CARE PLANNING

The impact of a cancer diagnosis on both the patients and family caregivers is well recognised, affecting the relational dynamics and coping of couples as a ‘unit’ rather than isolated individuals.\textsuperscript{58,59} The patient and their caregiver are required to adjust practically, socially, emotionally and existentially throughout the disease trajectory, adapting family roles, occupations and responsibilities.\textsuperscript{60} More recently, research has shifted from examining the individual experience of patients and caregivers to that of patient-caregiver dyads.\textsuperscript{61,62} The mutuality of this dyadic relationship may be conceptualised at three levels: ‘communication’, ‘reciprocal influence’ and ‘patient-caregiver congruence’.\textsuperscript{63}
A systematic review of dyadic experiences of couples facing advanced cancer identified changes in the nature of communication between dyads as a key experience following a cancer diagnosis.\textsuperscript{64} Patient-caregiver dyadic communication is consequential, with open communication improving support, functioning, resilience and cohesion but poor communication affecting mood, emotional security and relationship stability.\textsuperscript{65,66} A critical issue in dyadic communication is the lack of congruence in communication. Congruence is the agreement of shared perceptions of the different facets of the cancer experience between patients and caregivers.\textsuperscript{67} Research has examined patient caregiver congruence in symptoms,\textsuperscript{68} prognosis\textsuperscript{69} and psychosocial concerns,\textsuperscript{70} with findings indicating that improved concordance was related to lower caregiver burden\textsuperscript{71} and improved patient health outcomes.\textsuperscript{72}

Despite recognition of the importance of patient-caregiver concordance in communication, the Cancer Communication Assessment Tool (CCAT) remains the only validated instrument designed to examine congruence in communication, with higher scores indicating more significant discord.\textsuperscript{72} The CCAT has been validated internationally,\textsuperscript{73,74} confirming its utility as a measure for discord. Regardless of the dearth of instruments available to evaluate this vital area of cancer care, further exploration of communication concordance is warranted.

Finally, the need for dyadic involvement and importance of congruence in communication is well recognized in cancer ACP. Dyadic research in ACP has identified several key issues that are a source of conflict.\textsuperscript{75} These included difficulty thinking about dying and differences in values and experiences. Caregivers or surrogates in ACP seek more detailed information, are less ready to hear what the patient is saying and rely on what they already know about the patient, thus impeding or facilitating ACP engagement.

\textbf{2.5 SUMMARY AND CONCLUSIONS}

In this summary, I have reviewed the key areas of interest in this thesis: ACP in cancer, the vignette methodology, the dyadic approach and congruence in communication. This provides an overview of the early developmental work undertaken to set the context and provide the background for my interest in understanding how cancer patients conceptualise ACP. It further highlights my interest in exploring the utility of the VT in ACP research.
2.6 REFERENCES FOR CHAPTER TWO


41. Bakitas M, Dionne-Odom JN, Jackson L, Frost J, Bishop MF, Li Z. “There were more decisions and more options than just yes or no”: Evaluating a decision aid for advanced cancer patients and their family caregivers. Palliat Support Care 2017;15(1):44-56.


CHAPTER THREE

FINDINGS FROM EARLY PUBLICATIONS
This chapter summarises five of my previously published papers along the similar theme of ACP in cancer patients. These papers explore cancer patients' and caregivers' views and perceptions on ACP, the feasibility study's outcomes, and the VT's utility. It provides the early evidence for the subsequent work undertaken for this thesis in accordance with the Medical Research Council Framework for complex interventions. Following the summary of the 5 published papers, I will compare and contrast findings with that of the other significant literature presented in Chapter 2 and refer to limitations. I will also explore the relationship between these earlier study findings and the development of the intervention used in my main RCT study.

3.1 UNDERSTANDING HOW CANCER PATIENTS ACTUALISE, REJECT OR RELINQUISH ADVANCE CARE PLANNING. IMPLICATIONS FOR PRACTICE.¹

Our first published study (Appendix A) sought to explore how Australian cancer patients perceived ACP.¹ The study was conducted in a major tertiary centre in Melbourne, Victoria. Theoretical sampling was used to recruit cancer patients from the lung and gastrointestinal tumour stream. We conducted face-to-face interviews with eighteen adult cancer patients. Participants' understanding of ACP was initially explored, and they were then provided with written information on ACP. Participants subsequently met with a researcher and were provided with written vignettes outlining four cases of cancer patients at different stages of the disease trajectory. Participants were asked to reflect on the written vignettes when they answered a series of questions (see Table 1 in the article). The interview was recorded, transcribed and analysed using a constructivist research approach applying grounded theory methodology.

The analysis confirmed poor prior knowledge of ACP and that participants differed in their views about tolerable levels of debility and acceptability of life-prolonging treatments. Importantly, it identified ACP as a dynamic rather than cyclical process whereby patients can actualise, relinquish or reject its individual components (Figure 3). The actualisation of an ACP involves the iterative process of considering, conversing, planning and communicating a decision. Individual values, prognostic awareness, past experiences of illness, health perceptions and relationships with substitute decision-makers influenced reactions and uptake of ACP.
3.2 CANCER CAREGIVERS ADVOCATE A PATIENT AND FAMILY-CENTERED APPROACH TO ADVANCE CARE PLANNING.²

Our second published paper (Appendix B) mirrored the aims and methodology of the first paper. Written vignettes were modified to suit the caregiver.² Eighteen caregivers participated in semi-structured qualitative interviews, which were audio recorded, transcribed and analysed as previously described. Our findings confirmed caregiver support for ACP, the relational nature of ACP and the importance of a patient and family-centred approach to ACP (Figure 4). Caregivers articulated an awareness of potential distress that ACP conversations may cause and, like patients, sought the involvement of healthcare professionals when considering ACP. Numerous nuances influenced caregiver involvement and views in ACP, including family decision-making styles, culture and family hierarchies. Caregiver subsidiary planning and intentional overriding of patient wishes highlighted the relational element of ACP and the interdependent patient-proxy relationship that exists in
decision-making. Within the framework of relational identity, we suggested that patent agency warranted consideration beyond individual autonomy.

Fig 3.2 The “Shared Decision-Making Relational Elements” figure depicts how decision-making is part of patient- and family-centred care. Reprinted with permission from the Institute for Clinical Systems Improvement.

Our first two qualitative papers offered a unique contribution to the ACP literature. Multiple qualitative research studies have previously been undertaken, using semi structured interviews but ours were the first to use written vignettes to explore perceptions on ACP. A Canadian study which recruited ten oncologists, four cancer patients and four caregivers reported the importance of stakeholder engagement in ACP, with patients and caregivers welcoming ACP discussions with greater expectations on healthcare professionals. However, it did not seek to explore the nuances of how ACP is considered individually by participants.³ An American study of Latino cancer patients explored perceptions in greater detail, reporting the influence of key cultural, religious and familial beliefs and dynamics and the importance of integrating these values into ACP discussions.⁴ A multisite European ACP involving cancer patients and their substitute decision makers undertook a qualitative phenomenological study. Their finding demonstrated the benefit of the dyadic approach in ACP interventions with a deepening and realignment of mutual understanding between patients and their substitute decision makers. It however acknowledged the skills and professional facilitation required to manage interprofessional dynamics and relationships.⁵
3.3 A MIXED METHOD FEASIBILITY STUDY OF A PATIENT AND FAMILY-CENTERED ADVANCE CARE PLANNING INTERVENTION.

We conducted a prospective, longitudinal, mixed-method study (Appendix C), recruiting thirty cancer patient-caregiver dyads who had not participated in the earlier studies. Our intervention involved 1) Identifying and exploring gaps in knowledge and understanding of ACP, 2) Eliciting understanding of the role of ACP in cancer, 3) Tailoring the intervention to address unique decision-making needs and preferences, 4) Supporting the actualisation of an ACP, and 5) Summarising interview and assessment for additional support.

We achieved a recruitment rate of 47%. Our study confirmed the need for an ACP intervention; only 7% of patients had heard about or completed an ACP. We demonstrated high intervention fidelity, with all patients and caregivers completing the intervention. Additionally, overall compliance with assessments was high (87% for patients and 92% for caregivers), with low missing responses to items (<2.5% for patients and <1.0% for caregivers). Our findings found that patients reported lower decision conflict four weeks post-intervention, with small effect size improvements noted on clarity, perceived support in decision-making and certainty about a better choice being made. Improvements were observed in patients’ understanding and satisfaction with opportunities to consider future healthcare needs, caregivers’ confidence in discussions with health professionals, and opportunities to consider patients’ future healthcare needs. Understandably, patients reported that the process of considering an ACP evoked distress.

The overall completion of ACP documents could have been higher post-intervention, with only eleven documents from nine patients returned. Patients cited needing to prepare for ACP, an unwillingness to plan, satisfaction with current plans and busy lives as reasons for not completing the documents. We concluded that variability in intervention delivery tailored to individual preferences might be required for future interventions.

Our feasibility study was undertaken following a review of the literature that supported this approach when using the MRC Framework as the overarching research framework. A major limitation of our feasibility study was the lack of the use of a template for intervention description and replication (TIDieR). A Dutch ACP feasibility study utilised the TIDieR template effectively for a cohort of 20 patients with advanced illness, demonstrating feasibility of timely patient selection, preparation of patient and HCP,
scripted ACP conversation in a multidisciplinary setting and documentation. A 12-month feasibility RCT of patients with GIT cancer reported a 46% recruitment rate, comparable to our study but a higher ACP document completion rate of 45% in the intervention arm. A further feasibility study of young adults with cancer that incorporated ACP showed a 56% enrolment into the study with a high completion of an offered ACP program (85%). ACP document completion rates were not completed. Like our published ACP study, all of the above reported high levels of acceptability of the intervention offered.

3.4 EXPLORING THE UTILITY OF THE VIGNETTE TECHNIQUE IN PROMOTING ADVANCE CARE PLANNING DISCUSSIONS WITH CANCER PATIENTS AND CAREGIVERS.

In this study (Appendix D), we aimed to examine patients’ and caregivers’ perspectives on using the VT as a potential tool for facilitating ACP discussions. We used qualitative secondary analysis to analyse responses from 85 participants across three studies (3.1, 3.2 and 3.3), focusing on the respondents’ statements to interview questions specific to the VT.

Participants varied in their identification with scenarios, with caregivers more accurately identifying with individual scenarios. The vignettes provided an opportunity to prompt discussion on the patient’s overall health, for objective or evolving reflections, or to initiate ACP discussions. The examples of the various trajectories provided in the scenarios were confronting to some, yet others remained ambivalent about what they potentially represented.

Our above study concurs with other published findings supporting the utility of the VT, particularly in qualitative studies. Clinical vignettes were shown to be important in facilitating two-way interactions and allowed participants to follow and construct clinical outcomes in a logical and systematic sequence applicable to real-life clinical practice settings. Vignettes when combined with qualitative interviews can enable the exploration of complex public health issues. The use of the VT in our study was akin to others, whereby the vignettes provided structure to interviews but allowed certain responses to be investigated in greater depth. A scoping review of the use of experimental vignette studies to identify drivers in the variations of health care identified twenty one published studies that used a combination of written, video and pictorial vignettes. Poor study design
and evaluation of the credibility of the vignettes are identified as potential sources of bias that must also be considered in our own published studies.\textsuperscript{16}

\textbf{3.5 DOES IMPLEMENTATION MATTER IF COMPREHENSION IS LACKING? A QUALITATIVE INVESTIGATION INTO PERCEPTIONS OF ADVANCE CARE PLANNING IN PEOPLE WITH CANCER.}\textsuperscript{17}

This study aimed to examine how cancer patients who had completed ACPs interpreted and understood their ACP and how accurately the completed ACP documents represented their wishes (Appendix E). Fourteen cancer patients participated in interviews and had their ACP documents examined. Despite having completed ACPs, participants demonstrated a partial understanding of what an ACP entailed and expressed concern that their wishes would not be respected. Participants also demonstrated a need for more congruence between their verbally stated wishes to what was documented in their ACP. This was particularly relevant to issues pertaining to cardiopulmonary resuscitation, life-prolonging treatment or donation of remains to medical sciences. Nonetheless, completing an ACP was empowering for some and was viewed as a process that could reduce the burden of decision-making for families.

Our final study was completed independently from the first four but provided insight into the limitations of simply relying on document completion as a proxy for a true understanding of future care planning. Our cohort size was small but acceptable for a qualitative study.\textsuperscript{18} Despite there being many published studies exploring reasons for non-completion of ACP as well as gap analysis to identify systemic failures that restrict the implementation of ACP, there is a paucity of literature that examines patients or caregivers understanding of the implications of their decisions post completion.\textsuperscript{19,20} Thus, the completion of an ACP document in itself should not be considered a final act in decision making, with decisions revisited and reassessed at appropriate opportunities.

\textbf{3.6 SUMMARY AND CONCLUSIONS}

In this chapter, I have presented a summary of the findings from the first five papers published on the topics of ACP in cancer, the feasibility of an ACP intervention with patient-caregiver dyads, the vignette methodology and cancer patients' comprehension of their completed ACPs. This body of work provided me with the opportunity to consider how its
findings may be suitable for the development of further interventions. Several key features included:

1) The VT was acceptable in written format and provided an opportunity to consider how it may be extended in use in alternative formats. Based on previous published VDST studies, I elected to convert the written vignette to video vignettes. Our utility study confirmed the acceptance and benefit of the written vignettes, but we failed to examine the credibility of the VT through independent verification.

2) Our early qualitative papers suggested that personal values (both patients and caregivers) affected the consideration of how ACP may be contemplated and actualised. This formed the bases of our focus on values conversations. However, I failed in my early studies to evaluate what specific values were of particular prominence to participants and how they may be best portrayed through dyadic conversations. This was a major limitation in the subsequent development of the VDST intervention. Additionally, the examination of reliability and validity would have highlighted a number of other limitations. Despite the use of file notes and triangulation, resources limited the time for engagement with these methods and consensual validation.

3) Our feasibility study tested and confirmed the possibility of dyadic involvement, but we did not consider the measurement of congruence at this juncture. The use of the CCAT as a measure of congruence evolved in the planning of the RCT, which is an acceptable approach using the MRC Framework.

4) The progression of the study design from a longitudinal mixed method study to a multi-method study involving an RCT, qualitative and psychometric studies could have been assessed in greater detail. Ideally the validation of the CCAT done sooner may have demonstrated less than ideal psychometrics, which may have influenced its choice as an outcome measure and involvement in the RCT. Additionally the design of the RCT and its components could have been more robust, taking into consideration the iterative nature of ACP decision making and complexity of family involvement.

Nonetheless, this scholarship nurtured my knowledge of and interest in fostering the use of ACPs, exploration of further uses of the vignette methodology and values orientation within the dyadic context, thus providing the background context for the work undertaken in this thesis. The following chapter will provide an overview protocol.
developed for a randomised controlled trial. It will address the study design and methodology in detail, particularly the development of the video vignettes.

3.7 REFERENCES FOR CHAPTER THREE


CHAPTER FOUR

RESEARCH FRAMEWORK AND METHODOLOGY FOR RCT AND SUPPORTING STUDIES
In this chapter we will discuss the overarching framework used for this suit of studies, from the preliminary research conducted and published to the subsequent RCT and supporting studies. We opted to use the Medical Research Council’s Framework for complex interventions as the overarching framework to explore ACP in cancer. Our first set of studies explored the core elements of ACP in cancer and the utility of the VT before we endeavored to test the dyadic approach via a feasibility study. Below we articulate the principles behind the MRC framework and subsequently the rationale for using a mixed model methodological approach for our current body of work.

4.1 THE MEDICAL RESEARCH COUNCIL FRAMEWORK FOR COMPLEX INTERVENTIONS

Complex interventions in healthcare are described as interventions with several separate and critical interacting components, all of which impact health.\(^1\) Research involving complex interventions can focus on efficacy, effectiveness, theory or systems perspective to add further evidence to current knowledge.\(^2,3\) It seeks to explore a broader range of questions beyond achieving an intended outcome, e.g. exploring the further impact, value relative to resources available, understanding the influence of context and how the evidence may subsequently influence real-world decision-making.\(^3,4\)

Evaluations of complex interventions have posed practical and methodological challenges and as such, the MRC in the United Kingdom in 2000 published guidelines for the robust development, testing and appraisal of complex interventions.\(^5\) Despite this model being highly influential at first,\(^5\) the following limitations were described, including its linear model of evaluation (Figure 4.1),\(^6\) limited early phase piloting and development work\(^7\) and standardised models that were not contextualized.\(^8\) Subsequent considerations led to further recommendations on approaching the development, reporting and implementation of complex interventions and considering alternatives to RCTs.\(^5\) The above limitations identified within the framework led to subsequent revisions, with new guidelines published in 2006 and subsequently 2021.\(^3,5\)
Fig 4.1 MRC Framework for Complex Interventions.

Reprinted with permission from “Framework for design and evaluation of complex interventions to improve health” Campbell M et al. BMJ. 2000 Sep 16;321(7262):694-6.⁵

The most up-to-date guidelines suggest that complex intervention research can be considered in non-sequential phases: development or identification of an intervention, assessment of the feasibility of the intervention and evaluation design, evaluation and impact of the intervention (Figure 4.2).
Fig 4.2 Framework for developing and evaluating complex interventions. Reprinted with permission from “A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance” Skivington K et al. BMJ 2021;374

Six core elements should be considered at each phase to address the questions outlined in Table 4.1, with the answers used to decide how the research should proceed.

**Table 4.1 Six core elements to consider at each phase of the research**

- How does the intervention interact with its context?
- What is the underpinning program theory?
- How can diverse stakeholder perspectives be included in the research?
- What are the key uncertainties?
- How can the interventions be refined?
- What are the comparative resource and outcome consequences of the intervention?

4.1.1. Using the MRC framework to develop a complex intervention for ACP in cancer patients

In conducting our research on ACP in cancer, we have strived to embrace the MCR framework, appraising the numerous variables that may impact an ACP outcome.
4.1.1.1 Exploring theory

Our first two published papers on cancer patients' and caregiver views on ACP provided insights into how ACP was approached and perceived. The initial findings of both the patient and caregiver studies highlighted the ‘personalisation’ of the ACP process and led to the research team exploring how the concept of basic human values intrinsically motivate patients and caregivers to actively plan for their future care. Values are prioritized individually with behavioral and attitudinal consequences that follow from holding value priorities. Our intention was to draw on value theory as described by Schwartz in the development of our VDST. We will expand further on this theoretical basis in the discussion of the relevant chapters.

These early studies (individual patient and caregiver studies and subsequent dyadic feasibility study) also formed the basis for us to consider using patient-caregiver dyads as our unit of reference for future studies. Dyadic health theories related to patients with chronic illness have highlighted the importance of interdependence and communal coping. Dyadic theories have shown that couples demonstrate shared illness appraisals (e.g. this is ‘our’ problem rather than ‘your’ problem), shared responsibilities and the adoption of health-promoting behaviors. Our intention with adopting a dyadic approach in our research framework was to promote relationship-oriented motivation and positive support interactions in ACP and end-of-life decision making.

Finally, several treatment decision making theories exist that provide a framework by which to develop and test hypothesis and interpret data. These include normative, descriptive, and prescriptive theories of decision making, all of which may be considered in the development of decision aids such the VDST interventions used in other video vignette studies. All these theories seek to inform interventions to improve decision making. However, it is difficult to ascertain how best to incorporate value theory as discussed above alongside these decision-making theories in the development of an intervention. The above theoretical frameworks provided the initial avenue for us to consider the vignette methodology in ACP in the Australian context, but our primary focus was to consider development of the vignettes based on value theory, which will
4.1.1.2 Testing feasibility

We subsequently tested the feasibility of an intervention using the dyadic approach demonstrating a 47% consent rate but high levels of completion of outcome measures within this cohort. This phase further confirmed the utility of the VT, which we subsequently confirmed in a secondary qualitative analysis. We also developed and tested a set of questions confirming the understanding and benefit of the intervention on ACP.

4.1.1.3 Exploring uncertainties and refining the intervention

Our early work highlighted the importance of the dyadic approach and the significant gap in the Australian research space regarding using video VT in ACP. Further review of the literature and our qualitative work highlighted the need to focus on achieving patient and caregiver congruence in decision-making and the importance of individual values as the basis of EOL decision-making in cancer patients.

We recognise the opportunity to enhance our understanding of developing video vignettes using recommended guidelines and choosing to focus on depicting values conversations. Our inclusion of the CCAT to measure congruence in conversation was novel. Our RCT was the first to show improvement in concordance in communication with ACP. Our RCT also demonstrated that older patients responded better to values conversations and thus raised the discussion of how we better engage younger cancer patients in ACP discussions.

4.1.1.4 Implementation

There needs to be more implementation of VDSTs in the real-world clinical scenario, and questions arise on how we best incorporate such or future interventions into routine care. The challenge remains in cancer ACP regarding how best to ensure patients prepare for their future care whilst ensuring that any intervention minimizes distress and continues to engender hope in patients and caregivers. Following our preliminary work, we progressed using the MRC Framework for complex interventions to develop an RCT as our core theoretical approach to further evaluate the benefits of the integration of values conversations via a video VT format. In the section below,
we first present the methodology selected for the work developed and completed in this thesis.

**4.2 METHODOLOGY FOR RCT AND SUPPORTING STUDIES**

The aim of this section is to outline the overarching methodology used for the studies presented in the thesis, particularly focusing on detailing information that could not be accommodated within the chapters that were submitted for publication (Chapters 5, 6, 7 and 8). We commence with a description of the overall research design, the rationale for choosing this design and the principles we adhered to. As this is a multi-method study, it would be prudent to provide further detail on the methodology for each study in the individual Chapters. Detailed methodology for the RCT is offered in Chapter 4 (Protocol Paper) and further details of the qualitative study methodology and psychometric analysis is provided in Chapter 6 and Chapter 7.

![Fig 4.3 Schematic representation outlining core study and embedded studies.](image)

**4.2.1 RESEARCH DESIGN**

In this study we used a multi-method research design. A multi-method design occurs when two or more distinct pieces of work are conducted, each complete in itself to address research questions, a topic or a program. Studies may be a combination of...
quantitative methods, qualitative methods, or both, with projects implemented concurrently or sequentially. A multi-method design is distinct from a mixed method study whereby two or more different data collection and analysis methods are used in the same study, with subsequent triangulation of findings into one. In this thesis, I recognise three district methodologies – quantitative, qualitative, and psychometric analysis to analyse data arising from the RCT (quantitative), completed values directives (qualitative) and completed CCAT-PF (psychometric analysis). As such, they are each recognised as distinct studies (Figure 4.3).

4.2.2 PRINCIPLES FOR MULTI-METHOD DESIGN
In considering the use of a multi-method design, researchers are asked to adhere to several research principles. The first is to recognise the projects primary theoretical drive and adhere to its methodological assumptions. In this study, the primary theoretical drive was a quantitative study (an RCT) and formed the analytical core of the project. This was determined by the research questions and drove the approach to data and sampling. The secondary component was qualitative, and the sample was purposefully selected from the main RCT study. The role of the secondary component was to elicit a deeper dimension and perspective that could not be accessed by the first approach, with the aim of enhancing the description of emerging findings. Our third component, the validation of the CCAT-PF was developed to further explore the emerging conjecture of dyadic communication, with data drawn from the first component (the RCT) and subsequently expanded. Our second and third components were developed sequentially and not concurrently from the first component of the study.

4.2.3 VALIDITY, REFLEXIVITY AND ETHICS APPROVAL
In the design of each component of this research program, the issues of validity and reflexivity requires consideration. As much as possible I attempted to ensure as robust a design for the RCT as possible, with the limitations discussed in Chapter 5 and Chapter 6. To ensure validity and reliability, sample selection and recruitment will occur through standardised measures. We ensure that the appropriate design and consistent delivery of the intervention and usual care methods. Where possible validated tools will be used to
measure appropriate outcomes. It is however difficult to comment on how the developed VDST will affect the validity and reliability of these studies.

The validity of the qualitative studies will be ensured through appropriate sampling, coding techniques and subsequent triangulation of the data. Reflexivity of the researcher is critical to limit bias, with the need for the researcher to examine their own practices, judgments and belief systems during the data collection processes.

Ethical approval will be required from the relevant participating sites Human Research Ethics Committee before any research is undertaken.

4.3 REFERENCES FOR CHAPTER FOUR


29. Martha D, Sousa VD, Mendes IA. An overview of research designs relevant to
CHAPTER FIVE

VIDEO DECISION SUPPORT TOOL PROMOTING VALUES
CONVERSATIONS IN CANCER: PROTOCOL FOR A RANDOMISED
CONTROLLED TRIAL
5.1 DECLARATION BY CANDIDATE AND CO-AUTHOR STATEMENT


<table>
<thead>
<tr>
<th>Nature of contribution</th>
<th>Extent of contribution (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study conceptualization, literature review, design of methodology, manuscript preparation</td>
<td>75</td>
</tr>
</tbody>
</table>

**Candidate’s Signature**

13/6/2022

We, the undersigned, hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-author's contribution to this work:

<table>
<thead>
<tr>
<th>Co-Author</th>
<th>Contribution</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr E Georgousopoulou</td>
<td>Study design, statistical assistance, manuscript preparation.</td>
<td>07/09/22</td>
</tr>
<tr>
<td>Dr C O’Callaghan</td>
<td>Study design, statistical assistance, manuscript preparation.</td>
<td>07/09/22</td>
</tr>
<tr>
<td>Ms A Melia</td>
<td>Vignette development, manuscript preparation.</td>
<td>14/6/2022</td>
</tr>
<tr>
<td>Dr M Sulistio</td>
<td>Vignette development, manuscript preparation.</td>
<td>13/6/2022</td>
</tr>
<tr>
<td>Prof D Kissane</td>
<td>Study design, supervisory guidance and editing.</td>
<td>13/6/2022</td>
</tr>
</tbody>
</table>
5.2 PREAMBLE TO PROTOCOL PAPER

This chapter presents the protocol for the randomised controlled trial comparing outcomes from a Video Decision Support Tool demonstrating values conversations between patient-caregiver dyads and UC. This paper outlines in detail the methodology used in this study. It specifically focuses on developing the video vignettes in detail, articulating the use of guidelines for the preparation of the scripted video vignettes and the specific manipulations of scenarios developed, the values conversations depicted, and the ACP outcomes encouraged.

This protocol paper additionally addresses the calculation of the sample size required to conduct a fully powered study and the recommended processes for randomisation and blinding. It details the primary and secondary outcomes sought, the validated tools used to measure these and the statistical analysis applied. It also addresses how the facilitators were trained, and the processes used to manage distress, monitor data and manage confidentiality. Potential limitations of the planned randomised controlled trial are addressed. They include issues of recruitment, attrition, challenges of generalisability of findings and challenges that will arise with the attempt to convey 'values conversations' via video vignettes conceptually.

The VDST developed for this study can be viewed here: https://vimeo.com/281613839/eb2dba5311. The following documents developed for the study have been included in the Appendix: Patient/Caregiver Information and Consent Form (Appendix H), Patient/Caregiver Questionnaire (Appendix I), and ACP documents (Appendix J).

This paper has been published in BMC Palliative Care, a peer-reviewed open-access journal with a 2-year impact factor of 3.113 (2021). In accordance with the University of Notre Dame's guidelines for a thesis by publication, the manuscript has been presented in the original publication format of the journal. The tables and figures within the manuscript have been renumbered to generate a consistent presentation and order within the thesis. This article is printed here with permission from Springer Nature. It is licenced under the Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format http://creativecommons.org/licenses/by/4.0/ (Appendix K).
Video decision support tool promoting values conversations in advanced care planning in cancer: protocol of a randomised controlled trial

Natasha Michael1,2,3*, Clare O’Callaghan1,4, Ekavi Georgousopoulou5, Adelaide Melia1, Merlina Sulistio1,2,3 and David Kissane1,2,3

Abstract

Background: Views on advance care planning (ACP) has shifted from a focus solely on treatment decisions at the end-of-life and medically orientated advanced directives to encouraging conversations on personal values and life goals, patient-caregiver communication and decision making, and family preparation. This study will evaluate the potential utility of a video decision support tool (VDST) that models values-based ACP discussions between cancer patients and their nominated caregivers to enable patients and families to achieve shared-decisions when completing ACP’s.

Methods: This open-label, parallel-arm, phase II randomised control trial will recruit cancer patient-caregiver dyads across a large health network. Previously used written vignettes will be converted to video vignettes using the recommended methodology. Participants will be ≥18 years and be able to complete questionnaires. Dyads will be randomised in a 1:1 ratio to usual care (UC) or VDST group. The VDST group will watch a video of several patient-caregiver dyads communicating personal values across different cancer trajectory stages and will receive verbal and written ACP information. The UC group will receive verbal and written ACP information. Patient and caregiver data will be collected individually via an anonymous questionnaire developed for the study, pre and post the UC and VDST intervention. Our primary outcome will be ACP completion rates. Secondarily, we will compare patient-caregiver (i) attitudes towards ACP, (ii) congruence in communication, and (iii) preparation for decision-making.

Conclusion: We need to continue to explore innovative ways to engage cancer patients in ACP. This study will be the first VDST study to attempt to integrate values-based conversations into an ACP intervention. This pilot study’s findings will assist with further refinement of the VDST and planning for a future multisite study.


Keywords: Advance care planning, Cancer, Communication, End-of-life care, Complex Intervention, Decision aid
Background
All people have the right to make decisions about how they are cared for in the future. However, many lose this ability as they approach the end-of-life (EOL). Advance care planning (ACP) may provide an avenue to ascertain patients' wishes in circumstances where they are unable to articulate them due to a loss of capacity [1, 2]. A recent multidisciplinary panel of ACP experts defined ACP "as a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" [3]. Elucidating ACP enhances desirable EOL outcomes, including patient-caregiver confidence and satisfaction [4, 5], quality of death [2, 6], and family bereavement experiences [6]. ACP requires reflection and communication and is an iterative process that is both individualized and shared [7, 8]. Contemporary views have shifted from ACP focused solely on treatment decisions at the EOL and medically orientated advanced directives. It instead encourages conversations that communicate personal values and life goals to support patient-caregiver communication and decision-making [9], family preparation [10, 11], and the actualization of ACP's through innovative interventions [12].

Specific ACP challenges are recognized in cancer care, with ACP in cancer limited in completion, scope, timing, and translation into desired care [13]. Patients commonly prefer discussions later in their cancer journey [14], initiated by their treating physicians, and prefer multiple opportunities for conversations [13, 15]. The physician is required to strike a balance between engendering hope and maintaining truthfulness that ideally incorporates prognostic information [16]. Low uptake may be associated with standardized programs failing to capture the complex social and emotional nuances experienced by the cancer patient and their family across ages, genders, cancer types, and trajectories [17].

Cancer is a family experience, and the heightened involvement of family caregivers in cancer ACP studies is welcomed [10, 18]. Fluctuating awareness of treatment goals among cancer patients and their primary caregivers and the lack of concordance in patient-caregiver communication in cancer impacts effective care [19, 20]. However, cancer care provision in the ambulatory setting has augmented the opportunity to align patient-caregiver communication to support patient-caregiver dynamics, coping, adjustment, and psychological well-being [21]. Patients' and caregivers' assertive behaviors alongside caregiver presence in cancer consultations can reinforce patients' participation in care discussions. This then allows for the triadic alignment of goals between the patient, caregiver, and health professionals [22, 23]. Such opportunities may then allow us to explore how individual and shared family values may influence treatment decision-making.

ACP interventions involving cancer patients on the whole, have increased ACP documentation rates from 15 to 30%-40% but failed to achieve EOL care consistent with patients' preferences [24]. It is increasingly accepted that patient's values and beliefs are the best predictors of the choices they make relating to end of life goals and treatment decisions [25], leading to ACP research exploring SOL values and the development of values-based ACP documents [26, 27]. Incorporating values directives into ACP removes the emphasis of decisions on specific medical interventions, such as cardiopulmonary resuscitation and intubation. It allows a focus on questions related to personal and family relationships, future concerns related to health, spiritual care, and end of life contingency planning [26]. In maturing the research around SOL values, tools such as decision aids with designs responsive to diverse philosophical perspectives are needed, with the flexibility to change as patients gain experience with their personal illness course.

Video decision aids or Video Decision Support Tools (VDST) incorporating video vignettes in ACP are garnering considerable interest amongst academics, clinicians, and policymakers due to their ability to dynamically depict diminishing health states and the nature of different treatment options in culturally and ethically congruent manners. A recent systematic review and meta-analysis of 10 randomised controlled trials' (RCT's) (2220 patients) examining VDST to assist ACP found that patients who use a VDST were less likely to indicate a preference for cardiopulmonary resuscitation (pooled RR, 0.50; 95% CI 0.27–0.95) and acquired improved ACP knowledge [12]. Only four trials reported data on completion of advance directives, with no studies examining the effect on improved preparation in decision-making or patient-caregiver communication.

This study aims to build on the paucity of research exploring conversations about individual values between cancer patient-caregiver dyads and examining their impact on SOL decision-making and ACP. We hypothesize that patients exposed to a VDST that models values-based ACP discussions between patient-caregiver dyads can be an innovative approach to promote ACP in cancer. This study aims to evaluate the effect of a VDST depicting values communication on rates of completion of ACP, attitudes towards ACP, congruence in communication and preparedness for decision-making. The protocol is outlined according to the SPIRIT (Standard Protocol Items: Recommendations for Interventional Trials) guidelines [28].
Methods / design
Study design and setting
This is a prospective, RCT with two parallel groups receiving usual care (UC) or VDST intervention forms part of a research program of ACP in cancer developed in accordance with the Medical Research Council framework for developing complex interventions [29]. In this exploratory study, participants are enrolled in the study as dyads — a patient diagnosed with incurable cancer and a nominated caregiver. In this study, caregivers are defined as a relative, partner, or friend who has a significant relationship with the patient and provides them with social, psychological, and physical assistance [30].

The study will be conducted across three sites in a large not for profit health network Melbourne, Australia. ACP in the hospital is governed by legislation through a jurisdictional Medical Treatment Planning and Decision Act 2016 [31]. The Act establishes a single framework for medical treatment decision-making for people without decision-making capacity that ensures that people receive medical treatment consistent with their preferences and values. Standard forms under the Act allow for the appointment of a Medical Treatment Decision Maker (MTDM) and Support Person and completion of a Values and Instructional Directive (Table 1).

Participants and recruitment
Patients with non-curative cancer will be recruited from the oncology and palliative care across different sites at the health network. Eligible patients will have a diagnosis of incurable cancer and not have completed current ACP documents. Patients who have previously only appointed a MEPOA will be eligible to participate. Both patients and caregivers will have to be over the age of 18, be sufficiently proficient in English, and have a clinically determined prognosis of a minimum of 8 weeks post-randomization. Patients and caregivers will be ineligible for the trial if they are deemed too unwell and are unable to give informed consent due to cognitive or language barriers.

Development of video vignettes
The video vignettes will be developed from the findings of our preliminary research into ACP in cancer patients [7, 10]. These studies incorporated the use of written vignettes, depicting a cancer patient's scenarios across four stages of the cancer trajectory. In our preliminary studies, patients were depicted as declining in function and requiring various levels of care [7, 10, 32, 33]. Vignettes were presented to patients and caregivers in interviews and focus groups to elicit views on ACP and subsequently to patient-caregiver dyads as part of a facilitator-guided intervention in a feasibility study [32]. Qualitative secondary analysis on the use of written vignettes

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Components of an advance care plan/directive</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appointment of Medical Treatment Decision Makers and Support Persons</strong></td>
<td></td>
</tr>
<tr>
<td>Medical Treatment Decision Maker*</td>
<td>A medical treatment decision maker has the legal authority to make medical treatment decisions on behalf of the patient if they do not have the decision-making capacity to make a decision. It is the first person the patient lists who is reasonably available, and willing and able to make a decision. Only adults can appoint a medical treatment decision maker.</td>
</tr>
<tr>
<td>Support Person</td>
<td>A support person can access, or help a patient access health information relevant to their medical treatment. The support person does not have the power to make medical treatment decisions on the patient’s behalf.</td>
</tr>
<tr>
<td>Medical Enduring Power of Attorney</td>
<td>A medical enduring power of attorney authorizes another person to make decisions about medical care and treatment on a patient’s behalf if they do not have the decision-making capacity to make a decision. The person making the medical enduring power of attorney is called the appointer, and the person who accepts the appointment is the agent.</td>
</tr>
</tbody>
</table>

**Values and Instructional Directives**

| Values Directive | A medical treatment decision maker is legally required first to consider the patient's values directive when making decisions about their medical treatment. |
| Instructional Directive | An instructional directive is legally binding and communicates the patient's medical treatment decision(s) directly to their health practitioners. It is recommended that the patient consult a medical practitioner if they choose to complete an instructional directive. |

- An instructional directive will only be used if the patient does not have the decision-making capacity to make a medical treatment decision.
- The medical treatment decisions in the instructional directive take effect as if the patient has consented to, or refused to, begin or continue medical treatment.
- If only of the statements in an Instructional Directive are unclear or uncertain in particular circumstances, it will become a values directive.
- In some limited circumstances set out in the Act, a health practitioner may not be required to comply with an instructional directive.
- The patient has the option of consenting to or refusing future medical treatment.

*The appointment of a MTDM replaced the appointment of a Medical Enduring Power of Attorney (MEPOA). A MEPOA appointment made before the law changed is recognized under the new Act.

revealed that the vignettes provide a platform to promote values-based conversations and may facilitate congruence in communication between the patient and caregiver [33].

In developing the video vignettes, the research team will adhere to suggested guidelines for the preparation
of scripted video vignettes which are 1) deciding on the appropriateness of the use of video vignettes, 2) developing a valid script, 3) designing valid manipulations, 4) converting written scripts to video, 5) administering the videos [36].

The written script will be developed by senior clinicians, drawing from cases used in previous studies [7, 10]. Manipulations will include representation of patient-caregiver dyads from differing ages, gender, stages of illness and relationships e.g. older patient and spouse/partner; middle-aged patient and sibling; younger patient and friends). This, as well as settings and furnishing, will be selected to enhance the participant's perception of reality [34]. The video vignettes will depict dyads scenarios communicating across three stages of a cancer trajectory, with each stage introducing considerations for completion of different sections of an ACP (Table 2). Professional actors will be sourced from known professional college and university sources, and a pilot video will be created before the filming of the final videos. The video vignettes will be circulated to a multidisciplinary team for validation and approval and further editing before the final video intervention is created.

Study procedures
The study procedure is shown in Fig. 1. Participating clinicians will screen patients for eligibility, and interested eligible patients will be asked to nominate a participating caregiver. Eligible dyads will be informed verbally and in writing about the study and will be invited to meet with a research facilitator in their own homes or an allocated room in the hospital at an assigned date and time.

Patients and caregivers will be consented individually by the research facilitator and will complete individual baseline pre-questionnaires (Supplementary file). Participants will then be randomised as dyads to either the UC or VDST arm. All participants will be advised that participation is voluntary, they may withdraw at any time, and that all information gathered will be treated in the strictest confidence. Patients and caregivers will also be advised that non-participation will not affect their care or their choice to complete an ACP.

Patients from both groups will be advised to discuss their completed ACP with their general practitioner or treating specialist to clarify any questions. The completed ACP will have to be signed, witnessed and returned with the post-questionnaire in a stamped return envelope. Participants will be advised to return the questionnaires even if they choose not to complete the ACP. Participants will receive two telephone call prompts at two-week intervals on completion of the intervention as a reminder to return the completed documents. Returned ACP's will be scanned into the hospital's electronic record system, and a copy returned to the patient.

Sample size and power
Based on the primary outcome of the completion of ACP documentation and assuming a completion rate of around 37% for the control group, with a total of 86 participants/dyads (43 per group) we will be able to show a significant improvement to 67% completion for the VDST group (power of 80%, two sided 5% significance level). Assuming an estimated dropout rate of 30%, recruitment of 112 dyads will be required. Based on previous published studies, we felt that a sample of this size would give us sufficient methodological experience to conduct a subsequent fully powered study [12].

Quality standards
Randomization and blinding
Randomization occurs after completion of baseline assessments. An independent randomization administrator will complete randomization at the individual level using a computer-generated random number sequence in blocks of 6 in 1:1 ratio and with concealed allocation using numbered envelopes. The nature of the intervention makes it impossible to blind study participants. Treatment group assignments will therefore be non-blinded, but outcome assessors will be blinded to allocation.

<table>
<thead>
<tr>
<th>Vignette 1</th>
<th>Cancer stage</th>
<th>Values conversation depicted</th>
<th>ACP outcomes encouraged</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early cancer diagnosis (performance status)</td>
<td>Early diagnosis, good</td>
<td>Active treatment to preserve life at any cost</td>
<td>Appointment of a Medical Treatment Decision Maker and Support Person</td>
</tr>
<tr>
<td>Vignette 2</td>
<td>Progressive metastatic disease, deteriorating performance status</td>
<td>Sustaining a reasonable quality of life through illness. Reflection of values and re-prioritization of life choices</td>
<td>Completion of Values Directive. Consider when to discontinue cancer treatments / accept or refuse treatments based on acceptable quality of life</td>
</tr>
<tr>
<td>Living with serious illness</td>
<td>Advanced metastatic disease, increased dependence</td>
<td>Effects of progressive frailty on quality of life despite active treatment. Reflection of meaningful relationships and EOL values</td>
<td>Completion of Instructional Directive. Discuss cardiopulmonary resuscitation, invasive/life-prolonging interventions, preferred place of death, contingencies e.g. funeral plans, spiritual needs</td>
</tr>
</tbody>
</table>

5.2 Predicted scenarios depicted in the video decision support tool
Fig. 5.1 Study procedure

Participants advised to return questionnaires even if they choose not to complete ACP
Facilitator training and distress management
Research facilitators will be trained in ACP principles and familiarised with recent changes to legislation with the introduction of the Medical Treatment Planning and Decision Act 2016 [31]. They will additionally be familiarised with ACP and the specifics of the appointment of an MTDM and completion of Instructional and Values Directives. Given that the video vignettes may potentially elicit distress in participants, research facilitators will also be trained on how to respond to distress and procedures around seeking additional support for participants. Researchers will be advised to offer to discontinue the video if deemed appropriate.

Data monitoring and confidentiality
Research facilitators will be asked to complete field notes as part of the study monitoring plan. The project team will meet monthly to review the progress of the study. Adherence to the research protocol will be monitored throughout the study. Protocol violations or operational issues will be discussed and resolved at project team meetings. The study steering committee will monitor the study and provide ongoing oversight into early results. If necessary, modifications to the study will be made. To ensure confidentiality, data will be stored in a secure database. Information and measurements will be stored independently from identifiable personal information.

Study arms

Usual care
Patient-caregiver dyads will be provided with a verbal explanation of ACP, an ACP document, and verbal and written guidelines on how to complete the document. Questions will be fielded, and finally, participants will be provided with the patient and caregiver post-questionnaires to be completed individually and returned with the completed ACP in a stamped return envelope.

VDST group
Participants randomised to the VDST group will be shown the video on a mobile computer. The video will be viewed by patient-caregiver dyads simultaneously.

Table 4-3: Measures used pre and post UC and VDST

<table>
<thead>
<tr>
<th>Measures used</th>
<th>Patient Baseline: Pre UC/VDST</th>
<th>Post UC/VDST</th>
<th>Caregiver Baseline: Pre UC/VDST</th>
<th>Post UC/VDST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographics</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DASS-21</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACP Attitudes</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>CCAT</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>PDMS</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

DASS-21 Depression, Anxiety and Stress Scale, CCAT Cancer Communication and Assessment Tool, PDMS Preparation for Decision Making Scale

Research facilitators will offer to discontinue the video at any point if it elicits distress. Following this, the participants will be provided with a verbal explanation of ACP and be provided with the hospital's ACP document, and verbal and written guidelines on how to complete the document. Questions will be fielded, and finally, participants will be provided with patient and caregiver post-questionnaires to be completed individually and returned with the completed ACP in a stamped return envelope.

Outcome assessment
The primary outcome measure will be the completion of ACP documentation. We will specifically examine the completion of various sections of the ACP (Appointment of MTDM and Support Person, Values and Instructional Directives). The following secondary outcomes that will be assessed will be attitudes towards ACP, congruence in communication and preparedness for decision-making.

Data collected and measures used
Table 3 outlines the measures used at baseline and post-intervention. The baseline questionnaire will include the patient's and caregiver's demographic information, including age, sex, marital status, place of birth, the relationship between patient and caregiver, primary cancer diagnosis, and length of time living with the diagnosis. Patients will be asked if they had previously discussed prognosis with their doctor.

The following variables and outcomes will be assessed:

1. Baseline Depression, Anxiety and Stress scores. The DASS 21 scale is a validated 21 item self-reported questionnaire designed to measure the negative emotional states of depression, anxiety, and stress [35]. Evaluation of the DASS 21 in cancer has shown acceptable internal consistency reliability for the Depression subscale (α = .90) and Anxiety subscale (α = .70) with construct validity to measures of suicidal ideation, quality of life, self-rated health, and depressed mood [36].
2. Attitudes towards ACP. Understanding of, opportunities, distress, and confidence related to ACP will be assessed using a previously designed and tested questionnaire comprising nine patient and eight caregiver items, measured on a 10 point Likert scale [32].

3. Congruence in decision-making will be measured using the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF). CCAT-PF consists of 18 items and measures congruence in patient-caregiver communication with the analogous patient (CCAT-P) and family (CCAT-F) instruments, exploring preferences, values, and experiences in treatment decision-making. The CCAT-PF demonstrated internal reliability coefficients for the CCAT-P ($\alpha = 52$), CCAT-P ($\alpha = 60$), and CCAT-PF ($\alpha = 60$). Higher CCAT-PF scores are significantly correlated with greater patient depression and perceived family conflict, lower patient-caregiver assessment and well-being, and less expressiveness and family cohesion [37].

4. Preparation for decision-making will be measured using the Preparation for decision-making scale, a validated scale assessing patient and caregiver perception of an intervention's usefulness. Psychometric analysis has shown Alpha coefficients for internal consistency ranging from 0.92 to 0.96 and that the scale discriminated significantly between patients who did and did not find a decision aid helpful ($p < 0.0001$) [38].

Statistical analysis

Descriptive statistics will be presented as frequencies and relative frequencies for categorical variables, mean and standard deviation for normally distributed continuous variables, or median and interquartile range for continuous variables that are not normally distributed. We will examine secondary outcomes between the two groups comparing pre and post intervention changes with Chi-square or Fisher’s exact test for categorical variables and two-sample t-tests or Mann-Whitney test for continuous variables.

Additionally, multiple linear regression will be performed, addressing the effect of socio-demographic and clinical variables to explore factors associated with the rates of completion of ACP. All results obtained will be presented at a confidence interval of 95%. Thus $p < 0.05$ is assumed to be statistically significant. The statistical software SPSS 23 will be used in this analysis.

Discussion

We present the protocol for a pilot randomised control trial developed as part of a body of work exploring ACP in cancer in the Australian setting. This study follows from previous studies conducted by members of the research team, demonstrating the feasibility and acceptability of the written vignette technique, recruitment of patient-caregiver dyads, and completion of ACP's. The use of video vignettes as a decision aid is supported by a Cochrane review of 115 RCTs involving 34,444 participants showing that compared to UC, decision aids improve knowledge, accurate risk perception, likelihood of selecting options congruent with personal values, and reduce decisional conflict [39]. The video vignette technique has been proven to be acceptable and effective in several North American settings and, it is possible that this equally effective in the Australian setting [12].

A novel aspect of this study is the use of video vignettes to promote values discussion. The use of video to explore a values-based ACP paradigm has been shown to be successful in a single study [40]. This approach's potential benefit in increasing the uptake of ACP in cancer care may allow for more meaningful EOL care planning between patients and their families. Our use of patient-caregiver dyads is relatively unique to ACP video intervention studies. This is despite evidence that suggests the benefit of congruence in communication between patient and caregiver, particularly in the cancer setting [22].

Limitations

There remains a paucity of literature on the methodological challenges that may arise with video vignettes' development. Even the most realistic scripted video vignettes may differ from communication as it naturally unfolds. It is suggested that the manipulation of less defined concepts such as the 'communication of values' in our study through video vignettes poses specific challenges due to challenges in operationalizing such concepts.

Intervention studies in cancer cohorts typically demonstrate significant attrition rates due to progressive illness and high mortality [41]. Cancer patients also not uncommonly remain ambivalent or choose to relinquish or reject ACP as they potentially elicit death anxiety or other existential distress forms. Finally, this study provides an intervention at a single time point, is restricted to a single site and will not measure subsequent congruence between documented ACP decisions and EOL outcomes. It also limits recruitment to English-speaking participants with no provision made for those with limited health literacy and cannot participate.

Conclusion

We need to continue to explore innovative ways to engage cancer patients in ACP. This pilot study's findings will assist with further refinement of the VDST and planning for a future multisite study.
Supplementary Information
The online version contains supplementary material available at https://doi.org/10.1186/s12964-021-00794-3.

Acknowledgements
We thank Nerdia Morton and Gennoveg Murphy for their assistance with this study.

Authors’ contributions
NM conceived the study, developed the study protocol with COC and DK, drafted the manuscript, and is the study coordinator. MS and AM provided leadership in participant recruitment. EG designed the statistical analysis plan. All authors approved the final version of the manuscript.

Funding
This work was supported by the Cabiri Foundation Medical Oncology Research Grant and the Bethlem Griffith Research Foundation Grant (No. 1709). The funding body had no involvement in the design of the study, data collection, analysis and interpretation or writing of the manuscript.

Availability of data and materials
Not applicable. Data sharing is not applicable as this article has no datasets that have been generated or analysed yet. The datasets generated during the study will be available from the corresponding author on reasonable request.

Declarations
Ethics approval and consent to participate
The study protocol was approved by the Monash Health Research Ethics Committee (Reference Number: RES-20-0006-1120). Participants will only be enrolled into the study if they provide written informed consent.

Consent for publication
Not applicable as the manuscript does not contain data from any individual person.

Competing interests
The authors declare that they have no competing interests.

Author details
1Supportive, Psychosocial and Palliative Care Research Department, Cabiri Health, Melbourne, VIC, Australia. 2School of Medicine, Sydney Campus, University of Notre Dame Australia Darlinghurst, Darlinghurst, NSW, Australia. 3Faculty of Medicine, Nursing and Health Sciences, Monash University, Melbourne, VIC, Australia. 4Departments of Psychosocial Cancer Care, St Vincent’s Hospital, Sydney, NSW, Australia.

Received: 27 October 2020 Accepted: 10 June 2021
Published online: 24 June 2021

References

Publisher’s Note
Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.
5.3 SUMMARY AND CONCLUSION

This chapter provides an overview of the proposed randomised controlled trial protocol, with key concepts, design, methodology and analysis outlined. Despite the increasing prevalence of video vignette methodology in ACP, our proposed study was the first to attempt to use video vignettes to explore their impact on completing an ACP as a primary outcome.

The ACP literature continues to report low uptake of ACP in the cancer population. Many patients report a willingness to discuss ACP but a reluctance to complete formal documentation. It thus challenges clinicians and researchers to consider novel interventions and alternative primary and secondary outcome measures. The decision to have the completion of ACP documents as the primary endpoint was motivated by research that showed the benefit of VDSTs in ACP, but this was predominantly limited to participants electing not to have cardiopulmonary resuscitation. In this study I did not analyse the effect of the intervention on individual components of the ACP. My inclusion of the measure of congruence as an outcome as measured by the Cancer Communication Assessment Tool attempts to explore the benefit of ACP on dyadic communication. It also continues to measure attitudes towards ACP, using questions designed and tested by the research team. Importantly, as ACP is intended to assist patients and families in preparing for future care, the Preparation for Decision-Making scale was incorporated.

The most novel aspect of designing the proposed RCT was converting the proposed written vignettes into video vignettes. This involved the identification of critical values that the research team wanted to convey in conversations, the development of appropriate scripts to enable the expression of these values, the selection of appropriate dyadic manipulations (spouse, siblings and friends), the training of actors and finally the filming and editing of material. The choice of using the vignette methodology was drawn from scant evidence that has shown its effects on patient outcomes. Research findings have implied that patients’ emotional engagement improves with the depicting of patient’s emotions\(^1\) and that vignettes allowed for relatability, relevance and motivation.\(^2\) We thus used this evidence to inform methodological decisions as we developed the video vignettes to enhance its ecological
validity for this study.

Appreciating the challenges in recruitment, retention and attrition in palliative care, we attempted to achieve a pragmatic sample size, considering the further limitations that may be posed by dyadic recruitment. Our target of a 37% completion rate was determined by the findings of our feasibility study and previously published literature. The proposed study procedure further outlined the challenges that would arise operationally in completing an ACP due to the legal requirements of clinician signatures, witnessing and scanning the documents into the electronic system. Additionally, the cohort for participants would be drawn from a site whereby patients have a reasonably high level of health literacy, with limited patients from culturally and linguistically diverse backgrounds. This may have limited the development of the values conversations and vignettes. Nonetheless, these preliminary vignettes may provide the template for more specific vignette development to suit individual communities. Finally, we departed significantly from the MRC Framework by failing to include consumer participation for feedback and modification of the proposal.

Legislative frameworks for ACP across Australia are varied but nonetheless, all embrace a values approach to ACP. Thus, the transferability of promoting values conversations is not a limiting factor, though due diligence must be given to cultural groups where there remain sensitivities around end-of life conversations. North American and many European jurisdictions continue to focus on the completion of Advance Directives that take on a more medicalised focused on ACP, though significant strides have been made to encompass a values-based approach towards ACP.

In conclusion, this protocol proposes an outline for a novel intervention aiming to improve the uptake of ACP in a cancer cohort. It sets the context for the first empirical paper (Chapter 5), which reports on the executed RCT and its findings.

5.4 REFERENCES FOR SUMMARY AND CONCLUSIONS

1. Visser LNC, Bol N, Hillen MA, Verdam MGE, de Haes HC, Van Weert JCM et al. Studying medical communication with video vignettes: a randomized study on how variations in video-vignette introduction format and camera focus influence analogue


CHAPTER SIX

PATIENT-CAREGIVER DYADS ADVANCE CARE PLAN VALUE
DISCUSSION: RANDOMISED CONTROLLED TRIAL OF VIDEO
DECISION SUPPORT TOOL
CHAPTER SIX

6.1 DECLARATION BY CANDIDATE AND CO-AUTHOR STATEMENTS


<table>
<thead>
<tr>
<th>Nature of contribution</th>
<th>Extent of contribution (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study conceptualization, literature review, design of methodology, manuscript preparation</td>
<td>75</td>
</tr>
</tbody>
</table>

**Candidate’s Signature**

13/6/2022

We the undersigned, hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-author's contribution to this work.

<table>
<thead>
<tr>
<th>Co-Author</th>
<th>Contribution</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Ekavi Georgousopoulou</td>
<td>Study design, statistical assistance and manuscript preparation.</td>
<td></td>
<td>14/6/2022</td>
</tr>
<tr>
<td>Dr Graham Hepworth</td>
<td>Study design, statistical assistance and manuscript preparation.</td>
<td></td>
<td>14/6/2022</td>
</tr>
<tr>
<td>Ms Adelaide Melia</td>
<td>Patient recruitment, data management and manuscript preparation.</td>
<td></td>
<td>14/6/2022</td>
</tr>
<tr>
<td>Ms Roisin Tuohy</td>
<td>Data management,</td>
<td></td>
<td>14/6/2022</td>
</tr>
<tr>
<td>Dr Merlina Sulistio</td>
<td>Patient recruitment and Manuscript preperation</td>
<td></td>
<td>13/6/2022</td>
</tr>
</tbody>
</table>
6.2 PREAMBLE TO EMPIRICAL PAPER ONE

This chapter presents the first empirical paper of the thesis. Considering the low uptake of ACP amongst cancer patients, I designed a novel intervention of a video decision support tool (VDST), as outlined in the previous chapter. My study was designed as an open-labelled randomised controlled trial (RCT), whereby participants were randomised on a 1:1 ratio to usual UC or the VDST. I hypothesised that by appealing to patient and caregiver values through demonstrating values-based conversations in the VDST, cancer patients would be more likely to appreciate the importance of ACP.

Based on preliminary work that I completed before my thesis (Chapter 3), I appreciated the complexity of ACP in the cancer population and the distress that ACP conversations could elicit. I also considered the importance of caregivers in the process of ACP and thus chose to recruit participants as patient-caregiver dyads. This dyadic approach to ACP is increasingly used in ACP research in recognition of a patient and family-centred approach to care. My previous studies confirmed the utility of the vignette technic and the feasibility of dyadic recruitment, as well as the appropriateness of the use of the Attitudes towards ACP questions. I choose to proceed with an RCT as the next step in keeping with the MRC framework for complex interventions that we applied to this body of work.

The video created for the VDST arm of this study can be viewed here: https://vimeo.com/281613839/eb2dba5311. Patient and caregiver consent, data collection and ACP documents are presented in Appendix H-J. This article is printed here with permission from BMJ Journals. It has been accepted for publication in BMJ Supportive and Palliative Care, 2022 (impact factor of 4.633) following peer review, and the Version of the Record can be accessed online at doi: 10.1136/bmjspcare-2021-003240. Reuse of this manuscript version is permitted strictly pursuant to the terms of the Creative Commons Attribution-NonCommercial 4.0 International (CC-BY-NC 4.0) http://creativecommons.org BMJ Authors Self-Archiving Policy, September 2018 https://creativecommons.org/licenses/by-nc
Patient–caregiver dyads advance care plan value discussions: randomised controlled cancer trial of video decision support tool

Natasha G Michael,1,2 Ekavi Georgousopoulou,2 Graham Hepworth,3 Adelaide Melia,1 Roisin Tuohy,4 Merlina Sulistio,1,2 David Kissane1,2

ABSTRACT

Objective Uptake of advance care planning (ACP) in cancer remains low. An emphasis on personal value discussions and adoption of novel interventions may serve as the catalyst to increase engagement. This study examined the effectiveness of a video decision support tool (VDST) modelling values conversations in cancer ACP.

Methods This single site, open-label, randomised controlled trial allocated patient–caregiver dyads on a 1:1 ratio to VDST or usual care (UC). Previously used written vignettes were converted to video vignettes using standard methodology. We evaluated ACP document completion rates, understanding and perspectives on ACP, congruence in communication and preparation for decision-making.

Results Participants numbered 113 (60.4% response rate). The VDST did not improve overall ACP document completion (37.7% VDST; 35.7% UC). However, the VDST improved ACP document completion in older patients (>70) compared with younger counterparts (<70) (OR=3.08, 95% CI 0.96 to 9.82, p=0.047), elicited greater distress in patients (p=0.015) and improved patients and caregivers ratings for opportunities to discuss ACP with health professionals. ACP improved concordance in communication (VDST ω=0.006; UC ω=0.045), more so with the VDST (effect size: VDST 0.7; UC 0.54). Concordance in communication also improved in both arms with age.

Conclusion The VDST failed to improve ACP document completion rates but highlighted that exploring core patient values may improve concordance in patient–caregiver communication. Striving towards a more rigorous design of the VDST intervention, incorporating clinical outcome scenarios with values conversations may be the catalyst needed.

Key messages

What was already known?

- Advance care planning (ACP) is a quality indicator in cancer.
- Rates of ACP document completion in cancer remain low.

What are the new findings?

- ACP improves concordance in communication in patient–caregiver dyads.
- Videos depicting values conversations may increase ACP uptake in older patients.

What is their significance?

A) Clinical
- Emphasis on personal values may encourage ACP.

B) Research
- The importance of concordance in communication requires further evaluation.

to progress ACP towards a more fulfilling process for those who partake in it.

Trial registration number ACTRN1262001035910.

BACKGROUND

Studies have long confirmed that patients with cancer continue to receive inappropriate aggressive care towards the end of life (EOL),1 causing unnecessary suffering, frequent hospitalisations, poor quality of life and disproportionately high health expenditure.2 Patients with cancer understandably harbour hopes related to life prolongation, tumour stabilisation and remission, which enhances coping and reduces distress.3,4 They, thus, inadvertently avoid, are ambivalent about or delay-seeking opportunities to meaningfully prepare for the EOL when there is
progressive disease. This is augmented by treating oncologists' reluctance to initiate truthful conversations with changing health circumstances, trajectories and treatment complexities. A diagnosis of cancer implicates the entire family, particularly caregivers, evoking anxiety and uncertainty, loss of roles and routines and existential concerns. Both patients with cancer and caregivers report challenges in acquiring information on treatment choices, possible outcomes and prognosis, leading to discordance in patient-caregiver communication and delayed or inappropriate action. Caregivers should, thus, form part of a triad of care, together with patients and clinicians, and require a realistic appraisal of their situation and involvement in EOL discussions to allow individual and shared family values to improve confidence and influence in EOL decision-making.

The identification of advance care planning (ACP) as a process that places patients at the centre of care has provided patients with serious illnesses and their caregivers an opportunity to aspire towards meaningful dying. ACP is defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care", and it is now defined as a key quality indicator in cancer care. ACP, thus, ensures that an individual's caregivers and doctors are aware of their health and personal preferences and that these preferences are respected in the event of an individual being unable to communicate their wishes. In 2016, one jurisdiction in Australia established a single framework for ACP, allowing for the appointment of a Medical Treatment Decision Maker and Support Person, completion of Instructional Directives and, importantly, a Values Directive. This growing emphasis on values directives reveals a considered paradigm shift in ACP, with the recognition that patients' values and beliefs are the best predictors of the choices made relating to EOL goals and treatment decisions. ACP interventions in cancer, on the whole, have increased ACP documentation rates from 15% to 30%-40% but failed to achieve EOL care consistent with patients' preferences. Programmes can, however, be more effective through repeated and interactive discussion sessions, interventions targeting multiple stakeholders and the use of decision aids. More recently, the use of video decision support tools (VDST) that incorporate video vignettes has been used to improve engagement with ACP. Patients assigned to a VDST showed improved ACP knowledge and were less likely to opt for cardiopulmonary resuscitation (pooled RR, 0.50; 95% CI 0.27 to 0.93). VDST in ACP has, thus, far focused on medical treatment preferences but could be used to harness opportunities for research on patient values in the ACP discourse.

Our preliminary studies were commenced in accordance with the Medical Research Council framework for developing complex interventions. We developed and tested the utility of written vignettes to explore ACP in cancer, highlighting shared decision-making and the dynamic nature of ACP as patients choose to actualise, relinquish or reject ACP Personal values, caregiver hierarchies and caregivers overriding patients desire contributed to a lack of concordance in decision-making. This current study aims to evaluate the effectiveness of video vignettes used as a VDST to model value-based ACP conversations between cancer patient-caregiver dyads and facilitate congruence in patient-caregiver communication. We hypothesised that the VDST is more likely than usual care (UC) to facilitate ACP document completion, improve understanding and perspectives on ACP, congruence in communication and preparation for decision-making. Here, we report on the quantitative analysis of this randomised controlled trial (RCT) with the qualitative analysis of completed values directive to be published subsequently.

METHOD
Design and participants
This open-label, parallel arm RCT was conducted at a large metropolitan hospital in Melbourne, Australia. Participants were screened sequentially in the oncology and palliative care inpatient and ambulatory settings by participating clinicians and enrolled as patient-caregiver dyads. Eligibility included patients with advanced cancer, who had not completed ACP documents and were able to nominate a willing caregiver. Patients and caregivers were ineligible if they were insufficiently proficient in English, were under the age of 18 or unable to consent due to language or cognitive barriers. Caregivers were defined as a relative, partner or friend who has a significant relationship with the patient and who provides them with social, psychological and/or physical assistance.

Eligible dyads were provided with a participation information sheet by a member of the research team. Interested dyads were allocated a time with a research facilitator in a private setting in the hospital or their own homes. This study is registered with the Australian and New Zealand Clinical Trials Registry.

Study procedure and randomisation
A detailed study procedure has been published and a summary is shown in figure 1. Following consent and prior to randomisation, dyads from both arms completed individual patient and caregiver baseline questionnaires. Dyads randomised to the VDST arm viewed an 11 min video on a mobile computer and were advised that it could be discontinued if it elicited distress. Dyads were then provided with the hospital's ACP document and verbal and written guidelines (online supplemental material) on how to
Figure: Study procedure. *Demographics, DASS-21, AACP, CCAT-PF, ** AACP, CCAT-PF, PDMS. ACP, advance care planning; AACP, attitudes towards advance care planning; DASS-21, Depression Anxiety Stress Scale; CCAT-PF, Cancer Communication Assessment Tool for Patient and Families; PDMS, Preparation for Decision-Making Scale.

complete the ACP documents. Dyads in the UC arm were only provided with the hospital’s ACP document and verbal and written guidelines (standard practice in the service). Participants were advised to return the signed and witnessed ACP documents and individual postquestionnaire via a stamped return envelope. Participants received two telephone call prompts at 2-week intervals as a reminder to complete and return the ACP.

Randomisation occurred through an independent randomisation administrator using a computer-generated random number sequence in blocks of 6 in a 1:1 ratio, with concealed allocation using numbered envelopes. Treatment arm assignments were non-blinded, but outcome assessors were blinded to allocation.

Development of VDST

Findings from our preliminary research revealed the utility of vignettes as a platform to improve patient–caregiver ACP communication and were used to develop the video vignettes. The previously written vignettes were adapted to scripted video vignettes as per guidelines: (1) agreeing on the use of video vignettes, (2) developing valid scripts, (3) designing valid manipulations, (4) converting written scripts to video and (5) administering the videos.
The vignettes depicted dyads considering completion of different components of an ACP and involved manipulations of dyads with differing ages, gender, stages of illness and relationships. Each manipulation introduced core EOL values to prompt further discussion. A multidisciplinary research team validated and approved the final VDST, which comprised an 11 min video displaying three permutations of a married couple, two siblings and three friends discussing their EOL values. These included the affirmation of relationships and trust, reminiscence of a life lived and friendships shared, recollections of previous losses, fears about the future and legacy planning and how these would shape their EOL choices.

Outcomes and measurements
The primary outcome was the completion of ACP documents. Secondary outcomes assessed were attitudes towards ACP, congruence in patient-caregiver communication and preparedness for decision-making.

Patients' and caregivers' basic demographic information was obtained at baseline, and patients were asked whether they had discussed their prognosis with their doctor. The following measures were used (online supplemental appendix 1) and completed prior to introducing the VDST or UC intervention:

- Depression Anxiety Stress Scale (DASS): The DASS-21 was used to observe for negative emotional reactions. It has shown strong reliability and validity against other measures of anxiety and depression in patients with cancer.

- Attitudes towards ACP ratings: level of understanding of ACP; satisfaction in ACP completion and distress raised by ACP completion were measured on a Likert scale from 0 to 10 on questions used in a previous feasibility study.

- Cancer Communication Assessment Tool for Patient and Families (CCAT-PF): the CCAT-PF with analogous patient (CCAT-P) and family (CCAT-F) instruments consists of 18 items within eight domains. Higher CCAT-PF scores correlate with poorer concordance in communication and are significantly correlated with greater patient depression and perceived family conflict, lower patient-caregiver assessment and well-being, and less expressiveness and family cohesion.

- Preparation for Decision-Making Scale: this validated scale assesses patient and caregiver perception of the usefulness of an intervention.

Statistical analysis
Based on the primary outcome of completion of ACP documentation and integration into the medical record, and assuming an integration rate of around 37% for the control arm, a total of 86 dyads (43 per study arm) was found to be needed to show a significant improvement to 67% integration for the intervention arm (power 80%, 5% significance level and two-sided testing).

Data from each study arm were explored separately using relative frequencies for categorical variables and mean (SD) or median (first and third quartiles) for continuous variables. Associations between categorical variables were explored using χ² tests (or Fisher's exact test when appropriate). Associations between continuous variables were explored using Pearson's correlation coefficient when normally distributed or when data were skewed.

For the CCAT variable, linear models (ANCOVA - Analysis of Covariance) were fitted with the postintervention value as the outcome and the explanatory variables being the study arm (UC vs VDST) and the preintervention (baseline) value. Paired sample t test was used to compare means within study arms between pre and post when the assumptions of normality were reasonably met (or the Wilcoxon test if otherwise).

Binary logistic regression models were used to examine associations between explanatory variables (study arm, in addition to other variables such as age (either as a covariate or under 70 vs over 70), gender or marital status) and the odds of completing the ACP documents on study completion. Interactions between study arms and other promising explanatory variables were tested. ORs were estimated, along with 95% CIs.

For comparing patient versus caregiver (a factor we labelled 'participant') on responses to the same questions, linear mixed models were fitted with dyad as a random effect, and the fixed effects being study arm (UC vs VDST), participant, study arm by participant interaction, and the preintervention (baseline) value of the same question. Study arms and participant means were adjusted by the mixed model to account for the other terms in the model.

For the CCAT-PF, only complete pairs of questionnaires sets were included in the analysis. Questionnaire sets where >40% of CCAT-P and/or CCAT-F items were missing were excluded from the analysis. Data imputations were performed based on the mean answers on the individual level for the CCAT-P/CCAT-F, where ≤40% of data were missing. All statistical analyses were performed using IBM SPSS Statistics V25.0 and Genstat 18th edition (VSN International, UK). P values <0.05 are reported as statistically significant.

RESULTS
A total of 393 patients were screened between August 2018 and November 2019 (figure 2). Of those eligible, 36.4% declined participation, most commonly due to a lack of interest. One hundred and nineteen patient-caregiver dyads consented and were randomised, with 1:3 (60:40%) of the eligible cohort completing an intervention and baseline questionnaire. On study completion, 60 (53.1%) sets of matched patient-caregiver postquestionnaires were available. The remaining postquestionnaires were unreturned or returned incomplete.

Table 1 details the sample characteristics. The majority of patients were women (53.1%) and
6.2 caregivers' man (64.6%), with most patients (69.9%) and caregivers (76.8%) born in Australia or New Zealand, with a mean patient age of 68 (SD 12.7) and caregiver age of 61 (SD 14.2). The main relationship between patient–caregiver dyads was spousal/partner (61.9%). Gastrointestinal cancers were the most common diagnosis (31.9%), with most living with a diagnosis for 1–5 years (38.1%). The majority (82.6%) had discussed their prognosis with their doctor. The study arms were well balanced, with only statistical significance between study arms noted for prognostic discussion with their doctor (p=0.009), with more patients in the UC arm avoiding discussion of prognosis. At baseline, levels of depression, anxiety and stress scores on the DAS-21 were equal between intervention and UC arms.

Primary outcome
There was no impact of the VDST intervention on ACP document completion. A total of 42 (37.2%) of all patients completed ACP documents; this included 20 (37.7%) in the VDST arm and 22 (36.7%) of the UC arm. Of the remaining total patients, 46.9% elected not to complete ACP documents, with 15.9% dying or deteriorating prior to completing documentation. There was no significant association between the intervention and ACP document completion (OR=1.05, 95% CI 0.487 to 2.25, p=0.907). Moreover, there was no association between ACP document completion and overall age, age ≤70 versus over >70, sex, diagnosis, marital status, nature of dyad relationships, primary diagnosis, time since diagnosis and prognostic discussion with doctor.

Within the VDST arm, completion of ACP documents was more likely in those over the age of 70 (52% (13/25)≥70 vs. 25% (7/28)<70; p=0.043), but no difference was detected in the control arm (p=0.734) when comparing the two age arms. When further stratifying binary logistic regression models by intervention to explore the aforementioned finding, in the VDST arm, being older (≥70) was associated with a greater chance of completing ACP documents at the end of the study compared with younger counterparts (<70) (OR=0.308, 95% CI 0.096 to 0.982, p=0.047). However, in the analysis of both arms combined, the interaction of arm and age over >70 vs ≤70 was not significant (p=0.213).
<table>
<thead>
<tr>
<th></th>
<th>All patients (n=112)</th>
<th>Usual care n=60</th>
<th>Video n=52</th>
<th>All caregivers (n=112)</th>
<th>Usual care n=60</th>
<th>Video n=52</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in years, mean (SD)</strong></td>
<td>68.1 (12.7)</td>
<td>68.4 (10.3)</td>
<td>67.8 (12.1)</td>
<td>60.6 (14.2)</td>
<td>59.6 (15.6)</td>
<td>61.8 (12.5)</td>
<td>0.434</td>
</tr>
<tr>
<td><strong>Sex, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.261</td>
</tr>
<tr>
<td>Female</td>
<td>60 (53.1)</td>
<td>35 (58.3)</td>
<td>25 (47.2)</td>
<td>40 (35.4)</td>
<td>25 (41.7)</td>
<td>15 (28.3)</td>
<td>0.169</td>
</tr>
<tr>
<td>Male</td>
<td>53 (46.9)</td>
<td>25 (41.7)</td>
<td>28 (52.8)</td>
<td>73 (64.6)</td>
<td>35 (58.3)</td>
<td>38 (71.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.263</td>
</tr>
<tr>
<td>Married/defacto</td>
<td>80 (70.8)</td>
<td>41 (68.3)</td>
<td>39 (73.6)</td>
<td>91 (83.3)</td>
<td>49 (81.7)</td>
<td>44 (83.0)</td>
<td>0.644</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>13 (11.5)</td>
<td>8 (13.3)</td>
<td>5 (9.4)</td>
<td>5 (4.6)</td>
<td>2 (3.3)</td>
<td>3 (5.7)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>12 (10.6)</td>
<td>7 (11.7)</td>
<td>5 (9.4)</td>
<td>3 (2.7)</td>
<td>1 (1.7)</td>
<td>2 (3.4)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>8 (7.1)</td>
<td>4 (6.7)</td>
<td>4 (7.5)</td>
<td>12 (10.6)</td>
<td>8 (13.3)</td>
<td>4 (7.5)</td>
<td></td>
</tr>
<tr>
<td>Place of birth, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.610</td>
</tr>
<tr>
<td>Australia/New Zealand</td>
<td>79 (69.9)</td>
<td>43 (71.7)</td>
<td>36 (67.9)</td>
<td>86 (76.8)</td>
<td>49 (81.7)</td>
<td>37 (71.2)</td>
<td>0.257</td>
</tr>
<tr>
<td>Europe</td>
<td>22 (19.5)</td>
<td>12 (20.0)</td>
<td>10 (18.9)</td>
<td>15 (13.4)</td>
<td>7 (11.7)</td>
<td>8 (15.4)</td>
<td></td>
</tr>
<tr>
<td>Other Asia Pacific</td>
<td>7 (6.2)</td>
<td>2 (3.3)</td>
<td>5 (9.4)</td>
<td>6 (5.4)</td>
<td>1 (1.7)</td>
<td>5 (9.6)</td>
<td></td>
</tr>
<tr>
<td>North/South America</td>
<td>5 (4.4)</td>
<td>3 (5.0)</td>
<td>2 (3.8)</td>
<td>5 (4.5)</td>
<td>5 (5.0)</td>
<td>2 (3.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Patient relationship to caregiver, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.125</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>70 (61.9)</td>
<td>38 (63.3)</td>
<td>32 (60.4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent/parent-in-law</td>
<td>26 (23.0)</td>
<td>16 (26.7)</td>
<td>12 (22.6)</td>
<td>7 (13.4)</td>
<td>7 (11.7)</td>
<td>3 (5.7)</td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>8 (7.1)</td>
<td>2 (3.3)</td>
<td>6 (11.3)</td>
<td>5 (9.0)</td>
<td>2 (3.3)</td>
<td>4 (7.5)</td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>4 (3.5)</td>
<td>1 (1.7)</td>
<td>3 (5.7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friend</td>
<td>4 (3.5)</td>
<td>4 (6.7)</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1 (0.9)</td>
<td>1 (1.7)</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Primary cancer diagnosis, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.023</td>
</tr>
<tr>
<td>Upper/lower gastrointestinal</td>
<td>36 (31.9)</td>
<td>20 (33.3)</td>
<td>16 (30.2)</td>
<td>38 (33.9)</td>
<td>21 (35.0)</td>
<td>17 (32.7)</td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>20 (17.7)</td>
<td>8 (13.3)</td>
<td>12 (22.6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>18 (15.9)</td>
<td>10 (16.7)</td>
<td>8 (15.1)</td>
<td>15 (13.4)</td>
<td>7 (11.7)</td>
<td>8 (15.4)</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>11 (9.7)</td>
<td>7 (11.7)</td>
<td>4 (7.5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haematological</td>
<td>9 (8.0)</td>
<td>5 (8.3)</td>
<td>4 (7.5)</td>
<td>8 (7.3)</td>
<td>5 (8.3)</td>
<td>3 (5.7)</td>
<td></td>
</tr>
<tr>
<td>Gynaecological</td>
<td>9 (8.0)</td>
<td>3 (5.0)</td>
<td>6 (11.3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>10 (8.8)</td>
<td>7 (11.7)</td>
<td>3 (5.7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Length of time living with the diagnosis, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.925</td>
</tr>
<tr>
<td>&lt;6 months</td>
<td>26 (23.0)</td>
<td>15 (25.0)</td>
<td>11 (20.8)</td>
<td>15 (13.4)</td>
<td>8 (13.3)</td>
<td>7 (13.7)</td>
<td></td>
</tr>
<tr>
<td>6 months to 1 year</td>
<td>19 (16.8)</td>
<td>9 (15.0)</td>
<td>10 (18.9)</td>
<td>14 (12.6)</td>
<td>9 (15.0)</td>
<td>5 (9.4)</td>
<td></td>
</tr>
<tr>
<td>1 to 5 years</td>
<td>43 (38.1)</td>
<td>23 (38.3)</td>
<td>20 (37.7)</td>
<td>43 (38.3)</td>
<td>23 (38.3)</td>
<td>20 (37.7)</td>
<td></td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>25 (22.1)</td>
<td>13 (21.7)</td>
<td>12 (22.6)</td>
<td>15 (13.4)</td>
<td>9 (15.0)</td>
<td>6 (11.7)</td>
<td></td>
</tr>
<tr>
<td>Discussed prognosis with doctor (n=92), n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.009</td>
</tr>
<tr>
<td>Yes, I have</td>
<td>76 (85.6)</td>
<td>37 (74.0)</td>
<td>39 (72.9)</td>
<td>76 (85.6)</td>
<td>37 (74.0)</td>
<td>39 (72.9)</td>
<td></td>
</tr>
<tr>
<td>No, I did not want to ask</td>
<td>9 (9.8)</td>
<td>9 (16.7)</td>
<td>0</td>
<td>9 (9.8)</td>
<td>9 (16.7)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>No, the opportunity has not arisen</td>
<td>7 (7.6)</td>
<td>6 (11.7)</td>
<td>1 (1.9)</td>
<td>7 (7.6)</td>
<td>6 (11.7)</td>
<td>1 (1.9)</td>
<td></td>
</tr>
<tr>
<td>Unanswered/missing</td>
<td>21</td>
<td></td>
<td></td>
<td>21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Completed ACP documents post intervention, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.531</td>
</tr>
<tr>
<td>Yes</td>
<td>42 (37.2)</td>
<td>22 (36.7)</td>
<td>20 (37.7)</td>
<td>42 (37.2)</td>
<td>22 (36.7)</td>
<td>20 (37.7)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>71 (62.8)</td>
<td>38 (63.3)</td>
<td>33 (62.3)</td>
<td>71 (62.8)</td>
<td>38 (63.3)</td>
<td>33 (62.3)</td>
<td></td>
</tr>
<tr>
<td><strong>DASS 21</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>8 (4.4)</td>
<td>10 (4.1)</td>
<td>8 (3.8)</td>
<td>8 (4.4)</td>
<td>10 (4.1)</td>
<td>8 (3.8)</td>
<td>0.264</td>
</tr>
<tr>
<td>Anxiety</td>
<td>10 (4.1)</td>
<td>10 (4.1)</td>
<td>10 (4.1)</td>
<td>10 (4.1)</td>
<td>10 (4.1)</td>
<td>10 (4.1)</td>
<td>0.368</td>
</tr>
<tr>
<td>Stress</td>
<td>12 (6.7)</td>
<td>12 (6.7)</td>
<td>10 (20.0)</td>
<td>12 (6.7)</td>
<td>12 (6.7)</td>
<td>10 (20.0)</td>
<td>0.250</td>
</tr>
</tbody>
</table>

Continuous data presented as mean (SD) and categorical data presented as frequencies (relative frequencies). P-values for continuous variable derived from independent samples Student’s t-test, for categorical variables, derived from Pearson’s χ² test.

ACP: advanced care planning; DASS 21, Depression Anxiety Stress Scales.
Secondary outcomes
Attitudes towards ACP

Table 2 shows the changes in ACP attitudes postintervention for patients and caregivers. Patients reported a significant improvement in understanding of ACP, following both VDST (p < 0.001) and UC (p < 0.001) but only those exposed to the VDST reported improved satisfaction with opportunities to consider ACP with health professionals (p = 0.039). Distress caused by discussing ACP with others was more significant in the VDST arm compared with UC (UC: pre 7.5 (5.9) vs post 6 (5.8), p = 0.171; VDST: pre 8 (5.25, 9) vs post 6 (5.9), p = 0.015).

Similarly, caregivers achieved improved understanding of ACP in both the VDST (p = 0.001) and UC (p < 0.001) arms as well as greater satisfaction in opportunities to consider ACP with health professionals in the VDST arm (p = 0.007). Caregivers also affirmed the importance of assisting patients with their ACP decisions, achieving a ceiling effect preintervention, thus not demonstrating a significant improvement in either arm. There was no significant change in caregiver distress following ACP discussions across both arms.

After adjusting for their individual responses at baseline, no significant differences were found between the VDST and UC arms when comparing the two arms for their postintervention responses for patients and caregivers.

Cancer-Communication Assessment Tool

For the total sample, patients and caregivers demonstrated similar scores in their CCAT-P and CCAT-F at baseline (table 3). Both arms demonstrated a significant reduction in CCAT-PF over time, demonstrating improved concordance in communication following VDST (p = 0.006) and UC (p = 0.045), achieving a moderate effect size, which was higher in the VDST arm (ES VDST 0.7 vs UC 0.54). However, when a covariate was added to adjust for baseline variables, no significant overall difference between VDST and UC was found.

For all participants, age was positively associated with higher CCAT-PF preintervention (r = 0.217, p = 0.021), whereas an inverse association was found with post-CCAT-PF (r = -0.262, p = 0.049), suggesting an improved concordance in all participants with age in both arms. When the patient’s relationship to the caregiver was not a spousal/partner relationship, increasing patient age was inversely associated with post CCAT-F (r = -0.473 p = 0.035).

Preparedness for decision-making

For the total sample, caregivers reported a higher preparation for decision-making scores (patient 60.8 (SD 23.0) vs caregiver 65.8 (SD 25.5)). There was no significant difference between the VDST and UC arm for both patients (60.4 (SD 20.6) vs 61.2 (SD 25.5), p = 0.931) and caregivers (61.8 (SD 23.3) vs 69.7 (SD 23.3), p = 0.200).

DISCUSSION

The primary outcome was not met in this study, with equal number of participants completing ACP documents in both arms. This may be attributed to the research facilitators prompting participants from both arms to return questionnaires, thus inadvertently encouraging the return of ACP documents by both arms at the same time. Restated, the addition of the VDST to one arm, was not powerful enough by itself to increase the overall rate of ACP document completion. The addition of further components to the VDST intervention such as written clarification of values discussed or a section of the video clarifying the importance of document completion may have improved our primary outcome. However, our secondary finding that older patients were more inclined to respond to the VDST by completion of ACP documents proved noteworthy. Life maturity brings about emotional and cognitive competence to allow for self-evaluation and a reconciliation of life’s purpose, and with this, the ability to discover the elements of one’s core belief system.30 ACP may be a more acceptable activity for older patients and their caregivers to engage in.

Importantly, we were able to demonstrate that ACP (regardless of intervention) improved patient–caregiver congruence in communication, with the potential for video interventions depicting value conversations benefiting older patients. The caveat is to note that VDST brings a risk of eliciting distress in patients, a comprehensible result as the reality of a finite life is faced when ACP is addressed. The findings of increased distress mirror that of other studies where communication about EOL issues in patients with serious illness have increased depressive or post-traumatic stress disorder symptoms in patients.31 32 However, it is possible that such distress may be reactive, therefore short lived and may not be evident in long-term follow-up.33 Concomitant emotional support may, therefore, be a necessary component if services are to promote ACP completion.

Our study is the first in Australia to use the video vignette technique in ACP, highlighting the potential for this video vignette methodology in cancer communication research and adding to evolving work exploring value-based ACP.33 34 Current models of ACP in cancer remain driven by autonomy principles and individual preferences, despite this simply increasing the appointment of substitute decision-makers over time but not opportunities for goal or value concordant care.34 One could argue that ACP requires contextualisation and adaptation to incorporate an understanding of the stressors of illness for families, especially those who rely on familial decision-making. We, thus, postulated that receptivity towards ACP and uptake would improve if we focused vignettes on demonstrating...
Table S.1 Patient and caregiver attitudes towards ACP

<table>
<thead>
<tr>
<th>Patient questions</th>
<th>Patients</th>
<th>Video</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Usual care</td>
<td></td>
</tr>
<tr>
<td>1 My current understanding of ACP is (0=poor; 10=best possible)</td>
<td>6 (4,9)</td>
<td>8 (6,10)</td>
</tr>
<tr>
<td>2 Opportunities to consider ACP with healthcare professionals has been</td>
<td>8 (6,9)</td>
<td>8 (7,9)</td>
</tr>
<tr>
<td>(0=unsatisfactory; 10=very satisfactory)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Discussing ACP with others would cause me (0=high distress; 10=low distress)</td>
<td>7.5 (5,9)</td>
<td>6 (5,8)</td>
</tr>
</tbody>
</table>

| Caregiver questions                                                               | Usual Care | Video |
|                                                                                  | Preintervention (n=60) | Postintervention (n=30) | Preintervention (n=52) | Postintervention (n=20) | p    | p*    |
| 1 My current understanding of ACP is (0=poor; 10=best possible)                  | 6 (3,8) | 8 (6,9) | <0.001 | 6 (3,5,8) | 8 (6,9) | <0.001 | 0.977 |
| 2 Opportunity to consider my family member/friend's ACP with healthcare           | 8 (6,9) | 8.5 (6,10) | 0.022 | 7 (5,8) | 8 (6,9) | 0.007 | 0.567 |
| professionals has been (0=unsatisfactory; 10=very satisfactory)                   |          |        |       |           |       |       |       |       |
| 5 Helping my family member/friend to make decisions related to ACP is (0=not      | 10 (10.10) | 10 (9,10) | 0.020 | 10 (9,10) | 9 (8,10) | 0.440 | 0.974 |
| important; 10=very Important)                                                     |          |        |       |           |       |       |       |       |

P-values within groups derived from paired t-tests

*P-value between groups derived from analysis of covariance of the answers postintervention, adjusted for the individual's answers preintervention.

ACP, advance care planning.
values clarification and values development within caregiver relationships. These meaningful dialogues demonstrated affirming relationships and trust, reminiscence of a life lived and friendships shared, recollection of previous losses or legacy planning through which patients may be able to make meaning of their dying. Our primary outcome may have been better represented though a measure of a validated or tested value scale, though we will clarify this further in our qualitative paper.

The challenge for palliative care providers then is how best to support values orientation reflection in younger patients or those less prepared for their dying. Future research could further explore the development of a values prompt list that invites consideration of key behavioural, spiritual, existential and spiritual concerns. Such a catalyst might stimulate patients and their families towards more meaningful EOL conversations and planning. Achieving concordance in communication may be the first step in the process of values clarification and ACE. While there remains limited research examining discordance in communication and its relationship to poor completion of ACP documents, family conflict is well recognised as a deterrent to appropriate EOL care planning. Patients who perceived their families to have differing preferences from their own face impediments to ACP. Our baseline CCAT-PF score of 25.4 was comparable to other international studies, but improvement in concordance in communication in both arms of the study highlights the opportunity ACP may provide. However, cancer communication concordance may not be static over time and is affected by open or negative communication patterns, prior relationship quality, relationship type and socioeconomic variables. The complexity of these systemic influences adds to research challenges in addition to considering the best time to introduce ACP in cancer.

The inclusion of dyads as the unit of reference in this study was motivated by conceptual models suggesting that ACP interventions in cancer can improve outcomes not just by increasing EOL knowledge but by improving autonomous motivation, competence in undertaking discussions and shared decision-making within trustful relationships. Caregivers have been identified as being more aware of communication problems than patients, with communication discord occurring more commonly between patients and younger caregivers and adult children of older patients. The inclusion of dyads in ACP allows an opportunity for deliberation, where the patient considers the next steps carefully with the caregiver, aiming for consensus, which in turn helps both parties.

Our study was limited by single site recruitment, thus limiting its generalisability and a heterogeneous cancer population. With close to two-fifths of those eligible declining participation and a fifth deteriorating
prior to completion of study requirements, we confirm that future planning evokes anxiety in patients with cancer and the dilemma of identifying the best timing for initiation of ACP. Additionally, those approached in the inpatient setting may have been too unwell and their caregivers preoccupied and, thus, less likely to engage in complex discussions. Furthermore, the study outcomes could have been impacted by statistically more patients in the UC arm having avoided prognostic discussions with their treating physician, the absence of longitudinal data and the lack of a clear ‘script’ for the researchers to avoid prompting participants from both arms to return questionnaires. Finally, the length of our VDST (11 min compared with ≤6 min in others) may have been a barrier to achieve more desirable outcomes.18

Our study may have set the scene to potentially refine the exploration of EOL values in the future, using video methodology with a more homogenous sample of cancer types and participant ages, with the possible use of a value prompt list to initiate discussions.

CONCLUSION

Despite opportunities to engage in ACP, the majority of patients with cancer have a desire to maintain hope and focus on the present, prefer clinician initiated discussions, with some having difficulty in dealing with this emotionally difficult topic.20 Our VDST intervention may have been strengthened by combining depictions of potential clinical outcomes, as previously demonstrated in video intervention studies,19 with demonstrations of dyadic value conversations. The additional focus on core patient values and achieving concordance in communication through shared recognition of these values may be the catalyst needed to progress cancer ACP towards a more fulfilling process for those who partake in it.

Acknowledgements

The authors acknowledge Nerida Morton and the staff of the Department of Palliative and Supportive Care who assisted with the study and the patients and families who willingly participated.

Contributors

NGM and DK designed the initial study; NGM and AM assisted with piloting and modification; NM, AM and MS led recruitment; RT assisted with data collection and management; NM, EG, RT and GH conducted statistical analysis; NM wrote the initial manuscript and all authors approved the final manuscript. NM is responsible for the overall content as guarantor.

Funding

This research was funded by the Bethlehem Research Foundation Grant (Grant Number 1709) and the Cabrini Medical Foundation Oncology Research Grant.

Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval

This study involves human participants and was approved by Monash Health Research Ethics Committee: RES-20-0000-112C. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. The datasets generated during the study will be available from the corresponding author on reasonable request.

ORCID iDs

Natasha G Michael http://orcid.org/0000-0003-3603-1358
Merilin Sulestio http://orcid.org/0000-0002-5610-4023

REFERENCES

6.4 SUMMARY AND CONCLUSION

In this chapter, I present a paper which examines the outcomes from an RCT comparing the use of a VDST with UC in a cohort of cancer patients in a Melbourne Metropolitan hospital. I achieved a 60.4% recruitment rate, and my primary outcome findings corresponded with that of other published studies showing that only approximately a third of participants enrolled in ACP intervention studies proceed to complete an ACP.

This was a negative study with several limitations already discussed in the published paper. Additionally, clinicians in the participating sites were aware of the study processes and clearly instructed and trained on the delivery of the intervention following randomisation. Therefore, there could have been inevitable imposing of the principles of the intervention arm on the UC arm, adding to the study contamination. The cohort of patients who agreed to participate may have been demonstrating readiness for ACP and thus be more inclined towards future planning conversations.1 We could have potentially assessed readiness by asking all eligible participants a single screening question such as ‘do you feel ready to discuss your future care with your doctor and caregiver?’ or using a validated tool such as the Readiness for Advance Care Planning Scale to measure readiness.2

Identifying the right ‘timepoint’ to introduce ACP conversations remains challenging.3 Most studies limit interventions to a prognostic timeline4 or to a single diagnostic group,5 but variability in readiness is present in all groups. Several ‘triggers’ for the appropriate timing to introduce ACP have been suggested which include when treatment intent changes from curative to palliative or when there is significant disease progression.4 Nonetheless, clinician experience suggests that there are significant sociodemographic, cultural and individual variables such as previous conversations and psycho-existential maturity that influence readiness.6,7

Despite the negative primary outcome, my study finding has been the first to demonstrate that a values approach to ACP may resonate more with the older cancer patient. This raises questions on what other innovative means we should consider when engaging younger cancer patients in ACP. Published literature has long confirmed that ACP conversations elicit distress, as such conversations bring to the
forefront the finitude of one's life. Nonetheless, these findings should not deter encouraging conversations within a supportive environment. It is possible that exposure to UC or the VDST may trigger the consideration for the completion and execution of ACP further down the track that could be measured in future longitudinal studies. My study has been the first to demonstrate improved patient-caregiver concordance in communication, with improvements in both arms and age. It raises the question as to whether the completion of an ACP should be the main outcome measure for future studies. Is it plausible to consider concordance in values as an outcome that may affect alignment of patients wishes to their end-of-life outcomes?

The video vignette methodology shows some potential based on findings of other VDST studies to improve engagement in ACP in cancer care and possibly beyond. Nonetheless, our use of the MRC framework was motivated by the appreciation that ACP is fundamentally a complex intervention. In considering the implementation of the intervention using the Template for Intervention Description and Replication (TIDieR) checklist, we demonstrated adherence to all recommendations except for the assessment of intervention fidelity, which may have provided some additional information for future studies. Engagement in ACP requires consideration of patient and caregiver motivations, health literacy, cultural nuances, competency in communication, opportunities for deliberation and, importantly, readiness for engagement. In most instances, ACP is offered to patients in a single interaction, with no ongoing follow-up if a patient feels unready at that point in time.

Focusing on personal values may open more avenues for engagement in ACP. Focusing on meaningful outcomes such as legacy planning, dignity at the end of life, life reflection, and memory-making may evoke less anxiety and distress. This approach may lead to more thoughtful and fulfilling considerations when compared to asking patients about their desire to limit treatment options. This more nuanced approach may foster a closer therapeutic alliance with clinicians and allow for a phased and considered approach to ACP.
6.5 REFERENCES FOR SUMMARY AND CONCLUSION


CHAPTER SEVEN

POSTURING VULNERABILITY AND RESILIENCE: A PHENOMENOLOGICAL CONTENT ANALYSIS OF CANCER PATIENT’S VALUES DIRECTIVE IN ADVANCE CARE PLANNING
7.1 DECLARATION BY CANDIDATE AND CO-AUTHOR STATEMENT

I, Natasha Michael, contributed to the following publication: Michael N, Symons X, Mendz GL, Kissane D. Posturing Vulnerability and Resilience: Phenomenological Content Analysis of Cancer Patients Values Directives in Advance Care Planning

<table>
<thead>
<tr>
<th>Nature of contribution</th>
<th>Extent of contribution (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study conceptualization, literature review, design of methodology, manuscript preparation</td>
<td>75</td>
</tr>
</tbody>
</table>

Candidate’s Signature 13/6/2022

We the undersigned, hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-author's contribution to this work.

<table>
<thead>
<tr>
<th>Name of Co-Author</th>
<th>Nature of Contribution</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Xavier Symons</td>
<td>Data coding and interpretation, manuscript preparation.</td>
<td></td>
<td>14/6/2022</td>
</tr>
<tr>
<td>Dr George Mendz</td>
<td>Data coding, and interpretation, manuscript preparation.</td>
<td></td>
<td>13/6/2022</td>
</tr>
<tr>
<td>Professor David Kissane</td>
<td>Study design, data interpretation, manuscript preparation.</td>
<td></td>
<td>14/6/2022</td>
</tr>
</tbody>
</table>
7.2 PREAMBLE TO EMPIRICAL PAPER TWO

In completing this thesis, I was keen to demonstrate my acquired skills across several different research approaches. Following the completion of the RCT, I sought to further develop my skills in qualitative methodology by undertaking qualitative analysis of values statements as part of this RCT.

Qualitative research allows for data exploration through five fundamental methodological approaches: ethnography, narrative, phenomenological, grounded theory, and case study. My decision to undertake a phenomenological content analysis was based on my desire to garner a deeper and more mature understanding of cancer patients experiencing illness. I was keen as a clinician not to simply encourage the completion of a VD but to facilitate thought and behavioural modifications that allow for illness adaptations. Despite the many qualitative analyses of ACPs, this is the first phenomenological analysis undertaken specifically on VDs.

Phenomenological analysis seeks to describe the essence or core structures and textures of the essential meaning of the lived experience of the phenomenon. As a clinician-researcher in this analysis, the challenge was approaching the data without any prior assumptions or theoretical frameworks. The reflection and introspection demanded through this methodological process required balancing the biases that I may have introduced out of reflexivity on my part. Though many content analyses have been completed on ACP, few have explored personal values within the context of reciprocation, vulnerability, adaptations and existentialism.

This paper has been published in the Journal of Pain and Symptom Management, a peer-reviewed open-access journal with an impact factor of 5.576 (2021). This article is reproduced with permission from Elsevier Inc., and as the author of this Elsevier article, I retain the right to include it in a thesis or dissertation (Appendix K).
Vulnerability and Resilience: Phenomenological Analysis of Cancer Patients Value Directives

Natasha Michael, MBChB, FRACP, FACHM, MRCP, MRCGP, MSc, Xavier Symons, BA, MA, MSc, PhD, George L. Mendz, MSc, MBioeth, PhD, and David Kissane, MD, BS, MFM, FRANZCP, FACHM, FACLP
Supportive, Psychosocial and Palliative Care Research Department (N.M., G.L.M., D.K.), Cabrini Health, VIC Australia; School of Medicine (N.M., D.K.), University of Notre Dame Australia, Darlinghurst, NSW, Australia; Faculty of Medicine (N.M., D.K.), Nursing and Health Sciences, Monash University, VIC, Australia; Plunkett Centre for Ethics (X.S.), St Vincent's Hospital, NSW, Australia; Institute of Ethics and Society (X.S.), University of Notre Dame, Australia, NSW, Australia; Sacred Heart Health Service (D.K.), St Vincent's Hospital, Sydney, NSW, Australia.

Abstract

Context. Personal values are individual conceptions of the desirable appraisals and actions that guide our attitudes and behaviour. Advance care planning (ACP) now emphasises the consideration of personal life goals and values expressed as a Values Directive (VD) to guide discussions concerning medical treatment.

Objective. To investigate the diversity of values, experiences and adaptations expressed in cancer patients VDs.

Methods. Contents of the VDs of ACPs of cancer patients who participated in a randomised control trial comparing a video intervention showing values communication between cancer patient-caregivers with usual care were analysed. Qualitative phenomenological content analysis was used to understand how participants made meaning of their lived experiences.

Results. Forty-two participants completed an ACP (37.2% response rate), with 97.6% of these completing a VD (57.1% female, mean age 72 years, 90.1% gastrointestinal cancer). Participants described diverse adjustments to frailty and adaptive coping with deteriorating functionality. Emotional and financial concerns were eased through experiencing benevolence and trust established through family and friendship bonds and reciprocation of care. Death anxiety and ambivalence were expressed concurrently with the experiential acceptance of dying. Secular and sacred rituals featured as an affirmation of their faith or beliefs.

Conclusion. Cancer patients seek to make meaning of their experiences, concurrently posuring vulnerability and resilience, despite conflicting emotions and experiences. Given that the choices people make as they approach dying relate to their most deeply held values, ACP conversations should explore how patients draw from their values and life goals to optimise their adaptations to illness.

J Pain Symptom Manage 2022;64:438–448. Crown Copyright © 2022 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. All rights reserved.

Key Words

Key Message
This article describes the phenomenological qualitative analysis of the Values Directive of 42 cancer patients who completed an Advance Care Plan. Findings highlight the need for clinicians to recognise cancer patients’ concurrent ability to posture vulnerability and resilience and to facilitate illness adaptation.

Introduction
There is something profoundly difficult in facing the reality of human vulnerability as one approaches death. Despite advances in cancer survival, cancer remains synonymous with death for the patient afflicted with the diagnosis. Therefore, unsurprisingly, much existential suffering is evoked by the uncertainty and unpredictability of the trajectory, equivocal treatment

Address correspondence to Natasha Michael, Supportive, Psychosocial and Palliative Care Research Department, Cabrini Health, 846 High Street, Prahran 3010 VIC, Australia. E-mail: amichael@cabrini.com.au

Crown Copyright © 2022 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. All rights reserved.
options, a sense of hopelessness, the loss of self and autonomy, and fear of being a burden. Thus, the cancer journey calls for adaptive coping responses, a recalibration of values and priorities, and mutuality of trust and cohesion between patients, families and clinicians. Paradoxically, a cancer diagnosis may provide an opportunity for life reflection, relationship building, and meaningful encounters. Herein lies the chance to plan for one's future and, if courageous enough, one's death.

Cancer patients have long reported feeling overwhelmed and excluded from treatment planning discussions. Few are aware of the importance of asking questions, the opportunity to understand more, the choices of refusing or considering alternative treatments, or knowing how to seek value-aligned care. Patients seek an appreciation of unwelcomed treatment effects on their lives. They require the fostering of hope even in the midst of despairing of times, and an understanding of how their priorities and perceptions of treatment may change over time. Many choose to delay end-of-life discussions until well into their illness trajectory, with some relinquishing or rejecting such discussions altogether.

Cancer Care Planning (ACP) is a preparatory process that strives to create the moment for cancer patients to partake more actively in preparing for their dying. ACP encourages a process of reflection and communication, whereby capable persons consider and talk about their wishes related to future health or personal care, in the event that they become incapable of doing so themselves. In planning for a 'good death', ACP typically endorses principles that shun unnecessary medical interventions and promotes choice on treatment options and venues of care and death, assuming a tone of peaceful acceptance. An international Delphi study identified tensions concerning ACP concepts, including whether ACP should address personal life goals and values or medical treatments. It recommends that ACP conversations commence by eliciting overall personal values, and these values could then be translated into more specific discussions concerning treatment over time.

Recent reviews have suggested that ACP is appropriate for people of any age of health status, but undoubtedly, its urgency becomes more apparent for those with a serious illness. Advance Care Planning has long been promoted in cancer patients with spastic success. A European multisite ACP intervention involving 442 cancer patients demonstrated a 33% document completion rate. Common views were that living well involved 'maintaining normal life', life prolongation and 'experiencing meaningful relationships', whereas the prospects of disease progression, pain and loss of independence elicited concern. Up to two-thirds of respondents indicated a preference for cardiopulmonary resuscitation, with home identified as the preferred final place of care for 84% of participants. A Canadian study involving 193 cancer patients showed benefit from encouragement and guidance from palliative care teams; important triggers for ACP completion were end-of-life care discussions (p = 0.02) and palliative care referrals (p < 0.0001). An American survey of 200 cancer patients reported that patients experiences with ACP had been neither comprehensive nor effective. The majority (43.5%) preferred conversations with their primary care provider owing to their trust and familiarity, and 82.5% reported that these discussions were a priority to alleviate familial guilt, maintain control, and prevent values of others from guiding their end-of-life care.

Personal values are individual conceptions of the desirable appraisals and actions that guide our attitudes and behaviour. Given that the choices we make as we approach dying relate to our most deeply held values, it is improbable that we could ascribe a good death to a single concept. On the contrary, it is proposed that one should seek to aid patients to consider multi-concept questions such as 'how can I best prepare to cope with the end of my life?', and 'what does death mean to those close to me?'. In doing so, the clinician strives to reinforce the patient's deeply set beliefs in response to illness and, ultimately, death.

Utilising the Medical Research Council's framework for developing complex interventions, we initially confirmed the utility of written vignettes as an avenue to explore ACP in cancer.

More recently, we evaluated the contribution of a Video Decision Support Tool (VDST) modelling values conversations between cancer patient-caregiver dyads in ACP. This study aims to use textual analysis of the contents of completed Values Directives (VDs) of cancer patients from our randomised controlled trial (RCT) to examine the diversity of values, experiences and adaptations expressed.

**Methods**

**Study Design, Setting and Participants**

This study represents a sub-study of a single site, open-label RCT of a video intervention involving cancer patient-caregiver dyads. Participants for the RCT were recruited from a large, not-for-profit health care in Melbourne, Australia. Participant eligibility included: diagnosis of a solid tumour or haematological cancer; age ≥ 18 years; sufficiently proficient in English and able to complete questionnaires and provide consent. Patients who completed an ACP as part of the primary outcome of the RCT were eligible for this study. Ethics approval was obtained from the organizations Human Research Ethics Committee (RES-20-0000-113C) and the trial was
registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12620001035910). The consolidated criteria for reporting qualitative research guided the study reporting.30

Data Collection
A total of 113 eligible patient-caregiver dyads in the RCT completed an intervention and questionnaires (53 VDST and 60 Usual Care), with 42 completing an ACP (Fig. 1).38 All participants were provided with the hospital’s ACP document to complete, which comprised 3 parts (Appendix 1): 1) the appointment of a Medical Treatment Decision Maker (MTDM) and Support Person; 2) a Value Directive; 3) an Instructional Directive. Completed ACPs were analysed for the purpose of this study.

Data analysis
The method of data analysis consisted of phenomenological content analysis39 that focuses on how people make meaning of their lived experiences. The authors approached the analysis without prior assumptions, definitions or theoretical frameworks, thus avoiding as far as possible the influence of their preconceptions. Responses to the appointment of a MTDM and support person and to closed questions in the Instructional Directives were summarised quantitatively. Free text responses were analysed using latent analysis that seeks to find the underlying meaning of the text by extending the data to an interpretive level.39 To facilitate the analysis, the content of free text responses to questions in the VDs of the ACP documents (Table 1) were extracted and imported into a qualitative data management software.35

---

![Study schema](image)

119 eligible dyads consented, enrolled and randomized 1:1

63 allocated to Usual Care

58 allocated to VDST

- 1 withdrawn from study

- 2 withdrew mid study
- 2 too unwell to proceed
- 1 prequestionnaire missing

60 completed allocated post questionnaires

53 completed intervention and allocated post questionnaires

22 patients completed ACP

20 patients completed ACP

53 patients chose not to complete ACP

18 patients died before completing ACP

---

86
Table 7.1
Questions asked in the Values Directive Component of the Advance Care Plan

We are all unique and have different beliefs, values and goals. Here you can say what is important to you. What does it mean to you to 'live well'? This information will be used by people making decisions for you to help them make the decisions that you would have made yourself. These statements are a guide to treatment decision making only. If you wish to legally refuse treatment, see Part 5 of this form.

1. I am currently receiving care and treatment for the following health conditions:
2. What is difficult for me to do now because of my health condition(s)?
3. What worries me about what will happen to my health in the future?
4. The following things worry or concern me unrelated to my health. For example: family concerns, hopes and fears, emotional issues, accommodation, people I do not want to be involved.
5. These are the things in life that have a lot of meaning for me (for example: enjoying activities, spiritual or religious beliefs, family or friends, pets, reading books, independence)
6. The following things are important to me and they may help my Medical Treatment Decision Maker to make medical decisions in the future for me (for example: special religious or cultural needs)
7. If I have an illness or injury and can no longer make treatment decisions for myself, I would most likely agree to (Please tick one box only)
   a. Any treatment that will make me live longer and are suitable for my medical condition (even if they could cause me distress).
   b. To be kept comfortable and be provided with treatments that are not distressing and mainly treatments aimed at relief of pain and other symptoms.
   c. For my Medical Treatment Decision Maker to decide on what is best for me, based on what the doctors tell them about me at that time.
8. Other things that are important to me are:
9. If I am nearing death, the following things are important to me (e.g. where I would prefer to die, spiritual/faith rituals or requests, who I would like with me, funeral preferences)

Initial analysis was conducted by NM who read the extracted texts to familiarise with the nature and tone of the responses, identified and coded 'Significant statements' (inductive descriptive labels), which were items of analytical interest, and formulated meanings from each statement. Coding was conducted per question rather than per participant. DK reviewed the coding completed by NM and discussed any discrepant views until consensus was reached. Overlapping or repeated statements were removed, and derived meanings were organised into formulated concepts, then clustered into subthemes. A further author (XS) examined data and analyses in order that discrepancies in emerging concepts and subthemes were compared and reconciled, thus improving methodological rigor. A formulated meaning was derived from each subtheme identified in the data, which was then integrated into textual description, creating a final composite description of the phenomena though an overarching theme. This analysis is illustrated in Table 2. Only NM and DK were directly involved in the clinical care of some participants.

Results

Data from 42 completed ACP documents were analysed, representing 37.2% of 113 patients completing the RCT study. Participant demographics and details of completed ACPs are summarised in Table 3. Most participants were female (57.1%), with a diagnosis of gastrointestinal cancer (30.1%) and a mean patient age of 73.9 (SD 11.4). Just over three-quarters of patients appointed a second MTDM, and an additional

Table 7.2
Development of the Analysis Schedule Exemplified with Codes, Categories and Subthemes

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Conceived meaning</th>
<th>Code unit</th>
<th>Subcategories</th>
<th>Category</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>I'm physically weak, anything requiring strength, flexibility or agility is difficult. Household chores for example, Bathrooms may become difficult as things evolve.</td>
<td>Physically weak.</td>
<td>Loss of physical Challenges</td>
<td>Physical dependency</td>
<td>Fear of dependency</td>
<td>Increased dependency, evokes anxiety</td>
</tr>
<tr>
<td>A peaceful environment at home, quality time spent with husband and family, walks in nice gardens, good movies, good books, painting and art classes.</td>
<td>Peaceful home environment</td>
<td>Quality time with family</td>
<td>Meaningful living</td>
<td>Meaningful activities</td>
<td>Quality and meaning in environment, company and tasks</td>
</tr>
<tr>
<td>Avoiding lifting heavy things, Avoid gardening (which I love). Going for a walk slower than I was. Driving the car. Standing to cook.</td>
<td>Avoid lifting, gardening (physically strenuous activity)</td>
<td>Slower than I was</td>
<td>Adapting to changes in physical capability</td>
<td>Adapting to dependency</td>
<td>Diverse and malleable approach to increased dependency</td>
</tr>
</tbody>
</table>

87
7.3

Table 7.3
Participants Demographic Characteristics and Details of Completed Advance Care Plan

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N = 42 (95)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>24 (57.1)</td>
</tr>
<tr>
<td>Male</td>
<td>18 (42.9)</td>
</tr>
<tr>
<td>Age in years: mean (SD) [range]</td>
<td>71.8 (11.4) [44-94]</td>
</tr>
<tr>
<td>Cancer Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>13 (30.9)</td>
</tr>
<tr>
<td>Gynecological</td>
<td>7 (16.7)</td>
</tr>
<tr>
<td>Lung</td>
<td>6 (14.3)</td>
</tr>
<tr>
<td>Breast</td>
<td>5 (11.9)</td>
</tr>
<tr>
<td>Gynaecology</td>
<td>5 (11.9)</td>
</tr>
<tr>
<td>Haematological</td>
<td>4 (9.5)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (4.8)</td>
</tr>
</tbody>
</table>

Part I – Appointment of MDTM and Support Person

<table>
<thead>
<tr>
<th>Appointment of MDTM 1 or MPOA</th>
<th>Yes 42 (100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appointed MDTM 2 (N=41)</td>
<td>Yes 32 (79.0)</td>
</tr>
<tr>
<td>No 9 (22.0)</td>
<td></td>
</tr>
<tr>
<td>N/A*</td>
<td>1</td>
</tr>
</tbody>
</table>

Appointed Support Person (N=41)

| Yes 17 (41.5) |
| No 24 (58.5) |
| N/A* 1       |

Completed Values Directive

| Yes 41 (97.6) |
| No 1 (2.4)    |

Options selected if unable to make decisions with an illness or injury:

If I have an illness or injury and can no longer make treatment decisions for myself, I would most likely agree to:

- Any treatment to live longer for my condition (even if it causes distress) 3 (7.5)
- To be kept comfortable with treatments that are not increasing (aimed at pain and symptom relief) 18 (43.9)
- For MDTM to decide following medical advice 22 (52.7)

Part 2 – Instructional Directive

Completed Instructional Directive

| Yes 38 (90.5) |
| No 4 (9.5)    |

Decision on Cardiopulmonary Resuscitation

| Autopsy resuscitation 12 (28.6) |
| Not for resuscitation 26 (61.9) |
| Unanswered 4 (9.5) |

Expressed desire to be considered for organ, eye and/or tissue donation

| Yes 20 (47.6) |
| No 18 (42.9) |
| Unanswered 4 (9.5) |

MDTM: Medical Treatment Decision Maker; MPOA: Medical Power of Attorney.

*Documentation for the appointment of a MPOA does not make provision for the appointment of a MDTM or Support Person.

**Patients were able to select more than one option.

two-fifths appointed a support person. There was no association between ACP document completion and overall age, sex, diagnosis, marital status, nature of dyad relationships, primary diagnosis, time since diagnosis and prognostic discussion with doctor.

There was a high completion rate of VVs (97.6%) and Instructional Directives (90.5%). Just over half the participants chose to relinquish decision making to their MDTM in the event of being unable to make treatment decisions for themselves due to an illness or injury. Of those who completed Instructional Directives, two-thirds opted not to have cardiopulmonary resuscitation and close to half expressed a desire to be considered for organ, eye and/or tissue donation.

The overarching theme of cancer patients' ability to posture vulnerability with resilience (Table 4) was supported by four subthemes as below:

Subtheme A: Acknowledging Frailty with Diverse Adaptations to Dependency

Participants described a multitude of adaptations to their loss of physicality and independence, with a loss of functionality such as "may lose total mobility" (Male, 72, Gastrointestinal) commonly described as the most debilitating part of illness Some expressed concerns regarding its impact on their ability to execute general, everyday tasks:

I'm physically weak, so anything requiring strength, flexibility or agility is difficult. Household chores, for example. Bathroom may become difficult as things evolve. (Female, 73, Lung)

Maintaining independence was associated with normality:

I would like to be a normal person, to do my own shopping, maintaining independence. (Female, 77, Gynaecological)

Despite this, adjustments, adaptations and coping through prioritisation of tasks were apparent, "Housework is negligible except for doing washing and getting meals" (Female, 72, Gastrointestinal); modification of expectations "going for a walk slower than I was" (Female, 71, Adrenal); acknowledgement of dependency "if my health deteriorates but I accept some level of dependencies" (Female, 66, Haematological); and sometimes acceptance, "Nothing really worries me... that is how I have handled everything from day one" (Female, 66, Gynaecological).

Trepidations regarding deteriorating functionality and its implications extended to their concerns for the future. Twelve participants expressed specific concerns about pain, and many desired a dignified death, "All I want to do is be pain-free and pass away with dignity" (880). Others alluded to their fear that loss of control would transpire with the loss of mobility, "that I will deteriorate and become unconscious and not be able to give direction" (Male, 74, Gastrointestinal).

Fifteen patients expressed concern for their family's future, emotionally or financially:
### Table 7.4

#### Existential Postures of Vulnerability and Alternative Constructive Stances

<table>
<thead>
<tr>
<th>VULNERABILITY</th>
<th>QUOTES</th>
<th>RESILIENCE</th>
<th>QUOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncertainty</td>
<td>Where it will spread next and what the impact will be (965)</td>
<td>Coherent direction</td>
<td>... love to have a project—something to plan (965)</td>
</tr>
<tr>
<td>Ambivalence</td>
<td>I'm concentrating on 'now' at the moment, I don't worry about what could be. I try and get through each chemo session and happy when I have energy again (925)</td>
<td>Acceptance of death</td>
<td>(I want to die) at home or at the beach with my family and friends; buries (sic) at (sacred location) (925)</td>
</tr>
<tr>
<td>Concern and grief</td>
<td>only thing that concerns me is not surviving this cancer and being there for my children as they grow up. I dream of growing old, travelling and enjoying the world with my husband and being a grandparent one day and helping my children when they become adults (923)</td>
<td>Courage and confidence</td>
<td>My children and their well-being both physically and emotionally is incredibly important to me. They are my number one priority at all times. I want to do whatever I need to do with this cancer treatment to survive as long as I can (923)</td>
</tr>
<tr>
<td>Idealised wishes for family</td>
<td>lifelong antagonist between (my) sons. I believe they will reconcile. Neither of my sons' own property. Most of my worries are about my children (922)</td>
<td>Fulfilment from family</td>
<td>Reminisced about music put together by (son A) on (my husband's) death. I would like (son A) and (son B) to do the same for me (922)</td>
</tr>
<tr>
<td>Loss of roles</td>
<td>To work at the same pace as I did when I was healthy. (I'm) impeded by compromised sciatic nerve affecting right leg. Inability to go to work and inability to be a fascinating person (924)</td>
<td>Direcdness to other</td>
<td>Time with mates (very precious). Reading, going to movies. Family and pet dog Sunny. Leisure driving in old Mercedes (924)</td>
</tr>
<tr>
<td>Loss of control</td>
<td>I have no control over my cancer; needing a tube to breathe (902)</td>
<td>Planning and action</td>
<td>Walking; stockbroker; watching movies; TV Series; Time with family (immediate); pet dog (902)</td>
</tr>
</tbody>
</table>

---

I am a little worried that my husband and sons won't ask or get emotional/ psychological support once I am gone to deal with their grief. (Female, 49, Gynaecological)

Financial is my biggest concern. Able to live in my house and support my son. Centrelink covers a small portion of costs. (Female, 49, Gastrointestinal)

Nonetheless, solace was gained by maintaining hope, "...lifelong antagonism between sons. I believe they will reconcile" (Female, 77, Gynaecological) and the attainment of peace "I enjoy solitude and

---

Fig. 7.4: Key expressed attitudes, priorities and life goals.
meditation, those little Zen moments" (Female, 75, Gynaecological).

**Subtheme B: Benevolence and Reciprocity of Family/Friends Caring**

Gratitude, trust and a sense of security established through family/friendship bonds were demonstrated throughout the cancer journey. A patient who expressed worry about the impact on illness on her family (other directedness) stated, "...worry about my personal comfort and pain levels as my condition deteriorates. I worry about being a burden on my family" (Female, 58, Gynaecological), was comitantly able to express her reliance on them, "physical tasks like cleaning and gardening can be very difficult or impossible, but my family looks after me" (Female, 58, Gynaecological).

Likewise, a patient who was a freelance worker described how her dependence on family support enabled her to sustain herself through treatment:

....not well enough for short bookings. Coordinating people/family to pick me up/drop off at hospital and look after me during recovery. I try and get through each chemo session and am happy when I have energy again. (Male, 74, Gastrointestinal)

This reliance was further qualified through descriptions of a meaningful life lived,

Love reading, love gardening, love Max the kitten, spending time with friends-out for dinner, family-being around them. Walking around neighbourhood, shopping, love to have a project-something to plan. (Female, 43, Gastrointestinal)

Care and reciprocity experienced by the family provided a sense of being valued. A patient disabled with his cancer described the daily care by his wife "good body hygiene including good grooming (attention to beard and nail) provision of sufficient fluids and good mouth care to prevent sensitisation of throat" (Male, 90, Haematological).

**Subtheme C: Death Anxiety, Ambivalence and Experiential Acceptance of Dying**

Participants cautiously and courageously mentioned the prospects of one's abject body in the final stages of dependency. A participant emphasised, "Where it will spread next and what the impact will be...Loss of bowel control and bladder control. The extent of pain I may feel towards the end". (Female, 71, Adrenal)

Death anxiety arose from fears of the process of dying "dying, choking - not being able to breath". (Female, 60, Breast)

One patient articulated the existential anguish of the aloneness of facing death,

I worry about death and the physical process. I have never observed death before. I would prefer to die alone. I do not expect my children to be there holding my hand. (Female, 77, Gynaecological)

Even so, some exhibited a preparedness to experience unpleasant or unwelcome thoughts and emotions of dying without struggling to solve or resist them, with one participant taking the approach of "concentrating on now. I don't worry about what could be" (Female, 49, Gastrointestinal). Another stated:

I am aware that my situation is dire and therefore I do not want heroic measures from the medical staff that is likely to prolong any suffering or pain or the suffering of my family. (Male, 74, Gastrointestinal)

Participants were concurrently able to posture their experience of vulnerability in conjunction with attitudes of strength and resilience. An elderly cancer patient with a terminally ill husband stated, "it is becoming difficult to care for my terminally ill husband and to keep up with household management" (Female, 88, Gynaecological) but was able to draw comfort from "the loving support of my two daughters". She further stated, "my wish is that my husband will slip peacefully and that I will have a little more time at least".

Likewise, a young mother expressed her anguish:

I do worry that my health will stop me from actively raising my children, I want to support them and be there for them. I am their parent and need to care for them" (Female, 43, Gastrointestinal). Nonetheless, her determination was evident in stating: "I want to do whatever I need to do with this cancer treatment to survive as long as I can.

**Subtheme D: Honoring Death through Secular and Sacred Rituals**

Eighteen participants specifically mentioned their desires for end-of-life religious or spiritual/secular rituals (5 Catholic, 4 Jewish, 3 Christian and 6 spiritual/secular). Appeals included, "Catholic by religion would like to receive last rites before I die" (Female, 72, Gastrointestinal) or "consult Rabbi for spiritual rituals" (Male, 74, Lung). A Church of England participant sought "regular blessings from my church" (Male, Lung, 98), specifically requesting a reverend by name.

Non-religious participants, sought solace through individualised rites, with one stating "I am not a religious person, so do not have any rituals or requests, but would like music playing in the room if I am nearing death, rather than having a silent room" (Female, 43, Gastrointestinal) or another specifically expressing a desire to be "buried at Arthur's Seat" (Female, 49,
Gastrointestinal) [a popular bayside location] or explicitly stating that "Executor is aware of my wishes for no funeral" (Female, 76, Breast).

Overall, many were able to articulate a preferred death-bed scenario, with 18 participants explicitly articulating a preference for a home death, "For my husband and immediate family to be by my side, preferably at home" (Male, 75, Gastrointestinal), occasionally accompanied by further written, "Please consult a letter with further instructions" (Female, 79, Breast) or spoken directions, "I have spoken to my sister, and she knows what I want" (Female, 79, Breast).

Discussion

Our completed RCT showed that values conversations improved ACP documentation in older patients (≥ 70 years old), elicited greater distress in patients, and importantly improved concordance in communication between patient and caregivers. In this sub-study, our analysis highlighted the ability of cancer patients to concurrently display both postures of vulnerability and strength as illustrated in Table 4. These opposing yet complementary stances are nuanced in the findings of the above themes and describes the overarching lived experience of the participants. Thus a clinician’s recognition of each patient’s sources of vulnerability and resilience potentially opens a therapeutic pathway to nurture movement towards their strength and thus overall adaptation of the patient’s behavior.

The standard process of ACP and the use of decision aids assumes rational choices, failing to consider individuals’ cognitive, affective, social circumstances and desires. Most patients reach a point of readiness to complete an ACP, which clinicians need carefully to recognize. Preferences regarding medical and end-of-life decisions are acquired through experience and wisdom, influencing decisions in serious illness and judgements made with inevitable trade-offs. These may include: What are the implications of prolonging life and living with greater dependency, placing financial and caregiving strain on families? What memory or legacy of the final weeks or months of life does one want to leave behind? How do you consider the implications of limiting life when others remain dependent emotionally or financially? Our high completion rates of VD’s suggest patients’ willingness to engage in enhancing value awareness in ACP conversations. Herein lies the opportunity for clinicians to encourage careful deliberation to enable a consolidated state of mind, reflective of what is held most desirable by those facing their mortality.

Our findings demonstrating patients diverse adaptability concurs with data that show that adaptability is a key factor in the healthy adjustment of the cancer experience. In many instances, adaptability to physical dependency or frailty occurs as patients seek to sustain meaning and understanding of the period of life that remains. In seeking coherence, purpose and significance, life can indeed be meaningful beyond the chaos of illness. Despite uncertainties, a response shift or reappraisal of life priorities may occur naturally in those seeking a coherent direction, whereas others may require help with more nuanced interventions. Research suggests that meaning centred psychotherapy may be required by some individuals to impact on adaptive coping and reduce psychopathology.

The reciprocation of care experienced within the patient-caregiver dyad engendered much hope for many. Rather than experience a state of dejection, caregivers’ emotional and moral solidarity installed a sense of security, despite patients’ trepidations surrounding increased dependency, concern for family and financial burdens. This ability of patients to tolerate imperfections and failings that comes with illness allows the benevolence of caregivers to emerge.14 Kleinman reminds us of the moral practice that is caregiving. "It is a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human." Nonetheless, concerns of patients remain about the caregiver’s ability to manage on an ongoing basis. Patients too were able to articulate a sense of benevolence, directing their concerns to others despite their own illness, with half of the cohort articulating a desire to consider tissue donation following their death.

For some participants, the experiential acceptance of death allowed for a 'present-focused approach', a willingness to experience unpleasant or unwelcome thoughts and emotions without struggling to solve or resist them. This mindful approach allows for the attainment of peace, providing freedom from weariness and internal turmoil. Others expressed ambivalence, simultaneously expressing both a will to live and a desire for death. The risk of a patient persisting in this ambivalent approach lies with caregiver burnout, inability to say goodbye, and later morbidity from an inadequate preparation for bereavement. Thus, when ambivalence is recognised, it remains a targeted intervention where possible, with the clinician encouraging 'death talk' to facilitate improved open end-of-life discussions, advance care planning, and value congruence in patient-caregiver communication.

The final theme denoting the importance of secular or religious rituals resonates with current interpretations of the dimensions of spirituality, which consist of either organised religion or secular approaches that focus on humanistic or existential precepts. Research suggests both the protective benefits of spirituality and acknowledges the benefits of a patient’s conscious commitment to values, which create an opportunity for
meaningful living. The increased secularisation of societies may require communication that focuses on deeply held personal and intrinsic values and may facilitate a more meaningful preparation for dying.

**Clinical Implications**

Completion of a VD as a component of an ACP can be regarded as the behaviour of a mature person with an awareness of the closeness of death. Our analysis has confirmed the presence of equanimity in the patient, acceptance of their frailty and the finitude of life, sustained benevolence to others they love, and the help that ritual offers as they negotiate this final passage of their life cycle. It thus stands as an aspirational task for the clinician to not simply support the completion of a VD but to subsequently ensure the facilitation of treatment and care plans that reflect value congruence so that patients and their families better negotiate this phase together.

**Strengths and limitations**

Our decision to analyse the content of VDs arose from a desire to obtain an experiential understanding of the interrelationships that arise when contemplating a VD. Nonetheless, this study has several limitations. It was conducted in a single site, limiting its generalisability. The initial coding was completed by a single researcher and analysis did not evaluate the impact of participants' prognostic awareness on findings or distinguish between those randomised to the VDST or UC. It is plausible that participants in the intervention video arm were more contemplative in considering their responses in their VD. Finally, in selecting a phenomenological analysis approach, the researcher's reflexivity may have understandably contributed an element of subjectivity to the findings.

**Conclusion**

The paradigm shift towards articulating values in ACP is now widely appreciated. Our findings suggest how a VD may be productively used by clinicians to guide patients in completing the tasks of living and better prepare them to die in a manner likely to generate a greater experience of a good death for all involved.

**Disclosures**

The authors declare no conflict of interest. This study was funded through the Bethlehem Research Foundation Grant (Grant Number 1709) and the Cabrini Foundation Medical Oncology Research Grant.

**Data Statement**

Data can be made available through direct correspondence with the corresponding author and pending approval from the ethics committee.

**Acknowledgments**

The authors thank the patients and families who participated in the study and the staff from the Department of Palliative and Supportive Care for their assistance.

**Supplementary materials**

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.jpainsymman.2022.07.015.

**References**


7.4 SUMMARY AND CONCLUSION

In this chapter, through phenomenological content analysis, I explored patients' ability to adapt to complex and changing circumstances when faced with a cancer diagnosis. Rather than focusing simply on the quantitative outcomes from the RCT, my use of latent analysis allowed me to delve deeply into the lived experiences of the patients through their documentation of wishes on the VD. This was conducted in detail through the formulation of meaning from significant statements, subsequent coding and the development of subthemes and themes.

Qualitative analysis allows for several methodological approaches which include ethnography, grounded theory, phenomenology, historical study and case study. Grounded theory and phenomenology are the most common approaches used. Grounded theory involves the construction of theory through the analysis of data without a prior hypothesis and the discovery of emerging patterns in data. Phenomenology on the other hand seeks to understand the lived experience and perspectives of participants through the evaluation of their life experiences. My choice of using a phenomenological approach was based on my desire to explore beyond long held assumptions about how patients’ values may be perceived or expressed when living with a serious illness and to identify the more subtle nuances of their lived experience. Nonetheless, my role as a senior clinician involved as the sole initial coder in the data analysis may have inevitably introduced an element of bias to the findings. This approach was a deviation from the normal recommendations of using two or more independent coders due to limitations of financial and personal resources.

Through the identification of key expressed attitudes, values and life goals, I was able to describe an overarching theme and subthemes, recognising a cancer patient’s ability to posture both vulnerability and resilience. Our unique approach to this content analysis is a move away from the traditional rationalistic approach of content analysis of ACP documents. It assumes that healthcare decisions are not made simply by stating individual preferences but involve more profound deliberations, drawing from experience, wisdom, and contemplation.

Methodologically it is complex to use a phenomenological approach to compare both the UC and VDST group. This could have been facilitated using simple
textual analysis which was beyond the scope of this paper. Additionally, our approach towards identifying themes and subthemes was strongly influenced by our intention to achieve not simply code saturation but meaning saturation. Code saturation is achieved when no additional issues are identified, with stability of the codebook. Meaning saturation on the other hand occurs at the point when we no further dimensions, nuances or insights of issues can be found. Meaning saturation is usually achieved later in the data and are drawn from conceptual rather than concrete codes. It is plausible that the subthemes are explored further in future studies to further explore diversity, clarity and depth of data.

I described four main themes. The description of patients' diverse adaptability to their illness allows clinicians to consider how best to facilitate discussions on the reprioritisation of life priorities. Supporting caregivers in caregiving allows for the emergence of benevolence and reciprocation. Likewise, understanding the risk of ambivalence and the importance of secular and spiritual rituals aid in preparation for a meaningful end to one's life.

The process of completing the RCT and data analysis evoked further questions about how to consider other approaches to engage patients to achieve value congruence. With only a third of those offered an ACP completing them and many willing to engage in conversations and documentation, clinical encounters at the bedside or in ambulatory care provide the opportunity to explore and discern where the opportunities for value alignment in clinical decision-making lie. ACP continues to be a single point in a time-specific task that fails to capture the essential, meaningful aspects of the experiences of living with an illness.

7.5 REFERENCES FOR SUMMARY AND CONCLUSION

CHAPTER EIGHT

PATIENT-CAREGIVER COMMUNICATION CONCORDANCE IN CANCER – REFINEMENT OF THE CANCER COMMUNICATION ASSESSMENT TOOL IN AN AUSTRALIAN SAMPLE
8.1 DECLARATION BY CANDIDATE AND CO-AUTHOR STATEMENT


<table>
<thead>
<tr>
<th>Nature of contribution</th>
<th>Extent of contribution (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study conceptualization, literature review, design of methodology, manuscript preparation</td>
<td>75</td>
</tr>
</tbody>
</table>

Candidate’s Signature 13/6/2022

We the undersigned, hereby certify that the above declaration correctly reflects the nature and extent of the candidates and co-author’s contribution to this work:

<table>
<thead>
<tr>
<th>Co-Author</th>
<th>Nature of Contribution</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Gorelik</td>
<td>Study design, statistical assistance, data interpretation, manuscript preparation.</td>
<td></td>
<td>13/06/2022</td>
</tr>
<tr>
<td>Dr E Georgousopoulou</td>
<td>Study design, statistical assistance, data interpretation, manuscript preparation.</td>
<td></td>
<td>07/09/2022</td>
</tr>
<tr>
<td>Dr Merlina Sulistio</td>
<td>Patient Recruitment, manuscript preparation.</td>
<td></td>
<td>13/06/2022</td>
</tr>
<tr>
<td>Dr Patrick Tee</td>
<td>Patient recruitment, manuscript preparation.</td>
<td></td>
<td>17/06/2022</td>
</tr>
<tr>
<td>Dr Katherine Hauser</td>
<td>Patient recruitment, manuscript preparation.</td>
<td></td>
<td>17/06/2022</td>
</tr>
<tr>
<td>Professor David Kissane</td>
<td>Study design, data interpretation, manuscript preparation.</td>
<td></td>
<td>13/06/2022</td>
</tr>
</tbody>
</table>
8.2 PREMBLLE TO EMPIRICAL PAPER THREE

This chapter presents the third and final empirical paper of the thesis. The findings from the completed RCT and my qualitative analysis (Chapters 5 and 6) provided the context for the final paper. In recognising the importance of enhancing value awareness, I further sought to understand the key concepts critical to delivering value-congruent care. In my previous published work, I chose to examine caregivers' views on ACP and subsequently test the feasibility of including patient-caregiver dyads in my study designs to explore the potential for the process of ACP in strengthening patient-caregiver communication and relationships. These early published studies highlighted the importance of dyadic communication in ACP.

I recognised the limited number of options available to researchers to measure improvement in patient-caregiver dyadic communication, with the CCAT being one of the few tools validated internationally. Our RCT showed an improvement in congruence in patient-caregiver communication following exposure to ACP, regardless of the arm of the study the dyads we allocated to.

The following chapter provides a synopsis of patient-caregiver dyadic communication and demonstrates my attempt to validate the CCAT in the Australian setting. I examined CCAT scores obtained from an Australian sample and the absolute difference between items and compared our findings with international samples. I additionally examined the internal consistency of the CCAT, demonstrating overall disagreement between patient and caregiver reporting of items. I additionally described a three-factor solution with moderate reliability for the CCAT. My overall assessment of the validity of the CCAT was limited by this study being a sub-study of the RCT. Thus, I was unable to assess validity against prespecified areas.

The following paper has been published online by Supportive Care in Cancer, a peer-reviewed journal with an impact factor of 3.359 (2022). This article is reproduced here with permission from Springer Nature and is licenced under the Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format

http://creativecommons.org/licenses/by/4.0/ (Appendix K)
Patient-caregiver communication concordance in cancer—refinement of the Cancer Communication Assessment Tool in an Australian sample

Natasha Michael\textsuperscript{1,2,3}, Alex Gorelik\textsuperscript{4,5,6}, Ekavi Georgiouopoulou\textsuperscript{2}, Merlina Sulistio\textsuperscript{1,2,3}, Patrick Tee\textsuperscript{1,2,3}, Katherine Hauser\textsuperscript{1}, David Kissane\textsuperscript{1,2,3,7}

Received: December 2021 / Accepted: 19 May 2022
©The Author(s) 2022

Abstract
Purpose The objective of this study was to expand the international psychometric validation of the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) within a sample of Australian cancer patients.

Methods Survey data from 181 cancer patient-caregiver dyads ≥18 years of age with solid or haematological cancers were analysed (85.4% response rate). Spearman’s rho was used to examine the correlation between CCAT-P and CCAT-F scores and weighted kappa the agreement between them. Exploratory factor analysis using scree plot and Kaisar–Guttman criteria was conducted to evaluate the scale structure. Cronbach’s $\alpha$ and Pearson correlation coefficients were used to measure internal consistency and concurrent validity respectively.

Results Mean scores were the following: CCAT-P 46.2 (9.8), CCAT-F 45.7 (9.4), and CCAT-PF 24.1 (8.0). We confirmed the poor concordance between patient and caregiver reporting of items in the CCAT-PF, with all but two items having weighted kappa values <0.20 and Spearman’s rho <0.19. We derived a three-factor solution, disclosure, limitation of treatment, and treatment decision making, with reliability ranging from Cronbach’s $\alpha=0.43$–0.53. The CCAT-P and CCAT-F showed strong correlations with preparation for decision-making (CCAT-P: $r=0.92$; CCAT-F: $r=0.93$) but were weakly associated with patient/caregiver distress related with having difficult conversations on future care planning.

Conclusion Preliminary validation of the CCAT-PF in the Australian setting has shown some similar psychometric properties to previously published studies, further supporting its potential utility as a tool to assess patient-caregiver dyadic communication.

Trial registration ACTRN12620001035910 12/10/2020 retrospectively registered.

Keywords Cancer · Communication · Caregiver · Validation · Questionnaire

\textsuperscript{55} Natasha Michael
michael@cabrini.com.au

1 Supportive, Psychosocial and Palliative Care Research Department, Cabrini Health, 646 High Street, Prahran, Melbourne, VIC, Australia

2 School of Medicine, University of Notre Dame Australia, NSW, Australia

3 Faculty of Medicine, Nursing and Health Sciences, Monash University, Melbourne VIC, Australia

4 Monash-Cabrini Department of Musculoskeletal Health and Clinical Epidemiology, Cabrini Health, Melbourne, VIC, Australia

5 Department of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine, Monash University, Melbourne VIC, Australia

6 Department of Medicine (RMH), University of Melbourne, Melbourne VIC, Australia

7 Sacred Heart Health Service, St. Vincent’s Hospital, Sydney, NSW, Australia
Background

A diagnosis of cancer is disruptive to family functioning, eliciting anxiety, distress, and not uncommonly causing interpersonal conflict between family members [1, 2]. Communication in cancer care is thus crucial but is recognised as complex, requiring a multifaceted approach in ensuring appropriate content, affect and delivery across multiple settings [3, 4]. Such complexity brings about discordance in patient-caregiver communication which is well recognised [5] and arises out of challenges in acquiring information about diagnosis, prognosis and treatment options [6], poor patient-caregiver goal alignment [7], limited supports to enable optimal coping [1], and an overall avoidance of open communication [8].

Cancer caregivers are thus now routinely recognised as forming part of the triad of care with patients and health professionals, with the goal of building trusting relationships, sharing information, eliciting concerns, and enabling patients and families to talk about their feelings and concerns [9, 10]. Patient-caregiver dyadic communication in cancer is to be encouraged, but has been described as ‘work’ [11] and is consequential, with poor communication increasing patient and caregiver depression, anxiety [12], and relational satisfaction [1]. Conversely, proactive discourse improves dyadic coping [1] and resilience [13], allowing for recovery from the many stresses associated with a cancer diagnosis.

Whilst methods and instruments exist to assess individual patient [3, 14] and caregiver communication [15, 16], there remain few valid and reliable instruments designed to capture the level of agreement (concordance) or disagreement (discordance) in cancer patient-caregiver dyadic communication to assist targeted interventions. One such instrument, the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) [17], was designed to assess patient-caregiver congruence in communication, with higher scores signifying greater discord.

Preliminary research on the psychometrics of the CCAT-PF by Smirnoff et al. in 190 American lung cancer patient-caregiver dyads demonstrated a mean CCAT-PF of 26.9 (SD 8.8), with test–retest reliability of 0.35 and Cronbach’s α of 0.49 [17]. Likewise, a Korean study of 990 heterogeneous cancer dyads identified a slightly lower mean CCAT-PF (23.7), with moderate internal consistency (Cronbach’s α: CCAT-P = 0.52, CCAT-F = 0.50, CCAT-PF = 0.60) [18]. This is in keeping with the CCAT-PF not being the summed scale of a single construct but of eight independent constructs that do not correlate well with each other. A subsequent German cross-sectional study of 189 cancer patient-caregiver dyads completed an exploratory factor analysis and described four factors within the CCAT-PF: disclosure (Cronbach’s α = 0.66), limitation of treatment (Cronbach’s α = 0.51), family involvement in treatment decisions (Cronbach’s α = 0.68), and continuing treatment (Cronbach α = 0.51) [19]. The disclosure subscale was found to be a valid and reliable instrument for identifying conflicting communication in at-risk patient-caregiver dyads, correlating with patient distress (r = 0.30, p < 0.0001), specific unmet needs (r = 0.25–0.32, p < 0.001), and negatively with social/family well-being (r = −0.31, p < 0.0001) [19].

High conflict scores on the CCAT-PF significantly correlated with greater patient depression and lower family expression of feelings and cohesion [17] but weakly with patient/caregiver perceived family avoidance of cancer care [18]. Both the CCAT-P and CCAT-F scores were weakly associated with mental health and quality of life outcomes [18]. The CCAT-PF has also been used longitudinally, with a recent 2-year study of 171 haematological cancer patient-caregiver dyads demonstrating that communication is dynamic over time, with race, income, and the quality of dyadic relationships affecting patterns of concordance [20].

This exploratory study was undertaken to examine the potential applicability of the CCAT-PF within the Australian setting. We sought to explore its early psychometric properties (internal consistency) and exploratory factor analysis across heterogeneous tumour types.

Methods

Study design and sample

This study formed part of a randomised control trial (RCT) exploring advance care planning (ACP) in cancer patient-caregiver dyads [21, 22], which follows through from preliminary published studies [23–26]. Dyads were randomised to a video supported intervention demonstrating conversations on end of life values or usual care. The study was conducted at an 850-bed metropolitan teaching hospital in Melbourne, Australia. Patients diagnosed with solid or haematological cancer were recruited from the oncology and palliative care services and were asked to nominate a willing caregiver. Patients and caregivers who were insufficiently proficient in English, aged > 18, or unable to consent due to cognitive barriers were excluded.

Following enrolment and written consent and prior to randomisation, patient-caregiver dyads completed an anonymous questionnaire which included the CCAT-PF. Patients and caregivers completed the CCAT-PF independently from each other as well as the Depression, Anxiety, Stress Scales (DASS-21) [27] (patients only), attitudes to ACP [25], and the Patient Decision Making Scale (PDMS) [25]. On conclusion of the RCT, sample size calculations indicated that
additional CCAT-PF data was required for sufficient reliability. Additional patients were recruited, with completion of the questionnaire implying consent. Ethical approval was granted by the institution's Health Research Ethics Committee: RES-20-0000-112C.

Measurements

**Cancer Communication Assessment Tool for Patients and Families (CCAT-PF)** [17]

The CCAT-PF (Appendix 1) was developed to measure congruence in patient-caregiver family communication, with the potential for it to be used as a clinical screening tool to assess the level of family risk for communication. The CCAT-PF has analogous patient (CCAT-P) and family (CCAT-F) instruments, which consist of 18 items within eight domains: general communication and interaction style, reluctance to report side effects, treatment and care goals, trade-off between side effects and quality of life, family support of decisions, patient and family perspectives about physicians’ decisions and communication, family communication (five items), and hospice care (one item). Responses for each item are reported on a 6-point Likert scale (1 = strongly agree/all the time, 6 = strongly disagree/never). Scoring instructions for the CCAT-P, CCAT-F, and CCAT-PF have been published elsewhere [17, 28]. The range of scores for the CCAT-P/CCAT-F is 18-108 and for the CCAT-PF is 0-90. Higher scores indicate greater conflict and therefore poorer concordance in communication.

**Depression, Anxiety, and Stress Scale (DASS-21)** [27]

The DASS-21 is used to observe negative emotional reactions (depression, anxiety, and stress). It has acceptable internal reliability for its depression subscale (α=0.90) and anxiety subscale (α=0.70), with concurrent validity to measures of suicidal ideation, quality of life, self-rated health, and depressed mood.

**Attitudes towards ACP** [25]

This is a non-validated scale developed by the research team and used in a previous feasibility study and the RCT intervention in patients and caregivers [21, 25]. It measures understanding of ACP, satisfaction, and distress experienced in undertaking ACP on a Likert scale from 0 to 10.

**Preparation for Decision Making Scale (PDMS)** [25]

The PDMS was used in the RCT intervention in patients and caregivers [21]. It assesses a participant’s perception of how useful a decision support intervention is in preparing them for making a health decision and communicating with their practitioner at a consultation, visit, and making a health decision. With strong internal consistency (α=0.92–0.96), it discriminates significantly between patients who do and do not find a decision support intervention helpful.

**Statistical analysis**

Incomplete pairs of CCAT-PF questionnaires whereby >40% of the CCAT-P and/or CCAT-F items were missing were excluded from the analysis [19]. Individual CCAT-P, CCAT-F, and CCAT-PF scores were calculated [17, 28] and presented as mean (SD) and the absolute difference between dyads. Allowing for data skewness, Spearman’s rho was used to examine the correlation between two scales and final CCAT-P and CCAT-F scores, whilst weighted kappa was used to examine the agreement between each item. Bartlett’s test of sphericity was used to assess the relationships between items and their suitability for the factor analysis, and the Kaiser–Meyer–Olkin criteria was used for sampling adequacy and to assess the strength of the relationships among the variables. Exploratory principal component factor analysis was undertaken to identify specific domains of this scale. Both scree plot and Kaiser-Guttman criteria were used to determine the number of factors to be included. Pearson’s correlation coefficient was used to assess correlations between various domains of CCAT, factors and DASS domains, PDMS total score, and Cronbach’s α to assess the internal validity. All analyses were performed using Stata16 (StataCorp LLC, College Station, TX, USA), and level of significance was set at p < 0.005.

**Results**

**Study participants**

From a total of 533 patients screened, 212 met the eligibility criteria, and data from 181 dyads were analysed (85.4% response rate) (Fig. 1). Cohort descriptions, including demographic and clinical data, are summarised in Table 1. The mean patient age was 69.1 (SD 12.9) and caregiver age 60.1 (SD 14.4). The majority of participants were female (patients 60.2%, caregivers 61.3%) and were married or in de-facto relationships (patients 68%, caregivers 81.8%). Most caregivers were spouses or partners of patients (59.1%), with close to a third being children or in-laws. Gastrointestinal cancer was the most common diagnosis (28.9%), followed by lung cancer (18.9%), with most having lived with their diagnosis for 1-5 years (36.3%).

103
Descriptive statistics and internal consistency of CCAT

The mean CCAT-P score was 46.2 (SD 9.8), and CCAT-F score was 45.7 (SD 9.4). The mean CCAT-PF score was 24.1 (SD 8.0). Dyads showed the greatest absolute differences for the following items: if treatment caused financial hardship for my family, I would not take it (2.1); I am willing to take treatment that causes me a significant amount of pain if I can live a few months longer (1.9); in general, side effects are not really important when I consider my larger goals of treatment (1.8); if treatment made me sick every day, I would not take it (1.6), my family’s acceptance of my treatment decisions depends on how much they like my doctor(s) (1.6). At the same time, 82.6% of patient-carers pairs provided an identical response to Q17 (My family blames my cancer on me not having taken better care of myself), and thus, this item was removed from the factor analysis due to its severe skewness (Sk = 2.7, kurtosis = 10.0).

The results reported in Table 2 show poor concordance between patient and caregiver items. There was minimal to no agreement between CCAT-P and CCAT-F (weighted kappa ranges from 0.01 to 0.31), with the strongest agreement attributed to questions 16 and 4: (frustration with family due to overprotection and willingness to undertake any treatment, hopeful that medical science will find a cure). The internal consistency (Cronbach’s alpha) was 0.58 for CCAT-P, 0.61 for CCAT-F, and 0.49 for CCAT-PF.

Item analysis and evaluation of the scale structure

As per the study by Huan et al. [19], we assumed different subdomains of familial cancer-related communication and thus completed a factor analysis on the discrepancy scores between CCAT-P and CCAT-F. The result of Bartlett’s test showed a satisfactory inter-correlation between items ($\chi^2 (136) = 259.1, p < 0.001$, after excluding question 17), suggesting a data set adequacy for the factor analysis and the Kaiser–Meyer–Olkin measure of sampling adequacy was low ($KMO = 0.56$) but satisfactory for the factor analysis.

A 3-factor or 4-factor solution was suggested following examination of the Scree plot and Kaiser–Guttman analysis. Factor 1 and Factor 3 were identical in both solutions. However, Factor 4 in the four-factor solution showed low internal consistency ($\alpha = 0.22$) thus making us opt for a 3-factor solution. The eigenvalues for these subscales were all > 1 and were as follows: Factor 1 2.24, accounting for 13.2% of the variance; Factor 2 1.83, accounting for an additional 10.8% of the variance; and Factor 3 1.44 accounting for an additional 8.9% of variance. The final three subscales corresponded with 32.5% of the total variance, with factor loadings of > 0.40 throughout (Table 3).

The pattern matrix in Table 3 revealed Factor 1 to consist of four items. This factor was labelled ‘disclosure’ and demonstrated moderate internal consistency. The second and third factor consisted of 4 items each, relating to treatment decisions and were labelled ‘limitation of treatment’ and ‘treatment decision making’ respectively, both with
Table 7.1 Participant demographics

<table>
<thead>
<tr>
<th></th>
<th>Patient</th>
<th>Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD)</td>
<td>69.1 (12.9)</td>
<td>60.1 (14.4)</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td></td>
<td>72 (39.8)</td>
<td>70 (38.7)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married/de facto</td>
<td>Widowed</td>
</tr>
<tr>
<td></td>
<td>125 (68.0)</td>
<td>24 (13.3)</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>14 (7.7)</td>
</tr>
<tr>
<td></td>
<td>Separated/divorced</td>
<td>18 (9.9)</td>
</tr>
<tr>
<td></td>
<td>Australia/New Zealand</td>
<td>Europe</td>
</tr>
<tr>
<td></td>
<td>124 (68.5)</td>
<td>37 (20.4)</td>
</tr>
<tr>
<td></td>
<td>Other Asia Pacific</td>
<td>9 (5.0)</td>
</tr>
<tr>
<td></td>
<td>North/South America</td>
<td>5 (2.8)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>6 (3.3)</td>
</tr>
<tr>
<td>Relationship to caregiver</td>
<td>Spouse/partner</td>
<td>Parent/parent-in-law</td>
</tr>
<tr>
<td></td>
<td>107 (59.1)</td>
<td>49 (27.1)</td>
</tr>
<tr>
<td></td>
<td>Sibling</td>
<td>8 (4.4)</td>
</tr>
<tr>
<td></td>
<td>Child</td>
<td>8 (4.4)</td>
</tr>
<tr>
<td></td>
<td>Friend</td>
<td>6 (3.3)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>52 (28.9)</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>34 (18.9)</td>
<td></td>
</tr>
<tr>
<td>Genitourinary</td>
<td>27 (15.0)</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>26 (14.4)</td>
<td></td>
</tr>
<tr>
<td>Gynaecological</td>
<td>15 (8.3)</td>
<td></td>
</tr>
<tr>
<td>Haematological</td>
<td>11 (6.1)</td>
<td></td>
</tr>
<tr>
<td>Skin</td>
<td>6 (3.3)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9 (5.0)</td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>&lt;6 months</td>
<td>42 (23.5)</td>
</tr>
<tr>
<td></td>
<td>6-12 months</td>
<td>29 (16.2)</td>
</tr>
<tr>
<td></td>
<td>1-5 years</td>
<td>63 (36.3)</td>
</tr>
<tr>
<td></td>
<td>&gt;5 years</td>
<td>43 (24.0)</td>
</tr>
</tbody>
</table>

Table 3 shows the Cronbach's $\alpha$ of the 3 identified factors: disclosure, $\alpha=0.52$; limitation of treatment, $\alpha=0.52$; and treatment decision making, $\alpha=0.43$. Regarding concurrent validity (Table 4), CCAT-P and CCAT-F both had strong Pearson correlations with corresponding decision-making (PDMS) scores for patients $(r=0.92, p<0.001)$ and caregivers $(r=0.93, p<0.001)$ respectively. At the emotional level, there was no significant correlation found between the DASS-21, CCAT-P, or CCAT-PF for any of the 3 factors. However, in exploring correlations between patient/caregiver communication and attitudes to ACP, the CCAT-F score showed a weak positive correlation with 'level of confidence in discussion of possible future health care needs/wishes with family members/friends' $(r=0.21, p=0.029)$ and the 'benefits of considering an ACP' $(r=0.19, p=0.044)$. Likewise, a weak positive correlation was found between the CCAT-F and 'distress caused by discussing my family member/s/friend's possible future care health needs/wishes with him/her' $(r=0.216, p=0.023)$ and level of confidence in discussion of possible future health care needs/wishes with health professionals $(r=0.214, p=0.025)$. There were no significant correlations between CCAT-PF and patient/caregiver attitudes towards ACP.

**Discussion and conclusion**

Our study extends the understanding of potential areas of discordant communication between cancer patients and their caregivers, reporting a mean CCAT-PF score of 24.07, which was marginally lower to that reported in the original American study (25.9) [17] and comparable to that reported in a Korean study (23.7) [18]. We confirm the overall disagreement between patient and caregiver reporting of items in the CCAT-PF and reinforce findings that demonstrated the multidimensional nature of dyadic communication across relatively distinct themes. Finally, we describe a three-factor model for the CCAT-PF, achieving sufficient moderate consistency.

A high number of psychosocial variables such as socio-economic variables, ethnicity, and relationship quality are known to affect dyadic concordance in cancer communication [20, 29, 30]. Thus, it is unsurprising that low kappa values (<0.2) were shown in the level of agreement between patient and caregiver reports for the majority of items, indicating disagreement between patient and caregiver in rating each item. Our findings reflect those of Siminoff et al. [17] and Shin et al. [18], with the overall disagreement similar to that reported in the Korean cohort (Spearman's rho 0.18 vs. 0.19) [18]. This confirms the appropriateness of the scale as a measure of discordance [17] and supports the view that overall, families avoid communication around distressing topics [31], regardless of the influence of culture and ethnicity on communication styles and discordance [20, 32].

Four of the five items with the highest absolute difference between CCAT-P and CCAT-F were similar to that found in the Korean cohort [18]. Items of discordance in both studies related to consideration of treatment decisions in financial hardship, prolonging survival despite pain, and tolerating treatment side effects in the context of broader treatment goals and priority towards the treating doctor.
<table>
<thead>
<tr>
<th>CCAT Item</th>
<th>Patient response</th>
<th>Caregiver response</th>
<th>Absolute difference between patient and caregiver</th>
<th>Correlation between dyads</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 My family plays a big role in the decisions I make about my cancer treatment</td>
<td>2.25 (1.64)</td>
<td>2.42 (1.62)</td>
<td>1.48 (1.56)</td>
<td>0.13</td>
</tr>
<tr>
<td>2 I hesitate to mention treatment side effects to my doctors or nurses</td>
<td>5.28 (1.34)</td>
<td>4.75 (1.44)</td>
<td>1.37 (1.47)</td>
<td>0.04</td>
</tr>
<tr>
<td>3 In general, side effects are not really important when I consider my larger goals of treatment</td>
<td>3.08 (1.75)</td>
<td>3.89 (1.61)</td>
<td>1.77 (1.36)</td>
<td>0.14</td>
</tr>
<tr>
<td>4 Medical science may find a cure for cancer so I am willing to take any treatment now to stay alive</td>
<td>2.53 (1.79)</td>
<td>2.69 (1.71)</td>
<td>1.37 (1.39)</td>
<td>0.28</td>
</tr>
<tr>
<td>5 If treatment caused financial hardship for my family, I would not take it</td>
<td>3.61 (1.94)</td>
<td>5.25 (1.35)</td>
<td>2.09 (1.83)</td>
<td>0.08</td>
</tr>
<tr>
<td>6 My family and I have different views about the goal of treatment</td>
<td>5.29 (1.34)</td>
<td>5.4 (1.11)</td>
<td>0.92 (1.36)</td>
<td>0.13</td>
</tr>
<tr>
<td>7 If treatment made me sick every day, I would not take it</td>
<td>3.08 (1.81)</td>
<td>3.04 (1.56)</td>
<td>1.59 (1.44)</td>
<td>0.17</td>
</tr>
<tr>
<td>8 I could see that there could be a point when taking treatment would be worth the discomfort it causes</td>
<td>2.26 (1.32)</td>
<td>2.13 (1.31)</td>
<td>1.22 (1.24)</td>
<td>0.16</td>
</tr>
<tr>
<td>9 I am willing to take treatment that causes me a significant amount of pain if I can live a few months longer</td>
<td>3.47 (1.92)</td>
<td>4.4 (1.69)</td>
<td>1.93 (1.61)</td>
<td>0.12</td>
</tr>
<tr>
<td>10 I value my family's judgement about treatment decisions</td>
<td>1.99 (1.37)</td>
<td>1.98 (1.02)</td>
<td>1.08 (1.15)</td>
<td>0.10</td>
</tr>
<tr>
<td>11 My family's acceptance of my treatment decisions depends on how much they like my doctor(s)</td>
<td>4.44 (1.90)</td>
<td>4.57 (1.69)</td>
<td>1.57 (1.67)</td>
<td>0.17</td>
</tr>
<tr>
<td>12 It is important to base decisions about my cancer treatment on sources of information other than my doctor</td>
<td>4.46 (1.61)</td>
<td>4.40 (1.37)</td>
<td>1.54 (1.34)</td>
<td>0.04</td>
</tr>
<tr>
<td>13 My family does not really listen when I talk about my cancer</td>
<td>5.32 (1.31)</td>
<td>5.55 (1.09)</td>
<td>0.90 (1.37)</td>
<td>0.01</td>
</tr>
<tr>
<td>14 I avoid talking about cancer to my family because I don't want to upset them</td>
<td>4.37 (1.53)</td>
<td>4.93 (1.39)</td>
<td>1.42 (1.35)</td>
<td>0.13</td>
</tr>
<tr>
<td>15 I don't tell my family about my problems because there is nothing they can do to help</td>
<td>4.58 (1.47)</td>
<td>5.22 (1.06)</td>
<td>1.23 (1.24)</td>
<td>0.13</td>
</tr>
<tr>
<td>16 I am frustrated when my family is overprotective of me because of my cancer</td>
<td>4.87 (1.50)</td>
<td>4.83 (1.36)</td>
<td>1.01 (1.12)</td>
<td>0.31</td>
</tr>
<tr>
<td>17 My family blames my cancer on my not having taken better care of myself</td>
<td>5.84 (0.60)</td>
<td>5.76 (0.79)</td>
<td>0.31 (0.78)</td>
<td>0.17</td>
</tr>
<tr>
<td>18 I would feel uncomfortable if the doctor began to talk to me about hospice care</td>
<td>4.72 (1.69)</td>
<td>4.91 (1.50)</td>
<td>1.45 (1.53)</td>
<td>0.10</td>
</tr>
<tr>
<td>19 Family members felt I would not take any treatment if I lived 2 months longer</td>
<td>46.15 (9.76)</td>
<td>45.73 (9.39)</td>
<td>2.47 (7.97)</td>
<td>0.19&quot;</td>
</tr>
</tbody>
</table>

These findings are in keeping with the known direct and indirect financial impact of cancer treatment which attribute to significant family stress [33] and the overestimation of cancer pain and other symptoms by caregivers [34]. Thus, a patient may choose to avoid treatment that may impose financial inconvenience or burden on family, and likewise, a caregiver may find it hard to witness a patient endure suffering with treatment that may cause significant symptoms, despite the opportunity for life prolongation.

High CCAT-P and CCAT-F scores were weakly associated with patient/caregiver confidence and distress related to having difficult conversations on future care planning and strongly associated with patient and caregiver preparation for decision-making. Patients and their loved ones can avoid discussion of prognosis [35] and lack the confidence to initiate dialogue with health practitioners [36] and hence stay away from conversations about end-of-life decisions for fear that these might provoke distress [37]. This general protective about avoiding distress [38] may block important discussions and limit openness to ACP. Despite this, and unlike the findings from the original study, we were unable to show a significant correlation between the CCAT-PF and patient depression and quality of life domain scores. This may suggest that in...
Table 9.3 Scale characteristics for CCAT items

<table>
<thead>
<tr>
<th>CCAT items</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.1 I don’t tell my family about my problems because there is nothing they can do to help</td>
<td>0.65</td>
<td>0.13</td>
<td>0.03</td>
</tr>
<tr>
<td>10 I value my family’s judgment about treatment decisions</td>
<td>0.59</td>
<td>-0.26</td>
<td>-0.50</td>
</tr>
<tr>
<td>15 My family does not really listen when I talk about my cancer</td>
<td>0.57</td>
<td>-0.00</td>
<td>0.20</td>
</tr>
<tr>
<td>14 I avoided talking about cancer to my family because I don’t want to upset them</td>
<td>0.57</td>
<td>0.11</td>
<td>0.01</td>
</tr>
</tbody>
</table>

Scale 2 Limitation of treatment

8.1 Would you feel uncomfortable if the doctor began to talk to me about hospice care | 0.01 | 0.69 | -0.00 |
16 I am frustrated when my family is overprotective of me because of my cancer | -0.08 | 0.67 | 0.08 |
7 If treatment made me sick every day, I would not take it | 0.12 | 0.51 | 0.22 |

Scale 3 Treatment decision making

6.1 My family and I have different views about the goal of treatment | 0.20 | -0.07 | 0.66 |
12 It is important to base decisions about my cancer treatment on sources of information other than my doctor | 0.24 | 0.25 | 0.58 |
11 My family’s acceptance of my treatment decisions depends on how much they like my doctor(s) | 0.22 | -0.09 | 0.57 |
9 I am willing to try treatment that causes me a significant amount of pain if I can live a few months longer | -0.27 | 0.13 | 0.52 |
1 My family plays a big role in the decisions I make about my cancer treatment | 0.53 | -0.07 | 0.04 |
2 I hesitate to mention treatment side effects to my doctor or nurses | 0.36 | 0.07 | 0.15 |
3 In general, side effects are not really important when I consider my larger goals of treatment | -0.18 | 0.17 | 0.17 |
4 Medical science may find a cure for cancer so I am willing to take any treatment now to stay alive | 0.17 | -0.27 | 0.05 |
5 If treatment caused financial hardship for my family, I would not take it | -0.05 | -0.22 | 0.24 |

Items excluded due to severe skewness
17 My family blames my cancer on my not having taken better care of myself

Eigen value | 2.24 | 1.83 | 1.44 |
Cronbach’s α | 0.53 | 0.53 | 0.43 |
Explained variance | 13.2% | 10.8% | 8.5% |
Total variance | 33.5% |

the Australian setting, it may not be presence of mood disorders such as depression and quality of life issues as such that contributes to discordance in communication, but more so a possible avoidance of conversations that are perceived to potentially cause distress [39]. Our factor analysis demonstrated a 3-factor structure for 12 of the 18 original items, based on a principal components factor analysis scree plot and Kaiser-Guttman criteria. We partially reproduced, with some variations in items, the disclosure and limitation of treatment scales and achieved a reasonably similar internal consistency in the disclosure scale as demonstrated by Haan et al. (α = 0.66 vs. α = 0.53) [19], and allowing for the diversity of themes being assessed, the overall reliability of the subscales is reasonable. Strong concurrent validity is demonstrated with a measure of decision-making. Our cohort representation of autonomous and reasonably well-educated patients with financial means may explain why some of the items in the original scale (1–5) may have resonated less with this study population and not loaded well onto factors evident here.

This study has several limitations. Firstly it was conducted in a single location, with a relatively affluent population with high literacy thus affecting generalizability within the broader Australian setting. Secondly, this was a sub study of a larger RCT [21, 22], and we were limited in the assessment of validity with more specific instruments than if we had planned this as a primary validation study. Finally, we did not follow up the CCAT longitudinally, which may have demonstrated more specifics of communication patterns over time in a cancer population.

Conclusion

There has been a dearth of measures of the concordance of communication between patient and caregiver, yet such communication is critical to care planning and
### Table 7.8 Concurrent validity of Cancer Communication Assessment Tool

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th></th>
<th>Caregivers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CCAT-P</td>
<td>CCAT-PF</td>
<td>CCAT-F</td>
<td>CCAT-PF</td>
</tr>
<tr>
<td><strong>Preparation for decision making</strong></td>
<td>0.915*</td>
<td>-0.07</td>
<td>0.929*</td>
<td>-0.07</td>
</tr>
<tr>
<td><strong>DASS-21</strong></td>
<td>-0.137</td>
<td>0.066</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>-0.085</td>
<td>0.135</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>-0.097</td>
<td>0.046</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Stress</strong></td>
<td>-0.108</td>
<td>0.076</td>
<td>0.094</td>
<td>0.095</td>
</tr>
<tr>
<td><strong>Atitudes to advance care planning</strong></td>
<td>-0.033</td>
<td>-0.046</td>
<td>0.112</td>
<td>0.015</td>
</tr>
<tr>
<td>Rating my current understanding of ACP</td>
<td>0.025</td>
<td>-0.17</td>
<td>0.147</td>
<td>0.092</td>
</tr>
<tr>
<td>Satisfaction with opportunity to consider my/my family member or friends possible future health care needs and wishes with health care professionals</td>
<td>0.092</td>
<td>-0.064</td>
<td>0.216*</td>
<td>-0.009</td>
</tr>
<tr>
<td>Distress caused by thinking about my/my family member or friends possible future health care needs and wishes if I become unwell</td>
<td>0.040</td>
<td>0.0002</td>
<td>0.159</td>
<td>0.017</td>
</tr>
<tr>
<td>Distress caused by discussing my/my family member or friends possible future health care needs and wishes with others/him or her</td>
<td>0.169</td>
<td>0.0308</td>
<td>0.214*</td>
<td>0.133</td>
</tr>
<tr>
<td>Importance of making and informing others about decisions related to my/my family members' or friend's possible future health care needs and wishes</td>
<td>0.209**</td>
<td>-0.147</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Level of confidence in discussion of my/my family members’ or friend’s possible future health care needs and wishes with health professionals</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Level of confidence in discussion of my possible future health care needs and wishes with family members/friends</td>
<td>0.192**</td>
<td>-0.155</td>
<td>0.183</td>
<td>-0.015</td>
</tr>
<tr>
<td>Benefit of considering my advanced care plan</td>
<td>0.030</td>
<td>0.003</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Importance of considering advanced care planning when living with a cancer diagnosis</td>
<td>0.133</td>
<td>0.015</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

* (p < 0.001)  
** (p < 0.05)  
*Questions completed in the RCT by patients only

---

8.4 decision-making at the end-of-life. Our preliminary validation of the CCAT-PF in the Australian setting has demonstrated some similar psychometric properties as in previously published studies. We perceive that this early Australian-based refinement of the CCAT offers an opportunity for its further refinement to confirm its utility as a reliable tool to assess dyadic communication and understand its impact. It paves the way for further research on how we evaluate communication in the clinical setting and improve outcomes for families as a unit of care.

**Supplementary Information** The online version contains supplementary material available at https://doi.org/10.1007/s00520-022-07163-7.

**Acknowledgements** The authors acknowledge Nerida Morton and Adelaide Melia and the staff of the Department of Palliative and Supportive Care who assisted with the study and the patients and families who willingly participated.

**Author contribution** NM and DK designed the initial study; NM led statistical analysis with assistance from AG, EF, and DK. NM, MS, PT, and KH led recruitment; NM wrote the initial manuscript, and all authors approved the final manuscript. NM is responsible for the overall content as guarantor.

**Funding** Open Access funding enabled and organized by CAUL and its Member Institutions. This research was funded by the Bethel Research Foundation Grant (Grant No 1709) and the Calvary Foundation Medical Oncology Research Grant.

**Availability of data and material** Calvary Palliative Care Research Department retains primary control of the data presented in this manuscript. Data may be made available for external review if permission is obtained.

**Declarations**

**Ethics approval** Ethical approval was granted by the institution’s Health Research Ethics Committee: RIS-20-0000-112C.

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

**Consent for publication** Not applicable.
Competing Interests: The author declares no competing interests.

Open Access: This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made. The images or other third-party material in this article are included in the article's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this license, visit http://creativecommons.org/licenses/by/4.0/.

References

8.4 SUMMARY AND CONCLUSION

This empirical paper was undoubtedly the most challenging for me to complete as it introduced me to a new methodological approach that I was unfamiliar with. In completing this paper and data analysis, I developed specific analytical skills in seeking correlations between scales and examining agreements between scale items. I also appreciated the use of exploratory principal component factor analysis and the concurrent use of the scree plot and Kaiser-Guttman criteria.

My findings confirm the ongoing challenges faced internationally by clinicians when introducing distressing topics. Patients and caregivers continue to demonstrate discordance in symptom tolerance, acceptance of financial burden and treatment side effects. Much of this may be attributed to the multidimensional nature of dyadic communication. Achieving triadic concordance in communication between patient, caregiver and clinician is the aspired ideal but far from an achievable reality.

My analysis proposed a three-factor solution for the CCAT, with the disclosure scale and limitation of treatment scale sharing some similar psychometric properties as a German validation study. However, our three-factor solution showed only moderate internal consistency, suggesting instability of the CCAT. Concurrent validity was most strongly associated with preparation for decision-making scores for patients and caregivers but limited in other areas due to the lack of use of validated scales. Significant bias may have been introduced with the cohort of patients selected for this validation study, as they comprised a highly literate and predominantly affluent population.

Ideally this validation work should have been completed prior to the RCT. It would have confirmed the limited psychometric properties of the CCAT-PF. However, this occurred as an incidental piece of work following the completion of the RCT. This early work calls for more robust studies to examine patient-caregiver congruence in communication longitudinally in the cancer population throughout the illness trajectory. Currently, the CCAT remains the only tool available to measure discord, and its unstable psychometric properties limit its promotion as a robust research tool. Nonetheless, there is potential for the disclosure scale, confirmed as the most reliable in our study and a corresponding German study, to be used as an independent subscale when exploring congruence. However, the low Cronbach α
values have to be taken into consideration when considering the appropriateness of this. This undoubtedly impacts the results of the RCT due to the low to moderate Cronbach α’s found in the validation study. The improvement in concordance should thus be interpreted with some degree of caution.’

Families as a unit remain central to decision-making as a patient's health deteriorates. In seeking value alignment and concordance, we offer opportunities to alleviate relationship strain and discord and address fears and concerns promptly and appropriately.
CHAPTER NINE

INTEGRATED GENERAL DISCUSSION
CHAPTER NINE

9.1 INTEGRATED GENERAL DISCUSSION

The Institute of Medicine defines patient-centeredness as "care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions". Thus, understandably, the choices we make as we face a serious illness such as cancer relate to our most deeply held values. Patients with an awareness of their values are likely to understand themselves in relation to their decisions, make decisions that they can live with, and be confident that they have gone as far as they are comfortable in making sense of the issues and assuming responsibility for what follows. Clinicians can aid patients in making overt their values to sustain their sense of integrity and thus enrich care.

However, when faced with a cancer diagnosis, decision-making and care planning are complex, and an emphasis is now placed on greater patient and caregiver involvement in decision-making. Cancer is also a family experience. Encouraging patients and families to reflect on their values promotes awareness of what matters, enables meaningful decision-making, and supports cancer-caregiver dynamics, coping, adjustment and psychological wellbeing. The emphasis now placed on ACP in cancer as a means to ascertain patients' wishes in circumstances where they cannot articulate them due to a loss of capacity has been a further initiative to drive values-based care. Elucidating ACP enhances desirable EOL outcomes, including patient-caregiver confidence, satisfaction, quality of death and family bereavement experiences. Contemporary views have shifted from planning focused solely on treatment decisions to having values-based EOL conversations, surrogate decision-maker preparation and motivating patients to actualise ACP through innovative interventions.

There are several well-recognised barriers to the adoption of ACP in cancer. Many patients lack prognostic awareness, and some employ denial as a coping mechanism. Many fail to appreciate that they may need a surrogate decision-maker later in their illness. Families are also protective and discourage the patient from having too gloomy a discussion, in the process missing the chance to understand their relative's attitudes and values more fully as they might apply to their care provision. There will also be administrative and instrumental barriers involved in
the format of an ACP document. Building therefore on the past decade's research into ACPs conducted by my clinical team, I set out here to use a decision support tool to promote the use of ACPs by patients and their caregivers.

This final chapter briefly reiterates the aims and rationale for the thesis and presents an integrative synthesis of the findings and their clinical relevance.

9.2 SUMMARY OF THESIS AIMS

This thesis presented research findings related to the development of an RCT, its execution and subsequent sub-studies utilising qualitative methodology and psychometric analysis. The overall aim was to extend our knowledge of ACP in cancer patients. I chose to build on previously completed research that confirmed the utility of the VT in ACP. In this instance, I sought to convert the written vignettes to video vignettes and focus on values conversations between patient-caregiver dyads, showing the video to participants as a video decision support tool (VDST).

The utility of VDSTs in ACP has been proven, with most interventions completed in the North American setting focusing on futile EOL interventions such as cardiopulmonary resuscitation and intubation/ventilation. By promoting value awareness and congruence, we sought to motivate patients to understand themselves in relation to their decisions, make decisions they are comfortable with, and assume responsibility for outcomes. We used the completion of an ACP as a surrogate measure of this outcome in our RCT, exploring further the nuances of experiences in our qualitative analysis. The improvement of concordance in communication as a secondary outcome of the RCT as a result of an ACP intervention (regardless of UC or VDST) triggered my interest in exploring the psychometric validity of the CCAT in the Australian setting.

9.3 OVERVIEW AND SYNTHESIS OF MAIN FINDINGS

ACP aims to ensure patients receive medical care consistent with their values, goals, and preferences, with caregivers and family members recognised as necessary parties in decision-making. As previously reported in Chapter two, ACP is now a quality indicator in cancer care, with recommendations for clinicians to engage in conversations early. Nonetheless, the challenge of ACP remains as to how best to maintain hope in the face of poor outcomes, who is best to instigate discussions,
and how to ensure that care is delivered in accordance with a patient or family member's wishes.\textsuperscript{21}

We sought to expand on previous research undertaken using the VT. Short video clips were developed to demonstrate values conversations between patient-caregiver dyads and presented to participants within the intervention arm of the RCT.

Based on the simple principle of modelling, those exposed to such conversations might appreciate the value of ACP and, thus complete documentation. We did not achieve the primary outcome but highlighted that this model might be more suited to an older cancer patient with greater value coherence attained through life maturity.\textsuperscript{22} We confirmed the distress generally elicited by ACP but showed the benefit of increased caregiver confidence in having conversations with health professionals and improved understanding of ACP.

An ACP now importantly constitutes a VD whereby patients articulate their desires for EOL contingencies. In the qualitative study, I explored the phenomenon that arose as patients contemplated the effects of their illness on their capacity to function and their desires for the future.\textsuperscript{23} The conflicting stances of vulnerability and resilience indicate the transformative ability of human capacity and point to the clinician's role in facilitating adaptations to illness and suffering.

Finally, I explored the psychometric qualities of the CCAT-PF questionnaire, confirming its role as a measure of discordance and appreciating the challenges involved in designing and validating such a tool.\textsuperscript{24} Areas of discordance corresponded to universal areas of family conflict that are well described in the literature. Below, I produce a short synopsis of each published paper.

9.3.1 Protocol Paper: The rationale for publishing this paper was to outline the steps I undertook in designing the RCT. The decision to undertake this study was based on the evidence of the benefits of VDSTs in ACP, as described in Chapter two. There were key considerations involved in the development of the study. First was the use of video vignettes, the second was the inclusion of patient-caregiver dyads, and finally, to ensure that outcomes measures reflected those used in the previously published feasibility study and other untested outcomes such as congruence in communication, as measured by the CCAT.

I had previously confirmed that the written vignettes provided an avenue to promote values conversations and were acceptable when presented to patient-caregiver dyads as the participatory unit in a study. Modification of the vignettes
depicted conversations across three longitudinal stages of the cancer trajectory, discussing a variety of values conversations and encouraging several potential outcomes (Table 4.2). The manipulation of scenarios depicting conversations across relationships, ages and scenarios provided some generalisability of the depictions to increase the likelihood of identification with the conversation being modelled.

This RCT was designed as an open-label trial as it was impossible to blind for the intervention. The study procedure was outlined, determining the primary (completion of ACP) and secondary outcomes (attitudes towards ACP, congruence in communication, preparation for decision-making) and points for outcome assessments. I defined UC and intervention (VDST) and determined the recruitment and consent process. Statistical assistance was sought to aid with sample size calculation and the process for randomisation. I described in detail the method of data collection and the developed or validated tools used to measure the outcomes pre and post-UC and VDST (Table 4.3). Finally, I provided details of the quality standards in place: facilitator training, distress management, data monitoring and confidentiality, and the study limitations.

9.3.2 Empirical Study One: The rationale for this first empirical study was to evaluate the effectiveness of video vignettes used as a VDST to model values-based ACP conversations between cancer patient-caregiver dyads and facilitate congruence in patient-caregiver communication. Our VDST intervention had no impact on the primary outcome, with just over a third of participants completing an ACP in both arms. This figure is in keeping with other published ACP intervention studies. Understandably, the recruitment diagram (Figure 5.2) confirms the challenges faced universally in palliative care around participant recruitment and attrition.

ACP documentation was greater in those aged ≥70, which is understandable considering the reflective maturity of ageing and the resultant openness to accept the finitude of life. Nevertheless, watching the videos evoked patient distress as dyads witnessed the reality of our human mortality and anticipated their deaths. Communication about EOL issues not uncommonly evokes distress. Some expression of such grief and distress is an inescapable dimension of the predicament being faced; it might be deemed a process of adaptive coping. Nonetheless, caregivers, in particular, benefited from an improved understanding of ACP,
opportunities to consider ACP and preparedness for decision-making with health professionals across both arms.

This study's most novel but the unsurprising finding was the improvement in concordance in communications across both arms, with improvements occurring with age. These findings highlight the opportunity that ACP provides to communicate more openly about poignant EOL issues and confirms the limitations that arise with a singular focus on document completion as an outcome.

9.3.3 Empirical Study Two: In this paper, I was interested in examining the diversity of values, experiences, and adaptations expressed by cancer patients in their value directives. The analysis of the forty-two completed VDs occurred through qualitative phenomenological content analysis and the use of NVivo qualitative analysis software\textsuperscript{27} to explore the lived experience of participants.

Overall, the finding of these studies provided insights that still needed to be addressed in previous publications. The empirical focus on ACP and its applicability to treatment limitations needed to have appreciated the deeper subtleties that arise in discussion or documentation. The descriptions of adaptability, caregiver reliance and reciprocity, death anxiety and ambivalence, and reliance on the spiritual and sacred have been well described in the literature. The distinctive contribution of this publication was the account of opposing yet complementary stances of vulnerability and resilience, describing diverse approaches to adjustment and coping. Family and friendship bonds enabled the expression of benevolence and trust and the reciprocation of care. As patients sought to make meaning and cope with the predicament of growing frailty and closeness to death, they oscillated between expressions of vulnerability and resilience, making explicit the opportunity for clinicians to support their strengths and foster adaptation in the process. A well-considered VD may instigate more mature patient-clinician decision-making that better enables the experience of a good death.

9.3.4 Empirical Study Three. The decision to proceed with the final empirical paper arose from an opportunity realized as we analysed the data from the primary RCT. The use of the CCAT has not been widespread, possibly due its unstable psychometrics or a limited appreciation of the importance of a measure of discordance as an outcome in interventions. Further validation studies in Germany\textsuperscript{28}
and Korea followed the initial psychometric work on the CCAT by Siminoff and colleagues.

We confirmed the functionality of the CCAT as an instrument to measure discordance by demonstrating overall disagreement between patient and caregiver reporting of items (Spearman’s Rho 0.18). Our mean CCAT-PF score was comparable to what has been reported internationally. These findings of discordance are unsurprising, considering the numerous variables that affect the coherence of dyadic relationships and the universal phenomenon of families avoiding communication around distressing topics. Areas of conflict relate to the financial impact of treatment, caregivers' perception of poorly controlled symptoms and avoidance of communication on prognosis. A stance of protectiveness is taken to avoid distress.

The subsequent factor analysis confirmed a 3-factor structure for 12 of the 18 original items and partially reproduced Haun's disclosure and treatment limitations scales in the German CCAT-PF study. However, our measure of the internal consistency of each of the described scales was only moderate, as measured by Cronbach α. Nonetheless, both patient and caregiver measures (CCAT-P and CCAT-F) showed strong concurrent validity with preparation for decision-making.

This Australian validation of the CCAT-PF highlights the importance of a measure of discordance, but questions remain as to the stability of the scale and its potential utility.

9.4 KEY FINDINGS FROM THE THESIS AND INTEGRATION WITH BROADER LITERATURE

In the following Table 9.1, I have highlighted the key findings that have arisen from this body of scholarship:
Table 9.1: Key findings from this thesis

1. The process of ACP provides an opportunity to stimulate communication about personal values that benefit the patient and their caregiver/family.
2. Videos depicting values conversations may increase ACP uptake in older patients.
3. Distress elicited by ACP should not be viewed negatively but can be understood not only as grief at illness but also oscillation between inherent vulnerability and adaptations based on resilience.
4. Promoting patient disclosure of concerns and vulnerability may assist communication and cohesion with family and caregivers.

Our quantitative outcomes simply acknowledge the uptake of ACP, it’s potential to cause distress and the possible benefit in achieving concordance. Statistical analysis does not lend itself to a deeper understanding of a patient’s experience of illness, even if objective measures of frailty and dependence are used as outcome measures. The use of qualitative methodology allowed for acknowledging frailty and dependence, appreciating benevolent care from family, expressing gratitude for the life lived and using rituals to honour and celebrate life that help patients move towards courageous acceptance of life's closure.

Our failure to achieve the primary outcome and the distress caused by ACP is in keeping with other national and international published studies. An Australian multisite RCT of an ACP intervention in patients with advanced cancer involved cancer-caregiver dyads and had a recruitment rate of 47% compared ours of 60.4%. It also failed to achieve the primary outcome of an EOL care that was consistent with patient preference. However, a systematic review of the efficacy of ACP interventions found more consistent evidence that ACP interventions improve proximal patient outcomes including quality of patient–physician communication, preference for comfort care, decisional conflict and patient-caregiver congruence in preferences.

In considering the results of the RCT in conjunction with the qualitative and validation study, the question arises as to how to incorporate key findings into future interventions and what outcomes best capture value alignment and concordance. If the MRC framework was to be considered as the overarching research framework for future studies, then further refinement of the current intervention is required,
considering context and underlying theory and stakeholder perspectives. Appropriate study design is important to capture the above and may include quasi experimental designs.

9.5 STRENGTHS AND LIMITATIONS OF THE RESEARCH

A significant strength of this body of work was the use of the MRC framework to explore the research area of ACP in cancer dynamically and iteratively. We have progressed from early exploratory work to feasibility and confirmatory studies (Appendix A-E). The RCT established the feasibility of using a VDST in an Australian setting, with a recruitment rate of 60.4%. Our studies posed several questions and we established several areas for future research: 1. future ways to explore EOL values, including the potential use of Question Prompt Lists (QPL) based on evidence showing the benefits of QPLs; 2. interventions to explore and improve patient-caregiver concordance in communication considering the paucity of research in this area; 3. interventions to recognise and enhance resilience in cancer patients to enable ways to transcend and overcome challenges.

The three empirical studies had several limitations. The RCT was conducted at a single site. The cohort of patients was from an area with high literacy, reasonable affluence, and limited racial diversity. Additionally, patients were recruited across tumour streams, stages of illness and diagnosis. All the above limits the generalisability of the findings. Participants from both arms of the RCT could have inadvertently been prompted to return the questionnaire and ACP documents due to the need for a precise script.

In the qualitative study, coding was undertaken by a single researcher, thus adding an element of subjectivity to the findings. A trade-off was accepted between the individuality of a doctoral scholar needing relatively independent work and the more usual team scholarship that can occur.

As the third empirical paper examining the psychometric properties of the CCAT was a sub-study of the RCT, I was limited in assessing the concurrent validity of the CCAT as the project was not designed with psychometric assessment in mind. Serendipitous studies arise from much scholarship. Finally, I did not explore prognostic awareness in participants, which may have impacted the studies' findings.
9.6 IMPLICATIONS FOR CLINICAL PRACTICE

ACP interventions can improve motivation to undertake difficult discussions through the clinician's ability to steer the conversations towards a focus on individual values. Using circular questioning styles, family meetings may identify areas of discord. Clinicians facilitate open but difficult conversations on prognosis, treatment limitations and EOL planning with patients and family members/caregivers. Getting them to articulate their views allows clinicians to address the issue of avoidance commonly occurring in ACP conversations. Critically aligning treatment and care plans with articulated values will achieve meaningful outcomes.

Future implementation studies suggest ways to incorporate videos on values conversations between dyads into routine clinical encounters in infusion rooms, ambulatory clinics, or community nursing visits. This is in keeping with recommendations for ACP to be addressed right through the cancer trajectory. Clinicians may choose to address different components at different times, with the appointment of a surrogate decision maker occurring early in infusion rooms and more complex discussions regarding prognosis and end-of-life wishes occurring in the ambulatory setting or during community visits. Clinicians may choose to address different components at different times, with recognition of key transition points of illness, such as failure or withdrawal of treatment or a severe complication of either cancer or its treatment, may suggest the appropriate time for a clinician to explore readiness for such ACP conversations. The qualitative study findings suggests areas for a clinician to focus on in conversation to enable patients to realign their values and priorities. Patients could be encouraged to allow family involvement in care to promote benevolence and reciprocity, to consider the use of sacred and secular rituals to facilitate acknowledgement of the rite of passage and appreciate the concurrent ability to be dependent and yet maintain independence. These recommendations may assist with the more gradual introduction, thus reducing distress and allowing for engagement with younger cancer patients.

The scalability of these findings and approach to promote ACP are worth further consideration. It requires consideration the variabilities within other populations, including culture, diagnosis, sociodemographic factors, and health literacy. The video methodology may not be acceptable to some, and individual or personal values may be considered differently. Despite this being a negative study, clinicians should be
encouraged to consider the video vignette model and focus on values discussions based on other published evidence that support the use of this approach in ACP.

**9.7 FUTURE RESEARCH DIRECTIONS**

Despite not achieving the primary endpoint, and concerns re the psychometric stability of the CCAT-PF and thus the reliability of the measure of congruence, we established several areas for future research. Our studies posed several questions. Firstly, following the finding of our RCT that showed greater engagement in ACP in older cancer patients, it would be useful to consider how to best encourage value reflection and ACP completion in younger cancer patients. Additionally, we could consider how we can appropriately depict the opposing existential postures found in the qualitative study in future videos. Secondly, our psychometric study validating the CCAT poses the question as to how concordance in communication is measured ideally, and how do we evaluate dyadic communication throughout the cancer trajectory. Thirdly, our qualitative study suggests that we should consider what indicators to suggest to a clinician that the patient or caregiver has attained adequate maturity to engage in meaningful ACP and EOL discussions? Fourthly, it may be worth considering additional outcome measures such as satisfaction with the intervention, reduction in anxiety, improved family communication and decision conflict and the measure of values using measures such as the Portrait Values Questionnaire. Finally, might combining decision aids (e.g., videos, question prompt lists, information sheets) enhance understanding and collaboration between the physician and patient to optimise care provision and would alternative trial designs such as quasi-experimental design or block randomisation provide better outcomes?

Our first consideration has been to explore the role of Question Prompt Lists (QPL) in enhancing patient-caregiver value awareness. Question Prompt Lists are structured lists of questions to encourage patient or caregiver question-asking during consultations with clinicians. QPLs have aided the facilitation of patient-clinician communication and, to date, have focused on topics primarily related to diagnosis, treatment and care options. However, for the patient and caregiver, the burden of illness encompasses various dimensions of quality of life, including emotional,
cognitive and existential concerns. As such, the scope of planning care for those who are seriously unwell requires a shift from a focus purely on a clinical decision to the reflection and enactment of personal values. This ultimately ensures the delivery of person-centred care.

We have recently completed the development and pilot testing of the first known Values QPL to enhance patient and caregiver value awareness. By using appropriate research methods, we should be able to demonstrate the success of this innovative instrument in promoting value awareness for meaningful discussions and decision-making. The results of this pilot study are beyond the scope of this thesis.

The decision to engage in a QPL intervention and the choice of questions asked by a patient indicate readiness for ACP conversations and provide an opportunity for a clinician to address patient and caregiver queries together to promote dyadic congruence. The QPL may be used on an ongoing basis through the trajectory of illness to allow for more confronting questions to be addressed at the appropriate time, allowing for the patient or caregiver to maintain control over the extent of information they were ready to receive.

Finally, given that the CCAT has yet to show robust psychometric properties to support its use as an ongoing measure of congruence, there is more work to refine and validate such a measure to enhance this clinical objective within this sphere of care provision.

9.8 CONCLUDING REMARKS
This thesis presents the first of a series of studies examining the use of a VDST in an ACP intervention within an Australian setting. My presented papers are novel in their description of the development of video vignettes that focus on conversations about personal values in EOL deliberations. This scholarship points to the challenges of discordance in communication and its impact on achieving value orientation, particularly in younger cancer patients. It reminds us of the unique human capacity for transformation, adjustment and adaptation in the face of vulnerability. These findings have instigated early research on complementary methods to engage dyads in early ACP conversations through developing and piloting a Values QPL.
The attainment of value awareness in a cancer patient requires adequate cognitive mastery over all relevant issues at hand, accepting responsibility for choices made and the trade-offs among all possible outcomes. Clinicians share the responsibility of recognising and facilitating patient-caregiver maturity in engaging in ACP in the timing and manner that suits everyone.

9.9 REFERENCES FOR CHAPTER NINE


27. NVivo qualitative data analysis software; QSR International Pty Ltd. Version 12, 2018.


REFERENCES FOR THE ENTIRE THESIS


8. Bakitas MA, Dionne-Odom JN, Jackson L, Frost J, Bishop MF, Li Z. “There were more decisions and more options than just yes or no”: Evaluating a decision aid for advanced cancer patients and their family caregivers. Palliat Support Care 2017;15(1):44-56.

REFERENCES


REFERENCES


41. Curtis JR, Back AL, Ford DW, Downey L, Shannon SE, Doorenbos AZ, et al. Effect of communication skills training for residents and nurse


REFERENCES


REFERENCES


REFERENCES


REFERENCES


Cancer Communication Assessment Tool in an Australian sample. Support Care Cancer 2022;30(9):7387-96.


135. NVivo qualitative data analysis software; QSR International Pty Ltd. Version 12, 2018.


planning in community-dwelling older persons (the STADPLAN study)—study protocol. Trials 2020;21(1):653.


REFERENCES


APPENDIX A

Support Care Cancer (2013) 21:2: 95-23205
DOI 10.1007/s00520-013-1779-6

ORIGINAL ARTICLE

Understanding how cancer patients actualise, relinquish, and reject advance care planning: implications for practice

Natasha Michael · Clare O’Callaghan · Josephine Clayton · Annabel Pollard · Nikola Stepanov · Odette Spruyt · Michael Michael · David Ball

Received: 18 October 2012 / Accepted: 25 February 2013 / Published online: 14 March 2013
© Springer-Verlag Berlin Heidelberg 2013

Abstract
Purpose: Although advance care planning (ACP) is recognised as integral to quality cancer care, it remains poorly integrated in many settings. Given cancer patients’ unpredictable disease trajectories and equivocal treatment options, a disease-specific ACP model may be necessary. This study examines how Australian cancer patients consider ACP. Responses will inform the development of an Australian Cancer Centre’s ACP programme.

Methods: A constructivist research approach with grounded theory design was applied. Eighteen adults from lung and gastro-intestinal tumour streams participated. Participants first described their initial understanding of ACP, received ACP information, and finally completed a semi-structured interview assisted by the vignette technique. Qualitative inter-rater reliability was integrated.

Results: Participants initially had scant knowledge of ACP. On obtaining further information, their responses indicated that: for cancer patients, ACP is an individualised, dynamic, and shared process characterised by myriad variations in choices to actualise, relinquish, and/or reject its individual components (medical enduring power of attorney, statement of choices, refusal of treatment certificate, and advanced directive). Actualisation of each component involves considering, possibly conversing about, planning, and communicating a decision, usually iteratively. Reactions can change over time and are informed by values, memories, personalities, health perceptions, appreciation of prognoses, and trust or doubts in their substitute decision makers.

Conclusion: Findings endorse the value of routinely, though sensitively, discussing ACP with cancer patients at various time points across their disease trajectory. Nonetheless, ACP may also be relinquished or rejected and ongoing offers for ACP in some patients may be offensive to their value system.

N. Michael (✉)
Department of Pain and Palliative Care, Peter MacCallum Cancer Centre, Peter Mac, Locked Bag 1, A’Beckett Street, Victoria, VIC 800, Australia
e-mail: natasha.michael@petermac.org

C. O’Callaghan · O. Spruyt
Department of Pain and Palliative Care, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia

C. O’Callaghan
Department of Oncology, The University of Melbourne, Melbourne, VIC, Australia

C. O’Callaghan
Department of Medicine, The University of Melbourne, Melbourne, VIC, Australia

J. Clayton
HannahCare Palliative and Supportive Care Service, Sydney, NSW, Australia

J. Clayton
University of Sydney, Sydney, NSW, Australia

A. Pollard
Department of Psychology, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia

N. Stepanov
School of Population Health and Melbourne Medical School, The University of Melbourne, Melbourne, VIC, Australia

M. Michael
Department of Cancer Medicine, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia

D. Ball
Department of Radiation Oncology, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia
Original Article

Cancer Caregivers Advocate a Patient- and Family-Centered Approach to Advance Care Planning

Natasha Michael, MBChB, FACHPM, MRCPI, MRCGP, MSc,
Clare O’Callaghan, PhD, RMT, Angela Baird, RN (BSc Hons), PGD Adv Clin Pract,
Nathaniel Hiscock, AMusA, and Josephine Clayton, MBBS, PhD FRCGP, FACHPM
Department of Pain and Palliative Care (NM, C.O., A.B.), Peter MacCallum Cancer Centre,
Melbourne, Victoria; Departments of Oncology and Medicine (C.O.), The University of Melbourne,
Melbourne, Victoria; Faculty of Medicine, Nursing and Health Sciences (N.H.), Monash University,
Melbourne, Victoria; Hammond Care Palliative and Supportive Care Service (C.O.), Greenwicht
Hospital, and Sydney Medical School (J.C.), University of Sydney, Sydney, New South Wales, Australia

Abstract

Context. Cancer caregivers have important roles in delivering practical, emotional, and end-of-life support to patients; however, they express multiple unmet needs, particularly information on future care planning. Early regular communication and decision making may improve access to timely information, alleviate anxiety, reduce uncertainty, and improve coping strategies.

Objectives. This study examines how cancer caregivers view advance care planning (ACP) to inform an ACP program in an Australian cancer center.

Methods. This study used a qualitative descriptive design with grounded theory overtones. Eighteen caregivers of patients from lung and gastrointestinal tumor streams participated in focus groups or semistructured interviews, which incorporated the vignette technique.

Results. Caregivers believe that, although confronting, ACP discussions can be helpful. Conversations are sometimes patient initiated, although caregivers may intend to sensitively broach conversations over time. Findings highlight the impact of caregiver hierarchies, adaptive family decision-making styles, and complex cultural influences on decision making. Some caregivers may develop subsidiary care intentions, based on “knowing” or overriding patients’ desires. Hindrances on caregivers supporting patients’ ACPs include limited information access, patient or caregiver resistance to engage in conversations, and ACPs association in oncology with losing hope. Many caregivers wanted professional support and further opportunities to obtain information, develop subsidiary plans, and help patients engage in ACP discussions.

Conclusion. Findings highlight the influence of cancer caregivers and family dynamics over ACP decisions and actualization of future care plans. A patient- and
APPENDIX C

Exploring the utility of the vignette technique in promoting advance care planning discussions with cancer patients and caregivers

Natasha Michael1,2,3, Clare O’Callaghan4,5, Josephine M. Clayton6,7

1 Palliative Care Service, Cabrini Health, Melbourne, Australia
2 Faculty of Medicine, Nursing and Health Sciences, Monash University, Melbourne, Australia
3 Peter MacCallum Cancer Centre, Melbourne, Australia
4 St Vincent’s Hospital, University of Melbourne, Melbourne, Australia
5 HammondCare Palliative and Supportive Care Service, Greenwich Hospital, Sydney, Australia
6 Sydney Medical School, University of Sydney, Sydney, Australia

ARTICLE INFO

Article history:
Received 28 September 2015
Received in revised form 26 January 2016
Accepted 19 March 2016

Keywords:
Advanced care planning
Qualitative research
Secondary analysis
Cancer

ABSTRACT

Objective: We aimed to specifically examine patients’ and caregivers’ perspectives about the use of the vignette technique (VT) integrating clinical scenarios, as a potential tool for facilitating advance care planning (ACP) discussions.

Methods: Secondary analysis of data from three studies that incorporated the VT, focusing on statements specific to use of the VT and using a qualitative descriptive design informed by grounded theory.

Results: Data from 85 participants were analyzed. Participants varied in their personal identification with scenarios, with caregivers being more accurate. Scenarios prompted consideration and participation in ACP discussions, sometimes steering conversations in directions that participants were ready to consider. However, scenarios also raised evolving distress in participants who may have chosen to avoid discussions.

Conclusions: For some patients, scenarios of possible clinical outcomes may provide a neutral platform to promote ACP conversations in a non-threatening manner and allow for exploration of ACP domains to greater depth.

Practice implications: Vignettes may be used in staff training through role-play or case discussions; as part of face-to-face interventions to improve knowledge and information processing and to facilitate the initiation of sensitive conversations. Their use in audio-visual formats may further enhance end-of-life dialogue and warrants further consideration.

© 2016 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

Despite advances in cancer treatment and survivorship, fear and stigma associated with cancer diagnoses remain [1]. For patients and caregivers facing cancer diagnoses, phases of disease progression involve comprehension of complex treatment options, irrespective of whether one has understood the diagnosis [2]. Numerous communication goals in advanced non-curable cancer include discussions about prognosis [3], experimental or palliative treatment limitations [4] and need for intensive palliative care support as patients approach end-of-life (EOL) [5]. Empathetic and meaningful conversations are needed, enabling patient and caregivers to maintain morale, quality of life and adaptive coping strategies [6]. Honesty and hope is required to ensure treatment cessation is not associated with professional abandonment [7], alongside appropriate judgement on how, when and where to initiate ACP [8].

Increasingly, advance care planning (ACP) is advocated in cancer care to ensure patients’ values and EOL goals are considered early [9]. ACP includes discussions about interventions to be considered in life limiting circumstances, the appointment of a substitute decision maker, and EOL contingencies such as preferred place of care and spiritual or religious considerations [10]. An ACP is only valid when a patient loses decision making capacity. However, verbalisation and/or documentation of a person’s wishes can facilitate shared understanding between patients and caregivers and reduce stresses associated with substitute decision making [11–13]. Conversely, when poorly timed and executed, ACP conversations with seriously ill cancer patients confront as they broach on the finality of death [14]. Thus a ‘not too much, too soon’
A mixed method feasibility study of a patient- and family-centred advance care planning intervention for cancer patients

Natasha Michael1,2*, Clare O’Callaghan1,3,4,5, Angela Baird5, Karla Gough3, Mei Krishnasamy2,6, Nathani Hiscock2 and Josephine Clayton7,8

Abstract

Background: Advance care planning (ACP) is a process whereby values and goals are sensitively explored and documented to uphold patients’ wishes should they become incompetent to make decisions in the future. Evidenced-based, effective approaches are needed. This study sought to assess the feasibility and acceptability of an ACP intervention informed by phase 1 findings and assessed the suitability of measures for a phase 3 trial.

Methods: Prospective, longitudinal, mixed methods study with convenience sampling. A skilled facilitator conducted an ACP intervention with stage III/IV cancer patients and invited caregivers. It incorporated the vignette technique and optional completion/integration of ACP documents into electronic medical records (EMR). Quantitative and qualitative data were collected concurrently, analysed separately, and the two sets of findings converged.

Results: Forty-seven percent consent rate with 30 patients and 26 caregivers completing the intervention. Ninety percent of patients and caregivers had or probably not written future care plans. Compliance with assessments was high and missing responses to items low. Small- to medium-sized changes were observed on a number of patients and caregiver completed measures, but confidence intervals were typically wide and most included zero. An increase in distress was reported; however, all believed the intervention should be made available. Eleven documents from nine patients were incorporated into EMR. ACP may not be furthered because of intervention inadequacies, busy lives, and reluctance to plan ahead.

Conclusions: In this phase 2 study we demonstrated feasibility of recruitment and acceptability of the ACP intervention and most outcome measures. However, patient/family preferences about when and whether to document ACP components need to be respected. Thus flexibility to accommodate variability in intervention delivery, tailored to individual patient/family preferences, may be required for phase 3 research.

Keywords: Advanced care planning, Palliative care, Patients, Caregivers, Cancer, Mixed methods research

Background

Decision-making in cancer care is increasingly complex as therapeutic options increase alongside ongoing ambiguity about acceptable outcomes for patients with advanced illness. Unexpected patient deterioration may necessitate difficult conversations and ad hoc decision-making, contributing to significant patient and family distress [1]. Early conversations between patients, caregivers and health professionals are encouraged to ascertain when cancer patients may want to consider treatment limitations to avoid inappropriate and aggressive care at advanced stages of illness [2,3].

Advance care planning (ACP) is a process whereby values and goals are sensitively explored and documented to uphold patients’ wishes should they become incompetent to make decisions in the future [4]. ACP conversations have broader benefits in enhancing patient...
Does implementation matter if comprehension is lacking? A qualitative investigation into perceptions of advance care planning in people with cancer

Anna Ugalde 1 · Clare O’Callaghan 2,3,4 · Clem Byard 5 · Samantha Breast 6 · Jenelle Mackay 6 · Anna Boltong 5,7 · Sondra Davoren 5 · Deborah Lawson 5 · Phillip Parente 8 · Natasha Michael 1,7 · Patricia Livingston 1

Received: 4 February 2018 / Accepted: 26 April 2018 © Springer-Verlag GmbH Germany, part of Springer Nature 2018

Abstract

Purpose While advance care planning holds promise, uptake is variable and it is unclear how well people engage with or comprehend advance care planning. The objective of this study was to explore how people with cancer comprehended advance care plans and examine how accurately advance care planning documentation represented patient wishes.

Methods This study used a qualitative descriptive design. Data collection comprised interviews and an examination of participants’ existing advance care planning documentation. Participants included those who had any diagnosis of cancer with an advance care plan recorded: Refusal of Treatment Certificate, Statement of Choices, and/or Enduring Power of Attorney (Medical Treatment) at one cancer treatment centre.

Results Fourteen participants were involved in the study. Twelve participants were female (86%). The mean age was 77 (range: 61–91), and participants had completed their advance care planning documentation between 8 and 72 weeks prior to the interview (mean 33 weeks). Three themes were evident from the data: incomplete advance care planning understanding and confidence, limited congruence for attitude and documentation, advance care planning can enable peace of mind. Complete advance care planning understanding was unusual; most participants demonstrated partial comprehension of their own advance care plan, and some indicated very limited understanding. Participants’ attitudes and their written document congruence were limited, but advance care planning was seen as helpful.

Conclusions This study highlighted advance care planning was not a completely accurate representation of patient wishes. There is opportunity to improve how patients comprehend their own advance care planning documentation.

Keywords Advance care planning · Advance directives · End-of-life · Preferences · Wishes · Statement of choices · Refusal of treatment certificate · Medical treatments

Introduction

Advance care planning (ACP) is a process whereby a person, in consultation with health care providers, family members and important others, makes decisions about their future health care, should they become incapable of participating in medical treatment decisions or providing informed consent [1]. ACP involves active contemplation by a person about their...

1, Faculty of Health, School of Nursing & Midwifery, Deakin University, 1 Gheringhap St, Geelong, VIC, Australia
2, Palliative and Supportive Care Research Department, Cabrini Health, Malvern, VIC, Australia
3, Institute for Ethics and Society, The University of Notre Dame, Sydney, Australia
4, Departments of Psychosocial Cancer Care and Medicine, St Vincent’s Hospital, The University of Melbourne, Fitzroy, VIC, Australia
5, Cancer Council Victoria, Melbourne, VIC, Australia
6, Eastern Health, Wantirna, VIC, Australia
7, Melbourne School of Health Sciences, University of Melbourne, Parkville, Australia
8, Eastern Health, Monash University, Box Hill, VIC, Australia
9, Sydney School of Medicine, University of Notre Dame, Sydney, Australia

Published online: 11 May 2018
Associate Professor Natasha Michael
Cabrini Health

Dear Researcher,

Study title: A pilot randomised control trial of a video decision support tool for advanced care planning in cancer patient caregiver dyads
Cabrini HREC Reference Number: 09-27-02-17
Monash Health Reference: RES-20-0000-112C

This is to inform you that recently Monash Health has entered into a Memorandum of Understanding with Cabrini Health to undertake Human Research Ethics Committee (HREC) Review on behalf of Cabrini Health, under the Monash Partners Human Research Ethics Review Platform.

Monash Health will provide HREC Review and approval on research projects proposed to be conducted at Cabrini Health, upon request by researchers at Cabrini Health. Following review, a governance application will then need to be submitted to Cabrini Health, so that Cabrini Health may authorise commencement of the study. As part of the arrangement, Monash Health has undertaken to transition HREC Review responsibility for current approved studies at Cabrini Health that have either been reviewed by the Cabrini Health HREC or by another reviewing HREC.

The above-mentioned project has been entered into our database and allocated with a local reference number. If you have any protocol amendments etc., please submit via email to research@monashhealth.org with the documents, along with providing the local Monash Health Reference, study title and document listing.

The following revised documents have been granted HREC Review Approval, in order to enable the transition. The remainder of the documents approved in the Cabrini Health HREC Letter of Approval will remain approved as they have not been altered in the transition arrangements.

- Master Patient Participant Information and Consent Form v7, dated 16 January 2020
- Master Caregiver Participant Information and Consent Form v6, dated 16 January 2020

A request for an annual progress reports will be sent to all Principal Investigators and Research Coordinators in early January 2020, with a request to submit an annual report by 30 April 2020.

If you have any queries, please contact Research Support Services at Monash Health on our main number 9594 4611.

Yours sincerely,

DEBORAH DELL
Manager, Research Support Services & HREC
Monash Health

Cc: Ms Deb MacDonald, Cabrini Health
Appendices

26 April 2022

A/Professor Natasha Michael & Professor David Kissane
School of Medicine
The University of Notre Dame Australia
Sydney Campus

Dear Natasha and David

Reference Number: 2022-0598
Project title: “A pilot randomised control trial of a video decision support tool for advanced care planning in cancer patient caregiver dyads”

Thank you for submitting the above project for review. It is noted that you have ethics approval for this project from Cabrini Health 09-27-02-17/Monash Health RES-20-0000-112C. Your application has been assessed as qualifying for a Cross-Institutional approval and is therefore exempt from HREC review. I am pleased to advise that ethical clearance has been granted for this proposed study.

All research projects are approved subject to standard conditions of approval.
Please read the attached document for details of these conditions.

Yours sincerely

Dr Erica Lewin
Research Ethics Officer
Research Office

cc: Professor George Mendz, Chair, SomS Research
APPENDIX G

Registering a new trial?

New videos on how to complete Step 3: Intervention, Step 5: Outcomes and Step 11: Data sharing are now available!

To achieve prospective registration, we recommend submitting your trial for registration at the same time as ethics submission.

The safety and scientific validity of this study is the responsibility of the study sponsor and investigators. Listing a study does not mean it has been endorsed by the ANZCTR. Before participating in a study, talk to your health care provider and refer to this information for consumers.

Trial registered on ANZCTR

Registration number: ACTRN1220000399920
Ethics application status: Approved
Date submitted: 18/07/2020
Date registered: 12/10/2020
Date last updated: 12/10/2020
Date data sharing statement initially provided: 12/10/2020
Date results information initially provided: 12/10/2020
Type of registration: Retrospectively registered

Titles & IDs

Public title: Using a video aid to support values conversations between patients and caregivers in advance care planning.
Scientific title: Video decision support tool promoting values conversations between cancer patients and caregivers to enable advanced care planning
Secondary ID: None
Universal Trial Number (UTN): U1111-1255-0868
Trial acronym: Linked study record

Health condition(s) or problem(s) studied:
cancer

Condition category: Cancer
Condition code: Any cancer

Intervention/exposure

Study type: Interventional

https://www.anzctr.org.au/TrialRegistration/TrialReview.aspx?id=380223&isReview=true
### Appendices

#### 28/10/2022, 14:02

<table>
<thead>
<tr>
<th>Description of intervention(s) / exposure</th>
<th>ANZCTR - Registration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Video vignettes will be developed from findings of our preliminary research into ACP in cancer patients and made into a 10-15 minute video. The video vignettes will depict scenarios of dyads communicating across three stages of a cancer trajectory, with each stage introducing considerations for the completion of different sections of an ACP (Medical Treatment Decision Maker, Statement of Values, Instructional Directive). A total of 6 vignettes will be created. Professional actors will be sourced from known professional, college and university sources, and a plot video will be created prior to the filming of the final videos. The video vignettes will be circulated to a multidisciplinary team for validation and approval and further editing before the final video intervention is received.</td>
<td></td>
</tr>
<tr>
<td>2. The sessions will be facilitated by a trained nurse and administered to patient-caregiver dyads – a patient with a diagnosis of incurable cancer and a nominated caregiver. In this study, caregivers are defined as a relative, partner, or friend who has a significant relationship with the patient and who provides them with social, psychological, and/or physical assistance.</td>
<td></td>
</tr>
<tr>
<td>3. The total duration of the intervention will be for 45 minutes. Participants will receive two telephone call prompts at two-week intervals following the intervention as a reminder to return the completed documents.</td>
<td></td>
</tr>
</tbody>
</table>

#### Intervention code (a) |

Behaviour

#### Comparator / control treatment |

Patient-caregiver dyads will be provided with an explanation of advance care planning (ACP) and be provided with the hospital's ACP document, and website and the hospitals written guidelines on how to complete the document (https://www.cabri.nsw.gov.au/assets/Advance-care-planning-ADVANCE-CARE-DIRECTIVE-INSTRUCTIONS-A4.pdf). Questions will be fielded, and finally, participants will be provided with the patient and caregiver post-questionnaires to be returned with the completed ACP in a stamped return envelope. Participants will receive two telephone call prompts at two-week intervals following the intervention as a reminder to return the completed documents.

#### Control group |

Active

#### Outcomes

**Primary outcome (a)**

The primary outcome measure will be the completion of advance care planning (ACP) documents provided to the participants. We will specifically examine completion of various portions of the ACP (Appointment of Medical Treatment Decision Maker and Support Person, Values and Instructional Directive).

**Timetable (a)**

At 2 weeks post-intervention / usual care with 2 follow up calls made at 2-week intervals if ACP documents are not returned

**Secondary outcome (a)**

Patient understanding of advance care planning (ACP) opportunities, distress, and confidence related to ACP will be measured using the Pre-post ACP Intervention Questionnaire (PPAQ) designed and tested in a previous feasibility study. It comprises a patient item, exploring understanding and perspectives on ACP and is measured on a 10-point Likert scale.

**Timetable (a)**

Patient PPAQ is measured immediately pre-intervention and completed at a single time point post-intervention by patients. The questionnaire is expected at 2 weeks post-intervention / usual care with 2 follow up calls made at 2-week intervals if ACP documents are not returned

**Secondary outcome (b)**

Congruence in decision-making will be measured using the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF). CCAT-PF consists of all items and measures congruence in patient-caregiver communication with the analogous patient CCAT-R and family CCAT-F instruments, exploring preferences, values, and experiences in treatment decision-making. The CCAT-PF demonstrates internal reliability coefficients for the CCAT-R (a = .58), CCAT-R (a = .56), and CCAT-PP (a = .63). Higher CCAT-PF scores are significantly correlated with greater patient depression and perceived family conflict, lower patient-caregiver assessment and well-being, and less expressive and family cohesiveness.

**Timetable (a)**

CCAT-PF is measured immediately pre-intervention and completed at a single time point post-intervention by patients and caregivers. Questionnaire are expected at 2 weeks post-intervention / usual care with 2 follow up calls made at 2-week intervals if ACP documents are not returned

**Secondary outcome (c)**

Patient preparation for decision-making will be measured using the Preparation for decision-making scale, a validated scale assessing patient and caregiver perception of the usefulness of an intervention. Psychometric analysis has shown Alpha coefficients (in internal consistency ranging from 0.7 to 0.8) and that the scale discriminated significantly between patients who did and did not find a decision aide helpful.

**Timetable (a)**

Patient preparation for decision-making is completed at a single time point post-intervention by patients. The questionnaire is expected at 2 weeks post-intervention / usual care with 2 follow up calls made at 2-week intervals if ACP documents and questionnaires are not returned

**Secondary outcome (d)**

Caregiver understanding of advance care planning (ACP) opportunities, distress, and confidence related to ACP will be measured using the Pre-post ACP Intervention Questionnaire (PPAQ) designed and tested in a previous feasibility study. It comprises 8 caregiver items, exploring understanding and perspectives on ACP and is measured on a 10 point Likert scale.

**Timetable (a)**

Caregiver PPAQ is measured immediately pre-intervention and completed at a single time point post-intervention by caregivers. Questionnaires are expected at 2 weeks post-intervention / usual care with 2 follow up calls made at 2-week intervals if ACP documents are not returned

**Secondary outcome (e)**

Caregiver preparation for decision-making will be measured using the Preparation for decision-making

https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=380233&isReview=true
APPENDICES

ANZCTR - Registration

scale a validated scale assessing patient and caregiver perception of the usefulness of an intervention. Psychometric analysis has shown Alpha coefficients for internal consistency ranging from 0.70 to 0.84 and that the scale discriminated significantly between patients who did and did not find a decision aid helpful (p < 0.0001).

Timepoint (g/l)

Caregiver preparation for decision-making is completed at a single time point: pre-intervention by caregivers. The questionnaire is expected at 2 weeks post-intervention / usual care with 2 follow up calls made at 2-week intervals if ACP documents and questionnaires are not returned.

Eligibility

Key Inclusion criteria

- Patients
- Patients with a diagnosis of cancer will be recruited from the oncology and palliative care services of Cabrini Health and the palliative care services of Cabrini Bethelham Hospital.
- Participants will be aged at least 18 years.
- Sufficiently proficient in English to complete questionnaires.
- Cognitively intact.
- Not having previously completed all components of an ACP/AD.
- Able to provide consent.
- Caregiver
- Caregiver of a patient participant.
- Aged at least 18 years of age.
- Sufficiently proficient in English to complete questionnaires.
- Able to provide consent.

Minimum age 18 years

Maximum age No limit

Gender Both males and females

Can healthy volunteers participate? No

Key exclusion criteria

- Patient
- Too unwell to participate in the study as determined by the patient's treating physician.
- Currently participating in more than two other studies in the hospital.
- Caregiver
- Known or demonstrated cognitive or psychological difficulties.

Study design

Purpose of the study Educational / counselling / training

Allocation to intervention Randomised controlled trial

Procedure for enroling a subject and allocating the treatment (allocation concealment procedures) sealed envelopes

Methods used to generate the sequence in which subjects will be randomised (sequence generation) Simple randomization using a randomisation table created by computer software. (i.e., computerised sequence generation)

Masking / blinding Open (masking not used)

Who is / are masked / blinded? Parallel

Intervention assignment Parallel

Other design features Not Applicable

Phase Efficacy

Type of endpoint(s) Efficacy

Statistical methods / analysis Groups will be compared for baseline values and for mean changes in outcome measures between baseline and study completion. Logistic regression will be used for the ratio of integration of ACP into the medical record. We will use linear regression adjusted for baseline values to evaluate group differences for the DCS and congruence CAT-5F outcomes. Based on the primary outcome of the integration of ACP documentation into the medical record and assuming an integration rate of around 37% for the control group, with a total of 86 participants, our analysis would show a significant improvement to 67% integration for the intervention group (power 80%, 5% significance level and two-sided testing). Assuming a mean change of 3.2 units in the DCS and a conservative estimate of the standard deviation at 7, with 86 participants, we would have 80% power to detect an improvement to 7.5 units for the intervention group. This sample size would have similar power to detect a difference in the mean change for congruence scores of about 6 units.

## APPENDICES

**Recruitment**

<table>
<thead>
<tr>
<th>Recruitment status</th>
<th>Completed</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Date of first participant enrolment</th>
<th>Actual</th>
<th>1/07/2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of last participant enrolment</td>
<td>Actual</td>
<td>25/11/2019</td>
</tr>
<tr>
<td>Date of last data collection</td>
<td>Actual</td>
<td>20/12/2019</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sample size</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Target</td>
<td>86</td>
</tr>
<tr>
<td>Accrual to date</td>
<td></td>
</tr>
<tr>
<td>Final</td>
<td>133</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recruitment in Australia</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment state(s)</td>
<td>VIC</td>
</tr>
<tr>
<td>Recruitment hospital (1)</td>
<td>Cabrini Hospital - Malvern - Malvern</td>
</tr>
<tr>
<td>Recruitment hospital (2)</td>
<td>Cabrini Hospital - Prahran - Prahran East</td>
</tr>
<tr>
<td>Recruitment postcode(s) (1)</td>
<td>3144 - Malvern</td>
</tr>
<tr>
<td>Recruitment postcode(s) (2)</td>
<td>3181 - Prahran East</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Funding &amp; Sponsors</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding source category (1)</td>
<td>Charities/Societies/Foundations</td>
</tr>
<tr>
<td>Name (1)</td>
<td>Cabrini Foundation</td>
</tr>
<tr>
<td>Address (1)</td>
<td>260-263 Wattletree Road Malvern VIC 3144</td>
</tr>
<tr>
<td>Country (1)</td>
<td>Australia</td>
</tr>
<tr>
<td>Funding source category (2)</td>
<td>Charities/Societies/Foundations</td>
</tr>
<tr>
<td>Name (2)</td>
<td>Bethlem Griffith Research Foundation</td>
</tr>
<tr>
<td>Address (2)</td>
<td>29/310 Cambridge Street Collingwood VIC 3066</td>
</tr>
<tr>
<td>Country (2)</td>
<td>Australia</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary sponsor type</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Cabrini Foundation</td>
</tr>
<tr>
<td>Address</td>
<td>181-183 Wattletree Road Malvern VIC 3144</td>
</tr>
<tr>
<td>Country</td>
<td>Australia</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary sponsor category (1)</th>
<th>University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name (1)</td>
<td>University of Notre Dame</td>
</tr>
<tr>
<td>Address (1)</td>
<td>160 Oxford St Darlinghurst, NSW 2010</td>
</tr>
<tr>
<td>Country (1)</td>
<td>Australia</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethics approval</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethics application status</td>
<td>Approved</td>
</tr>
<tr>
<td>Ethics committee name (1)</td>
<td>Cabrini Human Research Ethics Committee</td>
</tr>
<tr>
<td>Ethics committee address (1)</td>
<td>181-183 Wattletree Road, Malvern, VIC 3144</td>
</tr>
<tr>
<td>Ethics committee country (1)</td>
<td>Australia</td>
</tr>
<tr>
<td>Date submitted for ethics approval (1)</td>
<td>19/01/2017</td>
</tr>
<tr>
<td>Approval date (1)</td>
<td>27/02/2017</td>
</tr>
<tr>
<td>Ethics approval number (1)</td>
<td>09-27-02-17</td>
</tr>
</tbody>
</table>

https://www.anzctr.org.au/TrialRegistration/TrialReview.aspx?id=388223&isReview=true
APPENDICES

Summary

Brief summary

Many cancer patients and families strive to maintain hope in the face of adversity. Thus discussions on future care should be timed to follow adjustment to the diagnosis, recognise the capacity to integrate hope with truthful communication, and accommodate the preferences from those who hold diverse values and beliefs.

Our research program aims to promote a patient and family centered approach to ACP, respectfulful of individual patient preferences and values. We have previously described the iterative and dynamic nature of decision-making in cancer, the caregiver role in decision-making, the benefit of patient-caregiver dyads as an entity in ACP and introduced the vignette technique as an approach to facilitate discussions.

More recently, innovative approaches such as the use of video decision support tools (VDSST) have been used to elicit EOL care preferences. We aim to explore this novel way by modelling values-based EOL decision-making conversations between patient-caregiver dyads, to assist patients and their families to reach shared decision making.

We were awarded a Bethlehem Research Griffith Foundation Grant in 2018. To date 87 patient-caregiver dyads have been randomized to an intervention or control arm. Our preliminary statistical analysis suggest that we have to expand our sample size to ensure more meaningful outcomes.

Trial website

Trial related presentations / publications

Public notes

Contacts

Principal Investigator

Name
A/Prof Natasha Michael

Address
Cabrini Palliative and Supportive Care Department
646 High Street Prahran 3181 Melbourne VIC

Country
Australia

Phone
+61 3 95685027

Fax

Email
nmichael@cabrini.com.au

Contact person for public queries

Name
A/Prof Natasha Michael

Address
646 High Street Prahran 3181 Melbourne VIC
Cabrini Palliative and Supportive Care Department

Country
Australia

Phone
+61 3 95685027

Fax

Email
nmichael@cabrini.com.au

Contact person for scientific queries

Name
A/Prof Natasha Michael

Address
646 High Street Prahran 3181 Melbourne VIC
Cabrini Palliative and Supportive Care Department

Country
Australia

Phone
+61 3 95685027

Fax

Email
nmichael@cabrini.com.au

Data sharing statement

WILL individual participant data (IPD) for this trial be available, including data dictionaries?
No

No/undecided IPD sharing reason/comment

What supporting documents are/will be available?
No other documents available

Summary results

https://www.anzctr.org.au/TrialRegistration/TrialReview.aspx?id=360223&isReview=true
Video Decision Support Tool Promoting Values

Conversations in Advance Care Planning in Cancer:

Patient Information and Consent Form

Principal investigator: A/Prof Natasha Michael

Associate Investigators: Dr Ekavi Georgousopoulou, Dr Clare O’Callaghan,

Prof David Kissane
1 Would you like to take part in this clinical trial?

We would like to invite you to take part in our clinical trial. This is because you have a diagnosis of cancer. We are trying to understand how best to provide information on advance care planning to cancer patients and their caregivers.

This document tells you about the trial and describes what will happen if you decide to take part. If there is anything you don’t understand or want to know more about, please ask us. We will be happy to provide more information. This study has been approved by the Human Research Ethics Committee at Cabrini Health.

If you decide to go ahead, we will ask you to sign the consent form (the last page of this document). We will give you a copy of the complete signed document to keep.

2 Why are we doing this research?

Having early conversations about how best to care for you through your cancer journey is important. It allows health care professional caring for you to understand your values and how to consider them in decisions about your care. This is particularly important if you become too unwell to contribute to decision making. We are also interested in knowing who you would like to make decisions for you, if you become too unwell to make them yourself.

Advance care planning is a process that encourages discussions between patients, their caregivers and their treating team. It promotes shared decision-making between all parties and ensures that treatment and care decisions are made in accordance to your values and wishes. Including caregivers in decision making has been shown to help with coping and psychological well-being.

In our previous research we provided patients and their caregivers with short stories of patients (vignettes), through different stages of their cancer journey. Patients and caregivers used these stories to reflect on the patient’s own illness and to help them have advance care planning conversations. Though some found having these conversations difficult, the majority described the benefit of having such open discussions with their family members.

More recent research has shown the benefit of providing information to patients and caregivers in video format. We would like to investigate if Australian cancer patients and their caregivers benefit from having information provided to them via a video format.

3 Do I have to take part?

If you don’t wish to take part, you don’t have to. If you decide to take part and later change your mind, you are free to withdraw at any stage. If you choose not to take part, or if you choose to take part and then later withdraw, you will still be able to access your usual medical care. Your choice will not affect your relations with those treating you, or with this institution.

If you do withdraw your consent during the clinical trial, the research team will stop collecting personal information from you. But they will keep the personal information they have collected up to that point. There is a good reason for this. Sometimes, the law requires it. It is also retained for accurate measurement, the trial results must include all the data actually collected.

4 What are the main steps in the study?

This study involves patients and their caregiver participating together. We first need to confirm that both you and your caregiver are eligible to take part.

For this trial we need the help of male and female patients and their caregivers who will be greater than 18 years of age. Our participants will need to be English speaking and be of a clear mindset.

You must also not have previously completed an advance care plan (e.g. appointed a medical power of attorney, completed a statement of values or a refusal of treatment certificate).
If you are eligible, agree to participate and sign the consent form, you will be contacted by a researcher. You and your caregiver will be provided with a time to meet the researcher at Cabrini Health in a private setting.

You will be asked to provide some basic information about yourself and complete some questions. These will be simple questions about your background such as age and place of birth. There will be additional questions to understand how you make decisions, how you communicate with your caregiver and how useful you found the study.

Following this, you will be assigned to one of two groups.

You will have a 50% (like flipping a coin) chance of being allocated to either of the following:

**Control group**

You will receive information on advance care planning in a written form. You will be given options of which advance care planning documents you may choose to complete at each stage.

**Intervention group**

You and your caregiver will view a short 12-minute video on a portable computer together. The video will use professional actors to explain advance care planning and demonstrate examples of discussions between patients and their caregivers. The actors in the video will explain the options of which advance care planning documents you may choose to complete at each stage.

After taking part in the control or intervention group, you will have the following options

1. Immediately answering further questions or completing the questionnaires at home.
2. To complete or not complete an advance care plan with your caregiver. We recommend that if you choose to complete an advance care plan, you complete the documents at home to give you and your caregiver time to consider decisions. We request that documents are returned via a stamped envelope within 5 working days.

We expect the entire process to last for 45 minutes.

If we do not receive any documents from you after 1 week, the researcher will contact you by telephone as a reminder and to offer you the option of answering some questions over the phone.

If you chose not to complete the questions or advance care planning documents. The researcher will be interested in knowing the reasons for this.

If you do complete an advance care plan, you are free to alter the decisions made at any future date.

We may contact you to participate in a short interview by phone at the end of the study.

**5 Who is conducting and paying for this research?**

This research is being funded by the Bethlehem Griffiths Research Foundation. The research will be carried out by the Department of Supportive and Palliative Care at the Cabrini Institute.

**6 Could the researchers stop the study early?**

Yes, it happens sometimes. If it does, the study doctor will let you know and explain the reason behind the decision.

**7 What will happen to information about me?**

If you complete any advance care planning documents, we will obtain a copy of this and save it in your medical records at Cabrini Health. We will advise you on how to store and use the original copy and to send a copy to your general practitioner.
All other information about you will be kept confidential and securely stored. We will use and retain information that we collect about you only for this clinical trial. We will not disclose your information without your permission, except in compliance with the law.

Information about you may be obtained from your health records held at this institution and may be obtained from other health services for the purposes of research. If you sign the consent form, you agree to the study team accessing health records if they are relevant to your participation in this study.

All of the collected data will be coded. No personal information about you, such as your name and address will leave the study site, and in all study information sent out from the study site, you will be identified with a code number only. All of your collected information will be kept for at least 15 years after the end of the study. After the 15 years your identifying information at the institution will be permanently deleted from the computer system and any hard copies will be destroyed.

Australian and Victorian privacy law gives you the right to request access to your information that the researchers have collected and stored. The law also gives you the right to request corrections to any information about you that you disagree with. Please contact the study team (contacts on page 5 of this document) if you would like to access your information.

8 What are my responsibilities during the research?
If you agree to participate in this study you agree to be responsible for answering questions to your best understanding. You also agree to comply with the other conditions in this document. If you cannot, or do not wish to accept this responsibility, then we cannot accept you as a participant in the study.

9 What possible benefits might I get by taking part?
We cannot promise you any personal benefits from this research other than helping you to complete an Advance Care Plan. It is possible that by taking part you may be helping other cancer patients in the future by identifying strategies to enable easy and effective decision making.

10 What risks do I run by taking part?
There are no identifiable risks to you in partaking in this study. It is our aim to ensure you and your caregiver are adequately supported when deliberating choices for ongoing care. If you do find that some of the discussions cause you or your caregiver to be upset or causes conflict between your caregiver and yourself, please do not hesitate to inform us. Support and counselling will be provided to you at no cost by the organization.

11 What happens if I am injured as a result of my participation in this trial?
If you suffer any injuries or complications as a result of this trial, please contact us as soon as possible. We will help you to get medical treatment.

12 Will you pay me to participate in this trial?
There is no reimbursement or payment for this trial.

13 Can I have other procedures during this clinical trial?
This research should not interfere in any treatments or procedures you are planning to undertake.

14 What happens when the trial ends?
The data collected from you will be analysed together with others who have taken part in the study.

15 Will the results of the trial be published?
Yes it will. To protect your privacy, no information will be published that could identify you as a participant in this trial.

16 What if I have a question or need to make a complaint?
We have included several contacts for you below. Who you contact depends on what information you need.

For all study enquiries or if you want to talk to the study team at any time:

A/Prof Natasha Michael. Palliative Care, Cabrini Health.
Tel: 95085027. Email: nmichael@cabrini.com.au

If you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact:

Ms. Grace Wijnen. Acting Manager, Cabrini Human Research Ethics Committee & Research Governance, Cabrini Health.
Tel: 9508 3440. Email: gwijnen@cabrini.com.au
## Consent form

<table>
<thead>
<tr>
<th>Title</th>
<th>A pilot randomized control trial of a video decision support tool for advance care planning in cancer patient-caregiver dyads.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short title</td>
<td>Video tools to assist with care planning in cancer.</td>
</tr>
<tr>
<td>Protocol number</td>
<td>09-27-02-17</td>
</tr>
<tr>
<td>Project sponsor</td>
<td>Bethlehem Griffiths Research Foundation</td>
</tr>
<tr>
<td>Principal investigator</td>
<td>Natasha Michael</td>
</tr>
<tr>
<td>Clinical contact person</td>
<td>Natasha Michael</td>
</tr>
<tr>
<td>24-hour medical contact</td>
<td>03 95085027</td>
</tr>
</tbody>
</table>

Note: All parties signing the consent section must date their own signature.

### Declaration by participant

I have read, or have had read to me, and I understand the participant information and consent form.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the study without affecting my future health care.

I understand the purposes, procedures and risks of the research described in the trial.

I give permission for my doctors, other health professionals, hospitals, laboratories or ambulances outside this hospital to release information to Cabrini Health concerning my disease and treatment for the purposes of this trial. I understand that such information will remain confidential.

I consent to my treating doctor/s being notified of my participation in this study and any clinically relevant information noted by the trial doctor in the conduct of the trial.

I understand that I will be given a signed copy of this document to keep.

**Signature** ___________________________ **Date** __________

**Name of participant (please print)** ____________________________________________

### Declaration by trial doctor/senior researcher

I have given a verbal explanation of the clinical trial, its procedures and risks and I believe that the participant has understood that explanation.

**Signature** ___________________________ **Date** __________

**Name of trial doctor/ researcher** (please print) ____________________________________________

* A senior member of the research team must provide the explanation of, and information concerning, the clinical trial.
Video Decision Support Tool Promoting Values

Conversations in Advance Care Planning in Cancer:

Caregiver Information and Consent Form

Principal investigator: A/Prof Natasha Michael

Associate Investigators: Dr Ekavi Georgousopoulou, Dr Clare O’Callaghan, Prof David Kissane
1. Would you like to take part in this clinical trial?
We would like to invite you to take part in our clinical trial. This is because your family member/has a diagnosis of cancer. We are trying to understand how best to provide information on advance care planning to cancer patients and their caregivers.

This document tells you about the trial and describes what will happen if you decide to take part. If there is anything you don’t understand or want to know more about, please ask us. This study has been approved by the Human Research Ethics Committee at Cabrini Health.

If you decide to go ahead, we will ask you to sign the consent form (the last page of this document). We will give you a copy of the completed signed document to keep.

2. Why are we doing this research?
Having early conversations about how best to care for a cancer patient through their cancer journey is important. It allows health care professionals who care for the cancer patient to understand their values and how to consider them when making decisions. This is particularly important if the patient becomes too unwell to contribute to decision making. We are also interested in knowing who the patient would like to make decisions for them, if they become too unwell.

Advance care planning is a process that encourages discussions between patients, their caregivers and their treating team. It promotes shared decision-making between all parties and ensures that treatment and care decisions are made in accordance to the patient’s values and wishes. Including caregivers in decision making has been shown to help with coping and psychological well-being.

In our previous research, we provided patients and their caregivers with short stories of patients (vignettes), through different stages of their cancer journey. Patients and caregivers used these stories to reflect on the patient’s own illness and to consider having advance care planning conversations. Though some found having these conversations difficult, the majority described the benefit of having such open discussions with their family members.

More recent research has shown the benefit of providing information to patients and caregivers in video format. We would like to investigate if Australian cancer patients and their caregivers benefit from having information provided to them via a video format.

3. Do I have to take part?
If you don’t wish to take part, you don’t have to. If you decide to take part and later change your mind, you are free to withdraw at any stage. If you choose not to take part, or if you choose to take part and then later withdraw, your family member/friend will still be able to access their usual medical care. Your choice will not affect your relations with those treating the patient, or with this institution.

If you do withdraw your consent during the clinical trial, the research team will stop collecting personal information from you. But they will keep the personal information they have collected up to that point. There is a good reason for this. Sometimes, the law requires it. It is also retained for accurate measurement, the trial results must include all the data actually collected.

If you do not agree with this then we cannot allow you to join the clinical trial.

4. What are the main steps in the study?
This study involves patients and their caregiver participating together. We first need to confirm that both you and the patient are eligible to take part.

For this trial we need the help of male and female patients and their caregivers who will be greater than 18 years of age. Our participants will need to be English speaking and be of a clear mindset.

The patient must not have previously completed all parts of an advance care plan or directive.

If you are eligible, agree to participate and sign the consent form, you will be contacted by a researcher. You and the patient will be provided with a time to meet the researcher at Cabrini Health in a private setting.

You will be asked to provide some basic information about yourself and complete some questions. These will be simple questions about your background such as age and place of birth. There will be additional questions to understand how you make decisions, how you communicate with the patient and how useful you found the study.

Following this, you will be assigned to one of two groups.

You will have a 50% (like flipping a coin) chance of being allocated to either of the following:

**Control group**

You and the patient will receive information on advance care planning in a written form. You and the patient will be given options of which advance care planning documents the patient may choose to complete at each stage.

**Intervention group**

You and the patient will view a short 12-minute video on a portable computer together. The video will use professional actors to explain advance care planning and demonstrate examples of discussions between patients and their caregivers. The actors in the video will explain the options of which advance care planning documents the patient may choose to complete at each stage.

After taking part in the control or intervention group, you will have the option of immediately answering further questions or completing the questionnaires at home. We recommend that you and the patient complete the advance care planning documents at home to give you both time to consider decisions. We request that documents are returned via a stamped envelope within 5 working days.

We expect the entire process to last for 45 minutes.

If we do not receive any documents from you after 1 week, the researcher will contact you by telephone as a reminder and to offer you the option of answering some questions over the phone.

You may choose not to complete the questions and the patient may choose not to complete any advance care planning documents. The researcher will be interested in knowing the reasons for this.

If the patient does not complete an advance care plan, they are free to alter the decisions made at any future date.

**We may contact you to participate in a short interview by phone at the end of the study.**

**Who is conducting and paying for this research?**

This research is being funded by the Bethlehem Griffiths Research Foundation. The research will be carried out by the Department of Supportive and Palliative Care at the Cabrini Institute.

**6 Could the researchers stop the study early?**

Yes, it happens sometimes. If it does, the study doctor will let you know and explain the reason behind the decision.

**7 What will happen to information about me?**

If the patient completes any advance care planning documents, we will obtain a copy of this and save it in their medical records at Cabrini Health. We will advise the patient on how to store and use the original copy and to send a copy to your general practitioner.

All other information about you will be kept confidential and securely stored. We will use and retain information that we collect about you only for this clinical trial. We will not disclose your information without your permission, except in compliance with the law.

All of the collected data will be coded. No personal information about you, such as your name and address will leave the study site, and in all study information sent out from the study site, you will be identified with a code number only. All of your collected information will be kept for at least 15 years after the end of the study. After the 15 years your identifying information at the institution will be permanently deleted from the computer system and any hard copies will be destroyed.

Australian and Victorian privacy law gives you the right to request access to your information that the researchers have collected and stored. The law also gives you the right to request corrections to any information about you that you disagree with. Please contact the study team (contacts on page 5 of this document) if you would like to access your information.
8  What are my responsibilities during the research?
If you agree to participate in this study you agree to be responsible for answering questions to your best understanding. You also agree to comply with the other conditions in this document. If you cannot, or do not wish to accept this responsibility, then we cannot accept you as a participant in the study.

9  What possible benefits might I get by taking part?
We cannot promise you any personal benefits from this research other than helping the patient complete an Advance Care Plan. It is possible that by taking part you may be helping other cancer patients in the future by identifying strategies to enable easy and effective decision making.

10 What risks do I run by taking part?
There are no identifiable risks to you in partaking in this study. It is our aim to ensure you and the patient are adequately supported when deliberating choices for ongoing care. If you do find that some of the discussions cause you or the patient to be upset or causes conflict between the patient and yourself, please do not hesitate to inform us. Support will be provided to you at no cost by the organization.

11 What happens if I am injured as a result of my participation in this trial?
If you suffer any injuries or complications as a result of this study, please contact us as soon as possible. We will help you to get medical treatment.

12 Will you pay me to participate in this trial?
There is no reimbursement or payment for this trial.

13 Can I have other procedures during this clinical trial?
This research should not interfere in any treatments or procedures the patient will be planning to undertake.

14 What happens when the trial ends?
The data collected from you will be analysed together with others who have taken part in the study.

15 Will the results of the trial be published?
Yes it will. To protect your privacy, no information will be published that could identify you as a participant in this trial.

16 What if I have a question or need to make a complaint?
We have included several contacts for you below. Who you contact depends on what information you need.

For all study enquiries or if you want to talk to the study team at any time:

A/Prof Natasha Michael
Tel: 95085027. Email: nnmichael@cabrini.com.au

If you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact:

Ms. Grace Wijnen. Acting Manager, Cabrini Human Research Ethics Committee & Research Governance, Cabrini Health.
Tel: 95083440. Email: gwijnen@cabrini.com.au
Consent form

<table>
<thead>
<tr>
<th>Title</th>
<th>A pilot randomized control trial of a video decision support tool for advance care planning in cancer patient-caregiver dyads.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short title</td>
<td>Video tools to assist with care planning in cancer.</td>
</tr>
<tr>
<td>Protocol number</td>
<td>09-27-02-17</td>
</tr>
<tr>
<td>Project sponsor</td>
<td>Bethlehem Griffiths Research Foundation</td>
</tr>
<tr>
<td>Principal investigator</td>
<td>Natasha Michael</td>
</tr>
<tr>
<td>Clinical contact person</td>
<td>Natasha Michael 03 95085027</td>
</tr>
<tr>
<td>24-hour medical contact</td>
<td>03 95085027 <a href="mailto:nmichael@cabrini.com.au">nmichael@cabrini.com.au</a></td>
</tr>
</tbody>
</table>

Note: All parties signing the consent section must date their own signature.

Declaration by participant
I have read, or have had read to me, and I understand the participant information and consent form.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the study without affecting my future health care.

I understand the purposes, procedures and risks of the research described in the trial.

I give permission for my doctors, other health professionals, hospitals, laboratories or ambulances outside this hospital to release information to Cabrini Health concerning my disease and treatment for the purposes of this trial. I understand that such information will remain confidential.

I consent to my treating doctor/s being notified of my participation in this study and any clinically relevant information noted by the trial doctor in the conduct of the trial.

I understand that I will be given a signed copy of this document to keep.

Signature ___________________________ Date ____________

Name of participant (please print) ___________________________

Declaration by trial doctor/senior researcher
I have given a verbal explanation of the clinical trial, its procedures and risks and I believe that the participant has understood that explanation.

Signature ___________________________ Date ____________

Name of trial doctor/researcher† (please print) ___________________________

† A senior member of the research team must provide the explanation of, and information concerning, the clinical trials.
Video Decision Support Tool Promoting Values

Conversations in Advance Care Planning in Cancer:

A Randomised Controlled Trial

Patient Questionnaire

Principal investigator: A/Prof Natasha Michael

Associate Investigators: Dr Ekavi Georgousopoulou, Dr Clare O’Callaghan,

Prof David Kissane

Project No: 09-27-02-17    Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
PATIENT PREINTERVENTION QUESTIONNAIRE

Patient Identification No: ______________________

Patient Demographics

Researcher to tick the most appropriate answer or fill in the blank space provided.

1. Age _____  2. Sex □ Male  □ Female

3. Marital Status: □ Single  □ Married  □ Defacto  □ Separated/divorce  □ Widowed

4. Country of Birth ______________________

5. Nature of relationship to carer  □ Husband  □ Wife  □ Partner  □ Child  □ Friend  □ Other

6. What is your primary cancer diagnosis?
   □ Do not know  □ Breast  □ Prostate  □ Lung  □ Upper gastrointestinal (e.g. oesophageal, stomach, pancreas)
   □ Lower gastrointestinal (e.g. colorectal)  □ Other (please specify): ______________________

7. How long have you been living with your main diagnosis?
   □ Less than 6 months  □ 6 months to 1 year  □ 1 year to 5 years  □ More than 5 years

8. Have you discussed with your doctor what your prognosis is?
   □ Yes I have  What were you told? ______________________
   □ No I did not want to ask
   □ No the opportunity has not arisen

Project No: 09-27-02-17  Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer

176
DASS 21

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all - NEVER
1 Applied to me to some degree, or some of the time - SOMETIMES
2 Applied to me to a considerable degree, or a good part of time - OFTEN
3 Applied to me very much or most of the time – ALMOST ALWAYS

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Never</th>
<th>Some</th>
<th>Often</th>
<th>Almost</th>
<th>Always</th>
<th>D</th>
<th>A</th>
<th>S</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I found it hard to wind down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I was aware of dryness of my mouth</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>I couldn’t seem to experience any positive feeling at all</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I found it difficult to work up the initiative to do things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>I tended to over-react to situations</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>I experienced trembling (eg, in the hands)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>I felt that I was using a lot of nervous energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>I was worried about situations in which I might panic and make a fool of myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I felt that I had nothing to look forward to</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>I found myself getting agitated</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>I found it difficult to relax</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>I felt down-hearted and blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>I was intolerant of anything that kept me from getting on with what I was doing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>I felt I was close to panic</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I was unable to become enthusiastic about anything</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>I felt I wasn’t worth much as a person</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>I felt that I was rather touchy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>I felt scared without any good reason</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>I felt that life was meaningless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TOTAL
Attitudes to ACP: Please place a circle on the line below to indicate your answer.

1. I rate my current understanding of advance care planning as:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   Poorest possible understanding

   Best possible understanding

2. The opportunity to consider my possible future health care needs and wishes with health care professionals have been as:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   Unsatisfying as possible

   Satisfying as possible

3. Thinking about my possible future health care needs and wishes if I became unwell causes me the:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   Highest distress imaginable

   Lowest distress imaginable

4. Discussing my possible future health care needs and wishes with others would cause me the:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   Highest distress imaginable

   Lowest distress imaginable

5. Making and informing others about decisions related to my possible future health care needs and wishes is:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   Not important at all

   Extremely important

Project No: 09-27-02-17   Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
6. How do you feel about discussing your possible future health care needs and wishes with health professions?

[Scale from 0 to 10]

Lowest possible confidence

Highest possible confidence

7. How do you feel about discussing your possible future health care needs and wishes with family members/friends?

[Scale from 0 to 10]

Lowest possible confidence

Highest possible confidence

8. Considering my advanced care plan is:

[Scale from 0 to 10]

Not helpful at all

Extremely helpful

9. Considering advance care planning when living with a cancer diagnosis is

[Scale from 0 to 10]

Not recommended at all

Always recommended

Project No: 09-27-02-17 Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
### Cancer Communication Assessment Tool - Patient Version

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Half of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>My family plays a big role in the decisions I make about my cancer treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2.</td>
<td>I hesitate to mention treatment side effects to my doctors or nurses.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Mostly Agree</td>
<td>Slightly Agree</td>
<td>Slightly Disagree</td>
<td>Mostly Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>3.</td>
<td>In general, side effects are not really important when I consider my larger goals of treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4.</td>
<td>Medical science may find a cure so I am willing to take any treatment now to stay alive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5.</td>
<td>If treatment caused financial hardship for my family, I would not take it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>All of the time</td>
<td>Most of the time</td>
<td>Half of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>Never</td>
</tr>
<tr>
<td>6.</td>
<td>My family and I have different views about the goal of treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Mostly Agree</td>
<td>Slightly Agree</td>
<td>Slightly Disagree</td>
<td>Mostly Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>7.</td>
<td>If treatment made me sick every day I would not take it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8.</td>
<td>I could see that there could come a point when taking treatment would not be worth the discomfort it causes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9.</td>
<td>I am willing to take treatment that causes me a significant amount of pain if I can live a few months longer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>All of the time</td>
<td>Most of the time</td>
<td>Half of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>Never</td>
</tr>
<tr>
<td>10.</td>
<td>I value my family’s judgment about treatment decisions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Mostly Agree</td>
<td>Slightly Agree</td>
<td>Slightly Disagree</td>
<td>Mostly Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>11.</td>
<td>My family’s acceptance of my treatment decisions depends on how much they like my doctor(s).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>All of the time</td>
<td>Most of the time</td>
<td>Half of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>Never</td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>------------------</td>
<td>------------------</td>
<td>------------------</td>
<td>---------------------</td>
<td>-------</td>
</tr>
<tr>
<td>12. It is important to base decisions about my cancer treatment on sources of information other than my doctor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>13. My family does not really listen when I talk about my cancer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>14. I avoid talking about cancer to my family because I don't want to upset them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>15. I don't tell my family about my problems because there is nothing they can do to help.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>16. I am frustrated when my family is overprotective of me because of my cancer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>17. My family blames my cancer on my not having taken better care of myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Mostly Agree</td>
<td>Slightly Agree</td>
<td>Slightly Disagree</td>
<td>Mostly Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>18. I would feel uncomfortable if the doctor began to talk to me about palliative/hospice care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
PATIENT POSTINTERVENTION QUESTIONNAIRE

Preparation for Decision Making scale

Please show your opinion of [the educational material] by circling the number to show how much you agree with each statement.

<table>
<thead>
<tr>
<th>Did this material</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Help you recognize that a decision needs to be made?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Prepare you to make a better decision?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Help you think about the pros and cons of each option?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Help you think about which pros and cons are most important?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Help you know that the decision depends on what matters most to you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Help you organize your own thoughts about the decision?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Help you think about how involved you want to be in this decision?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Help you identify questions you want to ask your doctor?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Prepare you to talk to your doctor about what matters most to you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Prepare you for a follow-up visit with your doctor?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Attitudes to ACP: Please place a circle on the line below to indicate your answer.

1. I rate my current understanding of advance care planning as:

   [Scale with 11 points from 0 to 10]

   Poorest possible understanding
   Best possible understanding

2. The opportunity to consider my possible future health care needs and wishes with health care professionals have been as:

   [Scale with 11 points from 0 to 10]

   Unsatisfying as possible
   Satisfying as possible

3. Thinking about my possible future health care needs and wishes if I became unwell causes me the:

   [Scale with 11 points from 0 to 10]

   Highest distress imaginable
   Lowest distress imaginable

4. Discussing my possible future health care needs and wishes with others would cause me the:

   [Scale with 11 points from 0 to 10]

   Highest distress imaginable
   Lowest distress imaginable

Project No: 09-27-02-17    Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
5. Making and informing others about decisions related to my possible future health care needs and wishes is:

Not important at all  Extremely important

6. How do you feel about discussing your possible future health care needs and wishes with health professions?

Lowest possible confidence  Highest possible confidence

7. How do you feel about discussing your possible future health care needs and wishes with family members/friends?

Lowest possible confidence  Highest possible confidence

8. Considering my advanced care plan is:

Not helpful at all  Extremely helpful

9. Considering advance care planning when living with a cancer diagnosis is

Not recommended at all  Always recommended

Project No: 09-27-02-17  Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
## Cancer Communication Assessment Tool - Patient Version

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Half of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. My family plays a big role in the decisions I make about my cancer treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>20. I hesitate to mention treatment side effects to my doctors or nurses.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Mostly Agree</th>
<th>Slightly Agree</th>
<th>Slightly Disagree</th>
<th>Mostly Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. In general, side effects are not really important when I consider my larger goals of treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>22. Medical science may find a cure so I am willing to take any treatment now to stay alive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>23. If treatment caused financial hardship for my family, I would not take it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Half of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>24. My family and I have different views about the goal of treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Mostly Agree</th>
<th>Slightly Agree</th>
<th>Slightly Disagree</th>
<th>Mostly Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. If treatment made me sick every day I would not take it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>26. I could see that there could come a point when taking treatment would not be worth the discomfort it causes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>27. I am willing to take treatment that causes me a significant amount of pain if I can live a few months longer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Half of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>28. I value my family’s judgment about treatment decisions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Mostly Agree</th>
<th>Slightly Agree</th>
<th>Slightly Disagree</th>
<th>Mostly Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. My family’s acceptance of my treatment decisions depends on how much they like my doctor(s).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>All of the time</td>
<td>Most of the time</td>
<td>Half of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>Never</td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>------------------</td>
<td>------------------</td>
<td>------------------</td>
<td>----------------------</td>
<td>-------</td>
</tr>
<tr>
<td>30. It is important to base decisions about my cancer treatment on sources of information other than my doctor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>31. My family does not really listen when I talk about my cancer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>32. I avoid talking about cancer to my family because I don’t want to upset them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>33. I don’t tell my family about my problems because there is nothing they can do to help.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>34. I am frustrated when my family is overprotective of me because of my cancer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>35. My family blames my cancer on my not having taken better care of myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

**Strongly Agree** | **Mostly Agree** | **Slightly Agree** | **Slightly Disagree** | **Mostly Disagree** | **Strongly Disagree**
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>36. I would feel uncomfortable if the doctor began to talk to me about palliative/hospice care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Video Decision Support Tool Promoting Values

Conversations in Advance Care Planning in Cancer:

A Randomised Controlled Trial

Caregiver Questionnaire

Principal investigator: A/Prof Natasha Michael

Associate Investigators: Dr Ekavi Georgousopoulou, Dr Clare O'Callaghan,
Prof David Kissane
CAREGIVER PREINTERVENTION QUESTIONNAIRE

Patient Identification No: ____________________

Caregiver Demographics

Research Assistant tick the most appropriate answer or fill in the blank space provided.

1. Age _____  2. Sex  □ Male  □ Female

3. Marital Status:  □ Single  □ Married  □ De facto

□ Separated/divorced  □ Widowed

4. Country of Birth_________________________________________

5. Nature of relationship to patient  □ Husband  □ Wife  □ Partner

□ Child  □ Friend  □ Other_____

Project No: 09-27-02-17  Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
Attitudes to ACP: Please place a vertical mark on the line below to indicate your answer.

1. I rate my current understanding of advance care planning as:

   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

   Poorest possible understanding

   Best possible understanding

2. The opportunity to consider my family member's/friend's possible future health care needs and wishes with health care professionals have been as:

   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

   Unsatisfying as possible

   Satisfying as possible

3. Thinking about family member's/friend's possible future health care needs and wishes if he/she became unwell in the future would cause me the:

   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

   Highest distress imaginable

   Lowest distress imaginable

4. Discussing family member's/friend's possible future care health needs and wishes with him/her would cause me the:

   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

   Highest distress imaginable

   Lowest distress imaginable

Project No: 09-27-02-17    Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
5. Helping my family member/friend to make decisions related to his/her possible future health care needs and wishes is:

Not important at all

Extremely important

6. Making decisions on behalf of my family member/friend if he/she could not make them would give me the:

Highest

distress

imaginable

Lowest

distress

imaginable

7. How do you feel about discussing your family member’s/friend’s possible future health care wishes and with health professions?

Lowest

possible confidence

Highest

possible confidence

8. Having your family member/friend consider his/her advanced care plan is:

Not helpful at all

Extremely helpful

Project No: 09-27-02-17  Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
### Cancer Communication Assessment Tool - Caregiver Version

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Mostly Agree</th>
<th>Slightly Agree</th>
<th>Slightly Disagree</th>
<th>Mostly Disagree</th>
<th>Strongly Disagree</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>37. Our family plays a big role in making decisions about cancer treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. My family member/friend hesitates to mention treatment side effects to doctors or nurses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. In general, side effects are not really important when I consider the larger goals of my family member's/friend's treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40. Medical science may find a cure for cancer so I want my family member/friend to take any treatment now to stay alive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41. If my family member's/friend's treatment caused financial hardship, I would not want him/her to take it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. My family member/friend and I have different views about the goal of treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>43. If treatment made him/her sick every day, I would not want him/her to take it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44. I could see that there could come a point when taking treatment would not be worth the discomfort it causes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45. My family member/friend should be willing to take treatment that causes him/her a significant amount of pain if he/she will live a few months longer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46. My family member/friend values my judgment about treatment decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>47. My acceptance of treatment decisions depends on how much I like the doctor(s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>All of the time</td>
<td>Most of the time</td>
<td>Half of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>------------------</td>
<td>------------------</td>
<td>------------------</td>
<td>---------------------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>48. It is important to base decisions about cancer treatment on sources of information other than the doctor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>49. I can’t really listen when my family member/friend talks about his/her cancer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>50. I avoid talking about cancer to my family member/friend because I don’t want to upset him/her.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>51. My family member/friend does not tell me about his/her problems because he/she thinks there is nothing I can do to help.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>52. My family member/friend is frustrated when I am overprotective because of his/her cancer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>53. I blame cancer on my family member/friend not having taken better care of him/herself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>54. I would feel uncomfortable if the doctor began to talk to my family member/friend about palliative/hospice care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>
**CAREGIVER POSTINTERVENTION QUESTIONNAIRE**

**Preparation for Decision Making scale**

Please show your opinion of [the educational material] by circling the number to show how much you agree with each statement.

<table>
<thead>
<tr>
<th>Did this material</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Help you recognize that a decision needs to be made?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Prepare you to make a better decision?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Help you think about the pros and cons of each option?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Help you think about which pros and cons are most important?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Help you know that the decision depends on what matters most to the person you are caring for?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Help you organize your own thoughts about the decision?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Help you think about how involved you want to be in this decision?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Help you identify questions you want to ask the doctor?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Prepare you to talk to the doctor about what matters most to the person you are caring for?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Prepare you for a follow-up visit with the doctor?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Attitudes to ACP: Please place a vertical mark on the line below to indicate your answer.

1. I rate my current understanding of advance care planning as:

   | | | | | | | | | | 0 1 2 3 4 5 6 7 8 9 10
   
   Poorest possible understanding
   
Best possible understanding

2. The opportunity to consider my family member’s/friend’s possible future health care needs and wishes with health care professionals have been as:

   | | | | | | | | | | 0 1 2 3 4 5 6 7 8 9 10
   
   Unsatisfying as possible
   
Satisfying as possible

3. Thinking about family member’s/friend’s possible future health care needs and wishes if he/she became unwell in the future would cause me the:

   | | | | | | | | | | 0 1 2 3 4 5 6 7 8 9 10
   
   Highest distress imaginable
   
Lowest distress imaginable

4. Discussing family member’s/friend’s possible future care health needs and wishes with him/her would cause me the:

   | | | | | | | | | | 0 1 2 3 4 5 6 7 8 9 10
   
   Highest distress imaginable
   
Lowest distress imaginable

Project No: 09-27-02-17   Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
5. Helping my family member/friend to make decisions related to his/her possible future health care needs and wishes is:

![0-10 scale]

Not important at all

Extremely important

6. Making decisions on behalf of my family member/friend if he/she could not make them would give me the:

![0-10 scale]

Lowest distress imaginable

Highest distress imaginable

7. How do you feel about discussing your family member’s/friend’s possible future health care wishes and with health professions?

![0-10 scale]

Lowest possible confidence

Highest possible confidence

8. Having your family member/friend consider his/her advanced care plan is:

![0-10 scale]

Not helpful at all

Extremely helpful

Project No: 09-27-02-17    Patient/Caregiver Instruments pre-post V1 July 27, 2018

Video tools to assist with care planning in cancer
<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Half of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Our family plays a big role in making decisions about cancer treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3. My family member/friend hesitates to mention treatment side effects to doctors or nurses.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4. In general, side effects are not really important when I consider the larger goals of my family member's/friend's treatment.</td>
<td>Strongly Agree</td>
<td>Mostly Agree</td>
<td>Slightly Agree</td>
<td>Slightly Disagree</td>
<td>Mostly Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>5. Medical science may find a cure for cancer so I want my family member/friend to take any treatment now to stay alive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6. If my family member's/friend's treatment caused financial hardship, I would not want him/her to take it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7. My family member/friend and I have different views about the goal of treatment.</td>
<td>All of the time</td>
<td>Most of the time</td>
<td>Half of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>Never</td>
</tr>
<tr>
<td>8. If treatment made him/her sick every day, I would not want him/her to take it.</td>
<td>Strongly Agree</td>
<td>Mostly Agree</td>
<td>Slightly Agree</td>
<td>Slightly Disagree</td>
<td>Mostly Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>9. I could see that there could come a point when taking treatment would not be worth the discomfort it causes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>10. My family member/friend should be willing to take treatment that causes him/her a significant amount of pain if he/she will live a few months longer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>11. My family member/friend values my judgment about treatment decisions.</td>
<td>All of the time</td>
<td>Most of the time</td>
<td>Half of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>Never</td>
</tr>
<tr>
<td>12. My acceptance of treatment decisions depends on how much I like the doctor(s).</td>
<td>Strongly Agree</td>
<td>Mostly Agree</td>
<td>Slightly Agree</td>
<td>Slightly Disagree</td>
<td>Mostly Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td></td>
<td>All of the time</td>
<td>Most of the time</td>
<td>Half of the time</td>
<td>Some of the time</td>
<td>A little of the time</td>
<td>Never</td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>------------------</td>
<td>------------------</td>
<td>------------------</td>
<td>---------------------</td>
<td>-------</td>
</tr>
<tr>
<td>13. It is important to base decisions about cancer treatment on sources of information other than my doctor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>14. I can’t really listen when my family member/friend talks about his/her cancer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>15. I avoid talking about cancer to my family member/friend because I don’t want to upset him/her.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>16. My family member/friend does not tell me about his/her problems because there is nothing I can do to help.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>17. My family member/friend is frustrated when I am overprotective of his/her cancer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>18. I blame cancer on my family member/friend not having taken better care of him/herself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Mostly Agree</td>
<td>Slightly Agree</td>
<td>Slightly Disagree</td>
<td>Mostly Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>19. I would feel uncomfortable if the doctor began to talk to my family member/friend about palliative/hospice care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
Instructions for Completing Cabrini Advance Care Directive

This document provides information to assist you in completing your Cabrini Advance Care Directive (ACD). You can download and print the Advance Care Directive form from the Cabrini website: www.cabrini.com.au/advancenareplanning

If you need assistance completing the form, you can contact:
- your General Practitioner,
- your Medical Specialist, or

Who can complete the form?
Advance Care Directives are often undertaken when someone has a serious illness or is of advancing age. However, they can be made at any time. Younger, healthy people will benefit from completing an Advance Care Directive. Advance Care Directives are strongly recommended for people who meet the following criteria:
- Have severe illnesses that might in time lead to death, such as advanced kidney, lung or heart failure, cancer, progressive neurological disease or early dementia
- Residents being admitted to residential aged care
- Aged over 75 years
- Have multiple medical problems causing increasing frailty or reduced ability to perform usual activities
- Have clear wishes about what sort of medical treatment they would want if they were ever unable to make their own decisions.

In order to complete a valid Advance Care Directive, two witnesses, one of whom is a doctor, must sign to confirm that you have the capacity to understand all of the statements within the document. Neither witness can be someone you have appointed as your Medical Treatment Decision Maker.

A person under 18 years of age is able to make an Advance Care Directive and appoint a Support Person if they have the decision-making capacity to do so. However, only people over 18 years of age are able to appoint a Medical Treatment Decision Maker.

What is in the form?
There are 4 parts to the Advance Care Directive form:
1) Appointment of Medical Treatment Decision Maker and Support Person
2) Values Directives
3) Instructional Directives
4) Witnessing and signatures

You can complete all or part of Parts 1-3. Part 4 must be completed for Parts 2 & 3 to be valid.

You should draw a line through any sections of the Advance Care Directive form that you choose not to fill out.

This Advance Care Directive will automatically replace any earlier directives you have made, and the appointment of a Medical Treatment Decision Maker will replace any previously appointed Medical Enduring Powers of Attorney. It is recommended that you cancel previous directives or appointments by striking a line through each page and writing "cancelled" or "replaced" on all copies of the earlier forms.

If you have them available, you can use hospital patient identification stickers in the top right hand corner of each page of the document – you can ask Cabrini staff for the stickers. Otherwise you should write your name and date of birth on each page of this document.

Completing the form
The page numbers below refer to the page in the Advanced Care Directive (ACD) form.

PAGE ONE (of the ACD form)

Make: Make sure you fill in your own details at the bottom of page one.
Who: Appointment of Medical Treatment Decision Maker(s) and Support Person

Medical Treatment Decision Maker

Your Medical Treatment Decision Maker is the person who will be asked to make medical decisions for you if you are ever unable to. The first person on the hierarchy below who is available and willing to act in the role, and who has a close and continuing relationship with you, will become your Medical Treatment Decision Maker. If you appoint someone, they will be at the top of the hierarchy. It is worthwhile appointing your Medical Treatment Decision Maker, even if you are appointing someone on the hierarchy; this can make it easier for your family and friends to be clear about who you want to make decisions for you and can avoid confusion and uncertainty for them.

Medical Treatment Decision Maker Hierarchy:

1) A person appointed by you
2) A guardian appointed by VCAT
3) Your spouse or domestic partner
4) Your primary carer (not including paid carers or service providers)
5) Your oldest adult child
6) Your oldest parent
7) Your oldest adult sibling
8) The Public Advocate

If none of your appointed Medical Treatment Decision Makers or relatives are available, the Public Advocate will be asked to make medical decisions for you.

If you appoint a Medical Treatment Decision Maker using this form, any previous Medical Enduring Powers of Attorney that you have appointed will be replaced by the person/people you appoint with this form. If you have previously appointed a Medical Enduring Power of Attorney, it is the same as appointing a Medical Treatment Decision Maker with this form.

Only adults are able to appoint a Medical Treatment Decision Maker.

Using this form, you can appoint up to two Medical Treatment Decision Makers – the person listed second will only be approached if your first choice is unavailable or unwilling to act as your Medical Treatment Decision Maker.

The name, address and date of birth for your chosen Medical Treatment Decision Maker(s) must be completed.

The people you appoint as Medical Treatment Decision Maker must sign the form to say that they are willing to accept the appointment.

Support Person

Your Support Person's role is to help you make decisions and also to help your Medical Treatment Decision Maker to make decisions on your behalf if you are ever unable to do so. Your Support Person will not be asked to make decisions or your behalf. By appointing someone as your Support Person, you are granting them access to your medical information in order to assist decision making. Your Support Person may be the same person as your Medical Treatment Decision Maker, or a different person.

Witnesses (to appointment of Medical Treatment Decision Maker(s) and/or Support Person)

When you and your appointed Medical Treatment Decision Maker(s) and/or Support Person sign this form, you must do so in the presence of two witnesses who also sign the bottom of this page. It is the role of the witnesses to certify that you have completed this form willingly and without coercion, and that you have the capacity to make the decisions that you and your appointed representatives have made to enter into this agreement.

One of the witnesses must be an Authorised Witness; that is someone who is registered in specific occupations, including the following: dentist, legal practitioner, medical practitioner, nurse, optometrist, pharmacist, physiotherapist, psychologist, veterinarian, some post office agents, bank officers and clerks of court. Neither witness can be someone you have appointed as your Medical Treatment Decision Maker.

If you appoint a Medical Treatment Decision Maker and/or Support Person, it is recommended that you discuss your Advance Care Directive, and your personal wishes, with that person so that they might understand your thoughts if they are ever needed to act on your behalf. You can also discuss your Advance Care Directive with other family members or friends, and also with your health care providers.

Cabrini
What: Values Directives

In this section, you can write down information about what is important to you. This information is used by your Medical Treatment Decision Maker to help make decisions if you are ever unable to do so. These statements are not binding; they do not enforce decisions on your Medical Treatment Decision Maker; they simply guide your Medical Treatment Decision Maker to be able to imagine what decisions you would have made for yourself.

- What is important to you?
- What does it mean to live well?
- What things concern you?
- For example, do you want to live for as long as possible? Or are there things that you wouldn’t want to live without? If remaining independent is important to you, try to be specific about what it means to be independent, as people have different understandings of what this means. For some people, living independently means being in their own home, while others may be more concerned with being able to take care of their personal grooming, being able to maintain connections with family and friends, or being able to make decisions for themselves.

- Do you have specific religious or spiritual beliefs that might affect the type of medical treatment you want?
- Are there other people you would like involved in making decisions about your care?
- Are there things that you would want known if you are nearing death? These may include who you would like with you, where you would most like to be if possible (home, hospital, hospice), music you would like playing, or other spiritual or cultural customs.

Questions 1-9 will guide you in what you might like to write in this section.

We encourage you to write Values Directives, as these are very useful in guiding your Medical Treatment Decision Maker and your health care professional when making decisions for you. Recording your wishes and values is important even if you don’t appoint a Medical Treatment Decision Maker, as someone will still be asked to consider these statements when making decisions for you; this includes the Public Advocate who will have access to your Advance Care Directive if they are making decisions on your behalf.

What: Instructional Directives

In this section, you can make binding statements that will communicate your medical treatment decisions directly to your health care providers. If you make Instructional Directives, it means that you have already made these decisions and your Medical Treatment Decision Maker will not be asked to make these decisions on your behalf. You can use this section to give permission to health care providers to provide certain treatments for you if they are indicated, and you can also use this section to refuse treatments that you do not want.

Questions 10 and 11 relate to two specific examples of Instructional Directives which are commonly considered:

- the use of CPR to attempt to re-start breathing and circulation if they stop, and
- the opportunity to consider being an organ and/or tissue donor after you die.

If you do not wish to answer these questions, you can draw a line through them.

If you do wish to be considered for organ donation, be aware that there are certain medical interventions at the end of your life that are required for donation to be successful. It is recommended that you also register your wishes about organ and tissue donation on the Australian Organ Donor Register. More information about organ and tissue donation can be found on the Donatelife.gov.au website.

Question 12 allows you to add your own Instructional Directives.

It is very important that Instructional Directives are well written. It is strongly recommended they are discussed with your doctor before finalising this form, otherwise it is possible that your directives will be difficult to follow. For example, if you have written "under no circumstances do I wish to be kept alive by a machine that breathes for me"; this means that this treatment will not be provided to you even if it was only required for a short period of time, such as while you have an operation. Your doctor will help you to clarify exactly what it is you want, and how best to write it to ensure that it is clear.

Each Instructional Directive requires two parts: it is necessary to state the situation in which the directive should apply, and the treatment decision that you have made. It can also be helpful to include the reasons for your statement.
PAGE FIVE (of the ACD form) continued...

This will look like:

If I ever have ____ (illness or injury)____, I do / do not want ___ (treatment)____. Because ____________________

E.g. If I ever suffer a severe injury to my brain and it is thought that I would not be likely to recover from this injury enough to live independently, I do not want to be connected to any machines that will artificially prolong my life. This is because living independently is very important to me.

E.g. If it is required to save my life, I give consent to transfusion of blood and blood products. Although my family are Jehovah’s Witnesses, I do not share their religious belief.

If you write an Instructional Directive and it is not clear whether it relates to the condition for which medical treatment decisions need to be made, these statements will be considered Values Directives, and your Medical Treatment Decision Maker will be asked to consider these statements and then to make a decision on your behalf.

Make sure to only write binding instructions in the “Instructional Directives” section of this form, otherwise they will be considered Values Directives only.

Note that if you choose to make an Instructional Directive to refuse CPR in the event that your heart stops beating, you may not receive CPR in an unforeseen emergency (such as drowning or electric shock).

Keep in mind that your health care providers will only provide treatment that is medically appropriate, even if you have consented to it in your Advance Care Directive.

Where an Advance Care Directive contains a statement that would require an unlawful act to be performed or that would require a health practitioner to breach a code of conduct or professional standards, including the Catholic Code of Ethical Standards, these statements are void and have no effect but the remainder of the ACD remains valid.

PAGE SIX (of the ACD form)

Witnessing and signatures - to Advance Care Directive

This page must be completed for your Advance Care Directive to be valid. By signing this page of the form, you are confirming that you have completed the document freely and voluntarily, that is to say that no one has pressured you into writing anything in the directive.

You are also declaring that you understand the implications of all of the statements you have made in the directive. It is highly recommended that you discuss all of the statements within the document with your doctor to ensure it is well written and that you have considered all relevant information.

Your Advance Care Directive must then be signed by two witnesses, one of whom is a doctor. It is recommended that you do this with a doctor you know well, either your GP or your medical specialist. The second witness to the document does not need to be a doctor, but cannot be your Medical Treatment Decision Maker.

In the case of a child making an Advance Care Directive, one of the witnesses must be either a doctor or a psychologist who has completed prescribed training to witness the declaration of an Advance Care Directive of a minor.

The last section of Page 6 allows you to record the people who hold a copy of your Advance Care Directive. You can add to this section every time you distribute your directive to a new person. It is recommended that you keep the original document where you keep other important documents such as wills or passports.

If you are receiving treatment at Cabrini Hospital, a copy should be made and kept in your Cabrini medical record. You can ask for this to happen whenever you are admitted to the hospital, present to the Emergency Department, or visit for outpatient services. It is highly recommended that you give copies of the Advance Care Directive to at least the following people:

- Your Medical Treatment Decision Maker(s) and/or Support Person
- Your General Practitioner
- Your Medical Specialist(s)
- Your local hospital
MY ADVANCE CARE DIRECTIVE

This Advance Care Directive replaces any previous directives that I may have made. I understand that my values and beliefs may be different from those of the people I choose to make decisions for me and I ask them to make the decisions which I would make. I also understand that I can change my Advance Care Directive at any time.

This Advance Care Directive is in effect only when I do not have capacity to make my own decisions.

I have made this Advance Care Directive after discussion with the following health care providers (e.g. doctors, nurses, social workers, etc):

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Why?
Have your voice heard

It is good to think about your future health care needs and to discuss these with others.

If a time comes when you are unable to make your own decisions, someone else will be asked to make decisions on your behalf. You can choose who that person is and help that person to represent you by telling them what would be important to you at this stage in your life. This document suggests some of the issues you might like to discuss with both your doctor and the person you have chosen (or who will be chosen) to represent you.

The document is in four parts:

- Part 1: choose who you trust to speak on your behalf and who you want to have access to your medical information
- Part 2: express the values that are important to you to help your decision-maker
- Part 3: give binding instructions about certain medical situations
- Part 4: obtain signatures of witnesses to the creation of this document

You may complete all or part of Part 1, 2 and 3. Part 4 must be completed for this Directive to be valid.

Me
About me

<table>
<thead>
<tr>
<th>Name</th>
</tr>
</thead>
</table>

| Date of birth: / / |
| Address: |

202
<table>
<thead>
<tr>
<th>Part 1 – Appointment of Medical Treatment Decision Makers and Support Person</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Who?</strong> Who will speak for me? <strong>My Advance Care Directive</strong></td>
</tr>
<tr>
<td>This section allows you to document one or two people who you know well and trust to make health decisions in the event that you are unable to do so for yourself. The second person you list will only be asked if the first person is unavailable. You can also appoint a Support Person who will help you make decisions while you still have decision-making capacity – they will have access to your medical information. Your Support Person can also be your Medical Decision Maker. The people you select to be your Medical Decision Makers and Support Person must sign this page to accept the role.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medical Treatment Decision Maker 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>Address:</td>
</tr>
<tr>
<td>DOB:</td>
</tr>
</tbody>
</table>

**Acceptance of appointment:** I understand the obligations of an appointed Medical Treatment Decision Maker and undertake to act in accordance with any known preferences and values of the person making the appointment. I undertake to promote the personal and social wellbeing of the person making the appointment and have read and understand any advance care directive that the person has given.

<table>
<thead>
<tr>
<th>Name:</th>
<th>Signature:</th>
<th>Date:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Medical Treatment Decision Maker 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>Address:</td>
</tr>
<tr>
<td>DOB:</td>
</tr>
</tbody>
</table>

**Acceptance of appointment:** I understand the obligations of an appointed Medical Treatment Decision Maker and undertake to act in accordance with any known preferences and values of the person making the appointment. I undertake to promote the personal and social wellbeing of the person making the appointment and have read and understand any advance care directive that the person has given.

<table>
<thead>
<tr>
<th>Name:</th>
<th>Signature:</th>
<th>Date:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Support Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>Address:</td>
</tr>
<tr>
<td>DOB:</td>
</tr>
</tbody>
</table>

**Acceptance of appointment:** I understand the obligations of an appointed Support Person and undertake to act in accordance with any known preferences and values of the person making the appointment. I undertake to promote the personal and social wellbeing of the person making the appointment and have read and understand any advance care directive that the person has given.

<table>
<thead>
<tr>
<th>Name:</th>
<th>Signature:</th>
<th>Date:</th>
</tr>
</thead>
</table>

**Witnesses to appointment of Medical Treatment Decision Makers and/or Support Person:** I certify that the person making the above appointments and the person/people accepting those appointments appear to have decision-making capacity and have freely and voluntarily signed the document.

<table>
<thead>
<tr>
<th>Witness One: Authorised witness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature:</th>
<th>Date:</th>
</tr>
</thead>
</table>

| Qualification: | |

<table>
<thead>
<tr>
<th>Witness Two:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature:</th>
<th>Date:</th>
</tr>
</thead>
</table>
Part 2 - Values Directives

| What? What is Important to me? | We are all unique and have different beliefs, values, and goals. Here you can say what is important to you. What does it mean to you to 'live well'? This information will be used by people making decisions for you to help them make the decisions that you would have made yourself. These statements are a guide to treatment decision making only. If you wish to legally refuse treatment, see Part 3 of this form. |

1. I am currently receiving care and treatment for the following health conditions:

2. What is difficult for me to do now because of my health conditions?

3. What worries me about what will happen to my health in the future?

4. The following things worry or concern me unrelated to my health. For example: family concerns, hopes and fears, emotional issues, accommodation, people I do not want involved.

5. These are the things in life that have a lot of meaning for me. (For example: enjoying activities, spiritual or religious beliefs, family or friends, pets, reading books, independence.)
6. The following things are important to me and they may help my Medical Treatment Decision Maker to make medical decisions in the future for me (for example: special religious or cultural needs):

_________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________]
UR No.: 
Surname: 
Given Name: 
D.O.B.: 

Please read the instructions carefully before completing Part 3.

Part 3 – Instructional Directives

What? What treatment decisions have you already made?

If you wish your Medical Treatment Decision Maker and healthcare providers to be able to take into account your circumstances when you are no longer able to make decisions, you should use Part 1 and Part 2 of this form only. Part 4 must also be completed.

In Part 3 you can make binding statements called Instructional Directives that will communicate your medical treatment decision directly to your healthcare providers. It means that no-one else will be asked to make decisions about those treatments for you.

It is very important that you consult your health practitioner if you choose to complete an Instructional Directive, in order to ensure that it is written in a way that can be safely interpreted. If your Instructional Directives are unclear, they will still be considered as descriptions of your values.

To give more general guidance to your Medical Treatment Decision Maker see Part 2 of this form. Cross out this page if you do not wish to consent to or refuse any specific medical treatments.

10. Cardiopulmonary Resuscitation (CPR) involves chest compressions and artificial ventilation to manually save brain function, blood circulation and breathing for someone in cardiac arrest. These interventions are used when a person’s heart stops beating, and they may or may not restore life.

If my heart stops beating:

☐ Attempt resuscitation if clinically indicated
Or:
☐ Do NOT attempt resuscitation

Comment:


11. Organ donation: Very few people die in a way that allows them to be considered for organ donation. One organ donor can save or improve the lives of many others. Your family will be asked to confirm your consent for donation.

In the event that I am able to be considered for organ, eye and/or tissue donation when I die, I wish to be a donor:

☐ Yes ☐ No

12. Here you can write other Instructional Directives. Keep in mind that these should include details about the circumstances in which the directive will apply, as well as specifics of the treatments to which you either give or refuse consent e.g. "If I am ever suffering from (insert details of condition), I give my consent to/refuse (insert details of treatment)."
Part 4 - Witnessing and signatures

Your Declaration:
I make this Advance Care Directive and any appointments within it freely and voluntarily, and I understand the nature and effect of each statement within the Directive.

Name:

Signature: ___________________________ Date: ____________

Witnesses to the signing of this Advance Care Directive: I certify that the person giving this Advance Care Directive appears to have decision-making capacity and has freely and voluntarily signed the document in the presence of two witnesses, neither of whom has been appointed as a Medical Treatment Decision Maker. The person appears to understand the nature and effect of all statements made within this document.

Witness One: Registered Medical Provider
Name: ___________________________
Signature: ___________________________ Date: ____________
Qualifications: ___________________________

Witness Two:
Name: ___________________________
Signature: ___________________________ Date: ____________

Sharing your Advance Care Directive
I understand that it is important to discuss healthcare preferences with my GP, Medical Specialists, local hospital, my family/friends and particularly my Medical Treatment Decision Makers. I have discussed and provided a copy of My Advance Care Directive to the following people:

<table>
<thead>
<tr>
<th>Name</th>
<th>Contact Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
MANAGE ACCOUNT

<table>
<thead>
<tr>
<th>View Orders</th>
<th>Special Requests</th>
<th>Viewing Pay Deductions</th>
<th>Programs</th>
<th>Requests</th>
<th>Account Settings</th>
</tr>
</thead>
</table>

**Special Request Details**

**BMJ** - British medical journal

Article: A new framework for devising and evaluating complex interventions: update of classical research Council guidance

**GENERAL INFORMATION**

- **Request ID**: 60313474
- **Request Status**: Accepted
- **Request Date**: 27 Dec 2022
- **Note**: 0.00 USD

**ALL DETAILS**

**COMMENTS**

© 2020Copyright/Commas cancer | About | Terms & Conditions | Privacy | Accessibility | Feedback | Help

20°C Cloudy

208
Dear Bonnie, I previously obtained permission from the Institute of Clinical Systems Improvement to use the "Shared Decision-Making Relational Elements" figure that depicts how decision making is part of patient- and family-centred care in a published journal article. I have attached the article for your pursual and the mentioned diagram is on page 1073.

I would like to seek permission to use this diagram once again in my thesis to be submitted to the University of Notre Dame, Australia. I would be most grateful for your assistance.

With kind regards,

Natasha Michael

Hi Natasha;

Go ahead and use it. ICSI is now defunct, but you should attribute it anyway, or whatever works for your standards.

Bonnie Harris,
VP of Strategy, MedTech Momentum
M 612-801-0912
E bonnie@medtechmomentum.com
W medtechmomentum.com
From: Natasha Michael  
Date: Saturday, August 20, 2022 12:42 AM GMT


Dear Natasha Michael,

Thank you for contacting us.

Please note that, as one of the authors of this article, you retain the right to reuse it in your thesis/dissertation. You do not require formal permission to do so. You are permitted to post this Elsevier article online if it is embedded within your thesis. You are also permitted to post your Author Accepted Manuscript online.

However posting of the final published article is prohibited.

"As per our Sharing Policy, authors are permitted to post the Accepted version of their article on their institutional repository – as long as it is for internal institutional use only.

It can only be shared publicly on that site once the journal-specific embargo period has lapsed. For a list of embargo periods please see: Embargo List.

You are not permitted to post the Published Journal Article (PJA) on the repository."

Please feel free to contact me if you have any queries.

Kind regards,

Thomas Rexson Yesudoss  
Copyrights Coordinator

[Elsevier Permissions]
From: Natasha Michael
Date: Saturday, August 20, 2022 12:47 AM GMT

I request permission to use the above for my thesis from the article:

Dear Natasha Michael,

Thank you for your query.

Please note that, as one of the authors of this article, you retain the right to reuse it in your thesis/dissertation. You do not require formal permission to do so. You are permitted to post this Elsevier article online if it is embedded within your thesis. You are also permitted to post your Author Accepted Manuscript online. However posting of the final published article is prohibited.

“As per our Sharing Policy, authors are permitted to post the Accepted version of their article on their institutional repository – as long as it is for internal institutional use only.

It can only be shared publicly on that site once the journal-specific embargo period has lapsed. For a list of embargo periods please see: Embargo List.

You are not permitted to post the Published Journal Article (PJA) on the repository.”

Please feel free to contact me if you have any queries.

Kind regards,

Kaveri Thakuria
Senior Copyrights Coordinator

If you have any questions, please feel free to contact me.

Report Suspicious
Vulnerability and Resilience: Phenomenological Analysis of Cancer Patients Value Directives

Author: Natasha Michael, Xavier Symonds, George L. Menz, David Kessan
Publication: Journal of Pain and Symptom Management
Publisher: Elsevier
Date: November 2022

Copyright © 2022 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. All rights reserved.

Journal Author Rights

Please note that, as the author of this Elsevier article, you retain the right to include it in a thesis or dissertation, provided it is not published commercially. Reproduction is not required, but please ensure that you reference the journal as the original source. For more information on this and on your other retained rights, please visit: https://www.elsevier.com/about/our-business/policies/copyright/author-rights

CLOSE WINDOW
From: Natasha Michael
Date: Saturday, August 20, 2022 12:50 AM GMT

I am seeking permission to use the above in my thesis from the article
caregiver communication concordance in cancer – Refinement of the Cancer Communication
Assessment Tool in an Australian sample. Support Care Cancer. 2022; https://doi.org/10.1007/s00520-
022-07163-7.

Dear Natasha Michael,

Thank you for your query.

Please note that, as one of the authors of this article, you retain the right to reuse it in your
thesis/dissertation. You do not require formal permission to do so. You are permitted to post
this Elsevier article online if it is embedded within your thesis. You are also permitted to post
your Author Accepted Manuscript online.

However posting of the final published article is prohibited.

"As per our Sharing Policy, authors are permitted to post the Accepted version of their article
on their institutional repository – as long as it is for internal institutional use only.

It can only be shared publicly on that site once the journal-specific embargo period has
lapsed. For a list of embargo periods please see: Embargo List.

You are not permitted to post the Published Journal Article (PJA) on the repository."

Please feel free to contact me if you have any queries.

Kind regards,

Kaveri Thakuria
Senior Copyrights Coordinator
SOM | HCM - Health Content Management Visit

Fees: Permissions